Cry Freedom! Domination, disability and a republican reading of the U.N. Convention on the Rights of Persons with Disabilities

James Forbes BA, BA (Ed), LLB, MA (Ed), MSc, LLM

Thesis Submitted for the Award of PhD

School of Law and Government

Dublin City University

Supervisors: Dr Tom Hickey & Dr Aisling De Paor

August 2024

Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of PhD is entirely my own work, and that I have exercised reasonable care to ensure that this work is original, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

Signed:

ID No.: 15212438

Date: 29th August 2024

Table of Contents

Abstract

Utilising a phenomenologically informed critical methodology, and drawing on the direct experiences of blind and visually impaired people, the parents of persons with disabilities and professionals working within what is known as the disability sector, this dissertation begins from an intuition that a republican focus on freedom as non-domination has value to bring to the lives of persons with disabilities.

Matching this non-domination thesis against the idea (commonly associated with liberalism) that freedom consists in non-interference, the dissertation draws on the United Nations *Convention on the Rights of Persons with Disabilities 2007* (CRPD) and, specifically, its principles and three distinct rights – education, work and employment and living independently and being included in the community - to undergird an argument that republicanism offers a simple, unifying understanding of freedom as an entitlement held in common, across the human community. In this formulation the CRPD is read as of profound relevance to persons with disabilities and to all those who come, or might come, within the porous designation of *vulnerable.*

Presented as a theory for testing and, in particular, drawing on the scholarship of Philip Pettit, republicanism as presented in this dissertation is a politico-legal arrangement of ancient lineage. In its modern idiom, this same republicanism is now positioned as embodying an eminently realizable modern goal, specifically that being in a position to resiliently resist being – or having the potential of being - subject to another’s arbitrary whim or control offers a very full and persuasive account of what it is reasonable to expect of a decent state and a decent civil society, including that disabled people long deprived of their public dignity hold that dignity resiliently.

Acknowledgements

The proverb that ‘it takes a village to raise a child’ really ought to have an equivalent when it comes to *raising* a PhD. There are just so many people, at least a small village-full, whose ideas and thoughts and help and hugs and concern and prayers have sustained me up to this point. Although far too many to name, to each I owe a great debt. That said, particular mention is made of

- all those who so generously agreed to be interviewed and who shared their lifeworld so candidly; without the stories you offered this work would be arid
- Dr Tom Hickey and Dr Aisling de Paor, my much put-upon, extraordinarily gifted and unrelentingly supportive supervisors; I know my good fortune and my privilege in having had you at my side
- Maeve Mahon, Amanda Deaton, Christine Richardson, Katharine Howe and Tracy Walsh whose unbridled kindness and incredible reserves of patience and practical (read, technological) support kept me afloat when I so often came perilously close to sinking; my thanks are barely a beginning
- Mary Leonard, Gerry McCoy, Caroline McGarrity, Kathleen Haran, Mary Burke, Anita Cronin, John Horan and Joe O’Reilly among many others, have been extraordinary friends throughout, lightening the load and encouraging one foot forward at a time; I would have been lost without ye
- all of my colleagues in ChildVision and, particularly, the young people with whom I am privileged to work; almost everything I know worth knowing has been learned among ye
- Nora Walsh, Sr. Mary Anthony and Fr. Dasan Kuttikkatt – among the prayers of prayers you are each of an Olympic standard; I am deeply grateful
- Gearódíne McEvoy, Claire Barry, Sheelagh Brady, Danny Ilazi and Christina Andreeva – PhDs all - whose company in DCU and beyond was always a joy and an encouragement: I hope someday we do make it to Kosovo
- all of the staff in DCU’s School of Law and Politics, many of whom made valuable comments on my work as it progressed: in particular I want to thank Dr Tanya Ni Mhuirthile whose never less than forensic PGR appraisals I valued very much
- DCU’s Registry staff and the University itself for the generous support I received; in particular here I also remember with respect Professor Robert Elgie and Dr Vicky Conway

- and, finally, to the most precious, the most important and the most inspiringly wonderful people in my life: Mary, Euan and Elissa. In every significant way, this work exists because of each of you: I am so utterly grateful for you, all of my love.

Constitutions

Bunreacht Na hEireann 1937

Basic Law for the Federal Republic of Germany 1949

Table of Irish Legislation

Assisted Decision Making (Capacity) Act 2015

Child Care Act 1991

Children Act 1908

Children Act 1989

Citizen Information Act 2007

Disability Act 2005

Education Act 1998

Education (Admission to Schools) Act 2018

Education for Persons with Special Education Needs Act 2004

Education (Provision in Respect of Children with Special Education Needs) Act 2022

Education (Welfare) Act 2000

Employment Equality Act 1998

Equal Status Act 2000

Equality Act 2004

Equal Status (Amendment) Act 2012

Health Act 1947

Health Act 1953

Health Act 2004

Health (Amendment) (No.3) Act 1996

Health and Social Care Workers Professionals Act 2005

Human Rights Commission Act 2000

Lunacy Regulation (Ireland) Act 1871

Mental Health Act 2001

Prohibition of Incitement to Hatred Act 1989

Non-Irish Legislation

The Canadian Charter of Rights and Freedoms 1982

Table of case law

Ireland

Crowley v Ireland [1980] IR 102

Electoral (Amendment Act) 1996

Nano Nagle School v Daly [2018] IECA 11 E.L.R.249

O'Donoghue v Minister for Health [1996] 2 IR 20

O'Shiel v Minister for Education [1999] 2 ILRM 241

Re Article 26 and the Employment Equality Bill [1997] 2 IR 321

Ryan v Attorney General [1965] IR 294

Sinnott v Minister for Education [2001] 2 IR 545

European Court of Human Rights

Beldjoudi v. France 55/1990/246/317; 12083/86, Council of Europe: European Court of Human Rights, 26 February 1992

Pretty v. United Kingdom, Application no. 2346/02, Council of Europe: European Court of Human Rights, 29 April 2002

United Kingdom

A NHS Trust v DE [2013] EWHC 2562 (COP)

A Primary Care Trust v P [2009] EW Misc 10 (EWCOP)

Archibald v Fife [2004] IRLR 651

United States

Oliver M. Brown et al. v. the Board of Education of Topeka (KS) [1954] 347 US at 483

Buck v Bell 274 U.S. 200 (1927)

Olmstead v L.C. 527 U.S. 581, 587 1999

International Treaties and Treaty Bodies

United Nations

United Nations Charter (adopted 26 June 1945, came into force 24 October 1945)

UN Convention on Biological Diversity (adopted 5 June 1992, entered into force 29 December 1993) UNTS 1760

UN Convention to Combat Desertification (adopted 17 June 1994, entered into force 26 December 1996) UNTS 1954

Convention on the Elimination of All Forms of Discrimination against Women (adopted 18 December 1979, entered into force 3 September 1981) UNTS 1249

Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) UNTS 2515

Convention on the Rights of the Child (adopted 20 November 1989, entered into force 2 September 1990) UNTS 1577

Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (adopted 10 December 1984, entered into force 26 June 1987) UNTS 1465

Declaration on the Rights of Indigenous Peoples (adopted 13 September2007) (A/RES/61/295)

International Covenant on Civil and Political Rights (adopted 16 December 1966, entered into force 23 March 1976) UNTS 999

International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) UNTS 993

International Convention on the Elimination of All Forms of Racial Discrimination (adopted 7 March 1966, entered into force 4 January 1969) UNTS 660

International Convention for the Protection of All Persons from Enforced Disappearance (adopted 20 December 2006, entered into force 23 December 2010) UNTS 2716

International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families (adopted 18 December 1990, entered into force 1 July 2003) UNTS 2220

Optional Protocol to the Convention on the Rights of Persons with Disabilities (13 December 2006) A/RES/61/106

Optional Protocol to the International Covenant on Economic, Social and Cultural Rights (10 December 2008) A/RES/63/117)

UNESCO, 'Convention Against Discrimination in Education' (adopted 14 December 1960)

United Nations Framework Convention on Climate Change (adopted 9 May 1992, entered into force 21 March 1994) UNTS 1771

Universal Declaration of Human Rights (adopted 10 December 1948) UNGA 217 A (III)

Vienna Convention on the Law of Treaties (adopted 23 May 1969, entered into force 27 January 1980) UNTS 1155

United Nations Committees

Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities Working Group, established by General Assembly resolution 56/168 (19 December 2001)

Committee on Civil and Political Rights General Comment No. 18: Non-Discrimination (10 November 1989)

Committee on Economic, Social and Cultural Rights, 'General Comment No. 3: The Nature of State Parties’ Obligations (article 2(1) of the Covenant)' (14 December 1990) E/1991/23

Committee on Economic, Social and Cultural Rights ‘General Comment No. 5: Persons with Disabilities’ (9 December 1994) E/1995/22

Committee on Economic, Social and Cultural Rights ‘General Comment No. 4: The Right to Adequate Housing (Art. 11 (1) of the Covenant)’ (13 December 1991) E/1992/23

Committee on Economic, Social and Cultural Rights, ‘General Comment No. 16 on Article 3: The Equal Right of Men and Women to the Enjoyment of All Economic, Social and Cultural Rights' (11 August 2005) E/C.12/2005/4

Committee on Economic, Social and Cultural Rights, ‘General Comment No. 18: The Right to Work (Art 6 of the Covenant)’ (24 November 2005) E/C.12/GC/18

Committee on Economic, Social and Cultural Rights, ‘Concluding Observations on the Third Periodic Report of Japan (10 June 2013) E/C.12/JPN/CO/3

Committee on the Rights of the Child, 'General Comment No 5: General Measures of Implementation of the Convention on the Rights of the Child (arts 4, 42, 44.6)' (27 November 2003) CRC/GC/2003/5

Committee on the Rights of Persons with Disabilities, 'Jungelin v Sweden' (2011) CRPD/C/12/D/5/2011

Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Austria' (11 September 2013) CRPD/C/AUT/CO/1

Committee on the Rights of Persons with Disabilities, 'General Comment No. 2 on Article 9: Accessibility'(11 April 2014) CRPD/C/GC/2

Committee on the Rights of Persons with Disabilities, 'General Comment No. 3 on Article 6: Women and Girls with Disabilities (26 August 2016) CRPD/C/GC/3

Committee on the Rights of Persons with Disabilities, 'General Comment No. 4 on Article 24: Right to Inclusive Education' (25 November 2016) CRPD/C/GC/4

Committee on the Rights of Persons with Disabilities, 'General Comment No. 5 on Article 19: Living Independently and Being Included in the Community' (31 August 2017) CRPD/C/GC/5

Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Luxembourg' (10 October 2017) CRPD/C/LUX/CO/1

Committee on the Rights of Persons with Disabilities, 'General Comment No. 6: Equality and Non-Discrimination' (26 April 2018) CRPD/C/GC/6

Committee on the Rights of Persons with Disabilities, 'General Comment No. 7 on Article 4.3 and 33.3 of the Convention on the Participation with Persons with Disabilities in the Implementation and Monitoring of the Convention' (21 September 2018) CRPD/C/GC/7

International Labour Organization

International Labour Organization (ILO) *Concerning Forced or Compulsory Labour* Convention No 29 (28 June 1930)

International Labour Organization (ILO), *Constitution of the International Labour Organisation (ILO)* (1 April 1919)

International Labour Organization (ILO), *Declaration on Fundamental Principles and Rights at Work* (18 June 1988) as amended 10 June 2022) ILC.110/Resolution 1

International Labour Organization (ILO) *Discrimination* (*Employment and Occupation*) Convention No. 111 (4 June 1958)

International Labour Organization *Employment Policy* Convention 122 (15 July 1966)

International Labour Organization (ILO), *Freedom of Association and Protection of the Right to Organise* Convention No *87* (9 July 1948)

International Labour Organization (ILO) *Hours of Work* (*Industry*) Convention No. 1 (28 November 1919)

International Labour Organization (ILO) *Termination of Employment* Convention No 158 (24 November 1985)

European Union

Charter of Fundamental Rights of the European Union (adopted 7 December 2000, entered into force 1 December 2009) OJ C 326/02

Council Directive 2000/78/EC of 27 November 2000

Council of Europe

European Charter for Regional or Minority Languages (opened 5 November 1992, entered into force 1 March 1998)

Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention on Human Rights) (1950)

European Convention on the Legal Status of Migrant Workers (24 November 1977) ETS No. 93

European Social Charter (revised) (opened 3 May 1996, entered into force 1 July 1999) ETS No. 163

Framework Convention on the Protection of National Minorities (opened 1 February 1995, entered into force 1 February 1998) ETS No. 157

Organisation of American States

American Convention on Human Rights (adopted 22 November 1969)

Table of Abbreviations

CAT	Convention Against Torture and Other Cruel Inhuman or Degrading Treatment or Punishment
CCPR	Committee on Civil and Political Rights
CEDAW	Convention on the Elimination of All Forms of Discrimination Against Women
CESCR	Committee on Economic, Social and Cultural Rights
CoE	Council of Europe
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled Persons Organisation
ECHR	European Convention on Human Rights
ECtHR	European Court of Human Rights
EU	European Union
ICCPR	International Covenant on Civil and Political Rights
ICERD	International Convention on the Elimination of All Forms of Racial Discrimination
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICMW	International Convention on the Protection of All the Rights of All Migrant Workers and Members of Their Families
ILO	International Labour Organisation
NCBI	National Council for the Blind of Ireland
NI	Northern Ireland
OHCHR	Office of the High Commissioner for Human Rights
PA / PAS	Personal Assistant / Personal Assistance Service
UDHR	Universal Declaration of Human Rights
UK	United Kingdom
UN	United Nations
US	United States
VCLT	Vienna Convention on the Law of Treaties
VI	Visually Impaired or Vision Impaired
WHO	World Health Organisation

Chapter One:

Outlining a Research Posture

A city (civitas) … takes its name from the citizens who dwell in it. As an urbs, it is only a walled structure, but inhabitants, not building stones, are referred to as a city.[1]

1 Introduction

Starting from the premise that power is 'the first question of justice,'[2] this PhD dissertation posits a neo-republican reading of power to suggest that the liberal ideal of freedom – cornerstone of the Western democratic project – is insufficient to meet the justice entitlements of persons with disabilities. As emblematised in the United Nations Convention on the Rights of Persons with Disabilities[3] (hereafter the CRPD or the Convention) - together with certain developments preceding it – these entitlements now present unambiguously as a human rights issue.[4] Davis assists in putting this legal claim into context:

> [f]or centuries, people with disabilities have been isolated, incarcerated, observed, written about, operated on, instructed, implanted, regulated, treated, institutionalised and controlled to a large degree probably unequal to that experienced by any other minority group.[5]

The purpose of the CRPD is 'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.'[6] In its alignment with the Convention, the Irish state is signalling a formal intention to shift away from policies informed by a medicalised perspective on impairment and from laws to which disabled persons are strangers.[7] However, positing civil

---

[1] Isadore of Seville; quoted in Ferenc Horcher *The Political Philosophy of the European City* (Lexington Books, 2021) 5

[2] Rainer Forst Noumenal Power (2015) 23 (2) The Journal of Political Philosophy 111, 127

[3] *Convention on the Rights of Persons with Disabilities* (adopted 13 December 2006, entered into force 3 May 2008) UNTS 2515 (CRPD)

[4] Theresia Degener Andrew Begg 'From Invisible Citizens to Agents of Change: A Short History of the Struggle for the Recognition of the Rights of Persons with Disabilities at the United Nations' in Valentina Della Fina Rachele Cera Giuseppe Palmisano (eds) *The United Nations Convention on the Rights of Persons with Disabilities. A Commentary* (Springer, 2017) 1 - 39

[5] Lennard J Davis Introduction: the need for disability studies. In Lennard J Davis (ed) *The Disability Studies Reader* (Routledge, 1997) 1

[6] CRPD article 1

[7] Ireland signed the CRPD in 2007 and ratified it on 20 March 2018

society as 'our collective self'[8] this dissertation contends that so ingrained and so un-reflected upon are the prejudices and casual discriminations existing within the wider (sometimes styled mainstream) society towards disabled people that 'top down' governmental initiatives have little hope of promoting the widespread change that a full compliance with the CRPD requires. Indeed, to go further, if, as Meyers contends, that states subscribe to international human rights treaties in terms of 'myth and ceremony'[9] while actually changing very little in day-to- day practice then it must also be considered that the state itself may be a barrier to meeting human rights norms.

Thus, notwithstanding the richly innovative and (generally) emphatic nature of the Convention's approach to disabled people's rights, it is suggested that there is a chasm between enunciating rights and actively cultivating cultures within which these rights can take root and thrive. This dissertation turns on a republican proposal concerning how this chasm might be bridged. Amid concern that 'rights talk' can become inflated to the point that rights attainment is compromised, this republican proposal seeks to pare back to the basics and to suggest a basis on which all persons might agree on what individual freedom looks like within a free and vibrant public sphere, a renewed *civitas*. This dissertation contends that what is needed is a citizen driven heuristic energy, whereby a broad public consensus manifests, linking human rights to widespread moral claim: a broad-based civil society insistence that for *human* rights to hold their value they must be everyone's or else, in any meaningfully resilient sense, they are no one's. To this end, the CRPD is consciously represented as of transformational value to persons with disabilities and, also, to all who are vulnerable and marginalised in modern society. This claim is premised on reading the Convention – particularly in terms of its principles – as a freedom charter of wide applicability. It will be argued that such a reimagining of the Convention, aligned to the republican ideal, will strengthen the CRPD's capacity to deliver on its promise to persons identified as disabled precisely because it uses a freedom paradigm to unify all humanity in the desire to live richer, fulfilling and resiliently dignified lives.

2 Towards a research question: intuitions

By way of further preface to this dissertation proper, it is appropriate to name those intuitions which have given rise to it. The first has already been referenced but requires some brief further mention. It is that liberalism, the preeminent political and moral philosophy of Western modernity, has failed persons with disabilities. Although a system of thought which has many

---

[8] Fred Powell *The Politics of Civil Society* (The Policy Press, 2013) 32

[9] Stephen J Myers *Civilizing Disability Society* (Cambridge University Press, 2019) 64-65

different points of emphasis, liberalism has at its heart one paradigmatic assertion: the profound freedom of the individual. This is not to say that each person in the liberal construct is free to do whatever they wish. As Hobbes recognises, without some overarching authority restraining and regulating individual liberty a life is likely to be 'solitary, poor, nasty, brutish and short.'[10] But, although different strands of liberalism may emphasis one conception or another about how individual freedom is experienced or exercised, freedom itself is normatively basic. Hence, there exists an onus on a liberal state to protect everyone's personal liberty - and the rights associated with such freedom - and to ensure that whenever this liberty is interfered with such interference is justified and minimised, cordoned off as exception rather than rule.

Yet, as the Irish experience can perhaps be thought merely emblematic of, disabled people are outliers within the liberal project, their interests side-lined and ignored. Indeed, political liberalism's most significant modern theorist, John Rawls, says as much. Rawls expounds a deeply compelling social justice narrative wherein the least well-off in society are protected within a system in which no social group can advance at the expense of another.[11] Yet, when it comes to these groups freely negotiating a new, mutually beneficial, social contract, persons with disabilities are explicitly excluded. Instead, Rawls contends that the interests of 'severely' disabled people – meaning people with permanent cognitive and physical disabilities – must await a later, legislative stage post the social justice compact being struck by 'fully cooperating' (that is, non-disabled) members of society 'over a complete life.'[12] In the Rawslian imaginary, disabled people's needs must be relegated to a later consideration, their interests to be addressed not through the exercise of their own legitimate agency but by way of the kindness - perhaps, even, the charity - of others.[13]

The public worlds of persons with disabilities are well documented in terms of this relegation, describing experiences, *inter alia*, of social isolation, marginalisation, personal danger, indignity, institutionalisation, diminished citizenship and, even, contested personhood.[14] Indeed, the

---

[10] Thomas Hobbes *Leviathan* (first published 1651, Penguin Classics 1985) 186

[11] John Rawls *A Theory of Justice* (Harvard University Press 1971, 1999)

[12] John Rawls *Political Liberalism* (Columbia University Press, 2005) 20

[13] with respect to *significantly* disabled people, Rawls considers that their exclusion from the benefits of the 'justice as fairness' compact might be addressed via an extension of his theory but he admits to perhaps lacking 'the ingenuity to see how the extension may proceed.' Hence the recourse to other moral frameworks; see *ibid* 21

[14] see, for instance, Linda Barclay *Disability With Dignity* (Routledge, 2019); Seamus Taylor *Hate Crime Policy and Disability* (Bristol University Press, 2022); Alan Roulstone Kim Sadique Vulnerable to misinterpretation: disabled people, 'vulnerability', hate crime and the fight for legal recognition. In Alan Roulstone Hannah Mason-Bish (eds) *Disability, Hate Crime and Violence* (Routledge, 2013) 25 – 39; Katharine Quarmby *Scapegoat. Why We Are Failing Disabled People* Portobello Books, 2011); Colin Barnes

implicit rationale of the CRPD can be said to derive from an international acceptance that, as the world's largest minority, the rights of persons with disabilities have been, everywhere, poorly realised.

I turn now to the second intuition: that in actively seeking to realise the rights of disabled people phrasings of justice needs to be (at least, temporarily) subordinate to phrasings of freedom, the freedom referenced here being social or political freedom.[15] This is not to say that lack of freedom is not often likely to manifest as injustice and vice-versa. However, as a concept *justice* is an amorphous thing, such that its value as a communitarian good – that is, something on which there can be immediate and widespread agreement – cannot be assured, especially in circumstances where advancing one group's interests clearly indicates restricting another's. The scale of the challenge facing states in realigning the way in which people with disabilities are understood and treated within societies is huge, requiring not just a significant reprioritising of resources but also a concerted focus on fostering wide-spread attitudinal change. It represents an enormous and sustained act of public/private reimagining, a civil society compact alongside the bureaucratic and legal developments which a state can sponsor. When any person is viewed as *less* - less able, less capable, less attractive, less reliable, less teachable, less employable – the potential richness of what is to be a human being in civil society is diminished; perhaps, even, extinguished. Yet, intuitively, we know that the pull of culturally embedded notions of *normal* functioning and able-bodiedness too often marks disabled people out as objects of fear and pity, of curiosity and of contempt or, at its most positive, objects of charity. The effects of this are experienced politically but they are also endured subjectively, individually. Within this nexus, rights are vital, of course. Rights directly target injustice, the net result, hopefully, being that a person's natural freedom is restored, enhanced or recognised. But *disability* rights, as laid out in the CRPD, seek to transform not just the lives of individuals but the whole of society. This is both a moral and political goal. But if Western culture is suffused with unhelpful tropes about

---

Geof Mercer *Exploring Disability* (Polity Press, 2010); Susan M Schweik *The Ugly Laws: Disability in Public* (New York University Press, 2009); Patrick McDonnell *Disability and Society: Ideological and Historical Dimensions* (Blackhall Publishing, 2007)

[15] freedom is a complex ideal, at once resolutely personal yet ideological, as found, for instance, in oft-cited phrases such as 'the freedom of the markets' or 'the freedom-loving peoples of the world.' Long a constant of philosophers, theologians, priests, poets, artists, revolutionaries and despots alike, for some freedom is a cruel platitude, for others, the highest human goal, the quintessential mark of human advancement. The conception of freedom - or liberty - engaged with in this dissertation turns on the (Western) evolution and enshrinement of freedom as a political concept, a legal status originally brought into being to distinguish those who were not chattel slaves from those who were. In theorising its critical relevance to people with disabilities, the concept operates at many levels, including as a lens through which to view how social relations, social institutions and social attitudes impede disabled people's options and opportunities in the world

normality and able-bodiedness, then this focus on the *justness* of the disabled person's rights' claim – not as a disabled person but as a human being – is, I intuit, unlikely to be non-contentious, especially if that claim requires significant resource re-allocation.[16] If, however, we move to the premise that human freedom should be the first priority in articulating disability rights then it becomes more likely that the working out of rights begins from a place of agreement, particularly if we distil the essence of freedom as being resiliently outside the control of another. In this reading justice, perhaps, more specifically, distributive justice, plays a supplementary role, though no less important for that.

The concern here is that absent this freedom-first focus the state's embrace of the CRPD risks never being more than decorative fretwork. Hence, without widespread, concomitant civil society change, particularly perhaps in those most important of public fora, schools and workplaces and local communities, there is the very real likelihood that the rights claims embodied in the Convention do not meaningfully manifest in the daily, lived experiences of disabled people. Such a state of affairs would be the very antithesis of a truly dignified, deep and purposeful societal engagement with disability and its disempowering tropes.[17] The transformative, organic potential of the CRPD would remain profoundly un-realised even as, at the official level of government policies and the like, the rights talk discourse grows and grows. Snyder writes of 'the global human rights movement's thin penetration of its supposed source of power, global civil society.'[18] Historically, it was not always thus. For example, the same scholar situates colonial Britain's turn away from slavery as product of a coming together of Christian sentiment with a broader movement for democratisation, rights and social reform. As the CRPD looks to vernacularize rights for persons with disabilities as solid entitlements held against persons and against collective authorities – *trumps* in the view of Dworkin[19] - I suggest that a focus on a particular conception of freedom presents as a robust, unifying, trans-national way of energising the wider *civitas* to take seriously the human rights of disabled persons.

I move now to the third intuition, prefaced here first with a question. If liberalism fails persons with disabilities, despite its emphasis on protecting and advancing individual human freedom,

---

[16] for an extreme view on resource allocation see Helga Kuhse Peter Singer *Should the Baby Live? The Problems of Handicapped Infants* (Oxford University Press, 1985). More generally, in respect of how justice for persons with disability is phrased as primarily a resource issue see Nancy J Hirschmann 'Rawls, Freedom and Disability. A Feminist Rereading' in Ruth Abbey (ed) *Feminist Interpretations of John Rawls* (The Pennsylvania State University Press, 2013) 96 - 114

[17] such an engagement is provided for in CRPD article 8 (awareness-raising)

[18] Jack Snyder 'Empowering Rights Through Mass Movements' in Stephen Hopgood Jack Snyder Leslie Vinjamuri (eds) *Human Rights Futures* (Cambridge University Press, 2017) 91

[19] Ronald Dworkin *Taking Rights Seriously* (Bloomsbury, 1997)

and if the justice aspirations of persons with disabilities need more than an international legal agreement to realise them is there another politico-legal philosophy which might better serve? On the one hand, the conceptual and historic links between liberalism and human rights are strong ones. Hence, it would seem intuitively correct that if liberalism holds a broad public confidence, inclusive of political confidence, then what is required is likely to be something which seeks to supplement rather than replace the existing liberal consensus. More, this *something* needs to be straightforward if it is to engage the public imagination and unite a civic perception that freedom is everyone's legitimate expectation. Indeed, Marti and Pettit talk of an ideal which is 'sharable, realistic, and energising.'[20] So first this something must speak directly and compellingly to what freedom is, preferably utilising an idiom which resonates with peoples' hearts and minds and, ideally, such that the freedom interest of one citizen becomes plausibly the interest of each. Nor must it be overly idealised but, rather, must reveal its working out to be rational and achievable. Above all it must be person centred, by which I mean capable of being calibrated to the demands of individual dignity. In this then it presents instinctively that what is being aspired to is a mode of doing, a programme, its expectations focused on individual achievement rather than grand theory, on empowering rather than merely describing. In essence, it seems what is being proposed here is a paradigm shift.

One such paradigm shift has been the advent of the social model of disability.[21] The social model represents an extraordinary reimagining of disability, giving rise to a way of thinking about and connecting with disability which radically undermines centuries of ignorance and prejudice. Might this social model contain the answer to liberalism's deficiencies? Theorising disability as a social construct and not the inevitable consequence of impairment, the paradigm remains vivid and fecund. Person centred, conceptually straight-forward yet full of depth, it is of pivotal significance that the social model is identified as underpinning the CRPD.[22] Yet for all its positive features the social model is not the *something* this dissertation intuitively leans towards. Attractive as it is, the social model presents as lacking the intellectual heft and broad popular appeal necessary to offer a challenge to liberalism's failure to actively promote the freedom entitlements of persons with disabilities. Although widely debated within disability scholarship,

---

[20] Jose Luis Marti Philip Pettit *A Political Philosophy in Public Life* (Princeton University Press, 2010)

[21] see, for instance, Tom Shakespeare 'The Social Model of Disability' in Lennard J Davis (ed) *The Disability Studies Reader* (Routledge, 2017) 195 – 203; Michael Oliver *Understanding Disability* (Palgrave Macmillan, 2009)

[22] see Rannveig Trausadottir 'Disability Studies, the Social Model and Legal Developments' in Oddny Mjoll Arnardottir Gerard Quinn (eds) *The UN Convention on the Rights of Persons with Disabilities* (Marinus Nijhoff Publishers, 2009) 3 – 16; Rosemary Kayass Philip French 'Out of Darkness into Light? Introducing the United Nations Convention on the Rights of Persons with Disabilities' (2008) 8 (1) Human Rights Law Review 1

the social model has not proved to be a lingua franca, giving rise to only the barest whisper in the wider community. Further, even within disability scholarship there is debate as to whether, while an excellent diagnostic tool, the social model is not itself deficient in terms of delineating what needs to be *done* about overcoming the barriers the model identifies. Thus, I perceive the social model's chief function as a form of critical analysis. Aside, perhaps, from its truculent denial of the medical model approach to disability the social model has nothing distinctive to say about freedom.

I come now to the fourth intuition. There is an ages-old republican tradition, which, particularly in its modern turn, emphasises a distinctive understanding of freedom: freedom as non-domination.[23] To offer a brief summary of this idea – noting its particular association with the scholarship of Philip Pettit – non-domination recognises a person as free when she is not subject to arbitrary control or, indeed, the possibility of it.[24] This understanding is one that significantly differs from the conception of freedom championed by liberal theorists, that is, that freedom derives from simple non-interference, a conception I hold has failed disabled people and which, in any case, lacks robustness. My intuition is that this neo-republicanism (hereafter also referenced as contemporary republicanism or, simply, republicanism[25]) expresses a political ideal of freedom whose utility for persons with disabilities makes it not merely desirable but preferable to a liberal understanding. Given that within contemporary republicanism's ideal of freedom that domination can emanate from a person or an institution of some type, including a state, and given that disabled people routinely suggest that they are in others' or a system's control there seems here a potential nexus to be tested. Moreover, that this nexus has recently become an area of some academic interest confirms the value of this dissertation as a research piece. [26]

---

[23] in arguing for the pre-eminence of freedom as republicanism's core ideal this dissertation will, later, touch on other key themes too, principally, law, political participation, civic virtue and corruption; see Cecile Laborde John Maynor (eds) *Republicanism and Political Theory* (Blackwell, 2008); Iseult Honohan *Civic Republicanism* (Routledge, 2002)

[24] see, for example, Philip Pettit *On the People's Terms* (Cambridge University Press, 2012); Philip Pettit *Republicanism. A Theory of Freedom and Government* (Oxford University Press, 1997)

[25] the term civic republicanism is also much in use; for example see Marti and Pettit (n 20) and Honohan (n 23)

[26] among those who have produced valuable work in this area are Marie Sepulchre, 'Disability, Justice and Freedom as Non-Domination' (2022) 2 (1) The International Journal of Disability and Social Justice 11; Tom O'Shea, 'Disability and Domination: Lessons from Republican Political Theory' (2018) 35 (1) Journal of Applied Philosophy 133; Jurgen De Wispelaerea, David Casassas, 'A life of one's own: republican freedom and disability' (2014) 29 (3) Disability & Society 402

However, my particular interest in undertaking this dissertation arises from my fifth – and final – intuition. It is this: that in Western modernity so deep and so socially and legally entangled are the ways in which disabled people are thought of as dependent and vulnerable that disabled people are routinely oppressed. Such a view – analogous to the now commonplace acceptance of race and gender as vectors of injustice - is informed by Freire's awareness that oppression occurs whenever a person or a group seek to dehumanise another person or group for the purposes of controlling them.[27] Such an oppression disempowers, marginalises and engenders dependence, creating, in this version, 'a group whose members are in an inferior position to other members of society because they are disabled people.'[28]

This is a profoundly stark thought. Yet how else to explain the isolation, disregard, indignity, enforced dependence, poverty and, even, violence that persons with impairments often attest as their lot in life? How else to account for the sense of stigma, of shame and of social embarrassment which persons with impairments often report experiencing, even sometimes asserting that if impairment can be hidden, best that it be?[29] Being grounded, as contemporary politico-legal structures are, in the idea of human and political rights, this intuition turns, ultimately, on the sense that the dignity which the freedom paradigm confirms is reserved for *whole* people; just as, at various points from antiquity on, dignity was the sole preserve of the wealthy or males or whites or heterosexuals or Christians. For Mladenov the existential-ontological circumstances in which many people with impairments live can be characterised as a privation: 'the operation of defining an entity as a lacking version of another entity.'[30] From this feeds notions of an *othering* of impairment and its transformation into a discursive phenomenon that 'works as a structuring, constituting force, directly implying or tightly framing subjectivity, practice and meaning.'[31] Thus, people with impairments become a '*they*' defined

---

[27] Paulo Freire *Pedagogy of the Oppressed* (Penguin, 1993)

[28] Paul Abberley, 'The Concept of Oppression and the Development of a Social Theory of Disability' (1987) 2 (1) Disability, Handicap & Society 5, 7

[29] see, for instance, Yeongmin Mun, Suyoung Kim, 'The spectra of concealment and disclosure of disability: the experiences of people with mild disability in South Korea' [2022] 361; Nanna Mik-Meyer, 'Othering, ableism and disability: A discursive analysis of co-workers' construction of colleagues with visible impairments' (2016) 69 (6) Human Relations 1341; Jeffrey A Brune, Daniel J Wilson, 'Introduction' in Jeffrey A Brune Daniel J Wilson (eds) *Disability and Passing* (Temple University, 2013) 1 – 12; Daniel J Wilson 'Passing in the Shadow of FDR: Polio Survivors, Passing, and the Negotiation of Disability' in Jeffrey A Brune Daniel J Wilson (eds) *Disability and Passing* (Temple University, 2013) 13 - 35

[30] Teodor Mladenov *Critical Theory and Disability* (Bloomsbury, 2016) 5

[31] Mats Alvesson, Dan Karreman, 'Varieties of discourse: On the study of organizations through discourse analysis' (2000) 53 (9) Human Relations 1125, 1145

adversely by reference to people without impairments: let's say, an '*us*'.[32] In such a reading, the potential for domination is immense. But so too the potential for an emancipation that spreads beyond the artificial, socially constructed category of '*the disabled'* and reaches into every circumstance in which *any* human finds themselves arbitrarily subject to another's whim. On its face, what the Convention promotes is a pragmatism that frees people from the notion that difference can be legitimately used to discriminate against people with impairments, or to deny them the opportunities for inclusion in society as full citizens. The Convention's recognition of disabled persons as rights-bearers aligns naturally with the republican perspective on freedom as non-domination in that what is expressed is a baseline universal principle: society itself is fatally diminished if, as a matter of common acceptance, citizens are not resourced to stand on an equal footing with each other.[33] More, it is suggested that the Convention – perhaps, particularly in its comprehensive articulation of principles – offers a rich potential for two-way traffic, in terms of informing what wider society owes to people with disabilities but also in terms of laying out the most comprehensive yet articulation of rights necessary for a shared flourishing across the human family, especially, perhaps, if allied with the republican conception of freedom as non-domination.

3 Aims of this dissertation

Hence, the ambition of this dissertation is twofold. It is to draw on contemporary republicanism as a pluralist, non-sectarian and – following Laborde[34] – a critical theory to purposefully challenge and successfully undermine the oppression of people with disabilities and, in this, to also help reframe the vulnerabilities commonly associated with impairments into a wider understanding of a shared civitas. In terms of this latter hope, I will offer a republican reading of the CRPD principles and those articles relating to education, work, and living independently and being included in the community to suggest how the Convention can be read as a freedom charter of value across a general population.[35] Of importance here to note, is that in this there is no intention to dilute or disrespect the CRPD's profound importance for persons with disabilities. Nor is it not to acknowledge that people with disabilities have particular and distinct

---

[32] Edward Said *Orientalism* (Penguin Books, 2003)

[33] Philip Pettit *Just Freedom. A Moral Compass for a Complex World* (WW Norton, 2014)

[34] Cecile Laborde *Critical Republicanism* (Oxford University Press, 2008)

[35] arguably, in its entwining of two categories of rights previously contended to be clinically separate – civil and political rights and social, economic and cultural rights – the CRPD opens a space for what Broderick terms transformative equality, requiring a root and branch ideological and systemic approach to change; see Andrea Broderick *The Long and Winding Road to Equality and Inclusion for Persons with Disabilities* (Intersentia, 2015)

forms of rights entitlements.[36] Rather, however, the contention is that in the postmodern[37] circumstances of neoliberalism the role of the state has become much more about promoting market freedom rather than individual freedom. In consequence, the social and political grammar of Western politics has changed in ways deeply detrimental to individual human wellbeing and to the shared, if inchoate, commitment - from the Universal Declaration of Human Rights on - to consciously promote collective human flourishing by focusing on specific human rights.[38] In the context of this, the very basic goods disabled people are promised in the Convention - including accessing an adequate education, finding and retaining decent employment and being able to secure appropriate accommodation – are emblematic of a panoply of human rights goods that are increasingly difficult to assure across the general population too. Hence, broadening this perspective out across the wider community – while also helping to shape a new awareness of who that (diverse) community is – is seized on here as an opportunity for a purposeful solidarity, based, in part, on an appreciation of a shared human precarity.[39]

4 Phrasing a research question; freedom and human rights

Outside of a relatively slight, but growing academic interest, within the mainstream discourse, freedom (used interchangeably in this work with liberty) is not a perspective often explicitly applied in discussing disability and impairment. Perhaps this may be because as a global construct, disability is possessed of a long history of being perceived in negative terms, as a limiter on autonomy and individuality – these taken to be central to freedom's realisation. Perhaps in the imaginary of people who perceive themselves as *not* disabled disability represents freedom's antonym, the very essence of what it is to be un-free. Yet, what are human rights if they are not markers of freedom, individual and collective? What is the CRPD if it is not

---

[36] for example, the CRPD recognises in its article 6 that women and girls with disabilities are subject to multiple discrimination

[37] in broad scope, the postmodern descriptor seeks to delineate a period in which previously dominant institutions are in decline and in which the pace of change is rapid. Postmodernism is often characterised by reference to phenomena such as globalisation, the breakdown of local communities, increasing individualism, mass consumerism, cultural diversity and a hyper-reality rooted in media and, increasingly, social media. Of particular relevance to this dissertation - and often identified with postmodernism - is the phenomenon of neoliberalism and its emphasis on the 'freedom' of markets. Also, of relevance to this work is the notion that postmodernism marks a sundering with the idea of grand, sweeping meta-narratives used as supposedly universal and absolute truths to legitimise certain totalising political or scientific projects. Instead postmodernism is associated with local narratives – *little* stories – to include voices previously drowned out. See Jean Francois Lyotard *The Postmodern Condition: A Report on Knowledge* (Manchester University Press, 1984); Mairian Corker Tom Shakespeare 'Mapping the Terrain' in Mairian Corker Tom Shakespeare (eds) *disability/postmodernity* (Continuum, 2006) 1 - 17

[38] *Universal Declaration of Human Rights* (adopted 10 December 1948) 217 A (III) UNGA

a statement of the legitimacy of disabled peoples' entitlement to be free agents in the world? Arendt captures this well when she writes:

> [t]he fundamental deprivation of human rights is manifested first and above all in the deprivation of a place in the world which makes opinions significant and actions effective.[40]

Committed to the assertion that human dignity and human freedom are intricately meshed, this PhD dissertation positions its treatment of freedom in ways consistent with the quality of belonging Arendt alludes to. Committed too to a human rights reading of disability which acknowledges the CRPD's realization as having profound consequences for the *whole* of social and political organisation, this dissertation takes as its starting point that disabled people have been and continue to be relegated to an inferior status. Indeed, the implicit rationale of the CRPD can be said to derive from an international acceptance that, as the world's largest minority, the rights of persons with disabilities have been, everywhere, poorly realised.[41] Hence, the Convention's resolute purpose 'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms of all persons with disabilities and to promote respect for their inherent dignity'.[42]

With this dignity foregrounded, and asserting that freedom as non-domination represents a form of resilient individual power for all those within the polity, I turn now to phrasing a research question. I trust this question opens up a critically informed space in which to engage with the lived experiences of three distinct – but distinctly intertwined – cohorts of research participants: adults with vision impairment, parents of disabled children and persons working in professional roles in or with disability service providers. Further, I frame this question with specific reference to the Irish polity, while recognising that every state's domestic success – or not – in substantively realising the CRPD is implicitly a matter of international concern, inclusive, on the negative side, of generating significant formal external criticism and, even, potentially, sanctions.[43] The research question is as follows:

> *Drawing on a contemporary republican perspective, prefaced on an understanding of vulnerability as a universal human feature and*

---

[40] Hannah Arendt *The Origins of Totalitarianism* (Harvest, 1968) 296

[41] according to the World Health Organisation (2023) one in six of the world's population or 1.3 billion people are estimated to experience significant disability; see https://www.who.int/news-room/fact-sheets/detail/disability-and-health

[42] CRPD article 1

[43] see Charles R Beitz *The Idea of Human Rights* (Oxford University Press, 2011)

> *explored in the context of both the CRPD and the Irish polity, what value is derived from a robust understanding of freedom for disabled people, disabled people's families and those working with and for disabled people?*

5 Contextualising the research question

The question acknowledges an understanding of vulnerability as a continuum.[44] Further, the discussion that follows upon this question engages three specific CRPD rights – education, work and living independently/community inclusion - and draws, also, on the Convention's eight general principles to suggest that, applying a republican rubric, the CRPD can be read as a freedom charter of immediate relevance to all persons, whether at present living with impairments or not. I indicate this, in part, by offering a specifically republican engagement with each of the general principles and the three substantive rights.

The discussion is further contextualised by situating contemporary republicanism alongside liberalism. As a theoretical model liberalism is posited to be insufficient to ground the human rights entitlements of disabled people because it is based on ableist presumptions that intrinsically frame duties owed to disabled persons in terms of distributive justice, for example through welfare supports. Hence, for persons with disabilities the freedom liberalism offers is by way of *gift*, an idea fundamentally at odds with the CRPD's central representation of disabled people as autonomous holders of rights.

There is, perhaps, a useful contrast to be drawn here with the capabilities approach. As largely elaborated by Sen[45] and, in respect of disability, in particular, by Nussbaum,[46] the capabilities paradigm is a theoretical approach designed to direct attention to the analysis of the salient features of what it is to realise a dignified life, particularly, in circumstances of adversity. At its heart is the idea of substantive freedom, the idea that a person has a right to live a life the person values and has reason to value, a life that enables a person to flourish. Originally

---

[44] see, for instance Martha Albertson Fineman 'Equality, Autonomy and the Vulnerable Subject in Law and Politics' in Martha Albertson Fineman Anna Grear (eds) *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics* (Ashgate, 2013) 11 - 27

[45] Amartya Sen 'Equality of What?' in Stephen Darwall (ed) *Equal Freedom. Selected Tanner Lectures on Human Values* (University of Michigan Press 1995) 307 – 330; Amartya Sen *The Idea of Justice (*Penguin Books, 2009)

[46] Martha Nussbaum 'Human capabilities, female human beings' in Martha Nussbaum, Jonathan Glover (eds) *Women, Culture and Development: a study of human capabilities* (Clarendon Press, 1995) 61 – 104; Martha Nussbaum *Women and Human Development: the Capabilities Approach* (Cambridge University Press, 2000); Martha Nussbaum *Creating Capabilities: the Human Development Approach* (Belknap Press, 2011)

formulated within the context of Sen's work in development economics, the capabilities approach eschews traditional economics' narrow focus on identifying economic development as simply a function of resource management, such as improving gross national product or ensuring personal incomes rises or supporting technological and industrial innovation. Rather, in Sen's understanding, important as these issues undoubtedly are, the real measure of development's success in a society is the degree to which that development is *for* a society and its individual members, rather than, say, to expand the economy or enhance people's status as producers and consumers of goods and services. In this reading, the key focus becomes the degree to which development diminishes un-freedom.

Particularly in Nussbaum's formulation of it, the capabilities paradigm is much friendlier to the interests of disabled people, framing their equality demands in terms of social justice in ways that are argued to be strongly affirmative of the human rights discourse.[47] My intention in holding up liberalism and the capabilities approach in this way is to show not just how republicanism can challenge and enrich both perspectives but also *be* challenged and enriched by them. After all, all three traditions, above all else, posit themselves as freedom focused, whatever their flaws in terms of range. This enrichment seems to me to be particularly relevant in terms of exploring harmonies between the capabilities approach and republicanism.[48]

In this way, I intend to draw out republicanism's unique – if largely inchoate - features for supporting the freedom interests of persons with disabilities and to present republicanism as a radical theory that offers robust protection against the arbitrary intrusions of others. I also seek to frame republicanism in terms of capacity building, specifically as a source of empowering resources for disabled people – such as education, employment and appropriate housing - so that persons with disabilities might more resiliently resist subjugation and other asymmetries of power. Finally, I posit freedom as non-domination as an important mechanism of convergence with the wider community, providing disabled people 'reason to identify with other people, and ultimately with the polity itself' and vice versa.[49]

---

[47] see Martha Nussbaum *Frontiers of Justice: Disability, Nationality, Species Membership* (The Belknap Press, 2006); indeed both Nussbaum and Sen have argued that the capabilities approach can form the basis of a theory of human rights, see Amartya Sen, 'Elements of a Theory of Human Rights' (2004) 32 (4) Philosophy & Public Affairs 315; Martha Nussbaum Capabilities and Human Rights (1997) 66 (2) Fordham Law Review 273

[48] see Philip Pettit 'Freedom in the Spirit of Sen' in Christopher Morris (ed) *Amartya Sen* (Cambridge University Press, 2010); Philip Pettit, 'Capabilities and Freedom: A defence of Sen' (2001) 17 (1) Economics and Philosophy 1

[49] Philip Pettit *Republicanism: A Theory of Freedom and Government* (Oxford University Press, 1997) 125

6 The research approach employed: a critical orientation

A unique feature of this dissertation and central to the contribution I wish to make to socio-legal scholarship is its tripartite engagement with blind and vision impaired persons (some of whom have additional impairments), parents of persons with disabilities and persons working professionally in or with services for disabled persons. Each of these cohorts is introduced in the methods section of this dissertation and a rationale is offered for each cohort's involvement in the research. At this point, however, it is useful to say something about the interdisciplinary methodological perspectives relied on in this work, and how these are deployed. To begin, contemporary republicanism, itself, is explicitly identified as a research programme,[50] and one, I believe, whose emancipatory ethic – prefaced on a politics of participation and ever-broadening inclusion – positions it within the critical tradition.[51] Situating non-domination alongside a free state and a free citizenry, Lovett and Pettit suggest a framework for 'a useful public philosophy.'[52] This framework can be explored, not just by thinking out its implications in theory, but also by putting them into political practice. Contemporary republicanism is available for use in the public square as well as in the academic seminar.[53]

The ambit for this research programme encapsulates justice in all its domains - social, political and international. More, Pettit asserts that whether the context is abusive private power (*dominium*) or abusive public power (*imperium*), every problem is addressable if an open posture is adopted to the question 'how best to promote the enjoyment of freedom as non-domination.'[54] This, then, is a research programme which potentially embraces and heuristically connects both the traditionally political and the traditionally non-political spheres.[55] It encompasses un-freedom instantiated by state power but also as found in a variety of relationships, including within what, in the lives of persons with disabilities, O'Shea usefully terms micro-dominations.[56] Indeed, Pettit himself often draws on examples of individual

---

[50] Marti and Pettit (n 20)); Frank Lovett Philip Pettit Neorepublicanism: A Normative and Institutional Research Program 12 2009 Annual Review of Political Science 11 - 29

[51] Laborde (n 34)

[52] Frank Lovett, Philip Pettit, 'Neorepublicanism: A Normative and Institutional Research Program' (2009) 12 (1) Annual Review of Political Science 11, 25

[53] Marti and Pettit (n 20) 160

[54] Pettit (n 33) xvii

[55] Iseult Honohan 'Republicans, Rights, and Constitutions: Is Judicial Review Compatible with Republican Self-Government' in Samantha Besson Jose Luis Marti (eds) *Legal Republicanism* (Oxford University Press, 2009) 83 - 101

[56] Tom O'Shea, 'Disability and Domination: Lessons from Republican Political Philosophy' (2018) 35 (1) Journal of Applied Philosophy 133. O'Shea defines micro-dominations as arbitrary intrusions into

personal circumstances to illustrate the non-domination thesis, contending that dominium may represent the most pervasive source of domination.[57] However, although pointing clearly to the research programme's potential in terms of disclosing the institutional and normative implications of republicanism's core ideals within the framework of both imperium and dominium, nonetheless, in respect of the latter, the research programme remains to be broadly tested. Rather, thus far, in the main, its utilisation is principally associated with the academy, for example in relation to exploring issues of public policy and institutional design,[58] as well as issues of transnational and global institutional design.[59] The programme's application within the more intimate spaces of the social bond remain largely uncharted.

In seeking to deploy republicanism as method, this dissertation is alert to the ways in which state power might oppress and perhaps even *disable* people living with impairments. Hence, for example, in the context of the liberal, democratic commitment to promote freedom I apply a republican lens in suggesting what the state should do and what it should *not* do in respect of promoting and supporting the specific human rights under discussion. That many of the barriers to achieving these rights are likely to entail domination in the republican sense seems to me a quite plausible avenue for exploration. However, it is plausible too to assert that for many persons living with impairments domination is multi-vectoral, not least because many disabled people require both interpersonal and institutionally mediated supports and accommodations to live dignified lives, inclusive of – but not confined to - state mediated supports.

In presenting republicanism as a critical method, it now becomes useful to situate contemporary republicanism within the wider critical theory tradition. In explaining why I believe this to be so I am indebted to Laborde's contention that such a juxtaposition better supports the researching of 'forms of domination which, being the product of indoctrination, manipulation, and norm internalization, remain invisible to their victims.'[60] Further, because critical theory – including critical disability theory (also termed, critical disability studies) – is premised on activism it strengthens modern republicanism's clear social justice resolve, permitting an openly emancipatory approach to research among oppressed people. Thus, since at its core the critical theory tradition focuses on the application of theory to practice specifically as this relates to the

---

another's choices which, although while each in themselves too minor to be contestable in a court or tribunal, cumulatively have a significant adverse impact.

[57] see, for example, Pettit (n 33)

[58] Frank Lovett Philip Pettit Neorepublicanism: A Normative and Institutional Research Program (2009) 12 (1) Annual Review of Political Science 11

[59] James Bohman 'Nondomination and Transnational Democracy' In Labordre and Maynor (n 23) 190 - 216

[60] Laborde (n 34) 23

practices of freedom the fit with contemporary republicanism seems natural. I return to this in greater detail in the methodology chapter, where I lay out critical theory's origins and its claim to be a research approach which is particularly attentive to the experiences of oppressed groups.

However, with specific reference to persons with disabilities, there is one further reason why I seek to situate contemporary republicanism within the broader critical theory context. It is this. Pettit's vision of a social order within which domination is robustly resisted comes up hard against a world within which persons with disabilities experience routine (and often un-reflected upon) oppression. That this oppression may derive from multiple sources, including attitudinal, environmental and cultural vectors, demands a research consciousness that is closely attentive to the lived experiences of disabled persons. Within the republican ideal, a well-ordered state secures – through its laws and practices, including welfare provision – that the everyday interactions of those living in the state are free from domination. Yet, as with Rawls' justice thesis, disabled people do not appear to fit comfortably into a contemporary republican analysis. Indeed, in the context of adjudging competing claims, Pettit identifies relevant claimants to include 'all adult, *able-minded*, more or less permanent residents' in a state.[61]

Again, as with Rawls, this disconnect with persons with disabilities must not be interpreted as disinterest. Rather, I fear it is perhaps something more damaging: a dismissal of agency and an expression of a (likely dominating) paternalism that misattributes the legitimacy of disabled persons' own values, interests and rationales in living lives of their own choosing. More specifically, within a research context it also highlights why a sole reliance on republicanism – even on a critical republicanism – as a research paradigm is problematic. This is so, not least, in the context of the common report that disabled persons have experienced research as done *to* them rather than *with* them. Hence, the need to ensure, first, that a social inquiry into the experience of domination does not, itself, dominate.

7 Research that matters; a word on methodology

This realisation opens up the idea that before proper recourse to a properly critical republican research analysis, there is the need for something akin to a methodological filtration system. Implicit in this is an intense reflexivity, a scrutiny of my own presuppositions and the epistemic privileges I grant myself. This is necessary because in asking the particular research participants in the instant research to reflect with me as researcher they are contracting with me that what is produced bears truthful witness, in distilled form, to their lived experiences in ways that

---

[61] Philip Pettit *On the People's Terms* (Cambridge University Press, 2012) 78 (emphasis added)

matter. Part and parcel of this contract is that I demonstrate rigour and reliability in respect of connecting theory to data. But, also, I must ensure that the voice of the research participant – not my own - is amplified with respect and dignity. I read this latter commitment as relating to the ideal of research as an empowering, emancipatory activity. With this foregrounded, here, I seek to reiterate why a more robust critical research orientation works as a valuable interpretative paradigm in the context of the instant research. I frame this in terms of finding a mechanism whereby I can *live* critical theory's overarching commitment to critical self-awareness as non-negotiable in the research process. As Forst insists, a theory only counts as critical if it understands itself as 'an activity that reflects back on itself and its own blind spots and exclusions in a self-critical manner.'[62]

Within the critical theory frame this is an ethical call to me as researcher to consciously stand apart from my own privilege and to interrogate my own biases, explicitly factoring these into the research process, aiming consciously to demonstrate what Bourdieu refers to as the objectification of the objectifying subject.[63] In doing this I reject the notion of the social world as an objective thing, that is

> as a spectacle offered to an observer who takes up a 'point of view' on the action….[and] proceeds as if It were intended solely for knowledge and as if all the interactions within it were purely symbolic exchanges.[64]

Denying the idea of an objective social world moves the nature of inquiry away from the notion that certainty subsists in the objective in favour of a profound, systematised engagement with the subjective, that is, perceiving how the world shapes consciousness and how consciousness shapes the world. In venturing this approach, I make recourse to elements of a critical phenomenology and, within that, to a method found in Dahlberg *et al.*[65] As elaborated on in Chapter Four, I do this because, as researcher, I cannot claim an emancipatory ethic without committing to a research approach which is fully dialogic, interrogating myself and my world so that I might better attune to the experiences of others and their worlds.

In engaging with critical phenomenology it presents not merely as a methodological choice among other choices. Rather, it presents as a profoundly radical way of encountering the social world and the distilled experiences of people living in it, operating not so much in the realm of

---

[62] Rainer Forst *Justification and Critique: Towards a Critical Theory of Politics* (Polity Press, 2014) 8

[63] Pierre Bourdieu *Pascalian Meditations* (Polity Press, 2000)

[64] Pierre Bourdieu *The Logic of Practice* (Polity Press, 1990) 52

[65] Karin Dahlberg Nancy Drew Maria Nystrom *Reflective Lifeworld Research* (Studentlitteratur, 2001)

what is seen but, specifically concerning itself with *ways* of seeing. Thus, the importance of having a sound working sense of the philosophical underpinnings of critical phenomenology as a method.

This radical nature of a critical phenomenology is captured in the sense that it is inherently vocational, that is, as method it is required not just to amass and describe data but also to exemplify a commitment 'to repair the world, encouraging generosity, respect and compassion.'[66] In this, it exemplifies a baseline requirement for research with persons with disabilities and their families, namely that any method employed be inherently emancipatory. Within its strongest meaning in modern disability research 'emancipatory' refers to a close tie between research and political activism. Indeed, Oliver has argued that the only research that merits doing in relation to people with impairments is that which directly improves lives by removing social and economic barriers.[67] Others, however, refute this narrowly focused activist requirement, holding that research with disabled people can be no less emancipatory for focusing on hearing positive stories, unconnected explicitly to a political agenda.[68] A critical phenomenology is comfortable with both these perspectives.

Tying this recourse to an emancipatory critical phenomenology back to an explicitly critical republicanism, it is useful to cite Laborde's recognition of republicanism as

> at bottom an ideal of progressive, egalitarian, and social-democratic citizenship, which points to a society where all citizens enjoy basic but robust civic standing, in the form of political voice, minimum personal autonomy, material capabilities, equal opportunities, and intersubjective mutual recognition as equals.[69]

Enfolded in this, I believe, is a societal, cultural and political invocation striking to the framers of the CRPD and to those vastly many disabled people and their families who find the present polity deficient in substantiating this vision to citizens with impairments.

---

[66] Gail Weiss Ann V Murphy Gayle Salamon 'Introduction' in Gail Weiss Ann V Murphy Gayle Salamon (eds) *50 Concepts for a Critical Phenomenology* (Northwestern University Press, 2020) xiv

[67] Mike Oliver, 'Changing the Social Relations of Research Production?' (1992) 7 (2) Disability, Handicap & Society 101

[68] see, for example, Tom Shakespeare *Disability Rights and Wrongs Revisited* (Routledge, 2014)

[69] Laborde (n 34) 254

8 Language use

As de Beauvoir phrases it, ‘the body is not a *thing*, it is a situation’.[70] In this, Beauvoir is reflecting, in part, on the agentive freedom maleness confers on bodies and the consequent restrictions and constraints this imposes on the female body. A similar reflection opens up in relation to the so-called disabled body. If, as Shilling contends, the body is the core project of modernity[71] - that is, the central focus of human identity – then claiming impairment as a positive becomes a political act of immense importance, I would say, even of republican importance. Doing so, in addition to confronting what Siebers calls the ideology of ability,[72] opens up the disabled body as an inter-sectional text, one which permits a deeper reflection on the essence of what it means to be human, and of what we share especially, perhaps, in a time of climate change, global insecurity and advancing artificial intelligence.

Although never neutral in any setting, language use in relation to impairment is particularly contested, reflecting the ‘countless ways in which difference is rearticulated as disability, disorder or deficit.’[73] A core concern of a critical phenomenological research approach is to attend to the language in use within discursive systems so it is appropriate here to briefly reference some main terms and phrases that reoccur in this dissertation’s discussion of disability. In part, this is offered in order to give explicit recognition to what is described as ‘a hierarchy of terminologies and oppressive metaphors’ relating to how words are used in disability contexts.’[74]

A particular debate exists in respect of the phrases ‘disabled person’ and ‘person with a disability’. Detractors of the former phrase advocate for a *person first* descriptor, arguing that it is inappropriate to employ a phrase which suggests that the entire person is disabled because of a specific impairment.[75] In part, this view may speak to a concern that too often when persons with disabilities are encountered what is seen first is the wheelchair, the while cane, the hearing aids or the picture boards and that this way of seeing occludes the person, confusing the person with the tools they use. Yet, there are also strong arguments voiced against the person first

---

[70] Simone de Beauvoir *The Second Sex* (Vintage Books, 2010) 68 (italics in original)

[71] Chris Schilling *The Body and Social Theory* (Sage, 1993)

[72] Tobin Siebers *Disability Theory* (University of Michigan, 2008)

[73] Linda J Graham, Susan Grieshaber, ‘Reading dis/ability: interrogating paradigms in a prism of power’ (2008) 23 (3) Disability & Society 557, 561

[74] David Johnston *An Introduction to Disability Studies* (Routledge, 1998) 11

[75] Tanya Titchkosky *Disability, Self and Society* (University of Toronto Press, 2003)

usage, contending that ‘person with a disability’ is polarizing and disempowering, and noting that we do not speak of a ‘person with a gender’ or a ‘person with a race.’[76]

Given this tension, this dissertation will use both ‘person with a disability’ and ‘disabled person’ (and their plurals) interchangeably, the intention being to show respect to both sides of the debate. Remembering, however, that the issue concerning this dissertation is less the individual body – and its nomenclature - as it is reforming ‘the disabled body politic.’[77]

Later, I also have recourse to the phrase ‘service user’. This is also a contrasted phrase, not least in respect of its perceived reductive nature and, also, the perceived negative connotations of the specific word ‘user’. However, I recognise the near ubiquity of the word across multiple domains and so employ it here, although always in quotation marks - that is, when I use it - to indicate my own discomfort with it.

However, standing behind these language debates is perhaps a lack of ease with the concept *disability* itself, a signifier of a somewhat nebulous notion whose social significance connects intimately to a myriad of shifting social, legal, economic and cultural processes. Arguably, for most of recent human history disability has been simplistically presented as a binary – a *you are* or *you aren't* construct – in which unfortunate, *afflicted* people *suffered* disability and healthy, *whole* people did not. This binary persists despite many decades of disability activism. Indeed, it is illustrated in the World Health Organization's (WHO) presentation of disability as an umbrella term denoting the negative interaction of impairment, activity limitation and participation restriction with multidimensional contextual factors, both particular to an individual and resulting from environmental factors.[78]

Turning to how other people are referenced in this work any recourse to the word ‘normal’ or any variant thereof is recognized as unhelpful and as implicitly disrespectful, as well as potentially disempowering, to persons with disabilities. Goffman describes how employing *normal* as a construct transmutes difference into stigma[79] and, in a postmodern context perhaps, Goodley reflects on how disabled children are alienated yet further by a culture of

---

[76] see, for instance, Richard Devlin Dianne Pothier ‘Introduction: Towards a Theory of Dis-Citizenship’ in Devlin R, Pothier D, (eds) *Critical Disability Theory. Essays in Philosophy, Politics and Law* (UBC Press, 2006)
[77] Stephen J Meyers *Civilizing Disability Society* (Cambridge University Press, 2019) 164
[78] World Health Organisation *The International Classification of Functioning, Disability and Health* (WHO, 2001)
[79] Erving Goffman *Stigma. Notes on the Management of Spoiled Identity* (Penguin Books 1990)

professionalised parenthood wherein the hope is to produce not merely *normal* but gifted or exceptional offspring.[80]

Again, certain phrases such as 'people who describe themselves as not disabled' are employed, although always self-consciously. For me, decisively the most accurate phrase I have found is coined by Irving Kenneth Zola who references 'the not yet disabled,' reflecting the reality that disability can occur in anyone's life, suddenly, randomly, as the result of aging, or a distracted driver, a mutating gene or some other physical or psychological or cognitive change.[81] Zola's phrase is the one I prefer to use. Not least, I employ it because in my own phenomenological bracketing/bridling[82] Zola's phrase seems the most true to the thoughts and personal circumstances and idiosyncrasies I bring to this research.

9 Vision impairment: measurement, numbers and aetiology

The terms 'visual impairment' or 'vision impairment' are used in this work as functional devices, indicating damage to the visual system – meaning both the eyes and/or the brain – such that the performance of ordinary daily living or educational tasks is impeded.[83] Phrased in this way, vision impairment can be used as an overarching descriptor for all sight problems, including blindness.[84] Also implicitly included, within a global context, are those sight disorders which can be remedied by using refractive correction, that is, spectacles or contact lenses, but which are inadequately available in economically poorer parts of the world. [85] Hence, the World Health Organisation (WHO) now defines visual impairment as falling within two groupings: distance vision impairment and near vision impairment.[86] Both groupings rely on the idea of visual acuity (VA). Commonly understood as referring to the clarity or sharpness of vision, in the United States – and, indeed, as often referenced in the wider English vernacular - VA is measured at a distance of twenty feet. Hence, the person who claims 20/20 vision is one who can be said to see clearly

---

[80] Daniel Goodley *Disability Studies* (Sage, 2017)

[81] Irving Kenneth Zola *Missing Pieces: a Chronicle of Living with a Disability* (Temple University Press, 1982)

[82] bracketing / bridling is explained in detail in Chapter four, but , for here, broadly, it references a conscious technique for recognising and setting aside one's preconceptions as a researcher

[83] Amanda Hall Lueck 'Comprehensive Low Vision Care' in Hall Lueck A, (ed) *Functional Vision: A Practitioner's Guide to Evaluation and Intervention* (AFB Press, 2004)

[84] It is recognised that this is not a universally agreed usage; however, it does have the perceived benefit of presenting vision impairment as part of a continuum of embodied experience which embraces sight and various nuanced experiences of sightlessness; see David Bolt, 'From Blindness to Visual Impairment: Terminological Typology and the Social Model of Disability' (2005) 20 (5) Disability & Society 539

[85] World Health Organisation *Global Initiative for the Elimination of Avoidable Blindness: Action Plan 2006 – 2011* (WHO, 2007)

[86] World Health Organisation *Fact Sheet: Blindness and Vision Impairment.* Available at https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment

at twenty feet what should normally be seen at that distance. In this vain, a notional person whose vision is 20/100 is one who requires to be at a distance of twenty feet from an object to see it with the same clarity that it can be seen by a person with 20/20 vision at one hundred feet distance. [87]

Different jurisdictions utilise different measurement scales. Thus, in Ireland and in the United Kingdom metres are used, meaning that a reading of 6/6 is considered a perfect VA.[88] Indeed, the WHO groupings also utilise metres with, for example, near vision impairment - a global challenge affecting over a billion people[89] - measured in terms of binocular presenting acuity of less than 6/12 at 40 centimetres. As for distance vision impairment, WHO employs a four-stage typography: mild (VA between 6/12 and 6/18), moderate (VA between 6/18 and 6/60), severe (VA between 6/60 and 3/6) and blindness (VA less than 3/60).[90] Taken cumulatively, estimates put the world's vision impaired population at 2.2 billion, with 75% of existing blindness and moderate or severe vision impairment identified as preventable or treatable conditions, making poverty a particularly significant predisposing factor.[91] Phrased another way, studies indicate that approximately 89% of vision impaired people now live in low-income countries.[92] By way of further emphasising the substantial variation in the causes between and within countries relative to the availability of affordable eye care services and general eye care literacy the main cause of vision impairment in Ireland for older people is age-related macular degeneration (AMD).[93] AMD is a progressive degenerative disease which typically manifests in those over 50 years of age and which results in loss of central vision while leaving peripheral vision intact.[94] Although some treatment is available for AMD there is no cure. By contrast, worldwide, the

---

[87] blindness is measured differently in different places but in the US the phrase 'legally blind' is used to indicate a visual acuity of 20/200 or less or whose visual field in the better eye, with corrective lenses, is 20 degrees or less; see the Social Security Act 1935. Missing from this definition is an account of how an individual might use residual sight

[88] Of course, visual acuity only measures one aspect of eye functioning. Other important vision skills, including peripheral vision, eye coordination, depth perception, focusing ability and colour vision, contribute to the person's overall vision ability.

[89] Srinivas Marmamula, Jill Keeffe, Rajesh Challa, Javed Mohd, Rohit C Khanna, 'Near-vision impairment and effective near-vision spectacle coverage in two districts in Telangana, India: a population-based cross-sectional study' (2021) 11 (4) BMJ Open 1

[90] note 85

[91] preventable or treatable refers here as any vision loss due to cataract (a clouding of the eye's lens), uncorrected refractive error (such as near-sightedness and far-sightedness), trachoma (a bacterial infection), glaucoma (optic nerve damage usually associated with fluid build-up), diabetic retinopathy (a complication of diabetes) or corneal opacity (scarring to the clear front layer of the eye).

[92] Laser Eye Surgery Hub Vision Impairment and Blindness Global Data and Statistics Q4 2020 Update at https://www.lasereyesurgeryhub.co.uk/data/visual-impairment-blindness-data-statistics/

[93] National Council for the Blind Ireland *Facts About Sight Loss* available at https://ncbi.ie

[94] Randall T Jose *Understanding Low Vision* (American Foundation for the Blind, 1989)

single biggest cause of blindness – affecting some 65 million people[95] - is cataract, a condition which can, routinely, be entirely reversed by a fifteen minute out-patient procedure.

In Ireland, some 54,810 people have self-identified as blind or vision impaired.[96] Of this number, 5% - or approximately 2,750 people – are identified as blind. However, even within this designation -'blind' - there is considerable variation in terms of what can be seen, including in terms of what eye specialists call useful vision. Indeed, although difficult to estimate, there is common agreement in the literature that only about ten per cent of people who come within the descriptor 'blind' have no light perception (NLP). More, Damon Rose, blind from birth and whose blind registration certificate bears the letters NLP, attests to the experience that, for him, not perceiving light does not mean living in an inevitable darkness. Rather, Rose describes a 'visual tinnitus' such that a 'built-in fireworks' display never goes away, even when he closes his eyes.[97] By way of contrast Hull, who became blind at the age of forty eight, describes a state of what he calls a deep blindness, such that even the very memory of seeing dwindled to nothing and concepts such as 'here,' 'there' and 'facing' lost all heuristic meaning.[98] Yet Sacks cites NLP blind people who represent themselves as visually confident – *seeing* their hands on a keyboard as they type, for example – and capable of reliably manipulating inner powers of visualization to extraordinary external effect.[99]

The types of personal accounts briefly mentioned here – what has been called 'a literature of witnessing'[100] - indicate a much more complex experiential reality of vision impairment than that which persists in mainstream – that is, supposedly non-disabled – culture.[101] From within this culture it would seems intuitively true to claim that vision impairment is a taken-for-granted state, an obvious and straight-forward phenomenon, measurable and definitive and tragic in the *loss* it represents. However, this dissertation seeks to suggest that vision impairment and blindness are *not* so obvious. Hence, it becomes important to tease out this culture which blithely claims otherwise, to understand its roots and at least something of the way in which

---

[95] World Health Organisation Blindness and Vision Impairment (26 February 2021) available at www.who.int/news-room/fact sheets/detail/blindness-and-visual-impairment

[96] 2016 Census, Ireland Central Statistics Office

[97] Damon Rose, '*Do blind people really experience complete darkness?'* 25 February 2015 at https://www.bbc.com/news/blogs-ouch-31487662

[98] John Hull *Touching the Rock: An Experience of Blindness* (Pantheon, 1991)

[99] Oliver Sacks *The Mind's Eye* (Picador, 2010)

[100] Siebers (n 72) 47

[101] see also M Leona Godin *There Plant Eyes* (Vintage, 2022); Maud Rowell *Blind Spot* (Inklings, 2021)

vision impairment has been socially constructed, its largely negative presence in the Western imaginary a product of 'the hegemony of the normal.'[102]

10 Vision impairment: a socio-cultural reading

Vision impairment, particularly blindness, holds an often contradictory, but, nonetheless, unique place in the Western imaginary. First, from antiquity comes images of the blind person as mythologised into a complex fusion: in some interpretations blindness indicating a punishment imposed by the divine, in others, blindness being a mark of some special calling, even as a conduit to a world beyond the visible. As Barasch has it, these interpretations are not necessarily contrary to each other, the double face of blindness in Greco-Roman times often being represented as arising from and resulting in an intimacy with the Gods.[103] None of this goes to minimising the sense of personal disaster blindness and other forms of vision impairment represent in antiquity. Nor is the mythologizing of blindness exclusive to the Greco-Roman world; for instance, in Norse mythology there is a blind God, Hoor. [104] But, arguably, it does feed into a still prevailing sense that in the continuum of impairment blindness remains simultaneously a deeply mysterious, frightening yet strangely familiar phenomenon. Schillmeier terms this 'the radical ambiguity of blindness,' indicating that what links ancient and modern cultures is their being prefaced on vision and light and, indeed, on 'the practices of face-to-face relations.' [105] Arguably, this idea is a fit with the frequency that blindness is identified in surveys as the impairment people dread most, indicating that to be deprived of visual information presents as the worst possible loss.[106] Perhaps too, there is an intuitive sense that to be vision impaired is to be isolated from the community: the face-to-face representing that social and political gathering that undergirds authentic, accountable, democratic participation.[107]

Second, there is the role early Christian topography plays in enforcing a particular cultural representation of vision impairment. This representation deepens the way in which blindness as metaphor is used and results in a distinct *othering* of vision impairment. In both the Old and

---

[102] Lennard J Davis *Enforcing Normalcy: Disability, Deafness, and the Body* (Verso, 1995) 49

[103] Moshe Barasch *Blindness: the History of a Mental Image in Western Thought* (Routledge, 2001)

[104] see, for instance, Michael David Mullaney *Children of a One-Eyed God: Impairment in the Myth and Memory of Medieval Scandinavia 2019* Electronic Theses and Dissertations. Paper 3538. Available at *https*://dc.etsu.edu/etd/3538

[105] Michael Schillmeier *Rethinking Disability* (Routledge, 2010) 42

[106] see, for instance, Maud Rowell *Blind Spot* (Inklings, 2021); Adrienne W. Scott Neil M. Bressler Suzanne Ffolkes John S. Wittenborn James Jorkasky Public Attitudes about Eye and Vision Health 134 10 2016 JAMA Ophthalmology 1111 - 1118

[107] see, for instance, Hannah Arendt *The Human Condition* (University of Chicago Press, 1998)

New Testaments, the healing of blind persons is a recurring event, its imagery speaking to a symbolic rescuing from the darkness of sin and eternal death. As to how this association of blindness with sin and suffering comes to shape the experiences of blind people Wheatley describes how in medieval Europe the increasingly fervent practice of *viewing* the sacred, consecrated Eucharistic host - rather than consuming it – marked out the visually impaired as *de facto* spiritually inferior.[108] Nor was the issue confined to participation in religious rituals. Following the Neoplatonic worldview, that sight is not alone a physical trait but also a function of the soul, the blind person's lack of fully functioning vision goes to her inability to properly apprehend God's goodness as manifest in nature.[109] Having the capacity to see physically was taken to exemplify having the sight to see spiritually, meaning in this latter sense the ability to access information about the world pre-inscribed on the human soul by the Creator.[110] Hence, in a world wherein the supernatural pattered every aspect of the human realm, to have a vision impairment was to be much more than merely physically disabled. Rather, it was also to have a cognitive disability such that the blind were literally *lost* in darkness, estranged from the light of God. Illustrative of this, Barasch draws on one partially surviving Italian fresco of 'a pack of ugly and deformed cripples and beggars,' two or three of whom represent blindness. Barasch asserts that while all the other figures in the fresco seek to flee the approach of Death, this specific group stand, arms outstretched, 'imploring him to relieve them from their pain and suffering.'[111] What is suggested here is the hopelessness – the despair – of having impairments and a sense that those actively fleeing Death have a moral worth, a *significance*, which blind and other disabled people's lives lack.

According to Barasch this association of blindness with profound moral fault survived well into the Renaissance period, by which time the image of the blind beggar had become a well-established trope. Barasch recounts how in this context blindness becomes associated with underhandedness, social deviancy, deceit and fraud.[112] Moreover, just as blind people become objects of suspicion so too do they emerge as figures to be taunted, lampooned and physically endangered for their perceived failings. Derrida writes that 'the expulsion of the beggar keeps

---

[108] Edward Wheatley *Stumbling Blocks Before the Blind: Medieval Constructions of a Disability* (University of Michigan Press, 2010)

[109] James F Burke *Vision, , the Gaze, and the Function of the Senses in* Celestina (Penn State University Press, 2000)

[110] Connie Scarborough *Viewing Disability in Medieval Spanish Texts* (Amsterdam University Press, 2018)

[111] Barasch (n 103) 117

[112] *ibid*

the outside within, and assures an identity by exclusion.'[113] Similarly, Davis talks about how disability undermines citizenship by disrupting the gaze of the *normal* citizen, requiring disability 'to be regulated, rationalized, contained.'[114] The totemic example of both this keeping the outside inside and the supposed maintenance of societal order to which Davis avers is, perhaps, the emergence of an extensive system of impairment-specific asylums and institutions, the earliest of which, for people with vision impairment, was the Hospice des Quinze-Vingts, founded in Paris in 1260. [115] Such institutions operated on multiple levels. The residents of the Quinze-Vingts, for example, became uniformed, officially licensed beggars[116] and, in this, there was not just an explicit separating out of the deserving from the un-deserving but also, a sort of nascent quality assurance at play: for *these* people pity might safely be felt and expressed – most usefully, of all, in charitable support of the institution itself.

Within the institutions - some styled asylums for the blind – strict regulatory regimes operated, with the people accommodated there being expected to be gratefully available for the edification of the wider public.[117] In thus being presented as 'instruments of redemption for non-disabled folk'[118] there was arguably every incentive for the institutions to contribute to a reductionist, stigmatising presentation of vision impaired people in particular and of wider issues of disability in general. As for those living with vision impairment outside the institutions – inevitably, the greater number[119] – Hayhoe argues that the wider societal perception of blindness continued to be largely influenced by the pedagogies developed within the institutions for the blind.[120] So, even as vision impairment began to lose its more apocryphal religious connotations, one totalising idea – Hayhoe terms it a myth – continued to dominate the wider societal understanding of blindness: that people who are blind are a homogenous community.[121] This is an iconography of vision impairment, as Michalko argues

---

[113] Jacques Derrida *Given Time: I. Counterfeit Money* (University of Chicago Press, 1992) 135

[114] Lennard Davis *Enforcing Normalcy: Disability, Deafness and the Body* (Verso, 1993) 129

[115] see Edward Wheatley, 'Blindness, Discipline, and Reward: Louise IX and the Foundation of the Hospice des Quinze Vingts' (2002) 22 (4) Disabilities Studies Quarterly 194

[116] *ibid*

[117] see, for example, Hazel McFarlane Out of Sight, Out of Mind: Blind Asylums and Missions in Scotland. In Roy

[118] Bill Hughes Invalidating Emotions in the Non-Disabled Imaginary. In Nick Watson Simo Vehmas (Eds.) *Routledge Handbook of Disability Studies* (Routledge, 2020) 89

[119] for example, the 1851 Irish Census – unique in contemporary Europe (including England and Wales) in its inclusion of data on vision impairment – reported that of the 7,587 blind people then identified as living in Ireland, only 12% were in institutions, in the main, workhouses; see Susan Mullaney, 'Sir William Wilde and provision for the blind in nineteenth century Ireland' [2016]185 Irish Journal of Medical Science 281

[120] Simon Hayhoe *Philosophy as Disability and Exclusion* (Information Age Publishing, 2016)

[121] *ibid*

> that "comes to us" — to blind and sighted people alike — always-already framed by and wrapped in the "one size fits all" conceptual and material cloak of culture. In this sense, there is no direct experience of blindness since, to experience it, is to experience a multitude of cultural representations of what it culturally means to be blind and to be sighted.[122]

In this context then, Michalko, himself blind, can acknowledge that the idea that vision impairment is the opposite of sight 'is a fact – even though it isn't true.'[123] Hence, the problematic binary persists, with every use of a jaded phrase such as 'the blind' displacing individuality and implicitly positioning people with vision impairment in a subordinate, inferior position to *normal* people, 'the sighted.'[124]

As to the enduring legacy of this seeing/unseeing binary, it has permitted the lived experiences of vision impaired people to be abstracted from, such that even as late as the Enlightenment, philosophers argued about the efficacy of educating blind people. Hence, Locke maintained it to be a futile activity while others, most prominently Diderot, insisted that the ability to reason was not conditioned on seeing.[125] Indeed, Hayhoe writes of how, from the Enlightenment on, 'the plight of the blind [became] an infamous object of fascination, like the Galapagos Islands to Evolutionists, for centuries to come.' [126] In this, vision impaired people became objects of academic interest far in excess of that shown towards people with other impairments. Partly, perhaps, this was because in times of political insecurity the blind person could be employed as a metaphor behind which a range of contentious subjects could be shielded. Arguably, too, deaf people aside, the blind person has had a corporeal presence in everyday society that yet still is not mirrored by people with other, perhaps more seemingly complex, impairments, and thus making it more likely that blind people are often hypothesised in public discourse. However, this hypothesised blind person's primary function is, invariably, not to enlighten from *within* her own unique experience of living with vision impairment. Rather, it has been to act as a comparator

---

[122] Rod Michalko. 'What's Cool About Blindness' (2010) 30 (3/4) Disability Studies Quarterly (no page)

[123] *ibid*

[124] see David Bolt, 'From blindness to visual impairment: terminological typology and the Social Model of Disability' (2005) 20 (5) Disability & Society 539

[125] see John Locke *An Essay Concerning Human Understanding* (first published 1689, Penguin Books, 1997); Denis Diderot Letter on the Blind for the Use of Those Who See (1749). In Lester G Crocker (Ed.) *Diderot's Selected Writings* (Macmillan, 1966)

[126] Simon Hayhoe *God, Money and Politics* (Information Age Publishing, 2008) 33

to better extol the superiority of sight; indeed, often, still, being blind is positioned as nothing more than a lack of sight.[127]

In circumstances such as these, 'when insight is equated to sight and light,'[128] it can hardly surprise that what evolves is a dominant culture which is described as being ocular-centric and ocular-normative. Indicated as complicit in dividing vision impaired people from the mainstream population (often, in 'seemingly innocuous and munificent ways'[129]), ocular-normativity has been referenced as 'the mass endorsement of visual necessity if not supremacy.'[130] Understood as a variant of ableism,[131] for Rodas the ocular-centric nature of a society created by the sighted *for* the sighted is suggested in the myriad English phrases in which blindness is *borrowed* to shape a world implicitly critical of *the blind*.[132] Thus, we talk of being blind drunk, in a blind rage or of being as blind as a bat or suffering blind panic or blind terror, of venetian blinds, blind alleys, blind spots and questioning how one could be so blind whenever we fail to see something deemed obvious. We talk superstitiously of the dark eye, bemoan the blind leading the blind and regularly query of other people 'are you blind?' Rodas writes:

> [t]his is blindness: Blindness and darkness. Blindness and deception. Blindness and visionary powers. All these go hand in hand, woven into the fabric of our language. Like the weight of air, the inescapable pressure of the atmosphere that is so ever-present to our bodies and our experience of life as to exist continually beneath the level of consciousness, the language that constructs blindness is so diffuse, and has so widely infiltrated our figures of speech, that it, too, is inescapable. Authenticity retreats.[133]

---

[127] again, see John Locke *An Essay Concerning Human Understanding* (Penguin Books, 1997) wherein Locke argues that without the idea of light there can be no light of ideas

[128] Michael Schillmeier, 'Othering blindness – on modern epistemological politics' (2006) 21 (5) Disability & Society 471, 475

[129] Ben Whitburn Rod Michalko 'Blindness/Sightedness. Disability studies and the defiance of de-vision' in Nick Watson Simo Vehmas (eds) *Routledge Handbook of Disability Studies* (Routledge, 2020) 219

[130] David Bolt, 'Radio blindness: interdisciplinarity, ocularnormativity, and young people's preparation for academia' (2020) 44(9) Journal of Further and Higher Education 1233, 1236

[131] ableism has been defined as those 'network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species typical and therefore essential and fully human. Disability then is cast as a diminished state of being human.' Fiona Campbell *Frontiers of Ableism* (Palgrave Macmillan, 2009) 19

[132] Julia Miele Rodas, 'On Blindness' (2009) 3 (2) Journal of Literary & Cultural Disability Studies 115

[133] *ibid* 129

The idea that vision – the most comprehensive of all our senses, according to Locke - is a fundamental component of what it is to live a complete human existence is at the heart of ocular-centrism. Thus, there is often assumed to be an innate unhappiness among people who are vision impaired (as, indeed, is often assumed about disabled people in general[134]) that *the gift of sight* has been denied them. Patronisingly, vision impaired people are often described as stoic and their accomplishment of the most mundane of daily tasks hailed as impressive. Even more disturbingly, there is concern that ableist meta-narratives can feed into disableist hate speech and hate crime.[135]

11 Overview of dissertation

Chapter One Having now introduced the dissertation and, in particular, drawing out the intuitions which underpin it, stating the research question and providing an account of the critical orientation which the research is shaped by, I offer here to an overview of what is to follow.

Chapter Two is entitled 'Theoretical constructs, interpretations and interrogations.' The sections here address republicanism and the main paradigms through which disability is accounted for in the Western tradition, principally the medical model and the social model. The chapter begins with a broad account of freedom in the Western imaginary and includes an overview of the human rights approach to disability. The chapter ends with a brief account of another theoretically significant approach to framing disability, the Capabilities Approach, indicating how an engagement with the Capabilities Approach suggests ways in which contemporary republicanism might better calibrate to accommodate a disability perspective.

Chapter Three is entitled 'The Convention on the Rights of Persons with Disabilities: making rights real.' The sections in this chapter provide an account of the CRPD, concentrating on its principles and on those articles addressing education, work and living independently and being included in the community. Discussion of the relevant articles – including the principles - is orientated around three axes: the broad socio-legal context, the substantive context of the right and a republican reading of the specific articles.

Chapter Four is entitled 'Methodology and Methods.' Having provided, in chapter one, a brief account of the philosophical underpinnings of the research approaches employed in this dissertation, that is, the critical orientations used, the sections in this chapter outline how these

---

[134] see, for instance, John Swain, Sally French, 'Towards an Affirmation Model of Disability' (2000) 15 (4) Disability & Society 569

[135] See, for instance, Leah Burch, ''You are a parasite on the productive classes': online disablist hate speech in austere times' (2018) 33(3) Disability & Society 392

methodologies have been operationalised, explaining how in the particular circumstances of the instant research methodological design is expressed as method. This chapter also addresses participant recruitment, research design and ethical issues.

Chapter Five utilising section headings which derive from the data, this chapter presents the authentic voices of research participants and in juxtaposing these insights with a contemporary republican commentary, seeks to indicate in its discussion how a contemporary republican reading can benefit disabled people in achieving and resiliently holding human rights.

Chapter Six concludes the dissertation and seeks to suggest how a properly disability-calibrated republicanism provides valuable assistance in supporting a resilient holding of rights and in potentially engendering a solidarity around the CRPD. The chapter indicates that there is nothing in contemporary republicanism inimical to a forthright extension to embrace a disability consciousness, drawing on Pettit's own summary of republicanism's claim to be a non-utopian theory of political realism to indicate how this can be achieved.

Chapter Two:

Theoretical constructs, interpretations and interrogations

The past is never dead. It's not even past.[1]

1 Chapter overview

The sections comprising this chapter provide the theoretical underpinnings of this dissertation offering accounts of republican theory alongside four paradigmatic accounts of disability, including the human rights model. The chapter ends with a consideration of the capabilities approach to disability and its plausible interface with contemporary republicanism.

2 Introduction

In Chapter One, I began from the premise that power is the first question of justice, asserting that the justice claims of persons with disabilities – as collated in the CRPD – require more than words to bring them to fruition. Here, in this chapter, I lay out the underpinning theories relevant to my argument that republicanism has the potential to energise a revitalised public sphere, a new *civitas*, taking seriously the responsibility to embrace disabled persons on equal terms. Later, in Part three I will extend this argument by offering a republican reading of three specific Convention rights. In Part three I will also lay out a claim, again utilising a republican lens, that the CRPD's general principles offer a potential bridge, unifying the long postponed or inchoate rights of persons with disabilities with the human needs and demeaned dignities of all those who, while not perhaps ostensibly disabled, might come within the descriptor 'vulnerable.'

But in this chapter, in addition to offering an overview of contemporary republican theory, tracing it from its Roman roots to the present, I also provide commentary on the two predominant disability paradigms; the medical or biomedical model and the social model, the latter often being cited as having influenced the CRPD.[2] It is submitted that an awareness of these two paradigms is crucial. Pivotal as they are to modern disability discourse – though by no means the only models in use – these paradigms, sometimes looming large, sometimes visceral, are reflected and refracted in the multiple ways *normal* is permitted its romanticised and

---

[1] William Faulkner *Requiem for a Nun* (Chatto and Windus, 1919) 85

[2] see, for instance, Rosemary Kayess, Phillip French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 (1) Human Rights Law Review 1; for a counterview see Katerina Kozou, 'Analysing the Definition of Disability in the UN Convention on the Rights of Persons with Disabilities: Is It Really Based on a 'Social Model' Approach?' [2017] 23 International Journal of Mental Health and Capacity Law 25

fetishized hegemonic status in Western culture, including legal culture. As Meekosha and Shuttleworth phrase it:

> [h]ow societies divide 'normal' and 'abnormal' bodies is central to the production and sustenance of what it means to be human in society. It defines access to nations and communities. It determines choice and participation in civic life. It determines what constitutes 'rational' men and women and who should have the right to be part of society and who should not.[3]

Finally, in this part I turn to another perspective from which to view the demands of disability justice, abstracting, in a sense, from the body and moving to the person as socially embedded, particularly addressing the question of capabilities and resources. This is an area which has been richly theorised by Sen and Nussbaum, in particular, and in this final section I place these scholars in tension with Pettitian republicanism, seeking to address a particular criticism to be made of republican theory that it pays scant attention to people with disabilities.

3 Republicanism

3.1 Republicanism: an elusive concept?

For all its seemingly evocative presence in modern political parlance, what republicanism actually means is a matter of some contention**.** For example, in an Irish context, the concept struggles to reclaim itself from association with the violent pursuit of national independence, invoking a language of insurrection, militarism and terrorism, with all its attendant tonalities of disconnection and dis-unity. In the United States to describe oneself as a republican is to invite a likelihood of being assumed to support a right wing political partisanship. In the United Kingdom and in countries such as Spain, Australia and Canada, the popular tendency is to view republicanism as primarily an ouster programme for hereditary monarchs. This latter idea has a particularly long significance, its roots drawing sustenance from numerous sources, including an ancient Hebraic tradition that equates mortal kingship with idolatry[4] and confers on republics

---

[3] Helen Meekosha Russell Shuttleworth What's so "Critical" about Critical Disability Studies? In Lennard J Davis (ed) *The Disabilities Studies Reader* (Routledge, 2017) 189

[4] Tom Paine's stridently polemical anti-monarchist argument in *Common Sense* (1776) draws heavily on this tradition, asserting – in a claim which appears to be based on the Hebrew Bible's 1 Samuel 8 - that monarchy is 'a form of government which the word of God bears testimony against.'

a divine favour,[5] an idea of especial resonance in pre- revolutionary and Cromwellian England.[6] Yet, despite its rhetorically stirring energy throughout history, anti-monarchism remains, according to Daly and Hickey, 'a relatively marginal concern in the republican history of thought.'[7] Even in France, where, as a legacy of the French Revolution and the Third Republic, the country's institutional life and social relationships might be described as self-consciously republican, there seems scant consensus about what a *state* republicanism supports, suggesting the idea lacks coherence. [8] Nor, of course, does the mere fact that many states describe themselves as republics necessarily, of itself, say anything significant about the content of their politics. The Union of Soviet Socialist Republics, for example, speaks not of liberte, egalite and fraternite but rather as a euphemism for a tightly controlled, centralist and autocratic single party regime. Hence, it might be said the question of what republicanism actually is remains in an imaginative flux, such that it may be more appropriate to talk not about republicanism but republicanisms.[9]

On one level, recalling Kellow's remark that *republic* is a noun in search of an adjective,[10] it could, perhaps, be suggested that republicanism might be identified as having an essentially porous nature, its meaning elliptical and contingent, its rhetoric statist rather than personal. However, rejecting this, this chapter offers an account of contemporary republicanism as embodying a particular understanding of freedom which, though ancient in origin, has remained reasonably stable over time and has at its core an ethic which today holds a rich normative potential both institutionally and individually. More, in presenting it as both a mode of social enquiry and a mode of social action, I seek to suggest that contemporary republicanism is particularly well-suited to grounding the needs of people to live well – individually and communally - in conditions

---

[5] Eric Nelson *The Hebrew Republic* (First Harvard University Press 2010)

[6] One strain of English thought at this time which conflates the virtues of republicanism with the virtues of the godly is associated with the poet – and republican - John Milton, see, for example, Dani Kasa, 'Arminian Theology, Machievellian Republicanism and Cooperative Virtue in Milton's Paradise Lost' (2016) 50 (4) Milton Quarterly 260

[7] Eoin Daly, Tom Hickey *The political theory of the Irish Constitution* (Manchester University Press 2015) 2

[8] For example, see Pierre Manent, 'The Tragedy of the Republic' [2017] 273 First Things 21; Christophe Bertossi, 'French republicanism and the problem of normative density' (2012) 10 (3) Comparative European Politics 248; Jean –Fabien Spitz The 'defense repubicaine': Some Remarks about the Specificity of French Republicanism. In Samantha Besson, Jose Luis Marti (eds) *Legal Republicanism* (Oxford University Press 2009) 281 -297;Jean Bauberot, 'Lacite and the Challenge of 'Republicanism'' (2009) 17 (2) Modern & Contemporary France 189; Laborde (n 34)

[9] John W Maynor *Republicanism in the Modern World* (Polity Press 2003)

[10] Geoffrey C Kellow Introduction. In Geoffrey C Kellow Neven Leddy (Eds.) *On Civic Republicanism* (University of Toronto Press, 2016) at 3

of neoliberalism, modernity and postmodernity, where discourses around power are routinely employed to marginalise subordinate groups, including persons with disabilities.

3.2 Contrasting republicanisms

It is not of purpose to this dissertation to provide a deep historical account of republicanism.[11] Of necessity, such an account would have to be a broad and intricately interwoven one, comprising multiple strands. This is so because, like socialism, republicanism cannot accurately be cited as one definitive entity, albeit that there is always, whatever the interpretative strand of republicanism, a central place for a concept of liberty, even if this cannot be said to be a wholly generic one. Hence, republicans who take their inspiration from the city-states of ancient Greece, and civic humanism in general, connect with an understanding of freedom that is intimately caught up with political participation as central to achieving the good life. For those who sit in these pews,[12] the *necessity* of this active engagement in securing individual liberty, of literally getting stuck-in, is all. Thus, Sandel argues for 'a revitalized civic life nourished in the more particular communities we inhabit.'[13] Only if there are 'proliferating sites of civic activity,' Sandel maintains, can loyalties be generated to larger political wholes.[14] Arguably, Sandel – and others like MacIntyre[15] and Taylor[16] - represent a theoretical republicanism shading into communitarianism,[17] a public philosophy which rejects the liberal claim that the good be determined by each individual and that the state be neutral among conceptions of the good.[18] Rather, Sandel argues in favour of a common good which 'requires deliberating with our fellow citizens about how to bring about a just and good society, one that cultivates civic virtue and enables us to reason together.'[19]'. At one with Aristotle, they assert that outside a *polis* – a

---

[11] for an excellent account see Iseult Honohan *Civic Republicanism* (Routledge, 2002)

[12] the phrase *neo-Athenian* has been employed; see Maynor (n 9)

[13] Michael J Sandel *Democracy's Discontent* (Harvard University Press, 2022) 277

[14] *ibid* 279

[15] Alasdair MacIntyre *Against the Self-Images of the Age* (University of Notre Dame Press,1979)

[16] see, for example, Charles Taylor 'Cross-Purposes: The Liberal-Communitarian Debate' in Nancy L Rosenblum (ed) *Liberalism and the Moral Life* (Harvard University Press, 1989) 159 - 182; Charles Taylor *Sources of the Self: The Making of the Modern Identity* (Harvard University Press, 1989); Charles Taylor 'What's Wrong with Negative Liberty' in Alan Ryan (ed) *The Idea of Freedom: Essays in Honour of Isaiah Berlin* (Oxford University Press, 1979) 175 - 193

[17] it should be noted none of the three ever refer to themselves as communitarians; see Communitarianism at https://plato.stanford.edu/entries/communitarianism/

[18] Amitai Etzioni, 'Communitarianism Revisited' (2014) 19 (3) Journal of Political Ideologies 241; see also Robert Putnam *Bowling Alone: the Collapse and Revival of American Community* (Simon and Schuster 2000)

[19] Michael J Sandel *The Tyranny of Merit* (Allen Lane, 2020) 209

political community – man cannot be self-sufficient.[20] Nor can man be unencumbered; that is, a person's views and their actions cannot be unaffected by the specifics of their own personal circumstances, their history, political culture and so forth.[21] Arguably there is a certain narrowness of range in this, captured perhaps in Rousseau's contention that larger, more diverse states do not loan themselves to successful republican government, holding that the larger the state, the more compromised the freedom.[22]

Pettit has suggested that a more accurate nomenclature for the type of republicanism with which Sandel and others identify, including Hannah Arendt, is Franco-German, thereby, in particular, indicating the influence Rousseau and Kant have had on 'this broadly communitarian version of republicanism.'[23] By contrast, *ad idem* with Pettit, the strand of republicanism from which this dissertation draws its focus is modelled after an understanding of rights and liberty which, in historiographical terms, is traced to the ancient Roman Republic. This strand - now intellectually predominant – is often referred to as neo-Roman or neo-republicanism[24] or civic republicanism, although Pettit also talks of the Italian-Atlantic republican tradition.[25] A republic theorised as coming within this tradition embraces three landmark, interrelated institutional components. These are, a range of constraints associated with a well-functioning mixed constitution, wherein the political power of different groupings is held in a creative equilibrium, the ready availability of opportunities whereby citizens can robustly contest laws and public initiatives, thereby holding power to account and, above all, a commitment to an ideal of freedom as non-domination. The three components will be returned to later in this chapter. However, before this elaboration, and having said a deep historical account is beyond this dissertation's scope, *some* historical context is required. This is so if only that to properly understand where an idea has come from and to attend what has been required of it in its working out in different contexts is to give impetus to where it might yet still go.[26] Thus in the

---

[20] Charles Taylor *Philosophy and the Human Sciences: Philosophical Papers 2* (Cambridge University Press, 1985)

[21] Michael J Sandel, 'The Procedural Republic and the Unencumbered Self' (1984) 12 (1) Political Theory 81

[22] Jean-Jacques Rousseau *The Social Contract* (first published 1762, Wordsworth 1998)

[23] Philip Pettit 'Two Republican Traditions' in Andreas Niederberger, Philip Schink, (eds) *Republican Democracy: Liberty, Law and Politics* (Edinburgh University Press, 2013) 170

[24] Philip Pettit *Republicanism: A Theory of Freedom and Government* (Oxford University Press, 1997)

[25] Philip Pettit Two Republican Traditions. In Andreas Niederberger Philip Schink (eds.) *Republican Democracy: Liberty, Law and Politics* (Edinburgh University Press, 2013); for a comparison between Roman republicanism and American republicanism see Cullen Murphy *Are We Rome? The Fall of an Empire and the Fate of America* (Houghton Mifflin Company, 2007)

[26] Maria Dimova-Cookson, 'Republicanism, philosophy of freedom and the history of ideas: An interview with Philip Pettit' (2010) 9 (4) Contemporary Political Theory 477

section which follows I offer both a brief account of republicanism's neo-Roman roots and its trajectory, juxtaposing this with some thoughts on one of republicanism's most influential enemies, Thomas Hobbes. In significant ways this survey offers a sense in which an elitist ideal becomes an intimate one and in which an understanding of freedom moves from an association with choices first and then persons to a profoundly radical switch.

3.3 The neo- Roman model

As laid out by the historians Polybius[27] and Livy[28] and derived in no small part from the statesman and philosopher Cicero's writings on law and politics,[29] the trajectory of this neo-Roman republicanism (hereafter, republicanism or contemporary republicanism) is traceable as powerfully present in the writings of Machiavelli [30] (even prompting Rousseau's observation that *The Prince*[31] - commonly held to be a training manual for despots - is really a subversive handbook for republicans[32]) and sustains the self-concept of Italian Renaissance city-states such as Florence and Venice.[33] Republican ideals pulsate as a common language with which to challenge widely prevailing authoritarian orthodoxies in the sixteenth and seventeenth century Polish-Lithuanian republic,[34] the seventeenth and eighteenth century Dutch republic[35] and the bloody - yet arguably, still surviving – English republic of the 1640s and 1650s.[36] Its rhetoric

---

[27] Polybius *The Histories* (Harvard University Press, 1929)

[28] James Hankins 'Introduction' in James Hankins (ed) *Renaissance Civic Humanism: Reappraisals and Reflections* (Cambridge University Press 2000) 1-13

[29] Marcus Tullius Cicero *The Republic and the Laws* (Oxford World Classics, 2008)

[30] Niccolo Machiavelli *Discourses on Livy* (first publish 1531, Oxford University Press, 2009); Niccolo Machiavelli *The History of Florence and the Affairs of Italy* (Renaissance Classics, 2012)

[31] Niccolo Machiavelli *The Prince* (first published 1532, Dover 1991)

[32] Jean Jacques Rousseau *The Social Contract* (first published 1762, Wordsworth 1998)

[33] see, for instance, Christine Shaw *Reason and Experience in Renaissance Italy* (Cambridge University Press, 2021); Quentin Skinner *The Foundations of Modern Political Thought. Volume One: The Renaissance* (Cambridge University Press, 1978); see also Fabrizio Ricciardelli *The Myth of Republicanism in Renaissance Italy* (Brepols, 2015)

[34] Richard Butterwick, *The Polish-Lithuanian Commonwealth: Light and Flame* (Yale University Press, 2020); Norman Davies *Heart of Europe*: *The Past in Europe's Present* (Oxford University Press, 2001); once Europe's largest republic - multi-cultural, multi-faith and multi-lingual - and with a long tradition of a non-hereditary elected monarchy and powerful local and national parliaments, the Polish-Lithuanian Commonwealth comes into effect in 1569, the union between the two nations having occurred in the late 14th Century

[35] Maarten Prak *The Dutch Republic in the Seventeenth Century* (Cambridge University Press, 2005). For an interesting account of how republican sentiment was hidden in allegorical folk tales see Arthur Weddteijn, 'The Power of 'Pliant Stuff;' Fables and Frankness in Seventeenth Century Dutch Republicanism' (2011) 72 (1) Journal of the History of Ideas 1

[36] see for example Rachel Hammersley, 'Lessons from the Land of Liberty' (2011) 61 (10) History Today ; see also the contention that if there is present the required institutional concern for promoting non-domination it is entirely plausible for a state to be republican even if monarchical in form in Marcia L Colish, 'The Idea of Liberty in Machiavelli' (1971) 33 (3) Journal of the History of Ideas 323

infuses the American and French Revolutions, as exemplified, for instance in the polemical brilliance of Tom Paine,[37] who echoes the vitality of the people's contestatory status when he asserts that republican democracy is 'too serious a matter to be entrusted to governments and ruling classes.'[38]

As reflected in the extensive scholarship of modern historians, in particular, political historians J.G.A. Pocock[39] and Quentin Skinner,[40] what is uncovered in this trajectory is, first, a republicanism which is acknowledged to be prone to civil unrest, intermittently violent, deeply stratified, unrelentingly patriarchal, rapaciously colonising and enslaving on a massive scale.[41] However, the Roman republic is also a unique *idea* in political and legal history, a four hundred and eighty two year evolving experiment in political consensus. Romans had experienced autocracy in the form of kings and rebelled against it.[42] Thereafter, the Romans initiated a republic– deriving from the Latin words *res* (the government) and *publica* (the community as a whole) and translating as 'the people's affair' or commonwealth.[43]

In identifying their state as a republic or commonwealth, these post-monarchy Romans were making a clear assertion that their polity was now the common concern of the people. In claiming this, the goal was to protect the liberty of the citizen by ensuring that no one man could ever again wield supreme power. But more, the Romans were also framing a new understanding, within which the freedom of the commonwealth becomes conceived of as consubstantial with the freedom of the individual, the one indivisible from the other.[44] Thus, the Roman republic's primary aim is not in extending freedom or in conferring equality among citizens but in guarding those values which distinguishes free man from slave, the *liber* from the *servus*.

Eminent amongst these values are free speech, private property and rights before the law. But the preeminent value, as commonly expressed in terms analogous to falling into enslavement

---

[37] Thomas Paine *Collected Writings* (Penguin Putnam 1955)

[38] John Keane *Tom Paine: a political life* (Bloomsbury 1996) 294

[39] J. G. A. Pocock *The Machiavellian Moment* (Princeton University Press, 1975)

[40] see, for instance, Quentin Skinner *The Foundations of Modern Political Thought. Volume One: The Renaissance* (Cambridge University Press, 1998)

[41] see, for instance, Tom Holland *Rubicon: The Triumph and Tragedy of the Roman Republic* (Abacus, 2003)

[42] for a compact history of the republic see David M Gwynn *The Roman Republic: A Very Short Introduction* (Oxford University Press, 2012)

[43] Quentin Skinner 'The Paradoxes of Political Liberty' in David Miller (ed) *Liberty* (Oxford University Press, 1991) 196

[44] Ch Wirszubski *Libertas as a Political Idea at Rome during the Late Republic and Early Principate* (Cambridge University Press, 1950)

or servitude, is that domination must be vigorously resisted.[45] Through an array of offices and assemblies which intricately balance power between one group and another, and through imposing strict term limits on office holders - including on any dictator appointed under the constitution to lead Rome in times of dire emergency – the priority of the political in protecting individual liberty is emphasised, particularly against corruption. In the creating of a shared political space liberty becomes understood not as a natural possession but, rather, as 'a status acquired politically with citizenship in a republic where government is carried out in the interests of the whole people.'[46] Only in such circumstances are Romans properly considered to be living under the rule of law.[47] All this contrasts sharply with the imagery invoked by Strunk as commonplace in the post-republican Rome as 'Romans tried to anticipate the emperor's desires, thereby engaging in ever-increasing self-censorship and adulation as they tried to outdo one another in their servility.'[48] Such imagery is repulsive to republicans.

3.4 Machiavelli and a free state

Held's contention, following the demise of the Roman republic in 27BC, that, in the Middle Ages, republican discourses effectively disappear from public consciousness is open to doubt.[49] Held claims *homo politicus* is now replaced by the medieval Christian *homo credens*, the political activist transformed into the prostrate soul. However, Black argues that since in its theology all persons share the same moral status, Christianity is a natural fit with the 'republican ethic of common, mutual rights.'[50] Indeed, St. Augustine puts a clearly republican spin on the issue of justice and the requirement to *do* justice when he asks '[j]ustice being taken away, what are kingdoms but great robberies? For what are robberies themselves, but little kingdoms?'[51] Nonetheless, whether or no, the next great flowering of republicanism undoubtedly occurs in the city-states of Renaissance Italy, being represented with unparalleled verve in the work of Machiavelli.

---

[45] see, for example, Valentina Arena *Libertas and the Practice of Politics in the Late Roman Republic* (Cambridge University Press, 2012)

[46] Honohan (n 11) 36

[47] Anthony Everitt *Cicero* (Random House, 2001)

[48] Thomas E Strunk *On the Fall of the Roman Republic : Lessons for the American People* (Anthem Press, 2022) 89

[49] David Held *Models of Democracy* (Polity Press, 2006)

[50] Anthony Black, 'Christianity and Republicanism: from St. Cyprian to Rousseau' (1997) 91 (3) The American Political Science Review 647, 647

[51] Cited in Paul J Cornish, 'Augustine's Contribution to the Republican Tradition' (2010) 9 (2) European Journal of Political Theory 133, 139

For Machiavelli, a republic is the highest form of state, hence the first issue to be addressed being how states are formed. Indeed, it is plausible to see both of his masterworks, *The Prince* and *The Discourses on Livy* as one treatise on the state, the former being about establishing a secure state and the latter about ensuring a free state. [52] So while there may be a role for princes or popes or potentates in (often brutality) setting up states, once having been established, popular republics are better at sustaining and maintaining the state's interests.[53] This republican turn is prefaced on a conception of the *vivero libero*, explained as a patriotic impulse, a love of liberty as a shared experience which citizens must defend together, through the mobilisation of a militia or citizen army.[54] However, the practices of freedom are more limited in Machiavelli's conception than in Aristotle's or Cicero's; there is no Athenian-style direct democracy or (semi) popular enfranchisement. Nor is there any suggestion in Machiavelli's thought that liberty exists as some sort of latter-day right. Rather, the republic Machiavelli favours is an unrelentingly bloodthirsty place, populated by harsh captains and fortified by terrifying executions and the judicious application of fear, occasionally cutting down an ambitious citizen as a lesson to others.[55] For Machiavelli, the importance of all this lies in his belief that what ultimately confounded republican Rome was its inability to renew its leadership when corruption set in.[56]

But, above all, Machiavelli turns to law and to the Roman mixed constitution as the primary means of promoting civic virtue and defending liberty. Machiavelli –asserting that invariably the rich wish to dominate and the poor wish to avoid domination - argues that non-republican forms of government are direct threats to civic freedom and the general good. Instead, he proposes a carefully balanced equilibrium between all the political factions in the state such that, in jealously guarding their power to scrutinise each other's legislative proposals, only those laws and institutions which support public liberty will be agreed. The net effect being that out of discord emerges the surest protection of freedom. For Machiavelli, disunity and factionalism provides liberty's greatest protection. In Rome's appearance of chaotic civic discord, Machiavelli finds more to praise than any degree of supposed political harmony. In a related vein, law must

---

[52] Philip Bobbitt *The Garments of Court and Palace* (Grove Press 2015); indeed, as Skinner has it 'the underlying political morality of both books is the same.' Quentin Skinner *The Foundations of Modern Political Thought. Volume One: The Renaissance* (Cambridge University Press, 1978) 183

[53] for an account of contradictions in Machiavelli's republicanism see Robert Black *Machiavelli. From Radical to Reactionary* (Reaktion Books, 2022); Mark Jurdjevic, 'Machiavelli's Hybrid Republicanism' (2007) 499 (CXXII) The English Historical Review 1228

[54] Honohan (n 11)

[55] Niccolo Machiavelli *Discourses on Livy* (first publish 1531, Oxford University Press 2003)

[56] Sara M Shumer 'Machievelli: Republican Politics and its Corruption' (1979) 7 (1) Political Theory 5

ensure that, other than in quite rare and time-framed specific circumstances, no one person should attain an untrammelled exalted role, civil or military, since this might undermine the general liberty.[57]

Machiavelli represents a compelling political turn which is at once a rejection of Roman republicanism and a startlingly modern reworking of it. The rejection rests on the assertion that it is no longer possible for political man to be the good man of the ancients, for whom the city presents as a community of free and equal individuals committed to virtue and the pursuit of the good. In this formulation, the potential for arbitrary interference is nullified by the cohesion within the civic space, buttressed by a strong constitution which lays out clear rules by which power is exercised – a picture of politics as a model of architectural reliability.[58] An emphasis on a formal equality is of particular importance. The state that allows itself be blinded to ability and talent in preference for appointing officials of lesser promise simply because the former lack public standing or wealth is a state which confounds liberty.[59] But Machiavelli is also a proponent of the stark message that a truly good citizen must know when *not* to be a good man. Thus, while the aim of a republic to be a bulwark against corruption remains inspirational to Machiavelli, as Viroli has it, in the struggle to rescue the community from domination and corruption '[t]he good man must become bad in order to achieve what classical republican writers have always considered the worthiest goal for a truly good man to pursue.'[60] In this configuration, virtue now may exist in actions which can appear perverse.

Hence, Machiavelli is set apart not only from his classical antecedents but from latter-day liberal theorists such as Berlin, Nozick and Rawls in his asserting that the coercive force of the law can legitimately be used to grant a degree of freedom which, because of man's natural corrupting ways, could not otherwise exist.[61] According to this rationale, as Skinner writes:

> If the coercive apparatus of the law were to be withdrawn, there would not be a greater degree of personal liberty with a diminished capacity to enjoy it. Due to our self-destructive natures, there would rather be a

---

[57] see, for example, John P McCormick, 'Subdue the Senate: Machiavelli's "Way of Freedom" or Path to Tyranny?' (2012) 40 (6) Political Theory 714

[58] Maurizio Viroli 'Machiavelli and the republican idea of politics' in Gisel Bock, Quentin Skinner, Maurizio Viroli (eds) *Machiavelli and Republicanism* (Cambridge University Press 1993) 143 - 171

[59] Niccolo Machiavelli *Discourses on Livy* (first publish 1531, Oxford University Press 2003) 1.58

[60] Maurizio Viroli Machiavelli and the republican idea of politics in Gisel Bock, Quentin Skinner, Maurizio Viroli (eds) *Machiavelli and Republicanism* (Cambridge University Press 1993) 170

[61] Quentin Skinner *Visions of Politics Vol 2 Renaissance Virtues* (Cambridge University Press 2002)

> diminution of personal liberty, a rapid slide towards a condition of complete servitude.[62]

In this, Skinner also helps us perceive that the freedom which Machiavelli holds dear is never really individual liberty *per se* but, rather, a form of collective liberty, the liberty not so much of the individual in the state but of the state itself, the supreme common good. This re-statement of the classical Roman idea of the free-state means questions of freedom are always teased out in the relationship between the individual and the state and expressed in terms of asking about the nature of the conditions which need to be fulfilled if the contending demands of personal liberty and political obligation are to be accommodated.[63]

Machiavelli's insights that conflict is necessary within the political community if liberty is to adhere, is a hard gospel. But, within the contestation of conflict, the individual experiences 'the felt need to secure their own liberty with laws and institutions.'[64] In Machiavelli's account, this felt need is generated – and generative – across every faction in the polity, it being implicit that as power waxes and wanes between contending groups there is political wisdom in providing against domination, even if only as assurance against one's own fate falling into shadow.[65] More, in this way, providing for the common good, including in circumstances where one's own immediate self-interest might be compromised, the individual good becomes intertwined with the common good, just, in a sense, as in republican Rome, individual liberty and the liberty of the state become intertwined.[66] These ideas are returned to later in this work, when I discuss what the republican polity owes persons with disabilities, particularly in the context of a traditional republican concern: a tyranny of the majority.

3. 5 Freedom within the modern idiom

A state committed to promoting non-domination is one intent on reducing the presence of arbitrary will and on rendering the republic 'proof against the vagaries of human nature.'[67] Such a state stands at odds with what is often perceived to be the liberal understanding, within which

---

[62] *ibid* 185

[63] Quentin Skinner *Liberty Before Liberalism* (Cambridge University Press 1998)

[64] Sara M Shumer, 'Machievelli: Republican Politics and its Corruption' (1979) 7 (1) Political Theory 5, 15

[65] there is in this something of the Rawlsian original position, an idea that helps tease out what social agreements look like if negotiations commence from a starting point of assumed equality; see John Rawls *A Theory of Justice* (Harvard University Press, 1971)

[66] see Honohan (n 11)

[67] Pettit (n 24) 230

freedom is a product of non-interference.[68] The distinction here is not academic nor a matter of semantics. Rather, it is at the heart of an ideological dispute which comes to dominate early-modern England – and by extension, its American colonies – such that Pocock talks of the ‘anglicization of the republic.’[69] In teasing out the non-domination/non-interference distinction and in tracing its implications for this dissertation – that is, in terms of people with disabilities - it is useful to begin by holding two 17th Century English contemporaries in a brief contention: James Harrington and Thomas Hobbes.

Hobbes is a social contractarian who believes that the collective security provided by government trumps individual freedoms, rescuing man from a calamitous state of nature which, absent strong government, is ‘solitary, poore, nasty, brutish and short.’[70] In this context, a person’s liberty is her most potentially damaging attribute, such that one person’s freedom alongside the (dangerous) freedom of others can only mean ‘warre as is of every man, against every man.’[71] Hence, human wellbeing requires that individuals cede their authority to act to a state now so comprehensive and awesome that all stand petrified in compliance before it.[72] Hobbes theorises sovereignty in terms of the state as constituting an artificial person, whether represented by a monarch or an assembly, but acting in the authority of all: ‘*[o]ne Person, of whose Acts a great Multitude, by mutual Covenants one with another, have made themselves every one the Author.’*[73] Hence, the surrender of individual freedom institutes an artificial *person*, the state, whose acts, whether just or unjust, are, quite literally, the acts of each person now embraced within the state. According to Ryan this reflects a sense ‘that there is no legal system unless all (or the vast majority) accept its requirements as obligatory.’[74]

For Hobbes a person’s ability to experience freedom is conditional upon them submitting to a very different sort of commonwealth than that envisioned in republican Rome. Within *this* commonwealth there is no right to free speech, as protestant reformers held at the time, or to other individual rights. Nor is there need for a mixed constitution - Hobbes dismisses it as

---

[68] There is an element of broad-scope here in that while the designation of freedom as non-interference has certainly has its liberal supporters, particularly, Isaiah Berlin, there is an argument that liberal progressives would not reject the non-domination thesis; see Thomas Hickey, *Liberty as Non-domination and Ethical Diversity in the Modern Polity* PhD dissertation, National University of Ireland, Galway (unpublished, 2010)

[69] J. G. A. Pocock *The Machiavellian Moment* (Princeton University Press, 1975) 401

[70] Thomas Hobbes *Leviathan* (first published 1651, Penguin Classics 1985) 186

[71] *ibid* 185

[72] Hannah Dawson *Hobbes* (Pegasus Books 2015)

[73] Hobbes (n 70) 228 (italics in original)

[74] Alan Ryan *On Hobbes* (Liveright Publications 2016) 89

‘mixarchy’ – since this dilutes the will of the people in their surrender to the sovereign (who or whatever that may be) and creates destructive confusion between competing constitutional entities. Were this ‘mixarchy’ to occur, as Pettit phrases it, the people ‘will still be a plurality, not a unity, a multitude, not a people.’[75]

At one with his rejection of a mixed constitution, Hobbes also denies the notion of the rule of law, as least as republicans understand the concept. In this, Hobbes is refusing to accept that the sovereign power can be restricted in their field of action, such that they also would be accountable to the law. More, a free man is simply one who ‘*in those things, which by his strength and wit he is able to do, is not hindered to do what he has a will to do.*’[76] Thus, within Hobbes’ commonwealth, freedom under government rests ‘on the silence of the Law.’[77] Hence, a person is free to do that which she has the ability to do and which is not expressly prohibited. This is freedom as non-obstruction or non-interference such that in Hobbes’ thinking ‘a relaxed absolutism left the citizenry freer than an austere republicanism.’[78] Asserting that the liberty the ancients boast of is really the liberty of the commonwealth, Hobbes argues that the misrepresentation of Greek and Roman liberty as adhering in individuals and as ‘favouring tumults, and of licentious controlling of the actions of their Sovereigns’ has resulted in so much bloodshed that never was ‘anything so deerly bought, as those Western parts have bought the learning of the Greek and Latin tongues.’[79]

Hobbes’ *Leviathan* is the antonym of republicanism. In his insistence that individual autonomy must subjugate itself to state sovereignty Hobbes places the power of state authority over the entitlement of individuals to act as free agents. However, James Harrington’s classic statement of republicanism - *The Commonwealth of Oceana* - describes as slaves those who lack control over their lives, living in a constant condition of anxiety concerning what might befall them.[80] Harrington’s tract is intended, in part, as a rebuff to Hobbes’ description of the citizen in *Leviathan*. The arbitrary power which Hobbes’ state can wield - notwithstanding the argument that every power it exercises has the people as its author - identifies *Leviathan* as the working out of ‘a conscious opposition to the juridical and republican account’ of freedom.[81] Indeed, Hobbes even anticipates the neo-republican argument that freedom is found in the absence of

---

[75] Philip Pettit *Made with Words: Hobbes on Language, Mind and Politics* (Princeton University Press, 2009) 120

[76] Hobbes (n 70) 262 (italics in original)

[77] *ibid* 271

[78] Alan Ryan *On Politics* (Penguin Books, 2012) 445

[79] Hobbes (n 70) 267-268

[80] James Harrington *The Commonwealth of Oceana* (Cambridge University Press, 1992)

[81] Quentin Skinner *Hobbes and Republican Liberty* (Cambridge University Press, 2008) at xv

domination with an argument that to be a free person is simply to experience a physical thing, to be a body in motion whose acting out of one's will and preference is un-impeded by external restraint, that is, freedom as non-interference. [82]

Vigorously opposing this view is Harrington's argument for 'an empire of laws, and not of men.'[83] Within this understanding, only those laws which citizens have been directly involved in formulating should be acquiesced to, the citizen – and not the state – being the source of law's legitimacy. Hence, as Lovett has it:

> [w]hat matters is that the subject of a despot enjoys his freedom *from* the laws merely at the whim of his master, whereas the free citizen of a republic *has no master* apart from the laws themselves – thus he is, in a sense, free *by* the laws.[84]

Enjoyed in the first instance by individuals – and only derivatively by collectives – Lovett emphasises that the liberty Harrington describes is prefaced on a formal design of political institutions, including a popular assembly which would approve or reject laws proposed by a senate. In this – whatever the flaws of the actual institutions proposed – Harrington is credited with demonstrating the plausibility of 'a community of equal citizens organized as a genuine empire of law, in which no-one is subject to the mastery of anyone else.'[85] However, in the public imaginary, Hobbes' autocratic, collectivist account of the state and the restricted liberty which flows from it prevailed over Harrington's nuanced and capacious republic, elbowing it (temporarily) off the main English political stage. Perhaps this happened, not least, because republicanism had become associated with a regicide, a joyless puritanism, and a Cromwellian regime every bit as despotic as any king. However, there is another reading of Hobbes possible and that is as an ideologue who drew on dystopian fears to re-invigorate the status quo, reflecting back to his audience a vision of a world that would only deteriorate further without strong leadership. Re-framing freedom as personal rather than political, it becomes an intimate, perhaps smaller thing, a matter of personal choices and good fortune. In such a re-framing, freedom is not a deep and shared human need and can thus be disassociated from the type of state in situ.

---

[82] *ibid*

[83] James Harrington *The Commonwealth of Oceana* (Cambridge University Press 1992) 8

[84] Frank Lovett, 'Harrington's Empire of Laws' (2012) 60 (1) Political Studies 59, 63

[85] *ibid* 72

3.6 Theories of domination: a wider context

As the originator of modern political theory, Hobbes' understanding of the state is prototypical of the way political science came to view domination, with Pettit contending that no one has had 'greater influence on the topic of liberty or freedom than Hobbes.'[86] However, before moving on to look further at the distinctively republican theory of domination it is useful to briefly survey some of the many other political and social theorists who have engaged with the concept.

For Marx, for example, domination is a cogent personification of the class struggle and derives its character from the economic manipulations that underpin the concept of social class.[87] However, this identification of domination as occurring in the context of individuals who are 'bearers of particular class relations and interests'[88] is criticised as obscuring a more intimate micro view, useful, for instance, in perceiving how the capitalist project, that is, the accumulation of capital, is linked, at the individual level, to the manufacture, through power, of the kind of productive bodies discussed in Foucault's work. [89] Renault rehearses an alternative view, citing many writers who claim that Marx was not alone concerned with the dominance of entities such as states and the owner classes (out of whose interests the state emerges) but also by 'the domination of individuals by 'abstractions' and 'things.''[90] This argument appears consistent with Marx's theory of commodity fetishism,[91] a construct summarised by Tanner in terms of how the real social relations that might exist between people as people - holders of real intrinsic value - are perverted into the appearance of produced *things* as having intrinsic, reciprocal value.[92]

Weber offers a classic distinction between power (*Mact*) and domination (*Herrschaft*). In this formulation power is presented as the probability that one actor within a relationship can assert his will, despite the presence of resistance.[93] Domination is understood by Weber as the probability that a command will be obeyed, an idea which carries an at least minimum content

---

[86] Philip Pettit, 'Liberty and Leviathan' (2005) 4 (1) Politics, Philosophy and Economics 131, 131

[87] See for example Karl Marx Fredrick Engels *The Communist Manifesto* (first published in 1848, Vintage 2010)

[88] Karl Marx *Capital Vol 1* (first published 1867, Penguin 2011) 92

[89] See for example Michel Foucault *Discipline and Punish: The Birth of the Prison* (Penguin 1991)

[90] Emmanuel Renault, 'Work and Domination in Marx' (2014) 15 (2) Critical Horizons 179, 181

[91] See, for example, a brief account in Etienne Balibar *The Philosophy of Marx* (Verso 2017)

[92] Robert Tanner, 'Marx's Theory of Commodity Fetishism as the Unstated Premise of *What is to Be Done*' (2001) 13 (1) Rethinking Marxism 57

[93] Ivan Szelenyi, 'Weber's theory of domination and post-communist capitalisms' (2016) 45 (1) Theory and Society 1

of voluntary consent, whether this compliance is, in Laborde's phrase, 'based on ulterior motives or genuine motives.'[94] As Weber puts it:

> 'every genuine form of domination implies a minimum of voluntary compliance, that is, an interest…in obedience…[C]ustoms, personal advantage, purely effectual or ideal motives of solidarity do not form a sufficiently reliable basis for a given domination.'[95]

Weber talks about domination being prefaced on a necessary belief in a system's legitimacy.[96] But Szelenyi hypothesises that such is Weber's sophisticated understanding of the social psychology of groups (for example, in terms of Weber's assertion that privileged groups hold that privilege only by believing their own *myths* about being privileged) that what can constitute belief in this context is actually likely to be something quite passive. Hence, **'**they will believe that the domination imposed on them is justified since at this point they cannot find a realistic alternative,' rather than because they do not know that there might be a better alternative. [97] Gramsci[98] also posits this idea of consent in relation to his idea of hegemony, when he theorises about the nature of the acquiescence given by the masses to the dominant group in society and the way in which the state and juridical government is used to legally enforce consent among the residue who do not 'spontaneously' offer it. However, in noting that many writers seem to use the words 'domination' and 'hegemony' interchangeably, Lovett observes that the ideological intent of the latter to shape and manipulate belief in a supposed natural order of things is such that whether hegemony and domination can always be the same thing is dubious. Lovett draws on the slave analogy, reminding that whoever might have found themselves persuaded by the voluminous amounts of pro-slavery theories generated in pre-Civil War America it was hardly likely to be slaves themselves.[99]

3.7 Conceptualising non-domination as a qualitatively different schema

As already said, rehearsing Hobbes' contentions about the nature of freedom is important because they have been uniquely influential. Thus, Skinner talks of a bewitching whereby for a long time the only ways freedom could be thought about were those which represented the

---

[94] Laborde (n 34) 153

[95] Max Weber *Economy and society* (first published 1921, University of California Press 1978) 212

[96] *ibid*

[97] Szelanyi (n 93) 3-4

[98] Antonio Gramsci in Quintin Hoare Geoffrey Nowell Smith (eds) *Selections from the Prison Notebooks* International Publishers 1971)

[99] Frank Lovett *A General Theory of Domination and Justice* (Oxford University Press 2012)

mainstream, Hobbesian intellectual tradition.[100] That this tradition is the same one that often reduced persons with disabilities to restricted, marginalised lives on the penumbra of social order, using law and social stigma to enforce exclusion and injustice, is, of itself, reason to lament the constraints on political imagination. But, more, arguably, this tradition remains intellectually dominant. Mediated into modern liberal theory through its adoption by the 19th Century progressive philosopher Jeremy Bentham, the notion that freedom consists solely in non-interference is reproduced in the 20th Century work of highly influential liberal theorists like Isaiah Berlin and John Rawls.

This idea of interference and domination being distinctive circumstances suggests it is useful at this point to draw attention to specific characteristics which separate freedom as non-domination from other ways in which freedom is conceived of in modern political thought. Indeed, Pettit's seminal work, *Republicanism*, begins with this very task by drawing explicit attention to Isaiah Berlin's influential identification of freedom as a binary construct.[101] Berlin postulates that liberty consists in two dimensions, expressed in terms of positive and negative liberty. [102] In this formulation positive liberty presents as a type of profoundly difficult to realise self – actualisation in which the individual is 'a doer – deciding, not being decided for, self-directed and not acted upon by external nature or by other men.'[103] It is the freedom of being one's own absolute master, that mastery including the control of one's own lesser selves or, as Berlin phrases it, 'self-mastery, with its suggestion of a man divided against oneself.'[104] Berlin argues that such is the ambiguity at the core of positive freedom that it can easily be perverted into injustice – for Berlin '[t]hat we cannot have everything is a necessary, not a contingent, truth.'[105] In his statement of liberalism's creed, Berlin rejects the idea that politics and the law can address itself to solving inner human division. In contrast to the Aristotelian and neo-republican traditions, Berlin defends political quietism, and, while alert to the dangers of what Tocqueville terms the tyranny of the majority,[106] asserts that the 'revealed preferences of ordinary men and women must be the limit and also the arbiter of all practical politics.'[107] Berlin contends positive freedom can be manipulated into a political weapon, creating a tyranny in which, as Rousseau has it, people may have to be *forced* to be free. In this, Berlin shares a

---

[100] Quentin Skinner *Liberty Before Liberalism* ((Cambridge University Press 1998)
[101] Pettit (n 24)
[102] Isaiah Berlin Two Concepts of Liberty. In Isaiah Berlin *Liberty* (Oxford University Press 2016) 166-217
[103] *ibid* 178
[104] *ibid* 181
[105] *ibid* 215.
[106] Alexis de Tocqueville *Democracy in America* (first published 1835, University of Chicago, 2000)
[107] Michael Ignatieff *Isaiah Berlin A Life* (Vintage 2000) 226

perspective with those critical theorists for whom the freedom prefaced on a faith in rationalism becomes the seedbed of a modernity in which the dream of mass freedom is memorialised by mass graves.

3.8 Pettit: setting the scene

Thus far, what is encountered is a conception of republican freedom –neo-republicanism – which is, I argue, intuitively attractive but fraught with contradictions. In taking some time to present this freedom within a broad historical perspective, I indicate these contradictions, not least that the model of freedom extolled is the freedom of the few, a freedom that excludes far more than it embraces, a point some have used to launch attack on the contemporary republican programme.[108] Indeed, within Machiavelli's account it becomes clear it is the freedom of the *state* which takes precedence over the freedom of the individual, who often appears incidental and, incidentally, vulnerable.

More, I suggest what is encountered is a conception of freedom which loses ground to a notion of liberty as simply the absence of external constraints or coercion, a way of thinking about liberty which I trace to Hobbes and which I indicate remains the bedrock idea of liberty within the liberal tradition. Finally, in this section I reference the well-rehearsed – and normatively significant - disdain in which Berlin holds positive liberty. I move now to discuss the revival of interest in republicanism, principally as it is associated with the scholarship of Philip Pettit. Pettit's is a body of work that is identified as representing a 'development of individual liberty as a subjectively experienced security that will arise in societies governed by clear normative expectations and an 'intangible hand' of shame and esteem.'[109] I now go on to discuss these normative expectations. As to representing questions of shame and esteem, I trust these will make themselves clear too as considerations melded through this dissertation.

Building on the histographical work of Quentin Skinner, Pettit's approach, arguably, radically moves republicanism into a frame well suited to a modern and pluralist society and offers a format within which liberty can be understood in a dynamic and distinctive way. This is so not least in the way the identity of the state as a *civitas* and the identity of the citizen as a *libertas* co-mingle and become symbiotic such that 'freedom is seen in the republican tradition as a status that exists only under a suitable legal regime.'[110] However, for Pettit this suitable legal

---

[108] see, for instance M M Goldsmith, 'Republican Liberty Considered' (2000) 21 (3) History of Political Thought 543

[109] Per Mouritsen Republican liberty and self-government in Iseult Honohan Jeremy Jennings (eds) *Republicanism in Theory and Practice* (Routledge, 2006) 36

[110] Pettit (n 24) 36

order is just the beginning, envisioning a legal, cultural and environmental infrastructure that supports republican freedom, one that exists and operates democratically on the people's terms. This means the presence of integrated systems – social, medical, juridical and the like – that overlap to provide a social minimum by way of protecting people in both the public and private spheres from arbitrary power. Within a republican ethos, these systems are rooted in an understanding of a shared common interest (perhaps, even an imperative) in which freedom as non-domination is prefaced as 'a gateway good,' that is, 'a good whose realization promises to bring the realization of other goods in its train.'[111]

Within Pettit's schema, freedom is not the only value in life or, even, the supreme one. However, he maintains that a state which consciously commits itself to providing for the freedom of its citizens is, axiomatically, committing to a range of other plausible goods too, well beyond the tolerances of what Roman republicans could countenance. Nonetheless, these Romans – male, moneyed and shockingly elitist – were the founders of a republican ideal of such enduring plasticity that today

> [f]reedom as non-domination is a pluralistic ideal, and may be expected to command allegiance across a wide spectrum of contemporary interest and opinion.'[112]

It is in this context then that I seek to argue that contemporary republicanism's value to persons with disability is of considerable untapped potential, presenting my arguments later in the form of a republican reading of elements of the CRPD. More, I contend that in such a reading the capacity to create mutually beneficial and humanly rich connections between persons with disabilities and the not yet disabled is significant. Indeed, I believe, such is this significance that the Convention might be read as a freedom charter for all those whose lives might be identified as vulnerable, whether with or (presently) without the presence of impairment.

3.9 Domination within the republican ethic: the capability to interfere

In the republican tradition freedom is 'a property of the person in the first place, and of choices or indeed societies in the second.'[113] However, domination is most always a function of the inter-

---

[111] Philip Pettit *Just Freedom* (W W Norton & Company, 2014) at xix

[112] Philip Pettit (n 24) 146

[113] Philip Pettit 'The General Will, the Common Good, and a Democracy of Standards' in Yiftah Elazer Genevieve Rousseliere (eds) *Republicanism and the Future of Democracy* (Cambridge University Press, 2019) 13

personal and it occurs in the presence of an imbalance of power.[114] Indeed, Lovett describes it as ‘a qualitative inequality in the distribution of social power.’[115] As already mentioned, what republicanism imports into this is the notion of arbitrariness – the idea, per Pettit, that a someone – a powerful other - has the capacity to interfere, by whim or at will, ‘in certain choices which the other person is in a position to make.’[116] Pettit clusters some important provisos around this three-part summary. The interference must makes things worse for the person who suffers the interference, the interference must be rendered intentionally (or, at least, negligently), adding that the broad categories under which it might be captured

> includes coercion of the body, as in restraint or obstruction; coercion of the will, as in punishment or the threat of punishment; and, to add a category that was not salient in earlier centuries, manipulation: this is usually covert and may take the form of agenda-fixing, the deceptive or non-rational shaping of people’s beliefs or desires, or the rigging of the consequences of people’s actions.[117]

Further, Pettit advises that in certain contexts acts of omission may be sufficient to invoke a claim of domination. Hence, profiteering or driving a hard bargain in circumstances where the weaker other party is compelled to accept may also constitute domination.[118] But, I turn now to emphasise a point of crucial importance. While interference of the type exemplified here is clearly dominating – in that the interference, taking no account of the vulnerable person’s interests, sweeps those interests aside in favour of interposing a powerful other’s own wishes – there can also be domination in circumstances where no interference actually occurs. Indeed, there can be domination even in circumstances where a powerful other has no intention of interfering and may even have foresworn interference. Often invoked by way of illustration is the benign and kindly master who is a paternal presence to his slaves, indulging them and permitting them anything they seek – anything, that is, other than formal release from the bonds of servitude. That this kindly master’s slaves esteem him and that the slaves of other (cruel and abusive) masters dream of being acquired by him is of no consequence. He is still a master, a *dominus*. They are still slaves, *servi*. That he retains the status of slave owner means he retains

---

[114] it is, of course, perfectly possible to experience structural domination as mediated, for instance, by a state agency, a company or a church. However, I hold to the point that even in such cases the experience is likely to be felt in relational effects

[115] Lovett (n 99) 85

[116] Pettit (n 24) 52

[117] *ibid* 53

[118] *ibid* 54

the potential to reverse his course and arbitrarily introduce the lash. His retinue are dominated because they are under his power and at his will, despite his kindliness.

This is a point then at which republicanism and traditional liberal conceptions of freedom pull away from each other. Whereas the latter may permit, drawing on opportunity arguments popularised by Bentham – but originated by Hobbes – that the antonym of freedom is interference, the republican must assert a more robust view: if one lives at the arbitrary will of another, whether that will be activated or no, one is not free. That another *can* interfere in one's choices or activities, without reference to one's interests or wishes, is sufficient to show domination.

Pettit directs our thoughts too to the person who finds herself in a situation whereby in order to protect her scope for personal action she has to kowtow to another – perhaps a boss or a public official, perhaps a spouse. Such a person has to fawn and be obsequious or perhaps she just cannot look that powerful other in the eye lest she give offence or in some other way place herself or her interests at disadvantage.[119] A person in such circumstances is a person forced to be tentative, to anticipate the other's moods, to play games, to self-censure, to mollify, to do whatever it takes, perhaps, to keep the powerful other on-side. Such a person, under a republican rubric is not free, even though her stratagems succeed. However, she is unfree because she lacks the status of an equal. The indulgence of a powerful other does not confer equality. Yet, based on a consideration of outcomes, such a person may be considered free within the liberal conception of freedom.

Hence, we come now to a certain nub. Within the broad liberal tradition, freedom is compromised only if there is interference. Within a republican reading, however, there can be domination without interference and there can be interference without domination. This latter circumstance arises when an interference is non-arbitrary. Thus, the Garda who acts entirely under lawful authority and arrests me, even as he carts me away unhappy and handcuffed in the back of a squad car, is not subjecting me to domination. Indeed, nor is he compromising my freedom; Pettit argues a distinction between compromising freedom and merely conditioning it. Citing Harrington's deference to the empire of laws and not of men, Pettit writes:

> [t]here will be systems of law available, at least in principle, which are entirely undominating and entirely consistent with freedom: not only

---

[119] see, for instance, Pettit (n 111)

> will they inhibit potential dominators and reduce unfreedom, they will do so without representing a form of domination in their own right.[120]

Under such laws, a person is secure in her normative power, living in a setting where she can reasonably expect that her claim to be treated in a certain way will be accommodated, or at least, some ill having occurred, that there will be remediation.

3.10 A closer look at arbitrariness

This brings us naturally to a reflection on what precisely arbitrariness means in the republican schema. In *Republicanism,* Pettit offers the image of the state *tracking the interests and ideas* of a person, indicating that to the extent this occurs an interference will not be arbitrary and, so, non-dominating.[121] To this Pettit adds the proviso that an interest has to be relevant if it is to be tracked. Relevance is defined thus:

> 'my relevant interests and ideas will be those that are shared in common with others, not those that treat me as exceptional, since the state is meant to serve others as well as me.'[122]

As to when interests are unlikely to meet the required standard of commonality, Pettit points to those that are factional or sectional but contends that a public discourse is necessitated wherein individual cases are made before any conclusive view is formed. There does appear to be a certain cumbersomeness in this phrasing. This is unfortunate, not least because Pettit and other republicans are of one mind that their theory of freedom is non-utopian, making it central, for ease of application, that key terms be easily understood.

In subsequent work Pettit addresses arbitrariness in different ways, for instance referencing *common avowable interests*.[123] As now explained, common interests are those considerations that are co-operatively admissible, meaning they are the sorts of things that people can raise with each other as matters relevant to be taken into account 'without embarrassment.'[124] More recently still, Pettit's preferred reference is to *uncontrolled* power as a synonym for arbitrary

---

[120] Pettit (n 24) 66

[121] Friedman queries this notion of *tracking*, offering the view that there are examples of human relationships where domination is not inconsistent with one person within the relationship being both considerate of and inconsiderate of the other person's interests, making it impossible to categorise relevance for the purposes of meeting Pettit's tracking; see Marilyn Friedman 'Pettit's Civic Republicanism and Male Domination' in Laborde and Maynor J, (n 23) 246 - 268

[122] Pettit (n 24) 55

[123] Philip Pettit *A Theory of Freedom: from the Psychology to the Politics of Agency* (Polity, 2001) 156

[124] *ibid*

interference.[125] But, the important point here is that while Pettit is moving to a distilling or simplifying of terms, the meaning is unchanged across his work. What counts as arbitrary power is something more than merely an exercise of power which is unpredictable, random or erratic. Rather, it is power which is its own reference point, exercisable at the will of its holder and being unconstrained by any *effective* and *external* constraint. Going to the first of these requirements, Lovett makes the point that 'there is no necessary correspondence between formal laws and effective constraints,' the contention being that laws are only effective if enforced.[126] Indeed, social norms may actually be more effective, notwithstanding a lack of formal status. As to the second requirement, any internal policing, as it were, of a capacity to interfere brings us back into the territory of the kindly master: only a constraint that references an independent third party meets the required standard.[127]

3.11 Reducing arbitrariness: the role of institutions

Within some stands of liberalism – and I count libertarianism as coming under liberalism's canopy - law and the institutions of the state are, at root, impediments to, or at least reductions of, liberty.[128] Republicans reject this.[129] Indeed, some republican theorists contend that liberalism itself, particularly as found in its close association with globalisation, has become a threat to liberty - not least, in neoliberalism's (perhaps not so) oblique reductions of freedom to *market*-freedom.[130] Linking back to contemporary republicanism's classical origins, republicans emphasise a political architecture comprising, *inter alia*, the rule of law, the separation of powers and a contestatory democracy as vital to sustaining and promoting non-domination. Of the first of these,

> [t]he idea of a rule of law argues in itself that law should be general and stable, and that it should be known, understood, and capable of being followed; let any of these conditions fall and it is not clear that law would properly serve the role envisaged..[131]

---

[125] Philip Pettit *On the People's Terms* (Cambridge University Press, 2012)
[126] Lovett (n 99) 97
[127] *ibid*
[128] see Robert Nozick *Anarchy, State and Utopia* (Blackwell Publishing, 1974)
[129] see, for instance, Eoin Daly, Tom Hickey, 'Religious freedom and the 'right to discriminate' in the school admissions context: a neo-republican critique' (2011) 31 (4) Legal Studies 615, 617
[130] see, for example, Robert S Taylor *Exit Left: Markets and Mobility in Republican Thought* (Oxford University Press, 2017); Robert S Taylor, 'Market Freedom as Antipower' (2013) 107 (3) The American Political Science Review 593
[131] Philip Pettit *The State* (Princeton University Press, 2023) 103

In essence, these internal rhythms of the law sustain it in place and constrain it from being arbitrary, following the traditional view laid down by Dicey that no one be punished or made to suffer 'in body or goods except for a distinct breach of law established in the ordinary legal manner before the ordinary courts of the land.'[132] As Dicey has it, the rule of law emphasises three elements, all of them consistent with republican principles: government through legal norms and procedures rather than unrestrained discretion, formal equality before the law and individual rights developed through precedent.[133]

Where contemporary republicanism extends on most traditional understandings of law is in assertions about the emancipatory potential of the law. Drawing on traditions that are intrinsically democratic, Pettit envisages a mixed constitution, with checks and balances in place, sufficient to ensure that there are effective contestatory mechanisms to enable people assert their claims resiliently. Within the republican ideal, this requirement around contestation is premised on an understanding of citizenship not as a status but as a *practice*. Seen from this perspective, contestation is the means by which citizens 'democratically control governmental power.'[134] Questions of civic virtue take centre-stage, the idea being that the individual citizen has been enculturated into a way of thinking, not least through the education system, [135] that recognises chaos in the abandonment of the common good in favour of elevating private individual and sectional interests. Hence, for instrumental reasons, the citizen's involvement in democratically-alive public discourse is to strengthen the processes by which freedom is maximised by ensuring that 'decision making tracks the interests and the ideas of those citizens whom it affects.'[136]

As presented in this modern idiom, republicanism is claimed as a particularly *fluid* doctrine, well suited to the contending realities of a pluralist and multicultural society, what Maynor terms 'a diverse citizenry.'[137] As we have seen, Machiavelli argues trenchantly for an institutionalised discord between contending factions within the polity, seeing it as both healthy and necessary, even unto bloodshed. While this is not something a modern republic would countenance, the principle of open, honest contestation remain vivid within the republican imaginary and is of

---

[132] Albert V. Dicey *Introduction to the Study of the Law of the Constitution* (Liberty Fund Inc, 1982) 110

[133] see Mark D Walters *A. V. Dicey and the Common Law Constitutional Position: A Legal Turn of Mind* (Cambridge University Press, 2020)

[134] Daly and Hickey (n 7) 69

[135] see Andrew Peterson, 'Civic Republicanism and Contestatory Deliberation: Framing Pupil Discourse Within Citizenship Education' (2009) 57 (1) British Journal of Educational Studies 55

[136] Pettit (n 24) 184

[137] Maynor (n 9) 117

central importance in terms of how diverse views can be accommodated within the non-domination ethic. For instance, for Pettit, the goal is to have in place a representative assembly which operates 'responsively rather than [as] an indicatively representative body,'[138] wherein self-interests give way to common interests. [139] Meanwhile, Maynor talks of a process which 'seeks to draw individuals and groups out of their narrow self-interested ways so that they themselves make the necessary contribution to their own non-domination.'[140]

However, from the point of view of accommodating persons with disabilities this talk of a diverse citizenry engaged in a responsive and a quintessentially *learning* contestation falls away, since, at least in terms of its most prominent theorists, republicanism cannot be said to have meaningfully reached out to include the world's largest minority in any substantive way. Indeed, Pettit's theory is accused of containing ableist elements.[141] As to why, in large part, contemporary republicanism eschews meaningful engagement with the lived reality of disability I meld some consideration of this throughout the dissertation. However, a brief word here about ableism is appropriate, not least because ableism is a barrier to the kind of coalition building the working out of the CRPD is likely to need if it is to succeed in significantly improving disabled person's political and social circumstances. Ableism and, indeed, the idea of an ableist society is, at root, prefaced on a valuation system that contends – perhaps *sotto voce* – that the good life and the well-lived life are incompatible with the presence of impairment. Ableism posits a hierarchy: instead of a 'collective humanness'[142] is found a social ordering incompatible with the idea that impairment is not axiomatically a barrier to a rich and satisfying life. Within the ableist perspective, disabled people, particularly those people with severe intellectual challenges, may merit pity and special provision but they can never be equal because the *normal* is prized and privileged above all else. In such circumstances, it can be no surprise that celebrated mainstream political theorists such as Rawls and Pettit – caring, compassionate thinkers though they are – frame their constructs within a hegemonic sociocultural worldview that positions disabled people as outside the norm, a special case.

---

[138] Pettit (n 125) 215

[139] for an argument questioning the likelihood of these see Ricardo Silva, 'Non – domination and Political Institutions: The Contested Concept of Republican Democracy' (2015) 9 (1) Brazilian Political Science Review 3

[140] Maynor (n 9) 160

[141] see Maire Sepulchre, 'Disability, Justice and Freedom as Non-Domination' (2022) 2 (1) The International Journal of Disability and Social Justice 11

[142] Daniel Goodley, Katherine Runswick-Cole, 'Becoming dishuman: thinking about the human through dis/abilty' (2016) 37 (1) Discourse: Studies in the Cultural Politics of Education 1, 1

In order to disrupt this worldview – itself a domination - it becomes important to understand where it comes from and how it works. This is the task of the remaining sections in this chapter, involving, first, a close reading of the medical, social and human rights models of disability. The chapter culminates in a juxtaposing of the capabilities model with contemporary republicanism. In doing so, I seek to suggest that in these two theory's insistent focus on freedom as having intrinsic rather than just instrumental value may be found harmonies beneficial to aligning republicanism with a robustly inclusive approach to disability.

4 Models of disability

4.1 Medical, social and human rights paradigms

People with disabilities have a long history of exclusion from society. Expressed in terms of the experience of belonging in civil society, people with disabilities can be characterised as continuing to endure 'a long fast.'[143] In a configuration within which ideals of social order and social status and the operation of the 'social system'[144] are intricately interlinked with the performance of recognised social roles, the dominance of images of health come to be presented as 'a 'normal' and stable state that underpins optimum role capacity.'[145] In contrast, illness and the state of being disabled - often seen (mistakenly) in common parlance as illnesses' straightforward corollary - becomes associated with instability, unproductiveness and dependence. Within this dichotomy, the idea type, the archetypical person, is the individual who conforms to an abled-bodied orthodoxy while those who do not reach this standard can be easily presented, *inter alia*, as 'unfortunate, useless, different, oppressed and sick.'[146] Similarly, Goffman suggests the idea that there are attributes which reduce the bearer 'from a whole and usual person to a tainted, discounted one,' using the idea of how stigma works in society to separate out notions of what it is to be normal from what it is to be *not* normal or abnormal. [147] In this suggesting an ordering which assigns the status of 'not quite human' to some.[148]

This dissertation rests on an assertion that people with disabilities continue to be excluded from an equal involvement in society.[149] The image of 'the long fast' or of persistent hunger or near-

---

[143] referencing the experience of living under Nazi domination, this phrase occurs in Simone de Beauvoir's *The Mandarins* (World Publishing Company 1956) 11

[144] See Talcott Parsons *The Social System* (Free Press 1951)

[145] Michael Oliver and Colin Barnes *The New Politics of Disablement* (Palgrave McMillan 2012) 39

[146] Paul Hunt *Stigma: the experience of disability* (Geoffrey Chapman 1966) 146

[147] Erving Goffman *Stigma. Notes on the Management of Spoiled Identity* (Penguin 1990) 12

[148] *Ibid* 15

[149] See, for example, Colin Barnes and Geoff Mercer *Exploring Disability* (Polity 2010), World Health Organisation (WHO) and World Bank *World Report on Disability* (WHO, World Bank 2011), Dan Goodley,

hunger captures something of the absence of people with disabilities from the institutions and orthodoxies of political, legal, cultural and socio-economic life, prefiguring, instead, a sense of countless lives lived in penumbra and mired in poverty,[150] educational under-attainment, unemployment and restricted access to the means to experience and assert their human rights. Hence, the dissertation theorises disabled peoples' exclusion across a number of domains, situating its discussion within a conceptual framework derived, *inter alia*, from Said's representation of the *Other*, Gramsci's[151] theory of how ideas can transmute into material forces and Foucault's assertions about knowledge, power and governmentality.

4.2 Socio-historical perspectives: stigma, industrialisation and the rise of the expert

Rothman's description of the 19th Century as the age of the asylum[152] seems apt in this context and expresses one dimension of Foucault's identification of the same period as the era of the great imprisonment.[153] Both theorists draw attention to the unparalleled historical process whereby a system of human disciplining and surveillance is brought to bear on all levels of society, whether in schools or prisons, hospitals or orphanages, the army or the workhouse. Indeed, Clear offers a specific Irish reading, describing the huge growth in Roman Catholic provision for segmented, segregated services focusing, *inter alia*, on disabled people as

> part of a wider tendency of all organisations, statutory or voluntary, secular or overtly religious, to put people who were perceived to be vulnerable or deviant or both into institutions.[154]

Foucault's perspective on the institutionalisation of people who deviate from what is regarded as the norm offers further insight. According to Foucault knowledge, and the power knowledge confers, derives from the examination of the abnormal by the normal.[155] Disease, difference and disability all present as contagions of chaos whereas ideals of health and wholeness represent order in the world. Hence, the way the Victorians medicalised the abnormal,

---

Bill Hughes and Leannard Davis (eds) *Disability and Social Theory: New Developments and Directions* (Palgrave Macmillan 2012)

[150] See for example Tony Emmett 'Disability and Poverty' in Erna Alant Lyle Lloyd (eds) *Augmentative and Alternative Communication and Severe Disabilities: Beyond Poverty* (Whurr Publishers 2005) 69-94; Sophia Mitra Disability and Poverty in Developing Countries: a Multidimensional Study [2013] 41 *World Development* 1

[151] Antonio Gramsci *Selections from the Cultural Writings* (Lawrence and Wishart 1985)

[152] David J Rothman *The Discovery of the Asylum: Social Order and Disorder in the New Republic* (Little, Brown and Co 1971)

[153] Foucault (n 89)

[154] Catherine Clear *Nuns in Nineteenth Century Ireland* (Gill and MacMillan 1987) 106

[155] See for example Michael Foucault *The Will to Knowledge: the History of Sexuality Volume 1* (Penguin 1990)

stigmatising and isolating difference and corralling disabled people into institutions, can be theorised as an exercise of power to protect the normal, a rationale which comes to its awful apotheosis in the eugenics movement.[156] The net effect of this 'unity of the medical gaze'[157] was an *othering* of difference and the further empowering 'of the already powerful while disenfranchising those who had the least social purchase.'[158] Drawing on Bentham's Panopticon,[159] the hospital (or asylum) now, from the end of the eighteenth century and the emergence of 'the 'clinical' sciences,'[160] becomes 'an 'examining' apparatus'[161] where 'the old form of inspection, irregular and rapid, was transformed into a regular observation that places the patient in a situation of almost perpetual examination.' [162] Each individual is reduced to the status of a case. In the process, the 'disabled' come to be viewed as a distinct group but crucially, in Leach Scully's view, the distinction arises for purely administrative purposes. [163] In this topology the doctor (or other administrator) becomes the wielder of 'a form of power which subjugates and makes subject to',[164] which pathologies the individual, imposing 'a law of truth on him which he must recognise and which others have to recognise in him.'[165] In this reading to embody disability becomes about disease, degeneration, deficit or defect. In sectionalising bodies into the *normal* and the *abnormal*

> the individual body becomes an element that may be placed, moved, articulated on others. Its bravery or its strength are no longer the principal variables that define it; but the place it occupies, the interval it covers, the regularity, the good order according to which it operates its movements[166]

---

[156] See for example Edward J Larson (ed) *Sex, Race and Science: Eugenics in the Deep South* (John Hopkins University Press 1996)

[157] Michel Foucault *The Birth of the Clinic* (Routledge 2003) 33

[158] Steven Seldon, 'Eugenics and the social construction of merit, race and disability' (2000) 32 (2) Curriculum Studies 235, 236

[159] Jeremy Bentham *The Panopticaon Writings* (first published in 1789, Verso Books 2013)

[160] Foucault (n 89) 191

[161] *Ibid* 185

[162] *ibid* 186

[163] Jackie Leach Scully, 'Drawing Lines, Crossing Lines: Ethics and the Challenges of Disabled Embodiment' (2003) 11 (3) Feminist Theology 265

[164] Michel Foucault, 'The Subject and Power' (1982) 8 (4) Critical Inquiry 777, 781

[165] *ibid*

[166] Paul Anthony Drake, 'The Elephant Man (David Lynch, EMI Films, 1980): an Analysis from a Disabled Perspective (1994) 9 3 Disability & Society 327,164

Finklelstein[167] explores the way in which definitions of disability underpin professional and political practice, suggesting that the institutionalisation of people with disabilities represents society defining them as socially dead. In this formulation, the role of the institution becomes that of mediating the transition from social death to physical death. Care becomes the management of social death. This stark equating of disability with social death expresses, it is suggested, a societal prizing of the *whole*, which, again, is derived from a sense that there is a state called 'normal' and another state called 'abnormal' or 'deviant'. Indeed, the graveyards of so many Irish institutions for disabled people and other marginalised groupings might be read as artefacts of a world where being disabled spoke of a protective segregation of the abnormal from the normal that endured even beyond death.

Goffman's[168] interrogation of the nature of stigma is of help here in delineating the deeper nature of social attitude to unacceptable difference, suggesting that there exists 'a shared normative system of grading and categorising people.'[169] Distinguishing between those who are 'discredited,' meaning those whose differentness is visible, and those who are 'discreditable,' that is, those whose difference is not immediately on show, Goffman theorises a complex, ideological structure of stigma enforcement which presents or withholds social acceptability, even, to the point, where the family of, say, disabled people can acquire a 'courtesy stigma.'[170] The challenge for those whose stigmatising feature is obvious is to recover their status and identity, perhaps by undergoing surgery or performing some acceptable, normalising activity, perhaps of such a type that (to employ Goffman's word) 'normals' might describe it as heroic (for example, a blind person learning to ski). For those who are 'discreditable' the issue also becomes about the presentation of self, '[t]o display or not display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when and where.'[171] Another strategy which Goffman identifies – common to the 'discredited' and the 'discreditable' - is to withdraw from social activity with 'normals,' a sequestration of the self, born of the expectation of rejection.

Goffman outlines how disabled people whose disability has always been present *grow* into their non-normal nature, made aware from childhood of their different status through the intermeshing negative attitudes of family and friends and the likely experiences of prolonged

---

[167] Vic Finkelstein 'Disability: an Administrative Challenge?' in Michael Oliver (ed) *Social Work: Disabled People and Disabling Environments* (Jessica Kingsley 1993) 19-39
[168] Goffman (n 147)
[169] Colin Barnes and Geof Mercer *Exploring Disability* (Polity 2010)
[170] Goffman (n 147) 44
[171] *ibid* 57

hospitalisations, educational segregation and inaccessible public environments. In these circumstances, *being disabled* becomes a given identity. In this context, Scott's study of the experience of being blind in American society is instructive, suggesting how specialist rehabilitation agencies work to socialise their clients into performing a stereotypical 'blind social role' such that these clients represent themselves as superior to those among their fellow visually impaired whom they perceive as persisting in *inappropriate* ideas about - and behaviours associated with - how to be blind in the world. [172]

In Goffman's telling, socialisation into *normal* society is the basis of a 'moral career,'[173] such that institutions and organisations working with disabled people become part of a custodial apparatus intended to enforce a narrow conformity cohering around the idea of what is and what is not acceptable.[174] Yet, Digby reminds that the mass institutionalisation of people whom might be described as anomalous – occurring in Europe and North America from the 19th Century onwards – is rooted in Enlightenment mores and born out of a 'burst of therapeutic and social optimism.' [175] In this formulation, institutions represent a markedly more benign response to human difference than previously existed in social history and, perhaps, may even be be thought to owe something to Rousseau's description of modern society as one where dependence has replaced independence as the mode of social functioning.[176]

Said offers another perspective in terms of the way in which social psychology underwrites the kind of segregation associated with institutionalisation. [177] Said says humans reinforce a culturally agreed identity, an '*us*', by reference to a '*them*', identifying this ages old process as the cultural creation of 'the *Other*'. Often, this *Other* becomes symbolic of something which is rejected or feared and this, in turn, serves to further justify the demarcation between '*us*' and '*them*'. The complexities of diverse groups are obfuscated and complicated political, social and economic questions of entitlement and citizenship become reduced, negated and, sometimes,

---

[172] Robert A Scott *The Making of Blind Men: a Study of Adult Socialisation* (Sage 1969)

[173] Goffman (n 147) 45

[174] See for example Erving Goffman *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (Penguin Books 1991); Peter Townsend *The Last Refuge: a survey of residential institution sand homes for the aged in England and Wales* (Routledge and Kegan Paul 1962) Kathleen Jones, A. J. Fowles *Ideas on Institutions* (Routledge and Kegan Paul 1984) The Commission to Inquire into Child Abuse (The Ryan Report) (Government of Ireland 2009)

[175] Anne Digby 'Contexts and perspectives' in David Wright Anne Digby (eds) *Historical Perspectives on People with Learning Disabilities* (Routledge, 1996) 5

[176] See for example David J Mayerhoff, 'Radical deinstitutionalization: Rousseau versus Freud' (2006) 15 (2) Journal of Mental Health 145; David Lay Williams *Rousseau's Social Contract: an introduction* (Cambridge University Press 2014); Michael J Thompson, 'Autonomy and Common Good: Interpreting Rousseau's General Will' (2017) 25 (2) International Journal of Philosophical Studies 266

[177] Edward W Said *Orientalism* (Penguin 2003)

what arises is what Brewer [178]explores as 'common sense racism,' a set of everyday (and often contradictory) pejorative maxims which can be read to encompass all oppression of minorities. Yet, Said – writing as an Arab Palestinian living, in particular, in America - also offers a reminder which both resonates with civic republican principles and crosses over to address ways of undermining the oppressive strictures constraining disabled people's lives:

> the production of knowledge best serves communal as opposed to sectarian ends; how knowledge that is non-dominative and non-coercive can be produced in a setting that is deeply inscribed with the politics, the considerations, the positions and strategies of power.[179]

4.3 Social disappearance and the imposition of a medical model

It is argued that the institutionalisation momentum for people with disabilities removed them from the pages of history. By this is meant that even the many who were not incarcerated - that is, the great majority of disabled people – ceased to have status as social actors (or potential actors), originators of history, and instead, are consigned to the category of the acted upon. Institutionalisation is presented here as a form of oppression, as a domination which removes agency and autonomy and erases citizenship and as a gathering in of the socially unproductive. What emerges is a 'new political anatomy of the body,'[180]made possible by new technologies of surveillance and classification and, in the practice of which, '[t]he Normal is established as a principle of coercion.'[181]

Reflecting on the commodification of medical life, Illich[182] observes that the practice of the modern check-up serves to turn healthy people into patients. In a similar way, the medical gaze, understood, here, in Foucault's terms of surveillance and classification, and harnessed to the institutionalisation momentum, may be described as turning disabled people into sick people. Whereas up to the eighteenth century people with disability were, in the main, part of a larger problem population whose chief determining feature was poverty,[183] from this period on an increasingly relentless industrialisation and urbanisation drew particular attention to those who

---

[178] John D Brewer, 'Competing understandings of common sense understanding: a brief comment on 'common sense racism'' (1984) 35 (1) The British Journal of Sociology 66

[179] Edward W Said 'Orientalism Reconsidered' in Roland Robertson, Kathleen E White (eds) *Globalisation. Critical Concepts in Sociology* Vol v (Routledge 2003) 4

[180] Foucault (note 89) 193

[181] *Ibid* 184. Foucault uses this phrase in relation to teaching but it is plausible that in the context of his overarching theory that he intends it to apply to other areas of power too

[182] Ivan Illich *Limits to Medicine* (Marion Boyars Publishers 1995)

[183] Patrick McDonnell *Disability and Society* (Blackhall 2007)

were deemed economically unproductive.[184] People for whom jobs might once have been found in a slower, more pastorally based economy were now marked as in the way, drawing on resources they made no contribution to. In a sense, institutions became hallmarks of this new excitement about productivity. Indeed, in England and Ireland the very name 'Workhouse' indicating that beyond their grim facades economic life was volarised as the essential good. A systematic othering of disability might now be said to be well underway, Foucault's great confinement is imminent and the disabled are, across Europe, about to be habilitated into productive workers. This view fits with the assertion by Barnes *et al*. that the origin of the category termed 'the disabled' is an administrative one, arising out of a desire to identify and manage the economically unproductive. [185]

By the nineteenth century the identity of the medical expert - Illich uses the image of the doctor as actuary[186]- who determines the boundaries between normal and abnormal is entrenched in Western consciousness. More, arguably, this bifurcation of humanity into normal and abnormal, driven by economic determinism and medicalised into a topic of study, reconfigures the abled bodied as those who must be protected from the disabled. Prejudice and social exclusion become social goods, an idea which ultimately reaching its awful apotheosises in the eugenics movement.

At the heart of this individual or biomedical model of disability sit issues of quantification, measurement, of diagnosis, definition and, inevitably, of comparison. Disability, illness and impairment are fused together in a causal relationship. The *problem* of disability is personally situated within an individual body and its degree or severity measured using clinical tests that position the disabled body in an adverse relationship with some notional whole, normal body. The disabled body becomes a site for treatment, for rehabilitation, correction or cure just as any additional, secondary problems – say, poverty, unemployment or social exclusion – are identified as existing, mainly, as a consequence of disability. Titchkosky terms this identification of disability with 'the problem body' as 'a reading coded for and by privileging non – impairment,' [187] a coding which implicitly associates disability as a failing of sorts, with its concomitant construction of the disabled person as, *inter alia*, vulnerable, dependent, a victim,

---

[184] Joanna Ryan, Frank Thomas *The Politics of Mental Handicap* (Penguin 1980)
[185] Colin Barnes, Len Barton, Mike Oliver *Disability Studies Today* (Polity 2001)
[186] Ivan Illich *Medical Nemisis: The Expropriation of Health* (Pantheon, 1982)
[187] Tanya Titchkosky, 'Disability in the news: a reconsideration of reading' (2005) 20 (6) Disability & Society 655, 662

asexual[188] and, even, living in a state of perpetual childhood.[189] Disabled people become identified not as individual contributors to society and the business of citizenship but as signifiers of otherness, as the social embodiment of their perceived impairments, as bodies or minds (or both) that badly work, partly work or don't work. [190]

4.4 A counter-narrative: the social model of disability

Conceptualising what a person ought to be in terms of physical or psychosocial ability and functioning transfers enormous power to the *expert*. If the locus of disability lies with the individual then, axiomatically, the help that individual is conjectured to need has to come from some external source.[191] The expert determines who can treat, who can and should be treated, what treatment should look like and how its success is measured. In pathologising disability along medical lines what emerges is a dominant discourse in which medical practitioners are entrusted by the wider civil society to take charge and to discharge their ages old responsibility to diagnose and to *do* something. This faith in expert knowledge is identified as one of the core features of modernism, itself a product of the Enlightenment, whereby key facets of everyday life are gifted over to professional spheres of influence.[192] These professional spheres offer frameworks for meaning making which, in effect, set the normative categories within which particular issues are conceptualised and discussed. In terms of disability what emerges from the medical model is a powerful cultural representation of people with disabilities which even as it stereotypes them exculpates the wider society. Thus, a disabled person's inability to find a job is attributed to the disability, rather than to the larger political, economic, and material forces at play in (the ableist) society.

In stark contrast, the social model of disability seeks to assert a very different narrative. Subscribers to the social model of disability seek to place experiences of exclusion and marginalisation at the centre of how disability is theorised. This model holds that disability has no intrinsic or innate nature but, rather, disability is a consequence of social processes and structures.[193] Schillmeier contrasts the social model with the biomedical model thus:

---

[188] Tom Shakespere, 'Disabled Sexuality: towards rights and recognition' (2000) 18 (3) Sexuality & Disability 293

[189] Michael Priestly *Disability: A Life Course Approach* (Policy Press, 2003)

[190] Teresa Meade, David Serlin 'Editors' Introduction' [2006] 94 Radical History Review 1, 1

[191] Eric Shyman, 'The Reinforcement of Ableism: Normality, the Medical Model of Disability, and Humanism in Applied Behaviour Analysis and ASD' (2016) 54 (5) Intellectual and Developmental Disabilities 366

[192] Anthony Giddens *Modernity and Self-Identity* (Stanford University Press 1991)

[193] Colin Barnes, Len Barton, Mike Oliver, *Disability Studies Today*. (Polity 2003)

> From the social/cultural perspective, other perspectives –notably the medical or techno-scientific view – have been criticised for treating disability as a condition that lies outside the realm of 'the social' or 'society'. It is argued that techno-scientific and medical practices do not reveal the social origin but the troubled 'nature' of individual being that visualises disability. [194]

For disability activists, in particular, the social model emerges as a trenchant criticism of the social oppression people with disabilities encounter.[195] While the biomedical model of disability posits a causal relationship between impairment and disability, with an inevitable emphasis on rehabilitation,[196] the social model denies this causality, contending instead that the term 'disability' refers not to impairment per se but to socially constructed 'barriers of prejudice, discrimination and social exclusion.'[197] Hence, impairment and disability *become* linked only through the machinations of a disabling society. As Finklestein phrases it, 'disability is the outcome of an oppressive relationship between people with impairments and the rest of society.' [198] The social model of disability is now recognised within the World Health Organisation's definition of disability statement that 'a person's functioning or disability is conceived of as a dynamic interaction between health conditions and environmental and personal factors.'[199] Moreover, as a construct, the social model permits an analysis of the dominant political and economic forces at work in society[200] and enables disabled people conceptualise disability as 'something imposed on top [of] our physical impairments by the way this society is organised to exclude us.'[201] As Sullivan phrases it:

---

[194] Michael Schillmeier, '(Visual) Disability – from exclusive perspectives to inclusive differences' (2008) 23 (6) Disability & Society 611, 611

[195] Mike Oliver *Understanding Disability: From Theory to Practice* (Palgrave MacMillian 2009)

[196] Tania Burchardt, 'Capabilities and Disability: The Capabilities Framework and the Social Model of Disability' (2004) 19 (7) 735; Stephen French Gilson, Elizabeth Depoy, 'Multiculturism and Disability: a critical perspective (2000) 15 (2) *Disability & Society* 207

[197] Jenny Morris, 'Including all children: finding out about the experiences of children with communication and/or cognitive impairments' (2003) 17 (5) Children and Society 337, 340

[198] Finklestein (n 167) 47

[199] World Health Organisation (2001) *International Classification of Functioning, Disability and Health* at 6

[200] Harlan Hahn Adjudication or empowerment: contrasting experiences with a social model of disability In Len Barton (ed) *Disability, Politics and the Struggle for Change* (David Fulton Publishers 2001)

[201] Union of the Physically Impaired Against Segregation (UPIAS) (1976) at https://disability-studies.leeds.ac.uk

> the social model, thus, provides a highly politicised account of disability which acts both as a counter-hegemony to medicalisation and as an agenda for the elimination of disability: the social model is a manifesto for change. [202]

By 'drawing attention to the ways in which dominant, non-disabled values and practices' [203] alienate people with disabilities, the social model reminds us how excluded disabled people are from power and privilege.[204] Alongside this, Miller *et al*. [205] draw attention to the socially constructed nature of *disablism*, which Thomas defines as 'discriminatory, oppressive or abusive behaviour arising from the belief that disabled people are inferior to others.' [206] Thus, a new politics of disablement[207] emerges, emphasising human rights and citizenship. [208] In particular, Rioux and Valentine identify the concept of citizenship as both a conceptual and practical space where disability and equality intersect; they write:

> the concepts of disability, equality and citizenship are central to advancing disability rights because the norms, standards, values and biases on which these theoretical concepts are built lead to particular standards and constructs of policy, programs and legal status. These in turn have an effect on whether the human rights of people with disabilities are respected or abridged. [209]

This focus on political rights also serves to highlight the way in which the enfranchisement perspective, specifically the understanding of participation as a fundamental right of

---

[202] Martin Sullivan Disabled People and the Politics of Partnership in Aotoaroa, New Zealand. In Len Barton (ed) *Disability, Politics & The Struggle For Change* (David Fulton Publishers 2001) at 94

[203] Bill Hughes, Kevin Paterson, 'The social model of disability and the disappearing body: towards a sociology of impairment' (1997) 12 (3) Disability & Society 325, 325

[204] *ibid*

[205] Paul Miller, Sophia Parker, Sarah Gillinson, *Disablism: How To Tackle The Last Prejudice* (Demos 2004)

[206] Carol Thomas *Female Forms: Experiencing and understanding Disability*. (Open University Press 1999) 9

[207] Mike Oliver *The Politics of Disablement* (MacMillian 1990)

[208] Marcia H Rioux, Fraser Valentine' Does theory matter? Exploring the Nexus between Disability, Human Rights and Public Policy'. in Dianne Pothier, Richard Devlin, (eds) *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law* (UBC Press 2003) 47 – 69; Theresa Man Ling Lee Multicultural Citizenship: the Case of the Disabled. In Dianne Pothier Richard Devlin (eds)) *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law* (UBC Press 2003)
87 -105

[209] Note 208, Rioux and Valentine 56

citizenship[210] links disabled people's struggle against oppression to that of other traditionally disenfranchised groups in society. Indeed, in a United Kingdom context, Crowther argues that there are still natural alliances to be formed by disability activists with others disadvantaged by, for instance, poverty and gender, not least because, for example:

> the economic exclusion of disabled adults is playing a central role in driving child poverty, with one in three children in poverty having a disabled parent. [211]

4.5 A critique of the social model

Mitchell and Snyder[212] argue that in vigorously asserting a refusal to assent to any pathologising of the disabled body, social model theorists are disconnected both from the simple materiality of the body and the body's tenuous, porous place in a world that is increasingly inhospitable to humankind, disabled or seemingly nondisabled alike. This refusal 'to give materiality its due'[213] in a neoliberal world where the subject 'has come to care too much for itself'[214] is positioned to represent a threat to life itself, *all* life, such that human agency becomes problematic, arguably, precisely because its ideation has failed to allow that other things – maybe *all* things – in the material world exert a kind of agency too. In this context Mitchell and Snyder ask what if we posit disability as 'an agentive switchpoint for human and non-human bodies mediating environmental toxicity levels rather than as individual corporeal failures?'[215] The argument emerging here is that a too narrow, all about us focus on the built environment – and on its political and policy equivalents – segregates disabled people from the pivotal role their experience of global environmental injustice can offer to the planet. There is, perhaps, something in this which is about understanding that to be human – any human – is to be vulnerable and that, akin to the prophetic, community orientated roles played by the blind seers and disabled shamans of antiquity the person with disabilities today can represent what Grear[216] describes as a 'kind of ground-level energising of political resistance' to a political hegemony and

---

[210] see for example Andrew Peterson *Civic Republicanism and Civic Education* (Palgrave Macmillan)

[211] Neil Crowther, 'Nothing without us or nothing about us?' (2007) 22 (7) Disability & Society 791, 792

[212] David T Mitchell, Sharon L Snyder, 'The Matter of Disability' [2016] 13 Bioethical Inquiry 487

[213] Diane Coole, Samantha Frost, (eds) *New Materialisms: ontology, agency and politics* (Duke University Press 2010) 7

[214] Andrew Poe, 'Review Essay: Things-Beyond-Objects' (2011) 19 (1) Journal of French and Fracophone Philosophy 153, 153

[215] David T Mitchell Sharon L Snyder The Matter of Disability (2016) 13 Bioethical Inquiry 487, 492

[216] Anna Grear, Vulnerability, Advanced Global Capitalism and Co-symptomatic Injustice: Locating the Vulnerable Subject in Martha Albertson Fineman, Anna Grear, (eds) *Vulnerability* (Ashgate 2013) 59

capitalist imperium which is disabling humanity as a species, perhaps fatally. The degree to which a social reading of disability can accommodate this reimagining is uncertain.

Schillmeier too takes a materialist perspective on the social model, arguing that differentiating between matters of 'society' and matters of 'nature' can serve to create a sense that the social model and the medical models are mutually exclusive, a position Schillmeier holds to be false. Rather, he conceptualizes them as mirror images of each other, attempting to lift the discussion out of the confines of what might be seen as self-perpetuating abstraction in favor of arriving at a practical synthesis, while also contending that the reality of 'the social' must never overshadow impairment 'as a key actor of disability.' [217] Arguably, the International Classification of Functioning, Disability and Health (WHO, 2001) appears to do the same, as does Best who points out that pain – a staple of many people's experience of disability – 'raises doubts about the validity of a socially constructed conception of impairment.' [218] Indeed, Williams observes that a strange paradox has arisen whereby the determination of social model theorists to move away from *the problem body* has resulted in the body being relegated entirely to the field of medicine and to the exclusively medical discourse. [219] Similarly, Matthews queries whether the social model's emphasis on the social, political and economic environments does not actually serve to leave out something important by marginalising questions of embodiment. [220]

4.6 Contrasting the social model and the human rights model

An important question now emerges as to whether, for all its ideological clout, the social model is robust enough to undergird the justice claims of disabled people. As previously illustrated, the way in which the social model disrupts oppressive thinking about disability represents the most significant paradigm shift, to date, in disability consciousness. The theory's central assertion that there is nothing necessarily causative between experiencing a physical and/or cognitive impairment and experiencing disadvantage, say, in terms of adverse employment status or living in non-ideal accommodation or enduring stigma, is a profound – and potentially, profoundly liberating – concept. However, for all its conceptual richness, in its basic orientation the social

---

[217] Michael Schillmeier *Rethinking Disability: Bodies, Senses and Things* (Routledge 2010) 19. For an interesting insight into impairment and disability as a function of colonialism, see Martin Sullivan Disabled People and the Politics of Partnership in Aotoaroa, New Zealand in Len Barton (ed.) *Disability, Politics & The Struggle For Change* (David Fulton Publishers 2001)

[218] Shane Best, 'The social construction of pain: an evaluation'(2007) 22 (2) Disability & Society 161,161

[219] Simon J Williams, 'Is anybody there? Critical realism, chronic illness and the disability debate' (1999) 21 (6) Sociology of Health and Illness 797

[220] Nicole Matthews, 'Contesting representations of disabled children in picture-books; visibility, the body and the social model of disability' (2009) 7 (1) Children's Geographics 37

model remains largely descriptive; it is essentially an analytic tool rather than a programmatic approach to change. Moreover, even if this is not true, while the medical model might be described as operating on a micro level – potentially drawing attention to social practices which misalign on an (eligible) individual basis – the social model requires that 'it is society that should be reshaped.'[221] It is suggested such is the sheer scale of this putative project, not least in terms of its amorphous and inevitably uneven nature, that it offers little in the here and now to address actual oppressive practice. Hence, although the social model uncovers the taken-for –granted assumptions that denigrate and disrespect and *disable* people its 'big idea'[222] identification of disability as oppression has not translated to widespread public support for radical change. Put simply, undeniably important as it is to disabled people themselves, there is no pressing incentive in the social model for change to occur from *inside* the wider societal milieu. By contrast, it is suggested the human rights approach to disability does provide such an incentive – and so, does support more robustly the justice claims of disabled people. The social model directs its criticism to oppressive social structures and attitudes at society - indeed, Oliver identifies capitalist society in particular[223] - but, other than in quite a general sense, it goes no further. In contrast, the human rights approach operationalises a focus on governments to ensure problematic structures and attitudes are attenuated through such mechanisms as improved law, public policy and consciousness raising.

Although often confused with each other, the human rights model of disability and the social model have some very significant differences. To begin, the social model is a general theory of disability, meaning that its impetus to explain inevitably means that complexity is scaled down to accommodate the need for a homogenised perspective. Hence, the social model cannot directly address the multi-layered diversity of disabled people's experiences, even, it can be argued, when what is in question are the experiences of, say, two people who apparently share all the external features of the same impairment.[224] A human rights based theory does not face this difficulty. Indeed, even though human rights instruments are often phrased in the plural – the rights of women, the rights of indigenous peoples – the subject of human rights is always a unique individual, 'a self-enclosed entity which transcends the various and fluctuating groups of

---

[221] Anita Silvers, Formal Justice. In Anita Silvers, David Wasserman, Mary B Mahowald, Lawrence C Becker (eds.) Disability, Difference, Discrimination: Perspectives on Justice (Rowman and Littlefield, 1998) 85

[222] Frances Hasler, 'Developments in the disabled people's movement' in John Swain, Vik Finklestein, Sally French, Mike Oliver, (eds) *Disabling Barriers, Enabling Environments* (Sage Publications, 1993) 278 - 283

[223] Oliver (n 207); Oliver and Barnes (n 145)

[224] see, for instance, the diversity of ways visually impaired people access text; Tom Shakespeare, The Social Model of Disability. In Lennard J Davis (ed) *The Disability Studies Reader* (Routledge, 2017) 195 - 205

which it may form a part.'[225] Thus, in the CRPD it is the individual with disabilities who is identified, on an equal basis with all persons, as the subject of human rights law.

More, arguably, there are disabled people who fall outside the logic of the social model, specifically those for whom no amount of social change will ameliorate their impairment circumstances, for instance those who endure chronic pain or constant debilitating fatigue or whose impairment occurs episodically. Considering these realities reminds that for persons in these types of circumstances a human rights based model of justice requires no qualifying status *other* than to be human – as, of course, is the case for all those with impairments, regardless of how these impairments present.[226] Further, a human rights approach to disability imports an intersectionality which, it is submitted, more precisely captures those aspects of disability which are complicated by, say, gender,[227] ethnicity, sexuality[228] and post-colonialism.[229] Indeed, in this context, Silvers talks of the social model 'misrepresenting disabled people by abridging who they are.'[230] Phrasing it more starkly still, such claims as 'disability is wholly and exclusively social'[231] draws the criticism that an ideologically driven insistence on the social reduces 'the multidimensionality of disability in a single-sided social constructionist dimension—a narrow caricature of real human conditions and considering disabled humans as "half-humans."'[232] All this said, however, Oliver responds that while social model theorists' *academic* focus is on 'the collective experience of disablement' – an experience of oppression - that is not to argue that the (inevitably) complex individual experiences of disability are not also visible and of concern

---

[225] Alan Supiot, *Homo Juridicus: on the Anthropological Function of the Law* (Verso, 2017) 188

[226] of related interest here, perhaps, is a criticism that the disabilities studies movement in general only reflects the milieu of its core founders, namely that of white, heterosexual men; see Chris Bell, Is Disability Studies Actually White Disability Studies? In Lennard J. Davis (ed.) *The Disability Studies Reader* (Routledge, 2017) 406- 415

[227] see, for instance, Alexandra Gartell, Klaus Baese,l Cornelia Becker, ''We do not dare to love:' women with disabilities' sexual and reproductive health and rights in rural Cambodia' (2017) 25 (50) Reproductive Health Matters 31

[228] see, for instance, George W Turner, Betsy Crane, 'Sexually Silenced No More, Adults with Learning Disabilities Speak Up: A Call to Action for Social Work to Frame Sexual Voice as a Social Justice (2016) 46 (8) British Journal of Social Work 2300

[229] see, for instance, Tsitsi Chataika, 'Disability, Development and Postcolonialism' in Dan Goodley, Bill Hughes, Lennard Davis (eds.) *Disablity and Social Theory* (Palgrave Macmillan 2012) 252 - 269

[230] Anita Silvers An Essay on Modelling: The Social Model of Disability, In D Christopher Ralston, Justin Ho, (eds) *Philosophical Reflections on Disability* (Springer, 2010) 19

[231] Michael Oliver *Understanding Disability: From Theory to Practice* (Macmillan, 1996) 35

[232] Dimitris Anastasiou, James M Kauffman, 'The Social Model of Disability: Dichotomy between Impairment and Disability' (2013) 38 (4) Medicine and Philosophy 441, 445

to them.[233] As Lawson and Priestley have it 'a social model lens is simply to refocus attention – to focus it on the social causes of inequality rather than on its biological causes.'[234]

As previously stated, The CRPD acknowledges its debt to the social model, as, indeed does the European Union's disability policy which commits to ensure the effective implementation of the CRPD across member states and within EU institutions.[235] But in the Convention's intention 'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity'[236] something significantly more happens. The Convention moves beyond highlighting – as the social model does – the power differential between disabled people and a wider society designed and operated *for* the not yet disabled (and which manifests in disabled people being treated as *less*) and into a positive assertion that human rights apply equally to everyone, without qualification. This happens by virtue of a modern depiction of dignity shorn of being contingent on any special status or competencies and, instead, understood as inherent in simply being human. Expressed in the idea of human rights as universal,[237] this conception moves dignity away from being the property of an elite few[238] to being a characteristic common to everyone, including disabled people. Hence, in framing disability as a human rights issue the humanity of every person with disabilities is emphasised and their essential dignity affirmed.

In characterising the social model as 'a stepping-stone in struggles for civil rights reforms and anti-discriminatory laws in many countries' Degener suggests that a significant impetus to this type of advancement is the desire to portray the needs of disabled people as consisting of more than just welfare payments and social policy reforms. [239] But again, in framing disability within a human rights paradigm attention is drawn to the necessity of incorporating the wider needs of disabled people alongside those of all people as consisting not just of civil and political rights but also of economic, social and cultural rights. That these rights have traditionally been held to exist

---

[233] Oliver (n 195) 48

[234] Anna Lawson Mark Priestley 'The Social Model of Disability: Questions for Law and Legal Scholarship?' in Peter Blanck, Eilonoir Flynn (eds) *Routledge Handbook of Disability Law and Human Rights* (Routledge, 2017) 7

[235] European Disability Strategy 2010 – 2020: A Renewed Commitment to a Barrier-Free Europe

[236] CRPD article 1

[237] see, for instance, Jack Donnelly *Universal Human Rights in Theory and Practice* (Cornell University Press, 2013)

[238] Jeremy Waldron *Dignity, Rank and Rights* (Oxford University Press, 2012)

[239] Theresia Degener, A human rights model of disability. In Peter Blanck Eilonoir Flynn (eds.) *Routledge Handbook of Disability Law and Human Rights* (Routledge, 2017) 36

as discreet categories - in the main for political reasons[240] - is now arguably undermined by the CRPD which clearly enunciates both these, respectively, so-called first and second generation rights as, for all practical purposes, indivisible from each other.[241] Moreover, the existence of a separate protocol to the CRPD[242] which, subject to certain rules, affords direct recourse to the CRPD's monitoring mechanism, the Committee on the Rights of Persons with Disabilities, for individuals and groups of individuals who claim to be victims of a state party's violation of the Convention further strengthens the institutional competence to respond directly to human rights concerns. Though optional and therefore only applying in those states which have separately ratified it, the protocol can be said to confirm the legal enforceability of economic and social rights. Again, marking a clear distinction between the human rights approach and the social model, the value of this for disabled people is that what is recognised here is that beneficial as a focus on civil rights undoubtedly is, the complex needs of many disabled people cannot be effectively realised without law underwriting a multi-vector approach which is calibrated to individual need.[243] Hence, for example, the Convention right of disabled people 'to have the opportunity to choose their place of residence'[244] – a civil right – is, for its realisation, likely to be intimately bound up with an economic entitlement, *inter alia*, to 'have access to a range of in-home, residential and other community support services, including personal assistance.'[245] Further, according to the Committee such supports 'are not restricted to services inside the home, but must also be able to extend to the spheres of employment, education or Political and cultural participation.'[246] Indeed, turning to the right to inclusive education and

---

[240] although not separated out for different treatment in the *Universal Declaration of Human Rights* (United Nations, 1948) Cold War rivalries – overwhelmingly inimical to human rights - are cited as having been particularly effective in ensuring that both 'sets' of rights would be governed by different Covenants, both adopted in 1966, the *International Covenant on Civil and Political Rights* (ICCPR) and the *International Covenant on Economic, Social and Cultural Rights* (ICESCR), both covenants having separate implementation timeframes. Note too, the introduction of the *Optional Protocol to the International Covenant on Economic, Social and Cultural Rights* (OP-ICESCR), see Claire Mahon, 'Progress at the Front: The Draft Optional Protocol to the International Covenant on Economic, Social and Cultural Rights'(2008) 8 (4) Human Rights Law Review 617. However, for a view that, whatever their formal international status, socio-economic rights are being undermined by neoliberal economics and globalisation see Paul O'Connell, 'The Death of Socio-Economic Rights' (2011) 74 (4) The Modern Law Review 532

[241] Gauthier de Beco, 'The Indivisibility of Human Rights and the Convention on the Rights of Persons with Disabilities' (2019) 68 (1) International and Comparative Law Quarterly 141

[242] Optional Protocol to the International Covenant on Economic, Social and Cultural Rights (10 December 2008) A/RES/63/117

[243] on this point it is also of relevance that the CRPD has articles, 6 and 7 respectively, which refer to the specific needs of women and children with disabilities; also, article 24.3 makes specific reference to the educational needs of deaf, blind and deaf-blind persons

[244] CRPD article 19(a)

[245] CRPD article 19(b)

[246] CRPD Committee *General Comment on Article 19: Living Independently and Being Included in the Community* (29 August 2017) CRPD/C/18/1 para 18

lifelong learning,[247] its framing within the context of the 'full development of human potential and a sense of dignity and self-worth'[248] and its explicit linking of this to the strengthening of respect for, *inter alia*, human diversity,[249] is also noted.

What is evident here, it is submitted, is the development of a human rights model of disability which is more comprehensive than the social model, enshrining a dynamic approach drawing on, particularly, the concept of the indivisibility of rights.[250] More, it is suggested that the CRPD's explicit concern with 'respect for inherent dignity [and] individual autonomy'[251]and its concern with human diversity as among its general principles marks the Convention out as situating impairment within the wider frame of a commitment to promote disability as an valuable expression of human diversity. This contrasts strongly with the social model. As discussed, the social model maintains a necessary distinction between impairment and disability, configuring disability as socially mediated injustice. Diverse issues are lost in this dichotomy. That chronic pain is a constant in the lives of many people with disabilities or that some disabilities require high degrees of dependence on others are but two examples of *facts* about bodies that the social model is accused of eliding.[252] But these sorts of circumstances – and, indeed, impairment *per se* – are accommodated within the human rights model without difficulty as, indeed, is the idea of being proud to be disabled.[253] This latter idea is described as being 'about disability as a positive personal and collective identity, and disabled people leading fulfilled and satisfying lives.'[254]

As Degener has it, the CRPD drafters were very conscious of the need not to make any negative judgement on impairment and how it might relate to quality of life. In part, as Degener also asserts, this is to underline that the CRPD is intended to apply to *all* persons with disabilities.[255]

---

[247] CRPD article 24

[248] CRPD article 24 1(a)

[249] CRPD article 3(d)

[250] Gauthier de Beco, 'The Indivisibility of Human Rights and the Convention on the Rights of Persons with Disabilities' (2019) 68 (1) International and Comparative Law Quarterly 141

[251] CRPD article 3(a)

[252] Jenny Morris *Pride Against Prejudice* (Women's Press, 1991)

[253] see, for instance Nadina LaSpina *Such Aa Pretty Girl: A Story of Struggle, Empowerment and Disability Pride* (New Village Press, 2019)

[254] John Swain, Sally French, 'Towards an Affirmation Model of Disability' (2000) 15 (4) Disability & Society 569, 570

[255] Theresia Degener A New Human Rights Model of Disability. In Valentina Della Fina Rachele Cera Giuseppe Palmisano (eds) The United Nations Convention on the Rights of Persons with Disabilities. A Commentary (Springer, 2017) 41 - 59

Hence, it is clear that the dependence which some people with complex disabilities may need to repose in others does not compromise their rights as enshrined in the Convention:

> Unlike other prior human rights treaties, the CRPD values, as a social good, the idea that people may need help from time to time, and that such help in no way diminishes their entitlement to dignity, autonomy, and equality, as a matter of international human rights law. The CRPD, therefore, expands our view of dependence, by specifically challenging the legal consequences of viewing people with disabilities as dependent.[256]

Again, dependence is something which the social model struggles to accommodate. Within the classic social model narrative dependency is a mark of powerlessness.[257] Oliver and Barnes develop this by delineating an ideological basis to how the idea of dependency is used to construct the notion of disability as a problem, indicating how neo-liberal economics opposes welfare programmes as undermining entrepreneurial culture.[258] In this reading, dependency becomes a mark of social worthlessness, of social failure, even to the point of targeting disabled people for public hostility and opprobrium.[259] Indeed, according to some theorists neo-liberal economics now forces disabled people to re-fight battles previously thought conceded, defending their basic needs from the effects of austerity.[260] Grover and Piggott talk about the disabled body becoming a metaphor for economic and social problems: ‘a screen onto which fears about ‘dependency’, worklessness and economic decline are projected.’[261]

5 The capabilities model of disability

5.1 Freedom and Disability: engaging a capabilities perspective

Historically, people with disabilities have lived constrained and, indeed, restrained lives, their perceived *needs* used to justify separation, segregation, institutionalisation, social and economic marginalisation and oppression. Within such a totalising worldview, a concept such as freedom

---

[256] Arlene S Kanter, ‘Let’s Try Again: Why the United States Should Ratify the United Nations Convention on the Rights of Persons with Disabilities’ (2019) 35 (1)Touro Law Review 301, 309

[257] James I Charlton *Nothing About Us Without Us: Disability Oppression and Empowerment* (University of California Press, 1998)

[258] Oliver and Barnes (n 145)

[259] see, for instance, Chris Grover, Linda Piggott, ‘Disability and Social (In)Security: Emotions, Contradictions of ‘Inclusion’ and Employment and Support Allowance’ (2013) 12 (3) Social Policy and Society 369

[260] see, for instance, Maria Berghs, Karl Atkin, Chris Hatton, Carol Thomas. ‘Do disabled people need a stronger social model: a social model of human rights?’ (2019) 34 (7-8) Disability & Society 1034

[261] Chris Grover, Linda Piggott, ‘Disability and Social (In)Security: Emotions, Contradictions of ‘Inclusion’ and Employment and Support Allowance’ (2013) 12 (3) Social Policy and Society 369, 376

may be represented as antithetical to disabled people's best interests, it becoming much more important to be able to say, for example, that disabled people are being *cared* for. Such a view equates impairment with a form of vulnerability which is inconsistent with personal agency. More, it is inevitably collectivist, resulting in what I choose to identify as a *the-ing* of impairment, a gathering in of people and their assignment to pre-determined services according to their perceived or ascribed disability: the blind, the mentally disabled, the autistic, the deaf and so forth. The gathered-in and labelled may be thought to fit appropriately into a neat Western social ontology. However, as the social model indicates, this is a society primarily organised to accommodate those held out as normal, that is, those identified as non-impaired, productive people.[262] Within both the liberal and republican conceptions of freedom, these are the people who can most easily exercise agency and who can make sustainable claims as to their personal liberties. Galvin and Todres define this agency as having 'the possibility of freedom to be and act within certain limits.'[263]

Galvin and Todres link agency closely with human dignity, noting that when agency is taken away there is a diminished personhood. Capability theorists such as Sen and Nussbaum note this too. Caught up with the idea of living flourishing, dignified lives, adherents of the capabilities approach place at the heart of their theory the assertion that a person has a right to live a life that she values and has reason to value. Sen summarises this as 'the freedom of individuals to live long and to live well.'[264] Inherently inclusive of persons with disabilities, as particularly exemplified in Nussbaum's work,[265] the capabilities approach commits to a form of social justice within which each person has the realisable potential 'to be fuller social persons, exercising our own volitions and interacting with – and influencing – the world in which we live.'[266] Within this, a distinction is traditionally offered between capabilities and functionings, the latter being 'an active realisation of one or more capabilities,'[267]the former being 'opportunity to select.'[268] The

---

[262] see, for example, Simo Vehmas Pekka Makela The ontology of disability and impairment. In Kristjana Kristiansen Simo Vehmas Tom Shakespeare (eds.) *Arguing About Disability* (Routledge, 2009) 42 - 56

[263] Kathleen Galvin, Les Todres, *Caring and Well-being* (Routledge, 2014) 12

[264] Amartya Sen *Development as Freedom* (Oxford University Press, 1999) 5

[265] see, for example, Martha Nussbaum 'Human capabilities, female human beings' in Martha Nussbaum, Jonathan Glover (eds) *Women, Culture and Development: a study of human capabilities* (Clarendon Press, 1995) 61 – 104; Martha Nussbaum *Women and Human Development: the Capabilities Approach* (Cambridge University Press, 2000); Martha Nussbaum *Creating Capabilities: the Human Development Approach* (Belknap Press, 2011)

[266] Sen (n 264) 15

[267] Martha Nussbaum *Creating Capabilities* (Belknap Press, 2011) 25

[268] *ibid*. In her first manuscript treatment of capabilities Nussbaum offers a distinction between basic capabilities, internal capabilities and combined capabilities; see Martha Nussbaum *Women and Human Development* (Cambridge University Press, 2000). Teasing these meanings out is not germane to this

model accommodates the multiple nuance of wide personal preference – swimming with dolphins, practicing the piano, sleeping until noon, being a naturist – identifying those things individuals have *reason* to value, alongside universally objectively valued goods such as food, health, shelter, work and education. Hence, Nussbaum theorises the value of capabilities in terms of them being spheres of freedom and choice. Nussbaum writes:

> [t]o promote capabilities is to promote areas of freedom, and this is not the same as making people function in a certain way. Thus, the Capabilities Approach departs from a tradition in economics that measures the real value of a set of options by the best use that can be made of them. Options are freedoms, and freedoms have intrinsic value.[269]

This prizing of freedom and its non-discriminating applicability to *all* persons marks the capabilities approach out as of profound importance within both disability theory and political theory. Indeed, Nussbaum offers a structure for theorising what a notional person is able to be and to do across a matrix of ten substantive, non-fungible, capabilities. In claiming that these capabilities are analogous to fundamental constitutional rights, Nussbaum is clearly marking out a political territory for her work, indicating the capabilities model to be 'an outcome-oriented approach that supplies a partial account of basic social justice.'[270] The ten capabilities are fundamental (or central) because they are 'implicit in the very notions of human dignity and a life that is worthy of human dignity,' and any failure to secure them amounts to a 'grave violation of basic justice.'[271]

In Nussbaum's formulation (restated and refined on a number of occasions but never substantially altered) an individual's ability to live a dignified life is prefaced on *all* these ten fundamental capabilities – some of which have sub-categories - being met, at least up to a threshold level.[272] They are: the capability of living a life of normal length; the capability of good

---

dissertation but suffice to say that there are differences in how Sen and Nussbaum employ terminology, with Nussbaum's usage around capabilities held to be more complex (See, for example, David A Crocker 'Functioning and Capability: The Foundations of Sen and Nussbaum's Development Ethic, Part 2' in Martha C Nussbaum, Jonathan Glover (eds) *Women, Culture and Development: A Study of Human Capabilities* (Oxford University Press, 1995) 153 – 198. What may be useful, however, is noting Nussbaum's endorsement in *Creating Capabilities* of Sen's story of two people who are starving. One of these people is starving because she lacks food; the other is starving because she is practicing a freely chosen religious observance. Both persons achieve the same functioning – malnourishment – but each have different capabilities, the starving person having no choice but to starve.

[269] Nussbaum (n 267) 25

[270] Martha Nussbaum *Frontiers of Justice* (Belknap Press 2006) 274

[271] *ibid* 155

[272] *ibid*

bodily health including adequate nourishment and shelter; the capability of bodily integrity, encompassing freedom of movement, freedom from assault, having opportunities for sexual satisfaction and reproductive choice; the capability of using the senses, to imagine, think and reason, including the development and cultivation of the senses through adequate education and in ways consistent with freedom of expression and religion; the capability of relationships with other people and things, including feeling love, grief, longing and justified anger and *not* having life blighted by fear and anxiety; the capability of formulating the concept of the good and reasoning critically about one's life plans; the capability to live for and with others and being treated as a dignified being, including support from institutions involved in protecting justice, freedom of speech and assembly; the capability of living in relationship to animals, plants and nature; the capability of joy, smiling and play; the capability of living one's own life rather than the life of someone else (including guaranteeing non-interference in personal choices and preferences); the capability of living one's own life in one's own environment and context, comprising political and material elements including the opportunities of free assembly, equal ownership and protection of property rights and being able to work as a human being.[273]

As to dignity and agency, for Nussbaum dignity has an intuitive core, its motion 'closely related to the idea of active striving.'[274] However, the worth of the liberties represented in the capabilities are underwritten not by 'vague intuitive appeals to the idea of dignity all by itself'[275] but by robust engagement to show that a given liberty is implicated in human dignity by demonstrating its relationship to other existing entitlements. In this spirit, Nussbaum concludes that both the Stoic and Kantian conception of dignity as always deriving from rationality and autonomy are flawed. This is so because, in the main, Kantian and Stoic philosophies proffer respect to a particular form of agency, that is, a single capability, rather than respecting the potential for all those various types of activities and strivings to be converted into actual functionings.[276] As Vorhaus has it:

---

[273] Nussbaum (n 267). In this work the capabilities are listed thus: 1 Life, 2 Bodily Health, 3 Bodily Integrity, 4 Senses, imagination, and thoughts, 5 Emotions, 6 Practical reason, 7 Affiliation, 8 Other species, 9 Play, 10 Control over one's environment

[274] Nussbaum (n 267) 31

[275] *Ibid* 32

[276] Martha Nussbaum Human Dignity and Political Entitlements. In *Human Dignity and Bioethics* (The President's Council on Bioethics, 2008) 351 – 380 available at https://repository.library.georgetown.edu/bitstream/handle/10822/559351/human_dignity_and_bioethics.pdf?sequence=1&isAllowed=y

> it is the human being as the bearer of human capacities in which dignity resides and to whom respect is due, and not, considered separately, any capacity for rationality, autonomy, or whatever.[277]

The account of human dignity from which Nussbaum and Sen operate does not rank and order human beings. Rather, it accepts the dynamic nature of human capacities as the basis on which political obligations are owed equally to human beings. The political conception of the person proposed here is one that:

> does not exalt rationality as the single good thing and that does not denigrate forms of need and striving that are parts of our animality. Indeed, it is crucial to situate rationality squarely within animality, and to insist that it is one capacity of a type of animal who is also characterized by growth, maturity, and decline, and by a wide range of disabilities, some more common and some less common.[278]

Kant advances the Stoic insight about the unique worth, the dignity, of every human person, showing how the instrumentalisation of the person must be resisted. However, the Kantian decision to locate personhood entirely in rational autonomy represents an abstracted rebuke to the personhood claims of disabled people (and, indeed, to others) such that the unique trajectory of every human life, experienced corporally and communally, is dishonoured and disavowed. In essence, the argument here is that if dignity is not available to *everyone* its availability to anyone must be doubted. Within the messiness of the unique human trajectory the suggestion that there can be dignity for some and non – dignity for others, the boundaries of these states shifting according to, say, illness, misfortune or age, undermines the reliability of dignity to be of value either in law or any other form of human dealing. The language of dignity is reduced to mere rhetoric while, in fact, the concept is operating as a cipher for an undemocratic recourse to real-world distinctions between partial and full humanity.

The status of dignity implicit in the capabilities model is a dignity which derives from *within* every human rather than as something conferred from without on *some* humans. In rejecting the Kantian dichotomy between personhood and the body, the capabilities model asserts the individually embodied and socially connected nature of a personhood which situates rational

---

[277] John Vorhaus, 'Dignity, Capability and Profound Disability' (2015) 46 (3) Metaphilosophy 462,467

[278] Martha Nussbaum Human Dignity and Political Entitlements. In *Human Dignity and Bioethics* (The President's Council on Bioethics, 2008) 351 – 380 available at https://repository.library.georgetown.edu/bitstream/handle/10822/559351/human_dignity_and_bioethics.pdf?sequence=1&isAllowed=y at 363

choice as only one indices among (an arguably incalculable) many of what it is to have dignity. It is a dignity comfortably at home in ordinary human life, in all its challenges and confusion, in all its achievements and aspirations, its successes and mishaps. For Nussbaum, human dignity 'just is the dignity of a certain sort of animal. It is the animal sort of dignity, and that sort of dignity could not be possessed by a being who was not mortal and vulnerable.'[279] Thus, the dignity Nussbaum attests to is a messy dignity, where old age, infirmity, accident or disability can disrupt moral rationality and, which, anyway, does not exist as separate to that messiness but is always interwoven into it and, in a very palpable way, interwoven too into the messiness of other peoples' dignity. As Formosa and Mackenzie have it:

> [t]o be a human being is to be a being whose existence and flourishing are dependent upon social relations with others, including relations of care and dependency, and whose rational capacities develop and change over the course of a human life.[280]

The prefiguring of dignity as an inevitable, and inevitably *social*, consequence of just being a human animal provides capability theorists with a powerful vision of a world where no-one falls outside an expansive conception of a model of justice which is flexible and responsive to even the most extreme of human needs. This account stands in marked contrast to, say, the implications for disabled persons of Kant's and Rawls' contractarianism and to Singer's and Harris' bioethics. For instance, focusing on what she perceives as the complex reciprocity found in the lives of people with mental impairments and those who share their lives, Nussbaum rejects the contractarian understanding of reciprocity to be wholly about mutual advantage, claiming this means people with intellectual disability are denied the full status of citizen.[281] Rather, Nussbaum's reliance on an argument about the inherent dignity of all human beings makes explicit the need to ensure life circumstances which support and advance that dignity.

The capabilities model provides a perspective within which freedom and its application to the concept of disability is phrased as a matter of practical political imperative. Hence, Hull reminds that whatever the esoteric use of freedom as a legal or even rhetorical concept 'it is realisable

---

[279] Nussbaum (n 270) 132

[280] Paul Formosa, Catriona Mackenzie, 'Nussbaum, Kant and the Capabilities Approach to Dignity' (2014) 17 (5) Ethical Theory and Moral Practice 875, 879

[281] Nussbaum (n 270); for a counter argument see Sophia Isako Wong 'The Moral Personhood of Persons Labelled 'Mentally Retarded': A Rawlsian Response to Nussbaum' (2007) 33 (4) Social Theory and Practice 579

freedom that is the stuff of value.'[282] Asserting that ascribed inability is a source of un-freedom, Hull contends that for people with impairments 'the living of a rough approximation to normal early twenty-first century life should count as an objective.'[283] In essence, this means access to basic social freedoms such as education, employment and social engagement must be counted as important political goals, not least because these represent gateways to other freedoms. Hence, what is being pointed to here is not just having the *formal* dignity of being able to claim that, in law, nothing impedes the pursuit or achievement of a particular goal but, rather, actually experiencing the *effective* dignity of being able to conceive of and achieve a personally worthwhile goal. Nussbaum asserts that this effective human dignity exists equally 'in all who are agents.'[284] More, Nussbaum asserts that 'the primary target of a theory of egalitarian justice ought to be the protections of freedoms so central that without them, an individual's life is not worthy of human dignity.'[285] Similarly Sen writes: '[j]ustice is ultimately connected with the way people's lives go, and not merely with the nature of institutions surrounding them.'[286]

Arguably, what is revealed here is a potential within the capabilities paradigm to capture forms of domination that distort the experiences of disabled people but which may fall short of overt discrimination. The disability literature abounds with first-hand experiences of what has been described as 'often a lack of fit' between theory-based suppositions and the lived experience of disabled people.[287] The damage done to disabled people's dignity in dealing with other people's difficulties with the way a disabled person looks or talks or walks, acts or simply *is* can be at least as debilitating – and, perhaps often, less tractable – than any institutional failing.

That the capabilities approach to justice – again, like the republican model – engages with people's lives *both* as they are lived and as these same people would wish to live them, reveals a concept of justice that is multi-dimensional, operating at every level of the inter-meshed, inter-

---

[282] Richard Hull 'Disability and Freedom' in Kristjana Kristiansen Simo Vehmas Tom Shakespeare (eds) *Arguing About Disability* (Routledge, 2009) 100

[283] *ibid* at 101

[284]Nussbaum (n 267) 31; within this precise phrase Nussbaum contends that the only humans who fall outside this rubric are those in a permanent vegetative state and those who are anencephalic

[285] Nussbaum (n 267) 31

[286] Amartya Sen *The Idea of Justice* (Penguin Books, 2009) x

[287] Anita Silvers A Diverse Theory of Justice for Disability. In Kimberley Browniee, Adam Cureton (eds.) *Disability and Disadvantage* (Oxford University Press, 2011) 164. As to examples see, for historical context, Susan M Schweik *The Ugly Laws: Disability in Public* (New York University Press, 2009; for contemporary accounts see, for example, Alan Roulstone, Hannah Mason-Bish (eds) *Disability, Hate Crime and Violence* (Routledge, 2014), Katharine Quarmby *Scapegoat: why we are failing disabled people* (Portobello Books, 2011); Carol Thomas *Female Forms: Experiencing and Understanding Disability* (Open University Press, 1999), Tom Shakespeare 'Cultural Representations of Disabled People: Dustbins of Disavowal?' in Len Barton, Mike Oliver (eds) *Disability Studies: Past, Present and Future* (Disability Press, 1997)

personal, societal and institutional order.[288] In this, justice is represented not as a distant, theoretical construct but as something vivid, as *within reach*; as something worked out in the daily beings and doings of individuals, families, relationships and workplaces and not just in the institutional sphere.

5.2 Contrasting republicanism and capabilities

As to whether the capabilities model endorses any particular vision of freedom Sen seems content that processes and opportunities which produce substantive freedom do not need to be further scrutinised as to the means by which this freedom is generated. This is so because, perhaps pragmatically, *effective freedom* [289] 'is not really concerned with the mechanisms and procedures of control.'[290] Thus, while in the republican idiom precisely discerning the nature of control can be said to be of central importance, within the capabilities paradigm what might be called a lucky freedom – such as that bestowed by a kindly master or fortuitous happenstance – is deemed sufficient. That such a freedom – at least in the republican idiom - is claimed to lack robustness is passed over. This is not to assert that Sen is indifferent to the richer interpretation of freedom which Pettit offers. Rather, the point is that Sen accepts that while freedom from domination is undoubtedly of great value it is not essential for well-being.[291] For Sen, the focus is on the substantive freedoms individuals have reason 'to attach great importance, including escaping avoidable mortality, being well nourished and healthy, being able to read, write and count and so on.'[292] Sen asserts that '[f]reedoms are inescapably of different kinds' and while the process and opportunity aspects of freedom can often go together, sometimes they do not,

---

[288] see, for instance, Ingrid Robeyns Gender and the metric of justice. In Harry Brighouse, Ingrid Robeyns (eds.) *Measuring Justice. Primary Goods and Capabilities* (Cambridge University Press, 2010) 215 - 235

[289] Sen uses this concept in earlier work as roughly co-incidental with his more recent opportunity construct, describing it as actually achieving things which the individual values; see Renee Prendergast The concept of freedom and its relation to economic development – a critical appreciation of the work of Amartya Sen (2005) 29 (6) Cambridge Journal of Economics 1145

[290] Amartya Sen Well-being, agency and freedom: the Dewey Lectures 1984 (1985) 82 (4) Journal of Philosophy 208. Elsewhere, Sen points out as fallacious the equating of freedom with control, arguing that in modernity a great many things perceived to be constituent of freedom are actually entirely outside a person's control; see Amartya Sen *Inequality Re-examined* (Oxford University Press, 1992)

[291] see, for instance, Tony Burns, ''Happy slaves?' The adaptation problem and identity politics in the writings of Amartya Sen' (2016) 43 (1) International Journal of Social Economics 1178

[292] Sen (n 264) 66; this type of basic list – notwithstanding his refusal (unlike Nussbaum) to endorse a substantive list of capabilities – occurs throughout Sen's work, see, for instance, Amartya Sen 'Equality of What?' in Stephen Darwall (ed) *Equal Freedom. Selected Tanner Lectures on Human Values* (University of Michigan Press 1995) 307 – 330, Amartya Sen *Inequality Re-examined* (Oxford University Press, 1992) and Amartya Sen, 'Human Rights and Capabilities' (2005) 6 (2) Journal of Human Development 151

meaning '[t]here can be conflicts between (1) having less inequality of freedoms and (2) getting as much freedom as possible for all, irrespective of inequalities.'[293]

Pettit argues that capabilities which can be described as 'favour – dependent'[294] should not be counted as real freedoms and criticises Sen's theory, *inter alia*, for not claiming freedom as a 'context–independent decisiveness.'[295] This decisiveness arises not because a person's preference is satisfied, even if this happens routinely, but that it is satisfied because it *is* that person's preference 'and not for any other reason.'[296] Indeed, Sen accepts that '[e]ven if one can get what one wants, indeed even if one *invariably* gets whatever one wants…it would still be relevant to know whether this effectiveness is dependent on the help or goodwill or favour of others.'[297] But for Sen, freedom is, inescapably, and, *irreducibly*, a 'plural idea,'[298] its heterogeneity expressed in the lives that individual human beings actually lead and value. To accept, as Pettit suggests,[299] that the capabilities approach be amended to accommodate (and, perhaps, even be subsumed into[300]) the republican understanding of domination is, in Sen's view, to undermine the capabilities' central focus on the importance of what a person can *actually* be and do. In this context, Sen draws attention to the example of a disabled person who, in case 1, is not helped by others and, as a consequence, is unable to leave her house. Case 1 reveals this person to be unfree because she lacks the capacity to leave her house. Sen contrasts this with two further cases. In case 2, the person is aided by volunteers through whose goodwill she is facilitated to go out and about whenever she wishes. In case 3, the person is mobile in precisely the same way, except instead of being facilitated by volunteers she is aided by well-remunerated servants.[301] While accepting the forensic ability of a republican analysis of case 2 to operate 'a particular discriminating power which the capabilities approach lacks'[302] Sen

---

[293] Sen (n 264) at 285 – 286; this accords in significant ways with the work of Philip Van Parijs whose theorises a universal basic minimum income as pivotal in guaranteeing real freedom for all; see Philip Van Parijs *Real Freedom for All: what (if anything) can justify capitalism?* (Clarendon Press, 1995)

[294] Philip Pettit, 'Capability and Freedom: A Defence of Sen' (2001) 17 (1) Economics and Philosophy 1

[295] *ibid* at 8

[296] *ibid* at 4

[297] Amartya Sen, 'Reply' (2001) 17 (1) Economics and Philosophy 53 (italics in the original)

[298] Sen(n 286) 305 n.*; Amartya Sen *Rationality and Freedom* (Belknap Press, 2002) 585

[299] Philip Pettit Capability and Freedom: A Defence of Sen 17 2001 Economics and Philosophy

[300] Pettit talks about 'functioning capability in Amartya Sen's sense' as a concept which is 'subsumed in the idea of nondomination;' see Philip Pettit, 'The Domination Complaint' [2005] 46 Nomos 112

[301] Sen, (n 297). These scenarios also appear in Sen's *The Idea of Justice* (n 286) but here case 2 permits that the helpers are either volunteers or directed by a local social security system. It is submitted in the book's treatment Sen does not notice a qualitative distinction, in republican terms, between a volunteer-based and a social security-based provision such that the ensuing analysis, absent any further detail about the workings of the latter, is somewhat flawed.

[302] Sen (n 286) 307

asserts that, within the capabilities framework, (and consciously setting aside any question as to the subservience of the servants) case 2 and case 3 both confer freedom.[303]

Above all, the capabilities approach is directed to the tangible enhancement of freedom across societies and cultures. Although the model easily accommodates collective action to bring about change, the axiomatic emphasis is on how this is enabled through a focus on the individual as an empowered actor in the economic, social and political realms.[304] In the capabilities construct making choices is about equalising the availability of opportunities and freedoms, rather than the equalising of resources; it is about *not* the share of goods but the relationship between persons and goods and, particularly, the use resources can be put to.[305] In the context of persons with disabilities, this draws attention to the critical importance of those societal and other factors at play that either inhibit or support a disabled person's ability actually to convert resources into opportunities to live fulfilling lives. Hence, it is suggested, that people with disabilities often have formally available choices – for instance those conferred by law or public policy – which are, in effect, denied or made very difficult to achieve by the prevailing norms.

5.3 What republicanism brings to capabilities

Throughout this sketch of the capabilities approach, there are numerous points of contact with Pettit's ideas. Pettit's methodology is to explore a theory of freedom which envisages agency (what he calls 'freedom in the agent') and well-being as inextricably connected.[306] Pettit promotes the idea of freedom as discursive control - something qualitatively superior to rational or volitional control – as a state of enjoyment in which A's relational circumstances with others are of such a quality that A is a discursively active agent. Pettit explains that this refers to 'the form of control that people enjoy within discourse-friendly relationships. An agent will be a free person so far as they have the ability to discourse and they have access to discourse that is provided within such relationships.'[307] Having this ability and access, A is not coerced or

---

[303] note, however, that a potentially interesting argument can be proffered in relation to Sen's interest in advancing self-respect as an important functioning (see, for example, Amartya Sen 'Capabilities and Well-Being' in Martha Nussbaum, Amartya Sen (eds) *The Quality of Life* (Oxford University Press, 1993) 30 -53) such that its possibility to be denied by having to rely on volunteers could, potentially, reconcile a capabilities and republican reading of case 2. Indeed, Nussbaum is even more explicit in relation to what she calls 'having the social bases of self-respect and non-humiliation' as part of her open ended list of central human capabilities. Doing so makes plausible a capabilities-based distinction between cases 2 and 3 compatible with a republican reading; see Martha Nussbaum (n 270) 77. In any event I believe we simply don't know enough about case 2 to say definitively that domination *is* involved

[304] Sen (n 264)

[305] Sen (n 292) 307 – 330

[306] see Pettit (n 123)

[307] *ibid* 70

dominated: she does not have to self-censor or actively inhibit another to achieve a personally favourable outcome. She does not have to look over her shoulder for fear the benevolence of another might end. If hers is a fortunate life, it is not because she is the beneficiary of either her own stratagems or another's good will. Unlike Nora, A is actually and resiliently free: her well-being and her agency coalesce. Pettit posits that if a person enjoys freedom as discursive control, whether in actual or virtual mode, and the person's avowable interests are tracked then certain forms of what might objectively appear to be coercion – what he terms 'friendly coercion' – are not inconsistent with the store of a person's freedom.[308] So, in this context, it becomes perfectly plausible that the support rendered to the person with impaired mobility in case 2 (above) may very well have no suggestion of domination about it, assuming it is not adjudged that what the disabled person is reliant on is not the volunteers' favour but rather their wish to offer an genuinely altruistic service. Indeed, Pettit gives the example of the person who relinquishes her passport to another's possession in order to deny herself the opportunity for impulsive travel abroad, permitting that the document only be returned in respect of travel that is at least a week away. In such a scenario, there is no domination but rather, a voluntary subjugation, the terms of which are always in the nascent traveller's control.[309] Contemporary republicanism is, therefore, alert to not setting people up 'in a solipsistic sort of independence from society in general or from other people in particular.'[310] It models 'the freedom of the city' – where communal laws and norms prevail that are constitutive of individual liberty – and not the 'freedom of the heath,' that state of natural freedom which so disturbed Hobbes.[311] As to how this city protects disabled people Pettit notes, in another scant reference, the (overarching) necessity of promoting socioeconomic independence, acknowledging that the goal

> of intensifying the non-domination of *the needy*, lessening the prospects of their being exploited or manipulated or intimidated by others, requires that they have what Sen describes as the basic capabilities for functioning in life.[312]

---

[308] *ibid* 77

[309] Pettit (n 111 (in Pettit's text))

[310] *ibid* at 49

[311] *Ibid* at 25

[312] Philip Pettit (n 24) 161 (emphasis added). Personalising it as if citing from his own experience, in this section of his book Pettit mentions 'handicapped' people – giving examples of those who have lost, or who have never had, the use of their legs, those who cannot perform routine intellectual tasks and those who cannot see – saying (at 160) that '[i]t scarcely needs arguing, if only because of the literary treatment that has been given to the theme, that in such an event I am going to be exposed to a degree of domination by those on whom I depend for managing my life.'

As to other points of specific commonality between Sen and Pettit's respective perspectives on freedom, both thinkers are *ad idem* about its intrinsic – rather than solely instrumental – value.[313] For Pettit the evil of domination can be said to frustrate the conception of liberty as an intrinsic good, indeed, as *the* 'gate-way good.'[314] Also, both theorists can be said to understand their respective schemas as research projects, methodologies seeking to understand freedom and its denial as, at root, *relationship* problems.

However, it is also precisely within this idea of relationship that the particular points of divergence between the capabilities and republican models can be best situated. For Pettit, it seems that without vigorous attention paid to those discrepancies of social power which might exist within a relationship (including a citizen's relationship with the state) even the very *possibility* of domination corrupts any potential for capabilities to flourish into real, enriching, socially dynamic, empowering freedoms. Thus, Nora's enjoyment of her life as a free person requires a constraint on her husband's ability, however latent, not to represent that enjoyment as *his* gift to her. It is precisely at this level of analysis that republicanism excels. For all its strengths, the capabilities' methodology does not generate a theory of 'the effects of social institutions on human welfare.' [315] Hamilton references how 'existing power relations secrete around themselves justifying practices, institutions and forms of rationality' suggesting that Sen's 'contextually bound' concern for capacities may struggle to provide conceptual tools to address these power distortions.[316] For Alexander, the effect of this, if true, is that 'without directly addressing the power relationships in the household, workplaces and society at large, it might be difficult to counteract deeply embedded capability inequalities.'[317] Absent a sustained focus on formal law to undergird capacities development (although this is proposed by Nussbaum) it is argued that capabilities theory might appear abstract and distant from so much human suffering. [318] Moreover, Sen's emphasis on freedom as an unfolding process perhaps is overly reliant on the promise of procedural democracy instead of engaging more rigorously with the (enduring) defects of substantive democracy.[319] In this context, Sen's defence– albeit in a

---

[313] see, for example, Mozaffar Qizilbash Some Reflections on Capability and Republican Freedom (2016) 17 (1) Journal of Human Development and Capabilities 22

[314] Pettit (n 111) xix

[315] Marianne T Hill Development as Empowerment (2003) 9 (2-3) Feminist Economics 118

[316] Lawrence Hamilton *Amartya Sen* (Polity, 2019) 91

[317] John M Alexander *Capabilities and Social Justice: The Political Philosophy of Amartya Sen and Martha Nussbaum* (Ashgate, 2008) 169

[318] see, for instance, Des Gasper, 'Is Sen's Capability Approach an Adequate Basis for Considering Human Development?' (2002) 14 (4) Review of Political Economy 435

[319] Amiya Kumar Bagchi, 'Freedom and Development as End of Alienation?' (2000) 35 (5) Economic and Political Weekly 4408

contained way - of capitalism as a mechanism of freedom, while not of a libertarian type, proceeds on the basis that there will be in place a full range of supports for individual autonomy, such as welfare supports.[320] While this expectation may reflect his view that economics is a branch of ethics, Sen's confidence that properly regulated capitalism can advance human freedom is now, arguably, superseded by a voracious neo-liberalist economics. Finally, a further concern is that Sen's theory fails to address paternalism, itself a rich source of domination, not least in the lives of disabled persons.[321] This lacuna is well articulated by Deneulin who writes:

> [h]ow can we observe whether the refusal to make use of given opportunities is the result of a free choice or the result of internalised beliefs or social norms? If women refuse to go to the literacy classes that are offered to them, how can we observe whether that refusal is the result of free choice or of internalised beliefs that being educated is unsuitable for women?[322]

Many of these criticisms of Sen's capabilities model are of particular concern in the context of disability, both as a social phenomenon and a lived experience. This is so notwithstanding that, particularly in Nussbaum's scholarship, the capabilities approach explicitly emphasises the capacity of persons with disability to be the autonomous, dignified authors of their own good. [323]

Both the capabilities approach and republicanism share a valorisation of dignity, speaking to a particular idea of the political. On the individual level dignity is thought of as grounding a person's resilience, specifically, a person's ability to resist dominating intrusion, a lack of dignity exposing that person to vulnerability, including to oppressive entanglements.[324] Hence, for instance, Pettit talks about the grievance of the wife who finds herself physically abused at will,

---

[320] see, for instance, Nadeera Rajapaska, 'Bringing Ethics into the Capitalist Model: Amartya Sen's Approach to Economic Theory and Financial Capitalism' (2015)13 (2) Revue Lisa (no page)

[321] see, for instance Andrew Power, Janet E Lord, Allison S deFranco, *Active Citizanship and Disability: Implementing the Personalisation of Support* (Cambridge University Press, 2013)

[322] Severine Deneulin, 'Perfectionism, Paternalism and Liberalism in Sen and Nussbaum's Capability Approach' (2002) 14 (4) Review of Political Economy 497, 502

[323] Martha Nussbaum Human Dignity and Political Entitlements. In *Human Dignity and Bioethics* (The President's Council on Bioethics, 2008) at 363 available at https://repository.library.georgetown.edu/bitstream/handle/10822/559351/human_dignity_and_bioethics.pdf?sequence=1&isAllowed=y

[324] see Marie Garrau, Cecile Laborde Relational Equality, Non-Domination and Vulnerability. In Carina Fourie, Fabian Schuppert, Ivo Wallimann- Helmer (eds) *Social Equality: On What it Means to be Equals* (Oxford University Press, 2015); Christian Schemmel Social Equality – Or Just Justice. In Carina Fourie, Fabian Schuppert, Ivo Wallimann- Helmer (eds) *Social Equality: On What it Means to be Equals* (Oxford University Press, 2015)

the employee cowed from making legitimate complaint and 'the welfare dependant who finds that they are vulnerable to the caprice of a counter clerk for whether or not their children will receive meal vouchers.'[325] Within the republican context the elevation of dignity draws attention to a particular conception of the person as a moral being, as somebody who, under the law, knows how they should be treated by (and how they should treat) others. In the same vein, Anderson asserts a person's entitlement to 'the capabilities necessary for functioning as an equal citizen in a democratic state' including those necessary to avoid or escape entanglement in 'oppressive social relationships.'[326] Within the wider republican ethic the dignity construct touches too on core concerns such as citizenship and democratic contestability. More, it invites ideas about the necessity for law to be under the control of a mixed constitution and of the array of other institutional and social arrangements and resources required to realise non-domination in daily life.[327]

5.4 What capabilities brings to republicanism

Nussbaum argues that her lexical list of capabilities has a prescriptive quality which *should* be enshrined at the level of constitutional guarantee, writing:

> 'it is by design that the capabilities list starts from an intuitive idea, that of human dignity, that is already basic to the constitutional framing in many of the nations of the world.'[328]

Extolling pluralism, Nussbaum promotes as common ground a 'political culture committed to a shared morality of human dignity,'[329] elsewhere suggesting important aspects of this culture will be 'the extension of stigma-free status to formerly marginalised groups' and that law protects people from insults to their dignity.[330] In conceptualising these issues Nussbaum draws, in part, on the sociological insights of Goffman who theorises the public shaming of others as a form of barrier building, a putative protecting of those who are *normal* by the stigmatising of those who's 'spoilt identity' marks them out as dangerous or potentially dangerous.[331] Nussbaum adds a further interpretation, suggesting that a reason people target others in this way derives from

---

[325] Pettit (n 24) 5

[326] Elizabeth Anderson, 'What is the Point of Equality?' (1999) 109 (2) Ethics 287, 316

[327] see, for instance, Eoin Daly Freedom as Non-Domination in the Jurisprudence of Constitutional Rights (2015) 28 (2) Canadian Journal of Law & Jurisprudence 289

[328] Martha Nussbaum (n 270) 155

[329] Martha Nussbaum *Political Emotions: Why Love Matters for Justice* (The Belknap Press, 2013) 140

[330] Martha Nussbaum *Hiding from Humanity: Disgust, Shame and the Law* (Princeton University Press, 2006) 3

[331] Goffman (n 147)

a 'kind of deeply irrational fear of defect that is part of a more general shrinking from something troubling about human life, a search for an impossible type of hardness, safety, and self-sufficiency.'[332] Linking this back to liberal plurality, and with specific reference to disability, Nussbaum writes:

> we know where we are if one of us is normal, the independent productive citizen, and the other has his eyes downcast in shame. What liberalism requires of us is, however, something more chancy and fearful, some combination of adulthood and childhood, and aspiration without the fiction of perfection.[333]

All this speaks to ways in which the capabilities model might deepen republicanism's utility in terms of probing concrete power relationships, particularly in terms of helping republicanism align with specific disadvantages arising from disability. Republicanism's historical record of denying equal consideration to slaves, women and non-citizens[334] still echoes in how little attention it accords disabled people.[335] Hence, as previously mentioned, there is, as with Rawls, a disheartening disconnect in Pettit's work concerning persons with disabilities – those, one presumes, whom he might think of as *not* 'more or less settled residents of a state who, being adult and able-minded can play an informed role at any time in conceptualising shared concerns.'[336] Similarly detached from the lived experience of disability is Lovett's identification of any form of social dependence as dominating relative to the social costs of exiting it – including psychological or subjective costs - requires that '[d]ependency should be thought of as a sliding scale.'[337] Axiomatically, such an understanding mitigates against the interests of persons with disabilities (and, indeed, children, aged people and a whole range of others), for many of whom dependence in some form or another is a necessary and possibly recurring rubric across an average day.[338] As Friedman observes

---

[332] Martha Nussbaum, 'Inscribing the Face: Shame, Stigma and Punishment' [2005] 46 Nomos 259, 286

[333] *ibid* 297

[334] see John S Dryzek *Democracy in Capitalist Times: Ideals, Limits and Struggles* (Oxford University Press, 1996)

[335] an exception here is Tom O'Shea Civic Republican Disability Justice. In Adam Cureton David Wasserman (eds) *The Oxford Handbook of Philosophy and Disability* (Oxford University Press, 2020) 212 – 228; see, also, Tom O'Shea, 'Disability and Domination: Lessons from Republican Political Philosophy' (2018) 35 (1) Journal of Applied Philosophy 133; Jurgen De Wisplaere, David Casassas, 'A Life of One's Own: Republican Freedom and Disability' (2014) 29 (3) Disability & Society 402

[336] Pettit (n 125) 75

[337] Lovett (n 99) 39

[338] see, for instance, Eva Feder Kittay, 'The Ethics of Care, Dependence and Disability' (2011) 24 (1) Ratio Juris 49

> [b]eing dependant on others for at least some times or some aspects of survival is the common lot of all human beings. There is nothing to scorn in dependency.[339]

Nonetheless, above all, perhaps, it is the capabilities approach's capacity to reconcile freedom with the acceptance of asymmetrical dependencies which places the model's ability to protect a person's dignity in a *variety* of situations at odds with republicanism as it is commonly presented. O'Shea notes the austere republican view on dependency with disdain, contending that 'dependence on care is often the foundation for the independence from subjection to the arbitrary will of others that republicans seek.'[340] However, O'Shea also argues that freedom from domination in real life circumstances of disability has to subsist in more than making domination an *ex ante* impossibility. Being alive to the potential for abuse implicit in every care-giving situation demands the existence of robust systems of review and redress. The goal here, then, is not just to dissuade domination occurring but, also, it is in terms of enabling *post hoc* responses to it that may well 'render such a power sufficiently non-arbitrary without simply eliminating it.'[341]

In this context, then, it is suggested that engaging with the capabilities model could help remediate contemporary republicanism's implicit reputation as an ableist theory, or, at least, a theory with ableist aspects. A disability-conscious republicanism is one that incrementally expands on Pettit's own – if underdeveloped – assertion that people should be 'assured of access to what Amartya Sen (1985) and Martha Nussbaum (2006) describe as the basic capabilities for functioning in their society.'[342] It is one that recognises the inevitability of certain asymmetrical dependencies while looking to strategies
that help ensure basic capabilities are understood as political entitlements applicable to people with disabilities at the *same* minimum threshold as everybody else. On this, Nussbaum argues that: 'if we say anything else, we fail to respect people with disabilities as fully equal citizens.'[343]

---

[339] Marilyn Friedman 'Pettit's Civic Republicanism and Male Domination' In Laborde and Maynor (n 23) 255

[340] Tom O'Shea Civic Republican Disability Justice. In Adam Cureton David Wasserman (eds.) *The Oxford Handbook of Philosophy and Disability* (Oxford University Press, 2020) 225

[341] *ibid* 226

[342] Pettit (n 111) 87

[343] Martha Nussbaum Human Dignity and Political Entitlements. In *Human Dignity and Bioethics* (The President's Council on Bioethics, 2008) at 363 https://repository.library.georgetown.edu/bitstream/handle/10822/559351/human_dignity_and_bioethics.pdf?sequence=1&isAllowed=y

It is one that recognises, *ad idem* with Nussbaum, that to parse political entitlement differently for persons with disabilities violates human dignity and deprives society of

> a strong incentive…..for making every effort we can to develop the capacities of people with disabilities to the point at which they are able to exercise their entitlements on their own.[344]

Such a disability-conscious republicanism is one that frees itself from Kantian influence and recognises agency not as an all-or-nothing proposition but as both a *skill* and a *process* requiring imaginative, patient and individually calibrated nurturing in applying republican principles to non-normative circumstances. Such a republicanism confronts oppression and marginalisation in all its effects – including micro-dominations – as morally serious,[345] placing less political authority with groups of professional experts in favour of privileging the voices of disabled people themselves, the experts in their own experiences.[346] Finally, such a republicanism is viscerally alive to promoting the visibility and legitimacy of disabled people within the contestatory *civitas*, of which we will talk more later. But for now an example of why this is particularly important derives from Europe's recent economic recession. Pace Goffman - and as history shows - great wrongs become easier to inflict when the humanity and dignity of those on whom they are visited has already been symbolically degraded. [347] Hence, in times of economic downturn or state fiscal pressure, disabled persons have found their access to public money and resources diminished.[348] This, notwithstanding disabled persons intuitive identity as likely to be those 'who require the most resource-intensive armament against domination.'[349] Indeed, this very identity may be pressed into use against disabled people as a perverse justification for why a lesser provision must occur to promote greater, neoliberal, freedoms.[350]

---

[344] *ibid*

[345] Orlando Lazar, 'Micro-domination' (2023) 22 (2) European Journal of Political Theory 217

[346] see Tom O'Shea, 'Disability and Domination: Lessons from Republican Political Philosophy' (2018) 35 (1) Journal of Applied Philosophy 133

[347] see, for example, Friedemann Pfafflin, 'The Connections Between Eugenics, Sterilization and Mass Murder in Germany from 1933 to 1945' (1986) 5 (1) Medicine and Law 1; Richard J Evans *The Third Reich in Power 1933 – 1939* (Penguin Books, 2005); Schweik (n 287); Adam Cohen *Imbeciles: the Supreme Court, American Eugenics and the Sterilization of Carrie Buck* (Penguin Books, 2017)

[348] see, for example, Tonje Gundersen, 'Human dignity at stake - how parents of disabled children experience the welfare system' (2012) 14 (4) Scandinavian Journal of Disability Research 375; Susan Flynn, 'The Current Economic Recession: Social Work Perspectives on its Impact on People with Intellectual Disability' (Spring 2015) The Irish Social Worker 31; Susan Flynn, 'Perceptions on Austerity; the Impact of the Economic Recession on Children with Intellectual Disability' (2017) 32 (5) Disability & Society 678

[349] Tom O'Shea Civic Republican Disability Justice. In Adam Cureton David Wasserman (eds) *The Oxford Handbook of Philosophy and Disability* (Oxford University Press, 2020) 217

[350] Wendy Brown *Undoing the Demos: Neoliberalism's Stealth Revolution* (Zone Books, 2015)

It may be used, also, to reinvigorate prejudices and hostilities against those already living on society's margins.[351] In such circumstances, instead of dignity, disabled persons routinely find doubt and disparagement, including the opening up of 'media rhetoric about skivers and scroungers that has left disabled people feeling stigmatised, vulnerable and isolated.'[352] Without a strong contestatory presence in the decision making processes of the state disabled people are voiceless in the face of such damaging rhetoric, bearers of moral failure rather than bearers of rights.

6 Conclusion

This chapter has presented the theoretical underpinning for this dissertation, engaging with contemporary republican theory and the dominant disability paradigms, contrasting medical and social model understandings. Contrasted too is the social model and the human rights model before, finally, drawing on the influential capabilities approach to help demonstrate a resonance between republican theory and disability theory. In postulating that contemporary republicanism stands accused of a broadly ableist perspective, this final part of the discussion indicates how republicanism might be reimagined to support a much more inclusive understanding of the non-domination research project.

---

[351] Lorraine Gaughin, Paul Michael Garrett 'The most twisted and unaccountable force in the state'? Newspaper accounts of social work in the republic of Ireland in troubled times (2012) 12 (3) Journal of Social Work 267

[352] Bob Williams-Findlay *Disability Praxis: The Body as a Site of Struggle* (Pluto Press, 2024) 145

Chapter Three:

The Convention on the Rights of Persons with Disabilities: making rights real

‘respecting human rights means respecting that every person is unique and is entitled to a life of dignity and choice.’[1]

1 Chapter overview

This chapter begins with the general principles undergirding the Convention as found in article 3 and then, in turn, offers contextualised readings of article 24 (education), article 27 (work and employment) and article 19 (living independently and being included in the community). At the end of each principle, I attach what might be thought of as a brief republican meditation, by way of indicating resonances between the principle and contemporary republicanism, while also seeking to suggest the comprehensive nature and range of republican concerns. I offer something similar in respect of each article**.**

2 Introduction

This dissertation seeks to suggest that contemporary republicanism has something valuable to offer disabled people in achieving, and resiliently holding, human rights. More, aligning with the view that the CRPD represents ‘the densest exposition of human rights by the UN to date,’[2] this dissertation suggests that within it there may be discerned an ecumenical scope. By this, I mean that, while clearly directed towards the disability domain, the CRPD is of practical importance to everyone within the (inevitably frail) human family, and particularly, those in immediate circumstances consistent with vulnerabilities, however these vulnerabilities arise.

As this comprehensive articulation of rights, the CRPD operates as the ultimate normative resource, its eight general principles, found in article 3, underpinning each of the rights and being intended to inform and guide the interpretation and implementation of the Convention. Contending that this is a useful way of structuring a broadly thematic overview of the Convention, this first section focuses on article 3.

From this work’s perspective, part of the explanation for this focus lies in the way article 3 supports the CRPD’s status as a framework convention. Understood as inherently flexible - and

---

[1] Desmond Tutu, ‘Forward’ in Olivia Bell, Philip Gready *The No-Nonsense Guide to Human Rights* (New Internationalist, 2006) 5

[2] Rosemary Kayess, Phillip French, ‘Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities’ (2008) 8 (1) Human Rights Law Review 1, 22

while technically no different in effect from that of any other international law treaty - a framework treaty's provisions are intended to establish overarching commitments, general obligations and basic institutional arrangements rather than, say, set unambiguous fetters on state power.[3] An obvious strength of a framework treaty over the more traditional international law format is its availability to dynamic development, comparable to a sort of on-going, real-time, engagement with emerging facts and practices. Indeed, this engagement is provided for in several ways within the CRPD. First, in respect of legislative and policy changes consistent with implementing the Convention there is a requirement that states 'closely consult with and actively involve' persons, including children, with disabilities; this requirement to be discharged 'through their representative organisations.'[4] Second, the CRPD imposes an obligation on states to monitor the implementation of the Convention at domestic level.[5] Third, in addition to the international monitoring provisions provided for in article 34 – specifically, the Committee on the Rights of Persons with Disabilities - article 33(3) expresses a further requirement that indigenous civil society, in particular persons with disabilities and their representatives, also be involved in the monitoring process. The level and complexity of these intersecting engagements emphasises the serious intent of the CRPD to embed meaningful, legally binding change for disabled people. But, they also serve to remind that legal measures, of themselves, are insufficient to ensure the protection and promotion of the fundamental rights of people with disabilities.[6] The *more* that is needed – as clearly recognised by the CRPD in article 8 (awareness raising) – is the widest possible level of public and political investment in recognising and actively supporting the simple rightness of the Convention's purpose. In striving to build this public solidarity and to harness its potential for dynamic development, arguably no one single provision is more valuable as a public rallying call than article 3. That value is there in the very pithiness of the principles, in the way they serve to cogently capture fundamental, unifying values, readily

---

[3] see Nele Matz-Luck, 'Framework Conventions as a Regulatory Tool' (2009) 1 (3) Goettingen Journal of International Law 459

[4] CRPD article 4.3. As per the Committee, representative organisations are defined as those which 'are governed, led and directed by persons with disabilities, are comprised by a majority of persons with disabilities themselves, and thus are representative of persons with disabilities. Furthermore, a clear majority of their membership is recruited among persons with disabilities.' Committee on the Rights of Persons with Disabilities General Comment No 7 on article 4.3 and 33.3 of the CRPD on the participation with persons with disabilities in the implementation and monitoring of the Convention (21 September 2018)

[5] CRPD article 33; the only other UN human rights instrument to mandate this is the Optional Protocol to the *Convention Against Torture* (CAT), however, it might be argued that the CRPD's inclusion of this requirement is, in fact, unprecedented, given that CAT's requirement resides in an Optional Protocol and not in that treaty's main text

[6] see Eilionoir Flynn *From Rhetoric to Action* (Cambridge University Press, 2011)

recognisable as coherent and attractive across every strata of modern society, resonating with other rights privations associated with, *inter* alia, gender, sexual orientation, age, ethnicity, socio-economic status and creed.

In this enlarging sense, then, the general principles set the broad conditions for the success of the Convention, describing a value system aimed at permeating not just the political consciousness of the state but also providing private actors with a template against which to measure the discharging of their responsibilities (too) to their fellow citizens. This is the sense, perhaps, in which article 3 is described as providing the CRPD's moral compass.[7] But, the principles can also be thought of as functioning as a reaction to the injustice persons with disabilities experience in societies, so in this way they can also be characterised as *subversive* of an existing oppressive, dominating order.[8] Moreover, in the context of this dissertation's specifically republican perspective, they also speak to underpinning an independence which is readily recognisable in a republican sense, that is, one synonymous with the absence of arbitrary power, whether manifesting in a person's individual circumstances or as expressed in terms of structural inequalities.

To draw these important points out, the next (but one) section briefly discusses each of these principles in turn, beginning with that of dignity, autonomy and choice and, thereafter, following the order in which each of the principles is laid out in the article. But, first, it is useful to make some brief preliminary points.

3 CRPD's general principles

3.1 The value of general principles

Within a republican perspective, freedom for disabled people is realised only when political and social power is restrained from arbitrary action, the *effectiveness* of the disabled person's citizenship unconstrained, her voice clearly articulated in the democratic contestation. Thus, again, the importance of engaging with the CRPD's general principles. In explicitly – and innovatively – including these principles within the Convention text it is hypothesised that the intention is to contribute conspicuously to the creation of a common space, across cultures and political and legal systems, within which what is owed to disabled persons can no longer be

---

[7] Gerard Quinn, 'Key Note Address to German European Union Presidency Ministerial Conference: Empowering Persons with Disabilities, The UN Convention on the Human Rights of Persons with Disabilities: A Trigger for Worldwide Law Reform, Berlin, 11 June 2007'available at: http://www.eu2007.bmas.de/EU2007/Redaktion/Deutsch/PDF/2007-06-12-rede-quinn, property-=pdf, bereich=eu2007,sprache=de,rwb=true.pdf

[8] Antonio Cassese *International Law* (Oxford University Press, 2005)

occluded. Republicanism too is an ethic of the common space. Hence, this chapter addresses each of the principles in turn, eschewing engagement with them from an ontological or deep theory perspective but, rather, focusing on their practical function by exploring something of their textual, institutional and strategic aspects.

This approach reveals the principles' role within the Convention as having 'an inherent gap-filling function,'[9] suggesting how state and non-state actors can dialectically draw on them both for guidance in applying the Convention and as persuasive manifestations of an authoritative, if emerging, international consensus.[10] Hence, article 3 is described as 'a filter through which discrete pieces of existing law should be run to access conformity with the object and purpose of the CRPD.'[11]

In another sense, too, in international human rights law, general principles operate at a basic building block or a substratum level. Thus, while often lacking the precision to be regarded as identifiable and practical human rights *per se*, general principles are relevant to an individual's ability to enjoy a right while also strengthening the challenge to governmental and societal practice. Within a liberal conception, this twin effect derives from the pliability of general principles. But general principles also possess a core content which supports their normative power and allows them 'stand beyond the majoritarian bargain.' [12] Indeed, within the CRPD, the principles – all of them undefined except for non-discrimination – might be said to support an intentionally experimentalist application of the Convention,[13] the profoundest strength of their inter-linked, over-arching nature to be found in the involvement of disabled people in their drafting.[14]

3.2 The CRPD's novel approach to general principles

As suggested, divergences abound in jurisprudence about the nature of general principles, both in the domestic and the international setting, for instance, in terms of their role in legal

---

[9] Craig Eggett The Role of Principles and General Principles in the 'Constitutional Processes' of International Law [2019] 66 Netherlands International Law Review 197, 207

[10] see, for example, M Cherif Bassiouni A Functional Approach to 'General Principles of International Law' (1990) 11 (3) Michigan Journal of International Law 769

[11] Janet E Lord Accessibility and Human Rights Fusion in the CRPD: Assessing the Scope and Content of the Accessibility Principle and Duty Under the CRPD. Presentation for the Day of Discussion on Accessibility CRPD Committee UN- Geneva October 7 2010 at 6

[12] Takis Tridimas, 'The general principles of EU law and the Europeanisation of national laws' (2020) 13 (2) Review of European Administrative Law 11

[13] Grainne De Burca Robert O. Keohane Charles Sabel 'New Modes of Pluralist Global Governance' (2012) 45 (3) New York University Journal of International Law and Policy 723

[14] Arlene S Kanter *The Development of Disability Rights under International Law: From Charity to Human Rights* (Routledge, 2014)

reasoning.[15] However, these theoretical disputes are not the concerns of this chapter. Rather, the intention is to present the general principles explicitly underpinning the CRPD partly in terms of suggesting how they might each contribute to an international community of practice and partly in terms of the light they shine on the injustices disabled people experience. Hence, the principles are understood as normative and crosscutting, as simultaneously future-focused and rooted in the experiential here and now of disabled people's lived experiences.

In this context, explicitly stating general principles in a stand-alone article is innovative, such that the CRPD is unique among the core human rights treaties.[16] While not unknown in other types of international law instruments – and, indeed, a longstanding practice in international environmental agreements[17] - within a human rights treaty underpinning general principles are usually either inferred from the treaty text or derived from the document's preamble. For instance, the former is exemplified in General Comment number 5 from the Committee on the Rights of the Child.[18] Therein, the Committee identifies four general principles essential to the effective state implementation of the CRC, doing so by distilling down the essence of four key treaty articles.[19] In terms of exemplifying the latter, both the preambles of the ICCPR and the

---

[15] see, for example, Joseph Raz *Ethics in the Public Domain: Essays in the Morality of Law and Politics* (Oxford University Press, 1995)

[16] the seven preceding human rights treaties are: the *International Covenant on Civil and Political Rights*(adopted 16 December 1966, entered into force 23 March 1976) UNTS 999 (ICCPR); the *International Covenant on Economic, Social and Cultural Rights*(adopted 16 December 1966, entered into force 3 January 1976) UNTS 993 (ICESCR);
the *Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment* (adopted 10 December 1984, entered into force 26 June 1987) UNTS 1465 (CAT); the *Convention on the Elimination of All Forms of Discrimination against Women* (adopted 18 December 1979, entered into force 3 September 1981) 1249 UNTS (CEDAW); the International Convention on the Elimination of All Forms of Racial Discrimination (adopted 7 March 1966, entered into force 4 January 1969) UNTS 660 (ICERD); International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families (adopted 18 December 1990, entered into force 1 July 2003) UNTS 2220 (ICMW); the Convention on the Rights of the Child (adopted 20 November 1989, entered into force 2 September 1990) UNTS 1577 (CRC). Since the CRPD two additional human rights instruments have been produced by the UN; the *International Convention for the Protection of All Persons from Enforced Disappearance* (adopted 20 December 2006, entered into force 23 December 2010) UNTS 2716 (ICPPED) and the *Declaration on the Rights of Indigenous Peoples* (adopted 13 September 2007), although this latter is a non-binding resolution

[17] see article 3, *UN Framework Convention on Climate Change* (adopted 9 May 1992, entered into force 21 March 1994) UNTS 1771; article 3 *UN Convention on Biological Diversity* (adopted 5 June 1992, entered into force 29 December 1993) UNTS 1760; article 3, *UN Convention to Combat Desertification* (adopted 17 June 1994, entered into force 26 December 1996) UNTS 1954

[18] UN Committee on the Rights of the Child General Comment no 5 (2003): General measures of implementation of the Convention on the Rights of the Child (27 November 2003) CRC/GC/2003/6

[19] per the CRC Committee, the general principles are to respect and ensure the rights set forth in the Convention to each child within a jurisdiction without discrimination of any kind (article 2), to place the best interests of the child as a primary consideration in all actions concerning children (article 3(1)), to protect the child's inherent right to life and states parties' obligation to ensure to the maximum extent

ICESCR assign dignity and equality as principles, while CEDAW's preamble 'affirms the principle of the inadmissibility of discrimination and proclaims that all human beings are born free and equal in dignity and rights.'

Most of the principles affirmed in the CRPD are found elsewhere in the UN treaty architecture.[20] That said, the utility of giving these principles an explicit emphasis lies, perhaps, in the urgency for disabled persons of turning human rights (and human rights talk) into rights-based practices which genuinely empower people too long mired in marginalisation, paternalism, poverty and chronic deprivation. Relating all this to the claim that republicanism constitutes an important theoretical construct for advancing these rights-based practices, it is contended that engaging systematically with article 3 lays a necessary foundation for doing this, partly by suggesting important ways in which the CRPD has significantly altered the way human rights can be conceptualised for *all* persons,[21] and partly by its providing the clearest of statements, yet, about the intrinsic *worth* of the human person.

3.3 Inherent dignity, autonomy and choice

In referencing '[r]espect for inherent dignity' article 3(a) explicitly connects the CRPD to the central tenet of modern international human rights law. It also links the CRPD to a philosophical humanist tradition which – while perhaps beginning to flower conspicuously during the Enlightenment - can be traced back to the ancient world of Cicero and the Stoics. Indeed, the latter rehearsing the earliest known systematic recourse to dignity as something normative in society.[22] Taken as a shorthand for the proper, respectful way a person deserves to be treated, for Hobbes, dignity represents a man's public worth[23] and for Kant it expresses – at least in respect of some notional rational person - the central tenant of human ethics, that a person must never be used, either in their own person or in the person of another, as a mere means.[24]

---

possible the survival and development of the child (article 6) and to ensure the child's right to express his or her views freely in "all matters affecting the child", those views being given due weight (article 12)

[20] Sarah Arduin Article 3 General Principles. In Ilias Bantekas Michael Ashley Stein Dimitris Anastasiou (eds.) *The UN Convention on the Rights of Persons with Disabilities. A Commentary* (Oxford University Press, 2018) 84 - 105

[21] see Frederic Megret, 'The Disabilities Convention: Towards a Holistic Concept of Rights' (2008) 12 (2) The International Journal of Human Rights 261

[22] Comprising both Greek and Roman disciples, the Stoics first come to prominence in Athens in the early 3rd Century BC; see, for example, John Sellers *Stoicism* (Routledge, 2014)

[23] Thomas Hobbes, *Leviathan* (first published 1651, Penguin Classics, 1985)

[24] Immanuel Kant *The Metaphysics of Morals* (first published 1797, Cambridge University Press, 1996)

Although the subject of enduring controversy and debate,[25] within this dissertation – *ad idem* with the CRPD – the dignity construct is taken as pivotal in the building of a common worldview about the essential attributes of what it is to be human and the proper entitlements which flow from this. Within this construct dignity ceases to be associated with an elite and is recognised as a property of every human. Waldron suggests that this conceptual move from only some human beings having dignity to *all* humans having is accounted for in terms of drawing a distinction between *sortal* dignity and *condition* dignity.[26] The latter represents a form of dignity dependent on certain actions occurring, such as being appointed to some high office or acquiring a prestigious qualification or arriving at a certain, perhaps venerable, stage in life. As such, Waldron describes condition dignity as both highly dependent on circumstances and highly susceptible to the vicissitudes of those circumstances, meaning it is a form of dignity which can be lost or impugned. By contrast, sortal dignity can never be lost but rather persists as a universal and enduring reality, prefaced simply on the fact that each human is of the same sort as every other human.

Contextualising this in terms of human rights these can now be said to be rooted firmly in the concept of individual human dignity as something which is both inherent and inviolable.[27] Indeed, Article 1 of the bedrock document of modern international human rights, the *Universal Declaration of Human Rights* (UDHR) asserts: '[a]ll human beings are born free and equal in dignity and rights'.[28] Written in the immediate aftermath of the barbarous cataclysm of the Second World War - in which the greatest loss of life was among civilians – the UDHR's insistent placing of dignity at the centre of a new world vision, while very much a product of its time, still speaks to the individual as possessing the inherent intrinsic value of a normative agent.[29] The expanding logic of this revitalised emphasis on dignity is discerned, for example, in the words of article 1 of the Federal German Republic's Basic Law, the *Grundgesetz*, which holds that: '[h]uman dignity shall be inviolable. To respect it and protect it shall be the duty of all state authority.'[30] Or, to phrase it in Dworkin's terms, dignity becomes the basic value society must

---

[25] see, for example, Michael Rosen *Dignity: its History and Meaning* (Harvard University Press, 2012); Samuel Moyn, 'The Secret History of Constitutional Dignity' (2014) 17 (1) Yale Human Rights and Development Law Journal 39; Samuel Moyn *Human Rights and the Uses of History* (Verso, 2017)

[26] Jeremy Waldron *Dignity, Rank and Rights* (Oxford University Press, 2012)

[27] the Convention appears to use 'dignity', 'human dignity' and 'inherent dignity' interchangeably; the same practice is followed in this work

[28] The *Universal Declaration of Human Rights* (adopted 10 December 1948 UNGA Res 217 A(III)) (UDHR) art 1

[29] James Griffin *On Human Rights* (Oxford University Press, 2008)

[30] Basic Law for the Federal Republic of Germany 23 May 1949

advance.[31] Moreover, within the specifically European context, while the *European Convention on Human Rights* (ECHR) does not explicitly mention dignity, the European Court of Human Rights (ECtHR) has affirmed that '[t]he very essence of the Convention is respect for human dignity and human freedom.'[32] This same assertion is reflected in the preamble of the European Union Charter of Fundamental Principles wherein the Union, *inter alia*, is held to be 'founded on the indivisible, universal values of human dignity, freedom, equality and solidarity.'[33]

Either explicitly or implicitly, the dignity paradigm permeates the whole of the UN human rights architecture. For example, CEDAW recalls 'that discrimination against women violates the principles of equality of rights and respect for human dignity.'[34] It is invoked in the *International Convention on the Elimination of All Forms of Racial Discrimination* [35] and in the *Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.*[36] In the *Convention on the Rights of the Child*[37](CRC) state parties are repeatedly enjoined to ensure children's dignity, including those who have been victims of any form of neglect, exploitation or abuse[38] or those who have infringed the penal law.[39] The CRC also requires that states 'recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.'[40] Inherent dignity is also closely linked to the concept of liberty, as expressed in article 10 (1) of the *International Covenant on Civil and Political Rights*[41] and in article 17 of the *International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families.*[42] Per article 13 of the *International Covenant on Economic, Social and Cultural Rights,*[43] developing a sense of human dignity is one of the goals of education, just as in the delivery of that education states must ensure 'school discipline is administered in a manner consistent with the child's human dignity.'[44]

---

[31] Ronald Dworkin *Justice for Hedgehogs* (Harvard University Press, 2011)
[32] Pretty v United Kingdom 2346/02 [2002] ECHR 427 para 65F
[33] *Charter of Fundamental Principles of the European Union* 2000/C 364/01 Preamble
[34] CEDAW Preamble
[35] ICERD (n 16)
[36] CAT (n 16)
[37] CRC (n 16)
[38] *ibid* art 39
[39] *ibid* art 37(c)
[40] *ibid* art 23(1)
[41] ICCPR (n 16)
[42] ICMW (n 16)
[43] ICESCR (n 16)
[44] CRC art 28(2)

As with dignity, the principle of individual - or personal - autonomy and independence, inclusive of a disabled person's right to make her own choices, is referenced both in the preamble[45] to the CRPD and in its general principles. However, unlike dignity, this referencing of individual autonomy represents another innovation in a core UN convention, the CRPD being the only such treaty to do so. Indeed, neither the ECHR or the EU Charter of Fundamental Rights reference the concept, although the ECtHR has contended that personal autonomy is an important principle undelaying the interpretation of guarantees contained in the ECHR's right to privacy (article 8).[46]

As further developed, for instance, in article 19 (living independently and being included in the community) the CRPD's inclusion of autonomy in both its preamble and its principles reaffirms the centrality of unimpeded choice in what it means to be a free person. In emphasising autonomy, the CRPD is asserting that the privations and indignities experienced by disabled people are not inevitable consequences of disability but rather flow from restricted opportunities for disabled people to claim and practice personal freedom. This may be most particularly evident in terms of recognising disabled persons as holders of socio-economic rights.[47] Certainly, the capacity of many disabled people to live independently is still obscured in the Western imagination by a history of institutionalisation. So too is the recognition of disabled peoples' capacities as workers adversely affected by tropes which conflate disability and dependence in negative ways, such that concepts like reasonable accommodation, accessibility and workplace supports are often misrepresented as burdensome issues of economic resources rather than as legitimate and liberating entitlement.

But what of autonomy as it relates to disabled persons' civil and political rights? Although undefined in the Convention, autonomy is most frequently associated with freedom (both positive and negative) and can be thought to have a distinctly political character, in the main focused on the right to do what one wishes with one's body. Hence Feinberg's assessment of autonomy's kernel as

> the right to make choices and decisions – what to put in my body, what contact with my body to permit, where and how to move my body through public space, how to use my chattels and personal property,

---

[45] CRPD preamble at (n)

[46] *Pretty v United Kingdom* at note 32

[47] see, for example, Francesco Seatzu Empowering Persons with Disabilities: Socio-Economic Rights as a Pathway to Personal Autonomy and Independence 18 2 2020 Northwestern Journal of Human Rights 136 - 157

> what personal information to disclose to others, what information to conceal, and more.[48]

But, of course, the immediate difficulty with this type of emphasis is that, in terms of people with disabilities, this focus on the body as the primary site of autonomy axiomatically compromises autonomy for those whose bodies may, in many significant ways, be subject to the control of others.

Such a juxtaposing draws attention to the proposition that autonomy, as both a goal and a practice, is the domain of the, so-called, able-bodied and able-minded. In this ableist formulation, autonomy requires a reflexive capacity, as exemplified in Berlin's theorising of the autonomy which positive liberty confers 'to be the instrument of my own, not other men's, acts of will.' Berlin talks of being 'a subject, not an object; to be moved by reasons, by conscious purposes,' and of 'deciding, not being decided for.**'**[49] To be autonomous within this frame is, it seems, to be capable of being self-aware, self-critical, to be responsible for and knowledgeable about one's own interests.[50] Again such a framing serves to exclude many – if not all – disabled persons. This exclusion is found in Rawls' hugely influential theory of distributive justice[51] just as it is in Raz's contention that a person must have a minimum rationality, meaning 'the mental abilities to form intentions of a sufficiently complex kind' if she 'is to be the maker or author of his own life.'[52]

This prejudicial, commonplace reading of autonomy is Kantian in origin. In Kant's empirical work people with disabilities, arguably *all* disabilities but certainly those thought of as having intellectual disabilities, are characterised as *excluded* not alone from the status of autonomous, moral agents - and, by implication, the citizenship that status confers - but also, potentially, from very personhood itself. [53] As Pinheiro summarises it:

> Kant's institutional provisions for moral development also operate as instruments for political exclusion. That is, the process of socialisation

---

[48] Joel Fineberg *Harm to Self: The Moral Limits of the Criminal Law* (Oxford University Press, 1986) 54

[49] Isaiah Berlin *Liberty* (Oxford University Press, 2016) 178

[50] see, for instance, Gerald Dworkin *The Theory and Practice of Autonomy* (Cambridge University Press, 1988) at 20; however, for a refutation that to be autonomous in this way necessarily results in personally beneficial outcomes see Sarah Conly *Against Autonomy: Justifying Coercive Paternalism* (Cambridge University Press, 2008)

[51] John Rawls *A Theory of Justice* (Belknap Press 1971)

[52] Joseph Raz *The Morality of Freedom* (Oxford University Press 1986) 373

[53] Robert Louden *Kant's Impure Ethics: from Rational Beings to Human Beings* (Oxford University Press 2000)

> and community in Kant are emancipatory instruments of progress only to the human subjects whose potential for civic development in the public sphere is properly expressed by their use of reason.[54]

Hence, the liberal, Enlightenment promise of freedom is revealed as prefaced on an understanding of autonomy which prizes a specific kind of rational ability – for instance, to will the law and work it communally - requiring, first, the ability 'to transition from the natural to the moral realm.'[55] Only when this is possible are the species-specific features of human beings activated, including access to the multiple and multiply cross-cutting familial, educational, legal, civic, political, cultural, scientific and religious institutions which help shape and define what it is to be moral and to behave morally in the modern world. However, absent the perceived inability to make this transition, the very institutions which Kant identifies as essential to socialisation and entry into the community become part of the apparatus of exclusion and, even, of sequestration. Indeed, drawing on Kant's writings about disability, including 'maladies of the head' and deafness, Pinheiro cites Kant's view that certain disabilities are forms of civic immaturity (a condition Kant also, at least in places, ascribes to women, regardless of age, and, temporarily, to male children[56]) and will require removal from the politico-civil state, perhaps by means of coerced institutionalisation.[57]

Legislatively and at various levels of national disability policy and practice, the increasing presence of a different understanding of personal autonomy can be attributed in many ways to the CRPD's framers' determination to break with this Kantian deficit model and its still enduring legacy. For example, following on from the UDHR and the ICCPR and the assertions therein that everybody has the right to personal liberty, article 14 of the CRPD specifies the duty on states to ensure that persons with disabilities, on an equal basis with others, enjoy the right to liberty, and that the existence of a disability shall in no case justify a deprivation of liberty. This duty,

---

[54] Lucas G Pinheiro 'The Ableist Construct' in Barbara Arneil, Nancy J Hirschmann (eds) *Disability and Political Theory* (Cambridge University Press 2016) 55

[55] *ibid*

[56] In contrast to his unyielding views on disability, Kant's theorising of women is, in some ways, quite traditional for its time but in others ways quite progressive, vacillating between describing women as passive citizens, incapable of voting or holding public office, to suggesting that their autonomy is equal to that of men such that they can aspire to active citizenship; see, for example, Helga Varda Kant and Women 98 4 2017 Pacific Philosophical Quarterly 653

[57] Pinheiro (n 54); for an interesting account of Kant's often neglected 1764 work 'An Essay on the Maladies of the Mind,' describing it as 'that austere, polemical text' but arguing that in privileging certain mental disorders it reveals much about how in exploring his own tendency to hypochondria and melancholia Kant frees his thought to develop in a decisive direction as a moral philosopher, see Monique David-Menard Kant's "An Essay on the Maladies of the Mind" and *Observations on the Feeling of the Beautiful and the Sublime* 15 4 2000 Hypatia 82

read in tandem with article 19 (living independently and being included in the community), article 28 (adequate standard of living and social protection) and, of course, article 12 (equal recognition before the law) serves to remind of the crucial importance of the principle of inherent dignity and personal autonomy in undergirding national movements against institutionalisation and its oppressive, dehumanising, dominating effects.

Indeed, this is especially so because the model of autonomy which the CRPD promotes is also deep enough to advance the justice claims of 'those who need more intensive supports.'[58] Hence, people who are identified by health and/or social services professionals as being severely or profoundly intellectually disabled are also held to be capable of making choices and expressing personal autonomy. In this, the feminist emphasis on autonomy as relational is helpful.[59] This work highlights the undesirability of and, perhaps, the mythical nature of, an idea that autonomy is synonymous with self-sufficiency. The importance of this theoretical perspective for persons with intellectual disability is captured in the observation that even people in particularly intellectually challenging circumstances 'are often able to make decisions for themselves, but not necessarily on their own.'[60] Captured in this phrase is the wider sense that *every* apparent act of autonomous decision-making nestles in a thick web of environmental, educational, familial and other socially embedded supports, such that the notion of independence itself needs to be interpreted expansively. Above all, perhaps, this expansiveness provides for the concept of advocacy as central to those people who cannot easily – or at all – express themselves in words.[61] In an Irish context a legislative remit for independent advocacy exists only under *The Mental Health Act* 2001.[62] However, in a wider sense, the importance of a

---

[58] CRPD preamble at (j); particularly instructive here is the scholarship of Joanne Watson whose work on strategies empowering profoundly intellectually disabled people to express their 'will and preference' in support, *inter alia*, of their article 12 rights rests on the premise that *everyone* is a communicator, see Joanne Watson The Role of Speech Language Pathology in Supporting Legal Capacity (2019) 21 (1) Journal of Clinical Practice in Speech Language Pathology 25; Anna Arstein-Kerslake Joanne Watson Michelle Browning Jonathan Martinis Peter Blanck Future Directions in Supported Decision Making 37 1 2017 Disabilities Studies Quarterly no page numbers; see also Listening to those rarely heard: Supported decision-making for people with severe to profound intellectual disability - video available at https://vimeo.com/21176882

[59] see, for example, Catriona Mackenzie Natalie Stoljar, (eds) *Relational autonomy: Feminist perspectives on autonomy, agency, and the social self* (Oxford University Press, 2000)

[60] Laura Davy, 'Philosophical Inclusive Design: Intellectual Disability and the Limits of Individual Autonomy in Moral and Political Theory' (2015) 30 (1) Hypatia 140

[61] Guðrún Stefánsdóttir, Kristín Björnsdóttir, Ástríður Stefánsdóttir, 'Autonomy and People with Intellectual Disabilities Who Require More Intensive Support' (2018) 20 (1) Scandinavian Journal of Disability Research 162

[62] although the *Citizens Information Act 2007* provides for the establishment by the Citizens Information Board of a Personal Advocacy Service (PAS), the service has not been commenced. Instead, the National

structured, legislatively provided-for approach to advocacy is implicit in the *Assisted Decision Making (Capacity) Act* 2015 which, *inter alia*, repealed the *Lunacy Regulation (Ireland) Act* 1871 and its infamous wards of court provisions.

3.4 A republican perspective (i)

As exemplified in Pettit's eyeball test, at the heart of contemporary republicanism sits a profound concern for the essential dignity of the individual and for individual autonomy and independence.[63] Thus, not being able to look another in the eye (unfortunately, an image not without ableist intonations[64]), or feeling utterly compelled to show another deference are affronts to dignity and autonomy because they indicate one has 'to live at the mercy of another' or is 'vulnerable to some ill that the other is in a position to arbitrarily impose.'[65] Hence, within the republican ethic resourcing each person to stand as each other's equal becomes essential to ensuring that liberty as non-domination is established and resiliently held.

In briefly teasing this out in the context of people living with impairment, what is emphasised first is that the inherent dignity of all human beings must be affirmed as *common knowledge*. Remember that Pettit offers a definition of domination which consists of three elements, namely that someone dominates or subjugates another where (i) D has the capacity to interfere, (ii) on an arbitrary basis, (iii) in certain choices that E is in a position to make.[66] Drawing on the work of philosopher David Lewis,[67] Pettit uses the phrase 'common knowledge' to indicate a further circumstance likely to apply in situations of domination. This is that - absent some subterfuge of the type as might arise in relation to those in a position to keep their manipulations shielded from public view - as a matter of general consciousness:

> the powerful must be aware that they have power over others, and that these others are aware that they are in the power of the powerful, and that the powerful know that the powerless are aware of this, and so on.[68]

Advocacy Service for People with Disabilities (NAS) has been established by the Citizens Information Board on a non-statutory basis

[63] Jan-Willem Van Der Rijt, 'Republican Dignity: The Importance of Taking Offence' (2009)28 (5) Law and Philosophy 465

[64] See Tom O'Shea' Civic Republican Disability Justice' in Adam Cureton David Wasserman (eds) *The Oxford Handbook of Philosophy and Disability* (Oxford University Press, 2020)

[65] Philip Pettit *Republicanism: A Theory of Freedom and Government* (Oxford University Press, 1997) 5

[66] *ibid* 52

[67] David Lewis *Convention* (Harvard University Press, 1983)

[68] Cillian McBride, 'Freedom as non-domination: radicalisation or retreat?' (2015) 18 (4) Critical Review of International Social and Political Philosophy 349

In Pettit's formulation, it is this common knowledge which backgrounds the inability of the subjugated to look their subjugators in the eye, the asymmetries of power on public display and taken for granted. Under the medical model this taken – for- granted-ness reduces those with impairments to incomplete persons, dependent on doctors, disability *experts* and a myriad institutions to diagnose and decide for them, a disabled person's citizenship dubious if not actually deleted, the goods of social belonging, at best, doled out as expressions of kindness, sympathy or charity. The common knowledge here becomes part of the apparatus of control. Such imagery is intuitively repugnant to an unencumbered – in this case, non-ableist - republican consciousness. Changing this common understanding – restoring or reaffirming disabled people's equal dignity as citizens – requires more than enhanced resources.[69] Rather, on a republican reading what is indicated here is an orientating of the republican research programme towards the CRPD's article 8 (awareness raising), utilising republican methodology to advance the Convention's intention to 'foster respect for the rights and dignity of persons with disabilities.'[70] Hence, if the imagery changes to a generalised perception that what unites us all is the idea that we are all equally vulnerable to domination – both dominium and imperium – then rescuing our threatened status as free citizens becomes a shared, universal project. In this dispensation, a new common knowledge becomes possible within which is foregrounded *not* that domination is taken for granted but, rather, that it must be equally resisted because each person has an equal share in human dignity**.**

3.5 Non-discrimination

Within the legal architecture of the CRPD non-discrimination and equality are both principles and rights.[71]As with innate human dignity, the principle of non-discrimination - taken, here, to connote the same idea as equality[72] - is a long-standing feature in international human rights instruments, operating as a 'basic and general principle relating to the protection of human rights.'[73] Hence, non-discrimination and equality stand out as the only human rights explicitly referenced in the *UN Charter*, thereafter, in quick succession, appearing in, *inter alia*, the

---

[69] Marie Sepulchre, 'Disability, Justice and Freedom as Non-Domination' (2022) 2 (1) The International Journal of Disability and Social Justice 11

[70] CRPD art 8.1(a)

[71] Committee on the Rights of Persons with Disabilities (2018), General Comment No. 6 on equality and non-discrimination at 12

[72] see, Evelyn Ellis, 'The Principle of Equality of Opportunity Irrespective of Sex: Some Reflections on the Present State of European Community Law and its Future' in Alan Dashwood Siofra O'Leary (eds) *The Principle of Equal Treatment in EC Law* (Sweet & Maxwell, 1997) at 180; Anne F Bayefsky 'The Principle of Equality or Non-Discrimination in International Law' in Stephanie Farrior (ed.) *Equality and Non-Discrimination Under International Law Volume ii* (Routledge, 2015) Chapter 4 (no page numbers)

[73] UN OHCHR CCRP General Comment No.18: Non Discrimination (UN 1989) at para 1

Universal Declaration of Human Rights, the *Charter of the Organisation of American States*, the *American Declaration on the Rights and Duties of Man*, The *European Convention for the Protection of Human Rights and Fundamental Freedoms*, the *International Covenant on Civil and Political Rights* and the *International Covenant on Economic, Social and Cultural Rights*. That said, the explicit identification of disability as a ground for discrimination only appears – and, here, only partially - for the first time in the CRC; the ICCPR, ICESCR, ICERD, CEDAW and the *International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families* are all silent on this matter.[74]

Within the architecture of the CRPD non-discrimination makes multiple appearances. In addition to its article 3 status as a general principle, it is referenced twice in the document's preamble, indicating that 'discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person' and noting that multiple or aggravated discrimination is a matter of particular concern.[75] Further, the principle appears as a general obligation under article 4 and as a stand-alone entitlement in article 5 (equality and non-discrimination) requiring states to, *inter alia*, guarantee 'equal and effective legal protection against discrimination'[76] as well as providing for 'specific measures' which, while not elaborated on, will not constitute discrimination if necessary to effect or accelerate *de facto* equality.[77] Non-discrimination is also referenced in the substantive provisions contained in articles 6 (women with disabilities), 23 (respect for the home and the family), 24 (education), 25 (health) and 27 (work and employment). Moreover, unlike any of the other principles found in article 3, the Convention offers a definition of discrimination, asserting that it consists of

> any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment, or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social,

---

[74] this said, it has been argued that such is the widespread acceptance of the non-discrimination and equality principles that they now form part of *jus cogens,* the international customary law: see, B C Ramcharan 'Equality and Non-Discrimination' in Louis Henkin (ed) *The International Bill of Rights: The Covenant on Civil and Political Rights* (Columbia University Press, 1981) 246 - 269

[75] CRPD preamble at (h) and (p) respectively; but see also (a), (b), (c), (e), (f), (r) and (x)

[76] CRPD art 5 (2)

[77] CRPD art 5 (4)

> cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.[78]

More, the CRPD Committee has also affirmed that the definition of discrimination on the basis of disability also extends to those effected by what Goffman calls courtesy stigma,[79] that is, people who are discriminated against based on an association with a disabled person or based on an erroneous imputation of disability.[80] The definition also covers a person discriminated against because she had a disability in the past or who has 'a disposition to a disability that lies in the future.'[81] Also, harassment is implicitly covered within the CRPD definition, as are both direct and indirect forms of discrimination. More, in showing discrimination, the Committee argues for a reversal of the civil burden of proof, placing it on the respondent rather than the claimant. [82]

The CRPD adopts a wide scope in respect of discrimination on the grounds of disability. In this, it can be usefully contrasted with the leading European Union legislation in this area, the *Employment Equality Directive*, whose ambit is limited to prohibiting discrimination on the basis of disability in relation to employment and vocational training only.[83] This comparison is particularly interesting given that the EU is itself a signatory to the Convention and had originally proposed that the CRPD model its non-discrimination provisions on the directive.[84] Instead, however, the Convention positions itself as the logical next stage in the development of non-discrimination norms already to be found in previous UN human rights instruments. This it does by importing a disability perspective into these norms, for example in relation to reasonable accommodation, and by ensuring that the specific demands made of them, which this

---

[78] CRPD art 2

[79] Erving Goffman *Stigma. Notes on the Management of Spoilt Identity* (Penguin Books, 1990)

[80] Committee on the Rights of Persons with Disabilities (2018), General Comment No. 6 on equality and non-discrimination at para 20

[81] Committee on the Rights of Persons with Disabilities (2018), General Comment No. 6 on equality and non-discrimination at para 20

[82] *Ibid* para 73(1)

[83] Directive 2000/78 [2000] OJL 303/16; for an overview of the directive and other EU anti-discrimination approaches see Mark Bell, 'The Implementation of European Anti-Discrimination Directives: Converging Towards a Common Model?' (2008) 79 (1) The Political Quarterly 36

[84] Grainne de Burca, 'The EU in the Negotiation of the UN Disability Convention' (2009) 35 (2) European Law Review 174; it is worthy of note that while the EU directive does reference reasonable accommodation in respect of education and vocational training a failure to provide it does not appear to be in breach of the directive, again, a weaker position than that which pertains under the Convention

perspective clarifies, are properly provided for. This includes updating pre-existing duties on states in the light of the CRPD.[85]

Asserting, promoting and protecting equality are central and longstanding aims of human rights law.[86] Indeed, in one form or another, equality appears in all the major international human rights documents,[87] loaning weight to the claim that it be considered 'the starting point of all other liberties.'[88]But the consensus around what, in practice, equality looks like shifts over time, meaning that dependent on which model of equality is in place the outcomes for disabled persons can be quite different. Three relevant models are identified: formal (or judicial) equality, substantive equality and inclusive equality.[89]

Aristotelian in origin,[90] the formal model of equality employs a similarly situated test which requires that alike is treated alike and that unalike is treated differently. Within the formal approach, laws and policies are designed to show procedural fairness, such that 'formal exclusionary laws are dismantled and overtly prejudicial behaviour prohibited'.[91] Thus, the model's rationale is satisfied not because *all* people are treated identically but, rather, because all those who share a differentiating characteristic are treated in the same way.[92] Within this model, disability is an irrelevance – just as the concept of an advantaged and a disadvantaged group is an irrelevance. Instead, formal equality presents as unambitious, its symmetrical intent potentially actually capable of perpetuating disabled peoples' disadvantage.[93] Sen suggests this potential for ill in his parable of the two people who are going without food, one because she is starving, the other because she is performing the religious ritual of fasting. Both, in a sense, are equally disadvantaged in their experience of hunger but only one has the ability to *choose* to be

---

[85] Lisa Waddington, Andrea Broderick, *Combating disability discrimination and realizing equality. A comparison of the UN CRPD and EU equality and non-discrimination law* (European Commission, 2018)

[86] for instance, article 1 of the UDHR holds that '[a]ll human beings are born free and equal in dignity and rights'

[87] see, for instance Oddny Mjoll Arnardottir A Future of Multidimensional Disadvantage Equality. In Oddny Mjoll Arnardottir Gerard Quinn (eds.) *The UN Convention on the Rights of Persons with Disabilities* (Matinus Nijhoff Publishers, 2009)

[88] Hersch Laurterpacht *An International Bill of Rights* (Columbia University Press, 1945) 115

[89] Committee on the Rights of Persons with Disabilities General Comment No. 6 (2018) on equality and non-discrimination

[90] Aristotle *The Nicomachean Ethics* (Penguin Classics, 2004)

[91] Sandra Fredman *Discrimination Law* (Oxford University Press, 2002) 7

[92] Donna Greschner, 'Does Law Advance the Cause of Equality?' (2001) 27 (1) Queen's Law Journal 299; Patricia Hughes, 'Supreme Court of Canada Equality Jurisprudence and "Everyday Life" [2012] 58 The Supreme Court Law Review Osgoode's Annual Constitutional Cases Conference 247

[93] see Sandra Fredman 'Disability Equality: A Challenge to the Existing Anti-Discrimination Paradigm' in Anna Lawson Caroline Gooding (eds) *Disability Rights in Europe: From Theory to Practice* (Hart, 2005) 199 - 218

well-nourished.[94] In this scenario, a formal equality intervention would infer similarity where, in fact, there is none and the model's inability to account adequately for different material circumstances – and not at all for structural inequality - will leave one person materially better off than the other.

Within the arc of UN international human rights law an eventual focus on substantive equality begins to becomes evident in what Arnandottir characterises as a shift away from an ethic of 'universal sameness.'[95] Valuable as formal equality is – especially in its targeting of direct discrimination – the approach lacks the nuance to address the kinds of asymmetrical structural inequalities which so trouble republicans and which the social model has been useful in identifying as emblematic of the continuing marginalisation of disabled people. Asserting that the civil and political rights framework prizes the 'archetype of the autonomous, free-standing individual' O'Cinneide [96]contends that in the period before the CRPD the 'mainstream legal vocabulary of human rights struggles to cope with the articulation of disability rights claims.' A focus on substantive equality seeks to address this difficulty head-on by ensuring that socially, politically and economically marginalised groups are not further disadvantaged through laws, policies and social practices which impose subordinating treatment on them.[97] Hence, this model, at root, operates from the premise that promoting equality in such circumstances may only be possible where people are not treated alike but, rather, are treated differently. Phrased colloquially, a substantive equality approach goes places formal equality cannot reach. By factoring into the equation the differences in outcomes which might result from the same treatment and, thereby, recognising the deleterious effects an ostensibly neutral rule might have, the substantive approach takes aim at indirect discrimination.[98]

For Fredman substantive equality operates across four dimensions:

---

[94] see Amartya Sen 'Capability and Well-being' in Martha Nussbaum Amartya Sen (eds) *The Quality of Life* (Oxford University Press, 1993) 30 - 53

[95] Oddny Mjoll Arnardottir 'A Future of Multidimensional Disadvantage Equality' in Oddny Mjoll Arnardottir Gerard Quinn (eds) *The UN Convention on the Rights of Persons with Disabilities* (Matinus Nijhoff Publishers, 2009) 47

[96] Colm O'Cinneide 'Extracting Protection for the Rights of Persons with Disabilities' in Oddny Mjoll Arnardottir Gerard Quinn (eds) *The UN Convention on the Rights of Persons with Disabilities* (Matinus Nijhoff Publishers, 2009) respectively, 170 and 171

[97] see, for instance, Jennifer Koshan, Jonnette Watson Hamilton, 'The Continual Reinvention of Section 15 of the Charter' [2013] 64 University of New Brunswick Law Journal 19; this article reviews the Supreme Court of Canada's interpretations of the equality rights provision in s. 15, *The Canadian Charter of Rights and Freedoms* 1982

[98] Jenny E. Goldschmidt, 'New Perspectives on Equality: Towards Transformative Justice through the Disability Convention?' (2017) 35 (1) Nordic Journal of Human Rights 1

> redressing disadvantage (the redistributive dimension); addressing stigma, stereotyping, prejudice and violence (the recognition dimension); facilitating voice and participation (the participative dimension) and accommodating difference, including through structural change (the transformative dimension).[99]

In this account, what is vividly captured is the idea that not all discrimination can be tacked to the malign acts of individual actors just as there is no benign social norm that just needs to be nudged back into kilter. Rather, in a disability context, the ways in which difference has become equated with inferiority derive from multiple, densely tangled, historically and culturally laden prejudices and fears which only individually calibrated and conscious acts of recognition and redistribution can begin to ameliorate. Hence, key substantive equality measures include

> the designation of quotas or institution of affirmative action policies to increase minority group participation in education or employment, and the imposition of a requirement to make structural adjustments to accommodate personal needs.[100]

More, whereas the formal model relies on individual claimants to initiate change, the substantive approach relieves this individual burden. Instead, while not eschewing a case by case approach, the prospect of also taking a systemic perspective increases the likelihood of promoting a more diffuse social change.[101]

The CRPD is clearly rooted in the substantive equality model. However, the Convention text is also an extension of that model. Fredman's identification of structural change as a dimension of the substantive model might be read to suggest transformational equality is merely a subset of that well-established category. Such an interpretation is not shared by the CRPD Committee. Rather, under the CRPD the transformational model of disability connects with – and extends - the social model construct, challenging the structural and ideological presuppositions which underpin dominant ableist interpretations of the world. Recognising an equality theory's need to resolve the 'dilemma of difference' the Committee asserts that the model of equality

---

[99] Sandra Fredman, 'Emerging from the Shadows: Substantive Equality and Article 14 of the European Convention on Human Rights' (2016) 16 (2) Human Rights Law Review 273, 274

[100] Kayess and French (n 2) 8; it is noted, however, that, (reasonable) accommodation apart, none of these mechanisms are mentioned in the CRPD

[101] Maria Ventegodt Liisberg *Disability and Employment. A contemporary disability human rights approach applied to Danish, Swedish and EU law and policy* (Intersentia, 2011)

developed throughout the CRPD is transformational, a model it refers to as inclusive equality.[102] Indicating that it 'embraces a substantive model of equality and extends and elaborates on the content of equality,' the Committee describes inclusive equality as comprising of:

> (a) a fair redistributive dimension to address socioeconomic disadvantages; (b) a recognition dimension to combat stigma, stereotyping, prejudice and violence and to recognize the dignity of human beings and their intersectionality; (c) a participative dimension to reaffirm the social nature of people as members of social groups and the full recognition of humanity through inclusion in society; and (d) an accommodating dimension to make space for difference as a matter of human dignity. The Convention is based on inclusive equality.[103]

That this 'new' vision of inclusive equality extends the existing understanding of non-discrimination within international law is illustrated in the way the CRPD addresses the issue of reasonable accommodation, as defined in article 2. It should be noted 'reasonable' in this context refers not to 'a qualifier or modifier to the duty' but, rather, to what is relevant, appropriate or effective for an *individual* disabled person in a discrete set of circumstances.[104]

Some scholars have suggested that the CRPD's drafters' claim that the Convention contains no new rights is a fiction, with rights such as reasonable accommodation (article 5) cited as one example to the contrary.[105] Defined as entailing 'necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden,'[106] a denial of reasonable accommodation is discrimination. More, described as an entitlement which 'spans all human rights' in the CRPD[107] and as 'an intrinsic part of the immediately applicable duty of non-

---

[102] Committee on the Rights of Persons with Disabilities General Comment No. 6 (2018) on equality and non-discrimination at paras 10 and 11

[103] *ibid* at para 11

[104] *ibid* at para 25(a)

[105] see, for example, Andrea Broderick, 'Of rights and obligations: the birth of accessibility' (2020) 24 (4) The International Journal of Human Rights 393; Arlene S Kanter, 'Do Human Rights Treaties Matter: The Case for the United Nations Convention on the Rights of People with Disabilities' (2019) 52 (3) Vanderbilt Journal of Transnational Law 577; by way of contrast see Kayess and French who argue that the CRPD does not create new rights but rather provides 'amplified formulations of human rights;' Rosemary Kayess Phillip French Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities (2008) 8 (1) Human Rights Law Review 1, 28

[106] CRPD art 2; the Committee has yet to provide an interpretation of what 'disproportionate' means

[107] Lisa Waddington Andrea Broderick *Promoting Equality and Non-Discrimination for Persons with Disabilities* (Council of Europe, 2017) 7

discrimination in the context of disability,'[108] the concept of reasonable accommodation can be theorised as now an integral part of the international legal order. The concept recognises the insufficiency of, for example, a blind person or a deaf person merely having equal access to an office based administration job, this being inadequate to provide protection against the indirect discrimination which will arise if, say, the putative employer fails to ensure appropriate forms of assistive technology are - or can reasonably be - put in place to ensure the disabled person can perform their work function to the required standard. In Article 5(3) the Convention is clear that the onus rests with states to 'take all appropriate steps to ensure that reasonable accommodation is provided.'[109] Moreover, that appropriate steps may not necessarily be limited to reasonable accommodation *per se* is suggested by article 5(4) which emphasises that '[s]pecific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities' will not be considered as discrimination under the Convention.[110]

Although a freestanding right, reasonable accommodation can, nonetheless, be taken as emblematic of the deep interconnectivity of rights within the CRPD, its unequivocal identification as part of the discrimination and equality principle indicating its relevance for both civil and political rights *and* social, economic and cultural rights. More, the concept draws into doubt whether the traditional distinction between these two stratum of rights continues to hold any meaning, given that the Committee has held that the duty on states to provide reasonable accommodation is not subject to progressive realisation.[111] However, the right is not absolute and notwithstanding that, to date, the Committee has not offered an definitive interpretation of 'disproportionate burden' there have been some indications as to relevant factors in respect of finding an denial of accommodation not to be in breach of article 5.[112] Hence, in *Jungelin v*

---

[108] Committee on the Rights of Persons with Disabilities General Comment No. 6 (2018) on equality and non-discrimination at para 23

[109] CRPD art 5:3

[110] *ibid* art 5:4; it is noted that other treaties also provide for positive action, for example, ICERD (art 1) and CEDAW (art 4), but these refer to 'special measures;' such, however, is the pejorative content of the word 'special' in a disability context that this phrasing was not deemed appropriate in the CRPD; see Waddington and Broderick (n 107) 43

[111] Committee on the Rights of Persons with Disabilities General Comment No. 5 (2017) on article 19 living independently and being included in the community at para 46

[112] the Committee has advised that the determination that an undue burden exists can only happen on a case by case basis and requires consultation with the relevant entity charged with breach of the duty and the disabled person concerned; it further advises that potential factors to be assed 'include financial costs, resources available (including public subsidies), the size of the accommodating party (in its entirety), the effect of the modification on the institution or the enterprise, third-party benefits, negative impacts on other persons and reasonable health and safety requirements. Regarding the State party as a whole and the private sector entities, overall assets rather than just the resources of a unit or department within an organizational structure must be considered;' see Committee on the Rights of Persons with Disabilities General Comment No. 6 (2018) on equality and non-discrimination at para 26(e)

Sweden the Committee confirmed that in determining what constitutes reasonable and proportionate accommodation states have a certain margin of appreciation, while also suggesting that cost may be a factor in finding no breach.[113] However, given the explicit identification of denial of reasonable accommodation as a distinct discrimination and given that the duty to accommodate is either an express or implied element in almost all of the Convention rights it seems unlikely that the question of burden can be interpreted in a restrictive way.[114] Indeed, the Committee contend that where respondents assert that reasonable accommodation places a disproportionate or undue burden on them that the evidentiary burden should sit with the duty bearer. Moreover, the state is also asked to ensure that 'effective, proportionate and dissuasive sanctions'[115] and 'adequate remedies'[116] are also in place to deter inappropriate use of this defence. Finally, to the issue of cost, the Committee has also expressed the view that the principle of dignity is also operant here. The example is given that if it is cheaper and less technically challenging for a restaurant owner to provide disability access through a back door 'every effort' should be made to make the front door accessible to persons with disabilities.[117]

In its development of inclusive – or transformative – equality, it is clear that the CRPD has a considerably more advanced approach than that of previously existing human rights instruments.[118] Thus, the progressive fleshing out of the non-discrimination and equality principle as found in the CRPD has significant implications for all human rights law and practice. By connecting the duty to reasonably accommodate with all of the substantive provisions in the Convention, including the socio-economic rights, there can be traced a direct line between equality – specifically, the targeting of deep-seated *inequalities* - and the dignity of the person.

---

[113] Committee on the Rights of Persons with Disabilities CRPD/C/12/D/5/2011 Jungelin v Sweden; it may be that the cost has to be significant: in the instant case adopting an intranet system to allow a visually impaired person to work as a claims investigator was estimated to be in the region of 2% of the state agency's annual budget – moreover, it would also have been necessary to hire an assistant for the claimant so that handwritten claims could be read to the claimant

[114] a British case of interest here is *Archibald v Fife* [2004] IRLR 651 wherein the (then) House of Lords held that rather than await a claimant to demand it, there is an onus on the employer to think proactively about reasonable accommodation, inclusive of how disadvantage might be removed for *perspective* employees with disabilities

[115] Committee on the Rights of Persons with Disabilities (2017) Concluding Observations on the initial report of Luxembourg at paras 10-11; Committee on the Rights of Persons with Disabilities (2018), General Comment No. 6 on equality and non-discrimination at para 31(f)

[116] Committee on the Rights of Persons with Disabilities (2013) Concluding Observations on the initial report of Austria, at para 13; Committee on the Rights of Persons with Disabilities (2018) General Comment No. 6 on
equality and non-discrimination at para 31(f)

[117] CRPD Committee General Comment on accessibility 2014 at para 24

[118] Andrea Broderick *The Long and Winding Road to Equality and Inclusion for Persons with Disabilities* (Intersentia, 2015)

If the Committee's vision of inclusive equality becomes the new norm then, as Degener has it, 'it is of utmost importance, to ensure that it is widely applied and not restricted to disabled persons only,' such a restriction being 'contrary to the harmonization of international human rights law as well as to the mainstreaming of disability into human rights law.'[119] Of relevance here too, is the Committee's clarity about the nature of disability as being just one of any given person's 'several layers of identities.'[120] Conversely, this introduces the important concept of intersectionality, where several grounds of discrimination operate in such a way that they are effectively inseparable. Persons with disabilities may be particularly prone to the kinds of cross-cutting negative synergies intersectional discrimination can generate, including those associated with the experience of being a minority within a minority.[121]

3.6 A republican perspective (ii)

For Pettit 'the very paradigm of injustice is the scenario where those of a certain caste or colour, religion, gender or ethnicity suffer discrimination under the institutions established by the state.'[122] Leaving to one side that Pettit does not mention disability in this context, arguably in this one quotation might be focused those criticisms of republicanism that it is perfectionist[123] or excessively utopian[124] or inferior to a properly functioning liberal regime.[125] However, what Pettit avers to in this sentence is that non-domination does not happen by accident, in isolation or through lucky happenstance but, rather, 'by virtue of social design.'[126] Two broad approaches characterise the type of social design required: the strategy of reciprocal power and, of

---

[119] Theresia Degener cited in Lisa Waddington Andrea Broderick *Promoting Equality and Non-Discrimination for Persons with Disabilities* (Council of Europe, 2017) 45

[120] Committee on the Rights of Persons with Disabilities General Comment No. 6 (2018) on equality and non-discrimination at para 9

[121] see, for example, Sarah Sheridan *A minority within a minority: deaf gay and lesbian people on their experiences within different communities* (MA Thesis, 2008) unpublished; see, also, Alice Abrokwa, ''When They Enter, We All Enter': Opening the Door to Intersectional Discrimination Claims Based on Race and Disability' (2018) 24 (1) Michigan Journal of Race and Law 15

[122] Philip Pettit *On the People's Terms* (Cambridge University Press, 2012) 78

[123] see, for example, Will Kymlicka 'Liberal Egalitarianism and Civic Republicanism: Friends or Enemies?' in Anita L Allen Milton C Regan (eds) *Debating Democracy's Discontent: Essays on American Politics, Law and Public Philosophy* (Oxford University Press, 1998) 131 – 148; see also John W Maynor *Republicanism In The Modern World* (Polity, 2003) and Frank Lovett, Gregory Whitfield, 'Republicanism, Perfectionism and Neutrality' (2016) 24 (1) The Journal of Political Philosophy 120

[124] see, for example, Sudhir Hazareesingh, The Utopian Imagination: Radical Republican Traditions in France, from the Enlightenment to the French Communists' in Bruno Leipold Karma Nabulsi Stuart White (eds.) *Radical Republicanism: Recovering the Tradition's Popular Heritage* (Oxford University Press, 2020) 215 - 238

[125] see, for example, Melvin L Rogers, 'Republican confusion and liberal clarification' (2008) 34 (7) Philosophy & Social Criticism 799; Geoffrey Brennan, Loran Lomasky, 'Against reviving republicanism' (2006) 5 (2) Politics, Philosophy & Economics 221

[126] Pettit (n 65) 67

particular interest to this discussion, constitutional provision.[127] Under such a provision, the state ensures an institutional response to domination that, in tracking the common good, validates the intersubjective status of the parties, 'protecting others by all the defensive and deterrent means at its disposal.'[128] A particularly strong protection on which the state can draw is law and the processes of public deliberation law requires in a democracy. Hence, Pettit's horror of a state that might permit characteristic-based discrimination. Such discrimination violates the notion of intersubjective status, further marginalising the already marginalised.

Yet, Laborde points to a trap here, evincing an example whereby formal republican institutional adherence to law (and, perhaps, a formal, controlled discourse) works counter to the interests of the vulnerable and marginalised. In explicitly orientating contemporary republicanism towards a critical stance, Laborde challenges the 'ethnicity-blind' doctrine of the French Republic as contributing to the very discrimination it seeks to disrupt:

> [b]y banning all reference to *race* in public discourse, official doctrine has been incapable of tackling *racism* in French society: by banning all references to ethnic *difference*, it has been blind to ethnic *discrimination*. Not only does the abolition of talk of race not mean the abolition of racism, but it also makes it much more difficult to confront. National republicans tend to put their faith into the inherently positive virtue of the iteration of abstract norms (such as the moral irrelevance of racial origins) without realising that in conditions where such norms are systematically violated (where discrimination on racial grounds is rife) such iteration is more likely to function as 'performative denial' – a wishful conflation of the claim that 'France should not be racist' with the claim that 'France is not racist.'[129]

Laborde here can be read as a warning of some significance in arguing for a republican reading of disability. Conceptualising discrimination against disabled people in similar terms – the conflation of 'society should not be ableist' with 'society is not ablelist' – republicanism can represent as a remote ideal, made remoter still by the failure of Pettit and what might be termed the republican intellectual elite to address issues of disability directly. This latter becomes all the more surprising when one considers that the disability sphere readily yields examples consistent

---

[127] *ibid*

[128] *ibid* 68

[129] Cecile Laborde *Critical Republicanism* (Oxford University Press, 2008) at 210 (italics in original)

with domination, all be it that Pettit contends that domination is ubiquitous in the modern world.[130] As to this lacuna, perhaps Farrell has it, when he writes of how contemporary normative political philosophies pay ‘lip-service’ to issues of discrimination associated with gender and race (and, by implication, other areas of concern such as disability) ‘assuming (through their silence) such forms of exclusion are no longer constitutive features of the basic structure of ‘modern’ polities.’[131] Hence, the wide ratification accorded the CRPD and its promulgation as national law across every state in Western Europe (and almost every state beyond) (and, of course, the EU itself) becomes in and of itself sufficient to demonstrate that disabled people are now within the (prized) mainstream, no longer *other*. Yet, across such matrixes as education, employment and community inclusion an often dismal, contra- narrative plays out, one where continued discrimination ‘can underpin domination by making it too difficult to escape from familial, romantic, or employment relationships where financial support is provided but significant arbitrary power is also held.’[132]

So why then faith in contemporary republicanism? Because distilling the essence of discrimination and social exclusion down to questions of social power seems intuitively as useful for interpreting disabled people’s experiences - and conceptualising practical remedies – as it does for, say, an undocumented migrant or an abused wife (both of whom, of course, may also live with impairment). Freedom as non-domination presents not as a philosophical practice but as ‘an articulation of a concern *all of us* have in our dealings with others.’[133] Understood as a gateway good, a society resiliently provisioned against non-domination is, axiomatically, interested in providing secure access to a range of other goods ‘like social, medical and judicial security, domestic and workplace respect and, more generally a functioning legal and economic order.’[134] Each of these examples maps on to articles in the Convention and indicates the capacity of republicanism’s research project to ground real-world change, targeting (in a riposte to charges of utopianism) ‘feasible initiatives and sustainable institutions, not just ideal measures.’[135] More, pace Sepulchre, there are reasons to contend that the apparent restricting

---

[130] Philip Pettit The Domination Complaint 46 2005 Nomos 87

[131] Liam Farrell, ‘Towards a critique of neo-republican reason: the subject, discursive control, and power in Pettit’s political theory’ (2023) 24 (3) Distinktion: Journal of Social Theory 405,406

[132] O’Shea (n 64) 224

[133] Philip Pettit, ‘Political realism meets civic republicanism’ (2017) 20 (3) Critical Review of International Social and Political Philosophy 331, 334 (emphasis added)

[134] Philip Pettit *Just Freedom: A Moral Compass for a Complex World* (W W Norton, 2014) xix

[135] Philip Pettit, ‘Political realism meets civic republicanism’ (2017) 20 3 Critical Review of International Social and Political Philosophy 331, 333

of republican theory to the able-bodied is an irrelevant criterion, suggesting that 'republican thought does not need to lean on ableist premises.'[136]

3.7 Full and effective participation and inclusion in society

According to the Committee, equality and non-discrimination constitute principles and rights which are the cornerstone of international protection guaranteed by the Convention as well as being an 'interpretative tool for all other principles and rights [therein] enshrined.'[137] They are central too to a life of dignity and the experience of autonomy. In this light, then, this dissertation turns to the remaining CRPD principles.

Described as 'a quintessential feature of the design of the CRPD'[138] the principle of participation, like that of non-discrimination, permeates the Convention. In addition to its status as a general principle, it features several times in the preamble, including in the (partial) definition of disability and as a Convention objective. [139] It also functions as a general obligation[140] and it pulses through many of the CRPD's substantive provisions, being, in particular, explicitly mentioned in respect of living independently and being included in the community (article 19), education (articles 24(1) and 24(3)), habilitation (article 26), political involvement (article 29), cultural life (article 30) and participation in international cooperation (article 32(1)). The principle also features prominently in relation to the national implementation and monitoring processes relating to the Convention (article 33(3)) and, at the international level, to the putative composition of the CRPD Committee (see article 34(3)'s reference to article 4(3)).

Although yet another novel introduction into international law as a general principle, participation as an important international ideal in the context of disability has a long lineage. It is referenced in the *Declaration on the Rights of Disabled Persons*,[141] the *World Programme of*

---

[136] Maire Sepulchre, 'Disability, Justice and Freedom as Non-Domination' (2022) 2 (1) The International Journal of Disability and Social Justice 11, 17

[137] Committee on the Rights of Persons with Disabilities General Comment No. 6 (2018) on equality and non-discrimination at para 12

[138] Sarah Arduin, Article 3 General Principles. In Ilias Bantekas Michael Ashley Stein Dimitris Anastasiou *The UN Convention on the Rights of Persons with Disabilities. A Commentary* (Oxford University Press, 2018) 97

[139] CRPD preamble at (e), (m), (o) and (y)

[140] CRPD art 4(3)

[141] Declaration on the Rights of Disabled Persons proclaimed by General Assembly resolution 3447 (XXX) of 9 December 1975

Action Concerning Disabled Persons,[142] the *Standard Rules*,[143] the CRC, the *Revised European Social Charter*[144]and the *EU Charter of Fundamental Rights*.[145] Traditionally too, the concept of participation is associated with a range of other entitlements which cohere around the right of political participation, as found, for example, in the UDHR and the ICCPR, such as freedom of thought, expression, assembly and association. Participation is also associated with those entitlements found in ICESCR such as the rights to take part in a community's cultural, recreational, leisure and sporting life.

Nonetheless, that the inclusive drafting process of the Convention included participation as a principle of the CRPD must be thought of as speaking to a marked, worldwide deficit in how disabled people themselves perceive their ability to take part in society in a meaningful and personally fulfilling way.

3.8 A republican perspective (iii)

In this context, it merits reminder that within the republican sensibility democratic participation and - in circumstances of non-domination - the consensual agreement such participation can engender is a core value. For Bellamy, these circumstances are distilled down to two: that, whatever the specific decision resulting from participation, citizens must feel that their status as equals in the decision-making process is not in doubt and that, if on the losing side, their integrity remains intact.[146] Hence, just as Pettit emphasises the tradition whereby democratic participation 'is a means of furthering liberty'[147] Bellamy reminds that freedom always has an intuitively personal core, that seeing oneself as a dignified self is the first grounding of every liberty.

It is suggested that the agentive participation of disabled people both within the wider society and within political and public life (*pace* article 29) contributes proactively not alone to how disabled people are perceived and treated but also to how disabled people perceive and treat each other and themselves.[148] Within this context, the potential is present for republican theory

---

[142] World Programme of Action Concerning Disabled Persons adopted by the General Assembly resolution 37/5 on 3 December 1982

[143] The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities adopted by the General Assembly resolution 48/96 annex on 20 December 1993

[144] Revised European Social Charter Council of Europe European Treaty Series 163 3 V 1996

[145] Charter of Fundamental Rights of the European Union 2012/C 326/02

[146] Richard Bellamy Republicanism, Democracy and Constitutionalism. In Cecile Laborde John Maynor (eds) *Republicanism and Political Theory* (Blackwell, 2008) 159 - 189

[147] Pettit (n 65) 30

[148] see, for example, Lisa Vanhala *Making Rights a Reality? Disability Rights Activists and Legal Mobilization* (Cambridge University Press, 2011)

to aid an increase in social and political power by revealing how disability can be 'an occasion for domination but also for fostering the capacities to combat it.'[149]

3.9 Respect for difference and acceptance of people with disabilities as part of human diversity and humanity

In emphasising diversity and pluralism as part of humanity's richness – in what is another unique provision - this principle of respect for difference and acceptance goes to the heart of the attitudinal changes which must flow from the CRPD within the wider society and polity if the Convention is to be ultimately adjudged successful. More, this principle speaks to the darkness at the heart of practices such as eugenics, institutionalisation and social segregation. It also speaks to the human experience of suffering and marginalisation to which all minorities are, and have always been, subjected. Epitomising the shift to the human rights model of disability and, indeed, resonating with an emerging awareness of intersectionality as a locus of concern for human rights, this principle reflects the social model understanding of disability as simply a part of human diversity. Challenging the glib assertion that there can ever be such a thing as the 'normal' body or mind, this understanding posits a new norm of *difference* as the essential human unifier. Moreover, it suggests how a human rights theory which is fully inclusive of persons with disabilities strengthens the human rights of others.[150]

The acceptance of people with disabilities as part of human diversity is referenced in the Convention's preamble and the principle itself is an underpinning for article 8 (awareness-raising), wherein states are required to combat stereotypes and prejudices[151] and to 'foster respect for the rights and dignity of persons with disabilities'.[152] More, this principle is closely aligned to the principles of respect for inherent dignity and the principle of equality of opportunity.

3.10 A republican perspective (iv)

Choosing to rely on the contention that contemporary republicanism's general quietude in respect of disability is oversight rather than intention it becomes plausible that republicanism's comfortableness with pluralism and diversity must include people with disabilities. Hence, in exploring a concept he calls *popular republicanism*, Kraus writes of how 'mistrust of diversity

---

[149] O'Shea (n 64) 216

[150] Kjersti Skarstad, 'Human rights through the lens of disability' (2018) 36 (1) Netherlands Quarterly of Human Rights 24

[151] CRPD art 8(b)

[152] CRPD art 8(a)

goes hand in hand with a static and essentializing view of the people's identity.'[153] In this, is contrasted republicanism's much more open view of society and the democracy embrace. In understanding these as systems that are improved when the inevitability of different groups having different stress points is accepted and even welcomed, republicanism finds value and, indeed, strength in paying conscious attention to conflict, as Machiavelli does. Thus, for people with disabilities the claim to be treated as equals, to be included in the political community, is prefaced on recognising that disability is an *imposed* thing, produced by particular social and economic relations and institutions. These relations and institutions, including austerity, exist because they are lucrative for the *few*. They exist because it is not *necessary* that they cease to exist. They exist because a popular misconception of *the disabled* [sic] permits the domination of people who are perceived as needing charity or rescuing or state subvention or watching or guarding or all the other litanies that justify hierarchical systems of power within the liberal hegemony. They exist because respect for difference and acceptance of disabled people remains more a prayer than a practice.

3.11 Equality of opportunity

As provided for in article 5(4) any specific measure necessary to accelerate the equality of persons with disabilities will not be discriminatory within the meaning of the Convention. This provision indicates that the CRPD framers recognise that such is the equality gap affecting disabled people that affirmative action by way of remedial function must have a place. Indeed, as referenced by the Committee on Civil and Political Rights (CCPR) 'the principle of equality sometimes require that State parties take affirmative action in order to diminish or eliminate conditions which cause or help to perpetuate discrimination.'[154] In essence, the rationale of this principle is in terms of creating conditions where an equalised starting position exists. However, while the principle provides for an enhanced opportunity to, say, live independently or achieve a good income it is not a guarantee of these outcomes. Rather, while the principle is compatible with good outcomes it is no less compatible with poor outcomes. Hence, within the CRPD, equality of opportunity's natural connection as a broad principle, then, is more to the inherent dignity of all human beings and respect for difference, these three principles to be taken together as a studied re-emphasis of the intrinsic worth of all persons with disabilities.

---

[153] Peter A Kraus, 'Popular Republicanism versus Populism: Articulating the People' (2021) 10 (10) Social Sciences 366, 372

[154] Committee on Civil and Political Rights General/ Human Rights Committee Comment No 18 non-discrimination at para 10

Equality of opportunity reminds, as phrased in the opening paragraph of the UDHR, that '[a]ll humans beings are born free and equal in dignity and rights.'[155] The principle is also read as a reminder and a re-emphasising of the Standard Rules assertion that

> the term equalisation of opportunities means the process through which the various systems of society and the environment, such as services, activities, information and documentation, are made available to all, particularly persons with disabilities.[156]

The Standard Rules continue:

> the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunities for participation.[157]

Understood in these terms, it becomes clear that the principle of equal opportunity has strong links with article 3(g) (equality between men and women) (discussed below), and to all the substantive rights in the Convention, including article 5 (equality and non-discrimination), article 12 (equal recognition before the law), article 13 (access to justice), article 14 (liberty and security of the person), article 17 (protecting the integrity of the person), article 19 (living independently and being included in the community), article 24 (education) and article 27 (work and employment) (these last three entitlements to be discussed in greater detail later). It is also of note that the CRPD Committee emphasises the clear connection between equality of opportunity and the principle of accessibility, to which this discussion soon turns.

3.12 A republican perspective (v)

Pettit separates contemporary republicanism from its pre-modern antecedents by reference to 'the inclusivist assumption that each is to count for one, none for more than one.'[158] In this, Pettit asserts that

> treating persons as equals does not necessarily involve equal treatment: it does not necessarily imply, for example, that each will get

---

[155] UDHR art 1

[156] UN General Assembly Resolution 48/96, *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, of 20 December 1993

[157] *ibid*

[158] Pettit (n 65) 110

> an equal share in whatever is taken as the good that the polity tries to provide.[159]

In this, it becomes plausible to claim that republicanism harmonises with the principle of equality of opportunity as contained in the CRPD, at least to the extent that what is covered are political – if not socio-economic – rights.[160] However, in circumstances of disability where systemic, long-standing asymmetries of power have disproportionally disadvantaged disabled people there are solid arguments for counting a disabled person as *more* than one. However, although Pettit does concede historical circumstances in which, say, it has been necessary to restrict the power and affluence of the rich to ensure equal freedom for all, he is unpersuaded about the notion that republicans might cast the polity's 'goal explicitly as equally-intense non-domination.'[161] Taking for his example children, Pettit contends that they 'and perhaps some other categories of people, are in a special position relative to the state and society.'[162] However, this special position does not take children – and, by analogy these *other categories of people* – outside the scope of enjoying non-domination. Rather, Pettit notes

> [p]arents and teachers would be allowed to exercise considerable interference in the lives of children…but the interference would be designed to track the children's interests *according to standard ideas*, and it would not constitute a form of domination.[163]

As to the deleterious effects of inequality, republican theorists – although perhaps in the main endorsing a (presumably compassionate) capitalism - recognise that too great disparities between rich and poor damage the social fabric and compromise the republican project.[164] Hence, Sunstein contends that since promoting non-domination takes precedence, states are permitted to over-ride the market if this is required.[165] Indeed, Sandel notes '[t]he explosion of inequality in recent decades …has enabled those on top to consolidate their advantage' not just in terms of wealth, but in respect of access to education, health care, housing, well paid employment and other necessary resources to live liveable lives.[166] The goal of liveable lives is

---

[159] *ibid* 111

[160] see, however, Philip Pettit, 'Freedom in the Market' (2006) 5 (2) Philosophy, Politics and Economics 131

[161] *ibid* 117

[162] *ibid* 119

[163] *ibid* 120 (emphasis added)

[164] not all republicans endorse capitalism. See, for instance Tom O'Shea, 'Socialist Republicanism' (2020) 48 (5) Political Theory 548

[165] Cass Sunstein *Free Markets and Social Justice* (Oxford University Press, 1997)

[166] Michael J Sandel *The Tyranny of Merit* (Allen Lane, 2020) 23

potentially compromised further by impairment, yet, '[a]s liberty is relocated from political to economic life'[167] of note too is the neoliberal assault on the (Western) welfare culture that largely underpins disabled people's ability to make their way successfully in a world not built for them.[168]

3.13 Accessibility

Accessibility, understood in its fullest meaning, goes to the very heart of turning the legitimate aspirations about rights contained in the CRPD into palpable enhancements in disabled people's lives. As such, the principle of accessibility stands as reminder that enjoyment of a right is primarily contingent on a person's ability to access it. As the Committee puts it:

> [a]ccessibility is a precondition for persons with disabilities to live independently and participate fully and equally in society. Without access to the physical environment, to transportation, to information and communication, including information and communications technologies and systems, and other facilities and services open or provided to the public, persons with disabilities would not have equal opportunities for participation in their respective societies.[169]

As a marker for this move from the rhetoric of 'rights talk' to the reality of resilient enjoyment, accessibility has long been an issue for disability rights activists. The Committee reminds that without this emphasis on achieving accessibility so many rights provisions predating the CRPD are without practical meaning for disabled persons. Hence, without access to the environment and without physically accessible public transport, freedom of movement - as enshrined in article 13 of the UDHR and in article 12 of the ICCPR - is moot. Similarly, freedom of opinion and expression, as found in article 19 of the UDHR and article 19(2) of the ICCPR, requires disabled people to have access to information and communication methodologies as a precondition to their ability to articulate their preferences across a range of social and political environments and activities. Contending that a denial of accessibility to the physical environment, transportation, information and communication technologies, and to facilities and services open

---

[167] Wendy Brown *Undoing the Demos* (Zone Books, 2017) 41

[168] see, for instance, Kayleigh Garthwaite, 'The language of shirkers and scroungers?' Talking about illness, disability and coalition welfare reform' (2011) 26 (3) Disability & Society 369; Sarah Parker Harris, Randall Owen, Robert Gould, 'Parity of participation in liberal welfare states: human rights, neoliberalism, disability and employment' (2012) 27 (6) Disability & Society 823

[169] CRPD Committee General Comment No 2 2014 Accessibility at para 1

to the public should be ‘viewed in the context of discrimination,’[170] the Committee further assert that by virtue of the ICCPR[171] and the ICERD[172] the right of access is already part of international human rights law.

Whether this latter point is true of accessibility in terms of the precise way in which the principle appears to be understood within the CRPD is unclear. Certainly, some scholars claim that here the CRPD again introduces something new into human rights treaty law, importing a reading of accessibility far broader than anything proceeding it,[173] including that provided for in the (non-legally binding) Standard Rules.[174] Instead, the CRPD approaches accessibility as having ‘multiple dimensions.’[175] Accessibility appears in the CRPD’s preamble,[176] as both a general principle[177] and a general obligation[178] and in a stand-alone article, article 9 (accessibility).[179] Further, several of the substantive rights in the CRPD reference accessibility obligations including article 19 (living independently and being included in the community),[180] article 21 (freedom of expression and opinion, and access to information),[181] article 27 (work and employment),[182] article 29 (participation in political and public life),[183] and article 30 (participation in cultural life, recreation, leisure and sport).

As a concept of varying levels of emphasis, accessibility appears in many other international law contexts, including in the *Climate Change Convention*, ICERD and CEDAW. For example, the ICCPR recognises the right of every citizen, as a general matter of equality, to access public services.[184] Nonetheless, to date, the concept receives its most extensive international law treatment in article 9 of the CRPD. The article commits states to take

---

[170] CRPD Committee General Comment No 2 2014 Accessibility at para 23

[171] ICCPR art 25(c) references a citizen’s right of access, on general equality terms, to public services

[172] ICERD art 5(c) and (f)

[173] Valentina Della Fina Article 3 [General Principles. In Valentina Della Fina Rachele Cera Giuseppe Palmisano (eds.) *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer, 2017) 119 - 136

[174] UN General Assembly Resolution 48/96, *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, of 20 December 1993, rule 5; rule 5 relates to access to the physical environment and to information and communications

[175] Valentina Della Fina Article 3 [General Principles. In Valentina Della Fina Rachele Cera Giuseppe Palmisano (eds.) *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer, 2017) at 130

[176] CRPD preamble at (v)

[177] CRPD art 3(f)

[178] CRPD art 4(1)(h)

[179] CRPD art 9 (accessibility)

[180] CRPD art 19(b)

[181] CRPD article 21(a), (b), (c), (d) and (e)

[182] CRPD article 27(1)

[183] CRPD article 29(a)(i), (ii), (iii)

[184] ICCPR article 25(c)

> appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.

The elaboration of these specific measures is quite detailed and reflects the wide range of access needs of different people at different points on the disability continuum. They include the developing and monitoring of minimum accessibility standards and guidelines, providing training on accessibility issues for stakeholders, promoting access to new information and communications technologies and systems, providing signage in Braille and in easy to read formats and providing live assistance such as guides, readers, and sign language interpreters. Crucially, article 9 requires states to ensure that the environment is accessible to all persons with disabilities in order to facilitate living independently and participating fully in all aspects of life – the environment here, in both an urban and rural context, including built structures but also transportation, information and communications.

However, despite 'being one of the most-debated provisions in the CRPD,' it remains unclear if the Convention intends to identify accessibility as a right or merely as a duty.[185] Clearly, in respect of the latter, Article 9 can be read as an overarching obligation imposing widespread responsibilities on states and private entities.[186] However, while not conclusive, neither within the body of the article or anywhere else in the Convention is any mention made of accessibility being a right *per se*. On this reading, it could be plausible to view accessibility as an important, cross-cutting, structural principle – a *precondition*, as the Committee has it[187] - rather than as a human right. On the other hand, it would appear frivolous to think that the numerous rights enunciated in an internationally binding Convention could have anything other than the most arbitrary of chances to contribute to human flourishing if accessibility is not afforded the superior – that is, justiciable - status of a right. Indeed, the Committee notes that a denial of accessibility 'should be viewed in the context of discrimination.'[188] But, there appears to be an

---

[185] Francesco Seatzu 'Article 9 [Accessibility]' in Valentina Della Fina Rachele Cera Giuseppe Palmisano (eds) *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer, 2017) 229

[186] Kayess and French (n 2) 1

[187] CRPD Committee General Comment No 6 2018 on equality and discrimination at para 40

[188] CRPD Committee General Comment No 2 2014 Accessibility at para 23

inherent problem in this though. Accessibility as provided for in article 9 appears to represent a socio-economic obligation, meaning that, if true, its realisation is traditionally deemed progressive rather than immediate.[189] However, tackling discrimination and promoting equality is an obligation of immediate realisation.[190] So, the question re-echoes: is denial of accessibility discrimination?

To assist in suggesting a plausible answer here it is useful to turn, briefly, to a concept closely aligned to – yet distinct from - accessibility, that of reasonable accommodation. The unjustified denial of reasonable accommodation is discriminatory.[191] But whereas reasonable accommodation always arises in respect of an individual claimant, accessibility relates to groups.[192] The Committee explains that this distinction means that accessibility is an *ex ante* duty on states to provide accessibility 'before individual request to enter or use a place or service.'[193] The state discharges this duty by setting and monitoring standards. However, reasonable accommodation is an *ex nunc* duty, meaning it comes into existence as soon as the individual requests it. Indeed, such an immediate duty can still arise even in circumstances where the state has met its accessibility duties, such as where a person's accommodation needs derive from a rare condition falling outside the scope of the standards already set. In this, it becomes evident that both the reasonable accommodation norm and the accessibility principle complement each other in promoting *de facto* equality and to guarantee equality of opportunity.[194]

3.14 A republican perspective (vi)

From the republican perspective, the cross-cutting nature of accessibility as a human rights principle is demonstrable across a range of spheres, many of them central to the republican project. Douzinas writes of how 'the structures of domination and oppression withhold social

---

[189] CRPD art 4(2); see, also, Broderick (n 105)

[190] see CRPD Committee General Comment No 6 2018 on equality and discrimination at para 12:'[p]romoting equality and tackling discrimination are cross-cutting obligations of immediate realization. They are not subject to progressive realization;' however, as to whether the distinction between civil and political and socio-economic and cultural rights still exists in the light of the CRPD see, for example, Frederic Megret The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights? 30 2 2008 Human Rights Quarterly 494 - 516

[191] CRPD article 2; see, also, CRPD Committee General Comment No 6 2018 on equality and discrimination at para 3

[192] CRPD Committee General Comment on Article 9 Accessibility 2014 at para 22

[193] CRPD Committee General Comment on Article 9 Accessibility 2014 at para 22; this point seems not dissimilar to the interpretation arrived at in the pre-Convention UK case of *Archibald v Fife* [2004] IRLR 651 as discussed at note 114

[194] Broderick (n 105) 393

recognition from what really matters to people.'[195]This reminds that having a right is as nothing to exercising that right, reminds too that absent a resilient means of resisting domination the disabled person is forever vulnerable to having her choice replaced, removed, misrepresented or ignored. So, from a republican view, perhaps the foremost institutional structures to which the accessibility principle speaks is the protection of a mixed constitution and access to a contestatory culture. Pettit understands it thus:

> These two elements must not only be present in order to trigger suitable responses, they must be present as a matter of common awareness: a matter manifest to all. [196]

These two elements map easily onto the so-called first-generation human rights, those that relate to individual entitlements to freedom and political participation and which protect against state interference. However, it seems clear that in the context of the CRPD accessibility links more directly to the second-generation phalanx of rights, those targeting issues of equality in the socio-economic domain. Does the republican perspective offer anything distinctive on these rights and, if so, how might this advantage people with disabilities? Certainly, in the longest portion of the long history of republicanism, a secure access to wealth, and, perhaps, specifically, property, is the defining reality of who could expect their citizenship to be protected.[197] However, contemporary republicans understand that *each* person's socio-economic wellbeing is crucial to the health of the polity, less there be 'the usurpation of government by income-heavy, concscience-light elites.'[198] To this end, Pettit explores questions of ensuring a basic income for all that is intuitively adequate, non-nullifiable and non-stigmatising.[199] Meanwhile, Casassas and De Wipelaere contend that republicanism supports not just the provision of the kind of economic floor a basic income represents, but also the necessity for a wide suite of interventionist policies to regulate private wealth in favour of both limiting elites' incentive and capacity for political interference and in the interests of promoting a more diffuse equality.[200] As to persons with disabilities, any mechanism which seeks to reduce the effects of social and

---

[195] Costas Douzinas *The End of Human Rights* (Hart Publishing, 2000) 324

[196] Pettit (n 122) 225

[197] for an interesting and wide-ranging development of Aristotle's prizing of agrarian democracy see Wendell John Coats JR Groundwork for a Theory of Republican Character in a Democratic Age. In Geoffrey C Kellow Neven Leddy (eds) *On Civic Republicanism: Ancient Lessons for Global Politics* (University of Toronto Press, 2016) 72 - 88

[198] Pettit (n 134) 192

[199] Philip Pettit, 'A Republican Right to Basic Income?' (2007) 2 (2) Basic Income Studies 1

[200] David Casassas Jurgen De Wispelaere Republicanism and the Political Economy of Democracy 19 2 2016 European Journal of Social Theory 283 - 300

economic marginalisation is worthy of consideration given that, in Ireland alone, the number of disabled people living in consistent poverty is almost four times greater than the population average.[201] More, people unable to work due to disability have a much higher risk of living in deprivation, with one in two disabled people living in this circumstance.[202] Also relevant here is the additional average annual costs associated with living with impairment, estimated in Ireland, at present, to range from between 8,700 euros and 12,300 euros.[203] Finally, there is the question of causation: living in poverty increases people's susceptibility to impairments such that a clear poverty-disability cycle exists.[204]

On its face, it can be held, in respect of the CRPD, that any discussion of the type briefly sketched here around basic income or any other financial supports to disabled persons belongs more properly alongside article 28 (adequate standard of living and social protection). This is true, or, at least true up to a point. However, absent a *principle* which directly targets the desperate reality that in many significant ways disability and poverty can be thought of as consubstantial concepts, it is contended here that attaching this discussion to the accessibility principle is appropriate. Indeed, this seems especially so if the principle is interpreted as a 'structural principle for living an independent life.'[205] In this context, it becomes evident that diminished income is an undoubted barrier to many, many disabled people's practical access to social inclusion, participation and non-domination. So, notwithstanding that the presented republican theorising of income is far more radical than that which any international Convention could perhaps plausibly adopt, it nonetheless serves to draw stark attention to the reality that poverty and disability exist in a multi-dimensional relationship the remedying of which is likely only amenable to radical solutions.

3.15 Equality between men and women

Recognised as a fundamental principle of international human rights law, equality between men and women is rooted in the United Nations purpose to achieve international co-operation in 'promoting and encouraging respect for human rights and for fundamental freedoms for all

---

[201] Central Statistics Office 2022 Survey on Income and Living Conditions (SILC) available at https://www.cso.ie/en/releasesandpublications/ep/p-silc/surveyonincomeandlivingconditionssilc2022/

[202] *ibid*

[203] Indecon International Research Economists *The Cost of Disability in Ireland* (Department of Social Protection, 2021)

[204] Rebecca Yeo *Chronic Poverty and Disability* (Chronic Poverty Research Centre, 2001) available at http://dx.doi.org/10.2139/ssrn.1754542

[205] Marianne Hirschberg, Christian Papadopoulos, ''Reasonable Accommodation' and 'Accessibility': Human Rights Instruments Relating to Inclusion and Exclusion in the Labour Market' (2016) 6 (1) Societies 3, 3

without distinction as to race, sex, language, or religion.'[206] This is further amplified in the UDHR's assertion that all the rights and freedoms set forth therein are available, 'without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.'[207] Moreover, equality between men and women is specifically provided for in both the 1966 Covenants and in the CEDAW.

The CESCR's General Comment number 16 helpfully offers a comprehensive treatment on equality between men and women indicating that '[g]uarantees of non-discrimination and equality in international human rights treaties mandate both de facto and de jure equality.'[208] Explaining that de facto (or formal) equality and de jure (or substantive) equality are different but interconnected concepts, the General Comment continues:

> [f]ormal equality assumes that equality is achieved if a law or policy treats men and women in a neutral manner. Substantive equality is concerned, in addition, with the effects of laws, policies and practices and with ensuring that they do not maintain, but rather alleviate, the particular disadvantages that particular groups experience.[209]

What is highlighted here is the cross-cutting nature of the equality obligation, indicating that it applies to all the rights found in the Bill of Rights. Indeed, on one level it might be argued that all that the CRPD does is explicitly phrase this human rights coverage – both as provided for within the Convention itself and in other UN instruments - as extending equally to men and women with disabilities. However, as the Committee on the Rights of Persons with Disabilities makes clear in its General Comment number 3, a particular invisibility afflicts women and girls with disabilities such that international and national laws and policies have historically neglected them while, simultaneously, laws and policies targeting women and girls have traditionally ignored questions of disability. The net effect of this invisibility is held to be the perpetuation of 'multiple and intersecting forms of discrimination against women and girls with disabilities.'[210] Given this, the equality principle must be read to also embrace positive, substantive measures

---

[206] United Nations Charter article 1(3)

[207] United Nations Declaration of Human Rights article 2

[208] Committee on Economic, Social and Cultural Rights General Comment 16 The Equal Right of Men and Women to the Enjoyment of All Economic, Social and Cultural Rights (article 3 of the Covenant) August 11 2005 E/C. 12/2005/4 at para 7

[209] *Ibid*

[210] Committee on the Convention on the Rights of Persons with Disabilities General Comment 3 Article 6 Women and Girls with Disabilities September 2 2016 C/GC/3 at para 3

necessary to ensure that women and girls with disabilities are protected against multiple and intersecting forms of discrimination.

3.16 A republican perspective (vii)

By definition, contemporary republicanism is profoundly concerned with the quality of male/female equality, contrasting sharply with the manifest disinterest pre-contemporary iterations showed towards women.[211] Of profound importance in remedying this republican defect is the eighteen century's Mary Wollstonecraft. Concerned with 'the tricks of the mind that make the unnatural appear natural'[212] Wollstonecraft understands well, like Gramsci, how the oppressed can be manipulated to oppress themselves and believe listlessly that things are always as they appear.

Stepping away from this antipathy, within the Western consciousness Wollstonecraft's *Vindication of the Rights of Women* offers an early manifesto for women's emancipation, arguing for coequal rights for women, coeducation,[213] women's entitlement to professional activity and an end to a passive, decorative femininity.[214] For Wollstonecraft, the political and civil position of eighteen century Western women ensures their material dependence but also serves to undermine men's independence, contending that because freedom from domination is always relational, securing it for women better secures it for men too.[215]

Today, that being a woman living with impairment is sometimes theorised as a double disability,[216] highlights anew how, even among a marginalised group such as disabled people, women are subject to additional sociocultural stressors – or what the CRPD terms 'multiple discrimination.'[217]

---

[211] see, for instance, Lena Halldenius *Mary Wollstonecraft and Feminist Republicanism* (Routledge, 2015); Anne Philips Feminism and Republicanism: Is this a Plausible Alliance?" 8 2 2015 The Journal of Political Philosophy 279–93

[212] Virginia Sapiro *A Vindication of Political Virtue: The Political Theory of Mary Wollstonecraft* (The University of Chicago Press, 1992) at 108

[213] it is important to note that Wollstonecraft does not use the (yet to arrive) word 'coeducation' and, in fact, transcends its limited modern meaning. As Laird has it: 'her creative conception of coeducation is not merely a system of public schooling, but a multi-institutional cultural configuration… 'calculated to strengthen the body and form the heart.'' Susan Laird *Mary Wollstonecraft* (Bloomsbury, 2008) at 110

[214] Mary Wollstonecraft *A Vindication of the Rights of Women* (first published 1792, Penguin, 2004); as to Wollstonecraft's republican credentials see Lena Halldenius *Mary Wollstonecraft and Feminist Republicanism: Independence, Rights and the Experience of Unfreedom* (Routledge, 2015)

[215] see, for instance, Lena Halldenius Mary Wollstonecraft and Freedom as Independence. In Jacqueline Broad Karen Detlefsen (eds.) *Women and Liberty 1600 – 1800: Philosophical Essays* (Oxford University Press, 2017) 95 - 108

[216] Kharnita Mohamed, Tamara Shefer, **'**Gendering disability and disabling gender: Critical reflections on intersections of gender and disability' (2015) 29 (2) Agenda: Empowering Women for Gender Equality 2; Lina Abu Habib, 'Women and disability don't mix!': Double discrimination and disability women's rights' (1995) 3 (2) Gender and Development 49

[217] CRPD art 6(1); in addition, General Comment No 6 refers to intersectional discrimination defining the difference thus: '"Multiple discrimination" according to the Committee is a situation where a person can

Hence, for example, Soorenian captures an important aspect when she theorises how disabled women experience hegemonic norms of physical beauty as

> negative and discriminatory social reactions both at an interpersonal level and when confronted with layers of degrading images of themselves in the media and other cultural discourses.[218]

Employment opportunities and other opportunities to be meaningfully present in the community are additionally compromised by a highly gendered approach, not least in circumstances where disabled women are expected to 'synchronise the complex temporalities that emerge with their caregiving responsibilities, often being both recipients of disability care and as caregivers of others.' [219] As to how contemporary republicanism might help here Pettit, – in a rare invocation of disabled people – acknowledges that, traditionally, advantage has accrued to men over women and 'to the abled-bodied or able-minded over the disabled.'[220] As to how these less powerful disabled women might be empowered, it falls first to accepting, as Habermas does, that existing institutions must be understood as intrinsically male in their design and teleological intention. [221] This 'systematic and unreciprocated transfer of power from women to men' creates dependencies even as women's energies are appropriated and absorbed by men whose comfort and status is advanced as a result. [222] These dynamics inevitably produce stereotypes around masculinity and femininity that ascribe *approved* ways of doing gender. In turn, these kinds of gendered readings of disabled women result in further indignities and brutalities, for instance linking notions of intense passivity and helplessness to potential for abuse and violence. Indeed disabled women are reported as two to three times more likely to be victims of sexual or physical violence.[223] Drawing data from what is called the developing

---

experience discrimination on two or several grounds, in the sense that discrimination is compounded or aggravated. Intersectional discrimination refers to a situation where several grounds operate and interact with each other at the same time in such a way that they are inseparable and thereby expose relevant individuals to unique types of disadvantage and discrimination.' CRPD Comment No 6 26 April 2018 UN Doc CRPD/C/GC/6 at para 19

[218] Armineh Soorenian Media, 'Disability and Human Rights' Michael Gill M, Schlund-Vials, CJ, (eds) *Disability, Human Rights and the Limits of Humanitarianism* (Routledge, 2016) 47

[219] Karen Soldatic *Disability and Neoliberal Formations* (Routledge, 2019) 131

[220] Jose Luis Marti, Philip Pettit *A Political Philosophy in Public Life* (Princeton University Press, 2010) 79

[221] Michel Rosenfeld Andrew Arato (eds) *Habermas on Law and Democracy: Critical Exchanges* (University of California Press, 1998)

[222] Iris Marion Young *Justice and the Politics of Difference* (Princeton University Press, 1990) 50

[223] see, for instance, Carolyn Frohmader, Helen Meekosha, Recognition, Respect and Rights: Women with Disabilities in a Globalised World. In Dan Goodley Bill Hughes Lennard Davis (eds) *Disability and Social Theory* (Palgrave Macmillan, 2012) 287 - 307

world, Keogh describes gender as a risk factor in becoming disabled, including from injury during labour and from complications arising from pregnancy.[224]

At its most fundamental, republicanism is not a formula against *any* form of rule but rather against arbitrary rule, the rule of a *dominus*. In this, law is not inimical to freedom – as it may well be perceived in respect of a non-interference reading of liberty – but, rather, central to the entire republican project. Hence, the importance of laws which vindicate and forcefully stand by equality, in this instance the equality of disabled women. But, can law ever address every instance of domination? What of the type of insidious domination Soorenian points to? Indeed, one scholar quotes Frank Isaac Michelman's reminder that 'much of the country's normatively consequential dialogue occurs outside the major, formal channels of electoral and legislative politics.'[225] However, laws to one side, for Pettit domination is also calibrated to the social and, indeed, he sometimes draws on vignettes from heterosexual marital life to demonstrate the intersubjective nature of domination.[226] From one feminist viewpoint, republicanism is attractive for several reasons. First, its dialogic structure opens more avenues for public justice, even as a function of publicity – something disabled women may particularly lack and which may be of benefit in relation to the adverse ways disabled womanhood is portrayed in the media and on-line. Second, there is its capacity to challenge the public tyrant and the private one using the same straightforward identikit to diagnose the evils of dependency, a particular concern in terms of the multiple discriminations visited on disabled women. Third, there is republicanism's vision of politics as something far larger than a looking after the self, again something of intuitive value to disabled women. [227]

3.17 Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

This principle directly maps language derived from articles 5 and 14 of the *Convention on the Rights of the Child* (CRC) onto the CRPD. Thus, the phrase 'evolving capacities of children' is read to indicate a balancing between children with disabilities and their care-givers, such that a disabled child's entitlement to be consulted, listened to and afforded increasing autonomy in exercising her rights cannot be taken away simply because she does not have strict legal

---

[224] Mary Keogh Disability, Gender and Development. In Charles O'Mahony Gerard Quinn *Disability Law and Politics: An Analysis of the UN Convention* (Clarus Press, 2017) 45 - 54

[225] Galya Benarieh Ruffer Legal Modes and Democratic Citizens in Republican Theory. In Andreas Niedberger Philip Schink (eds.) *Republican Democracy: Liberty, Law and Politics* (Edinburgh University Press, 2015) at 244

[226] see, for instance, Pettit (n 134)

[227] Anne Philips, 'Feminism and Republicanism: Is This a Plausible Alliance?' (2000) 8 (2) Journal of Political Philosophy 279

capacity. Such capacity is understood not just as a function of ageing but also as being closely connected to experiences, education, culture and levels of adult support and expectations.[228] Representing an important underscoring of the development rights of children as found in the CRC, this principle clarifies that *all* children need environments in which their capacities can evolve optimally, working in tandem with the CRPD's preamble recognition that disabled children 'should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children.'[229] The principle is amplified in article 7 which is dedicated to children with disabilities and which requires states to take all necessary measures to ensure the full enjoyment by disabled children of all human rights and to take into account 'the best interests of the child' as 'a primary consideration.'[230] Further, girls with disabilities are specifically mentioned in article 6 (women with disabilities) as subject to 'multiple discrimination.'[231] Access for girls with disabilities to social protection and to poverty reduction programmes are also specifically provided for in article 28 (adequate standard of living and social protection).

Children are specifically also referenced in several other provisions within the Convention. Article 4 (general obligations) describes children's right to be consulted 'through their representative organisations' in respect of the development and implementation of legislation and policies associated with the CRPD and in other decision making processes concerning issues relevant to disabled persons.[232] Article 16 (freedom from exploitation, violence and abuse) references the need for gender and age-sensitive assistance to help avoid, recognise and report exploitation, violence and abuse[233] and, also, the need for specifically child-focused legislation and policy in this area.[234] Children's registration rights immediately after birth, the right to a name, to acquire a nationality and, ideally, to know and be cared for by their parents are set out in article 18 (liberty of movement and nationality).[235] Children's equal rights in respect of family life are set out in article 23 (respect for home and family);[236] to inclusive education in article 24 (education); to health services in article 25 (health) and to play, recreation, leisure and sporting activities in article 30 (participation in cultural life, recreation, leisure and sport), including in the school system.

---

[228] see, for example, Gerison Lansdown *The Evolving Capacities of the Child* (UNICEF, 2005)
[229] CRPD preamble at (r)
[230] CRPD art 7(2)
[231] CRPD art 6(1)
[232] CRPD art 4(3)
[233] CRPD art 16(2)
[234] CRPD art 16(5)
[235] CRPD art 18(2)
[236] CRPD art 23(3), 23(4) and 23(5)

3.18 A republican perspective (viii)

Focusing on the evolving capacities of children in the way in which it is suggested the Convention intends, connects to a strong republican theme, namely, that of the common (or public) good. Within the broad contemporary republican family, different scholars emphasise different mechanisms by which the common life is to be operationalised, including some whose ideas are resonant of Aristotle's vision of the polis, the active citizen and his pursuit of the good life, this latter understood as a particular way of living that equates individual human flourishing with exercising civic virtue.[237] Hence, for instance, Sandel holds sharing in self-government and the sacrificing of individual interests to be of intrinsic importance.[238] In contrast, Pettit views the common good in a more diffuse way, indicating that a

> good will be common to the extent that it cannot be increased (or decreased) for any member of the relevant group without at the same time being increased (or decreased) for other members of the group: it has the sort of non-excludability that economists ascribe to goods like clean air and external defence.[239]

Positing freedom as non-domination as a common good – one that can only come about by design – Pettit writes of vulnerability classes (he gives examples of immigrant workers, black youths and people who are old and frail) contending that 'achieving the best in the way of non – domination' means 'eliminating the domination of all members of the class.'[240] In Pettit's formulation, as non-domination increases 'factors like caste, colour and culture, should decline in political significance: in significance as markers of vulnerability to interference.'[241] Although Pettit does not make specific reference to disabled people as constituting a vulnerability class, it is reasonable to postulate they would come within this thinking's ambit. This being so, it is also reasonable that children with disabilities would be seen as either a subset of such a group or, perhaps, a vulnerability class in their own right. Pettit talks of 'a single solidaristic cause, not just a sum of individual causes.'[242] Suggesting that people in vulnerability classes are oppressed,

---

[237] Iseult *Honohan Civic Republicanism* (Routledge, 2002)

[238] Michael Sandel 'A Reply to My Critics' In Anita L Allen Milton C Regan *Debating Democracy's Discontent: Essays on American Politics, Law, and Public Philosophy* (Oxford University Press, 1998) 319

[239] Pettit (n 65) 121

[240] *ibid* 123

[241] *ibid* 125

[242] *ibid* 124

Pettit theorises that the politics around domination cannot, by definition, be atomistic. Rather, achieving non-domination is an egalitarian goal such that 'the cause of freedom as non-domination will always have the dimension of a social and common cause for the people involved in pursuing it.'[243]

This is a radical endorsement of pluralism and of republicanism's capacity to shape a public sphere premised on – indeed, driven by – a commitment to ever greater inclusion. Indeed, Maynor draws on Machiavelli when talking of harnessing 'the dynamic energy created by difference and diversity.'[244] Within such a pluralism, the common good becomes something deliberated on and disputed over but which is navigable via a shared commitment to non-domination, utilising principles and institutions that, *inter alia*, ensure the interests of all, including vulnerability classes, are tracked. The net effect here becomes a plurality of free individuals fulfilling their life plans according to their individual will, bounded by a republican freedom.

However, even within a radical pluralism the interests of children and, perhaps, especially disabled children, can still easily be overlooked. This is why the Convention's recognition of disabled children as increasingly competent actors – allied to an implicit expectation that children's evolving capacities are nurtured - is useful to better factoring disabled people into republicanism's own evolution. The republican ethic recognises the need to socialise citizens into articulating and effectively representing their interests while, unlike liberalism, *not* 'bracket[ing] off their comprehensive identities.'[245] In a republican polity, the learning involved in doing this efficiently and appropriately – constructing a common good while retaining and, indeed, celebrating individuality – should be a feature of every childhood. Hence, for instance, civic education becomes a matter of cultivating and habituating the practices of republican freedom.[246] In turn, this draws attention to the crucial importance of 'the structure, methods and content of formal education.'[247]

For children with disabilities this formal education must mean ensuring careful, nuanced messaging to children about ableism, and otherwise combating its corrosive way of othering disability. It means promoting positive, affirming imaging of disability, celebrating disability rather than disparaging it. It means teaching appropriate means of contributing to different

---

[243] *ibid* 125

[244] Maynor (n 123) 133

[245] *ibid* 135

[246] Andrew Peterson *Civic Republicanism and Civic Education* (Palgrave MacMillan, 2011)

[247] Iseult Honohan Educating citizens: nation-building and its republican limits. In Iseult Honohan Jeremy Jennings (eds) *Republicanism in Theory and Practice* (Routledge, 2006) 199

forms of public debate and finding ways of making contestation the expected norm, perhaps, for example, in terms of promoting active student councils and ensuring representative membership of disabled children. It means addressing those taken-for-granted constraints that routinely consign children *qua* children to a socially constructed space separate to the adult world, defined more in terms of what childhood is *not* rather than what it is,[248] a problem exacerbated still more by the presence of impairment.[249] Above all, it means recognising that at least some of the power of adults in children's lives, disabled or no, are axiomatically dominating (tracking only adult interests) and that a republican theory of child rearing is not only possible but perhaps necessary to the working out of what a robust republican pluralist polity requires.[250]

In this context, there is a synergy to be found in positing a republican reading of 'the best interests' principle as found in article 7(2) of the CRPD and the need to ensure that in helping to decide what this may be in the case of the individual disabled child that paternalism is avoided.[251] Paternalism is, of course, inherently dominating since its effect is to subject another to a powerful other's judgement or will. There is clear scope too for a republican engagement with article 7(3) which requires states to take positive measures to ensure that disabled children can express their views freely on matters concerning them. A clear improvement on article 12(1) of the CRC which limits the same entitlement to children 'capable of forming' their view, the CRPD here not only describes a more comprehensive right for *all* children but it also maps directly onto the republic concern with the common good. This means here, surely, that disabled children will be invited and supported to make their views known on matters concerning them in ways that validate their dignity and contribute to them internalising the habit of not simply expecting but *requiring* to be consulted throughout their lives.

---

[248] see, for example, Philippe Aries *Centuries of Childhood: A Social History of Family Life* (Pimlico, 1996) Allison James Chris Jenks Alan Prout *Theorising Childhood* (Polity Press, 1998) David Archard *Children, Rights and Childhood* (Routledge, 2014)

[249] See, for instance, Miriam Twomey Clare Carroll (eds) *Seen and Heard: Exploring Participation, Engagement and Voice for Children with Disabilities* (Peter Lang, 2018)

[250] on what a republican child-rearing theory might demand see Anca Gheaus, 'Child-rearing With Minimal Domination: A Republican Account' (2021) 69 (3) Political Studies 748

[251] see Andrea Broderick Article 7 UN CRPD: Children with Disabilities. In Valentina Della Fina Rachele Cere Guiseppe Palmisano (eds) The United Nations Convention on the Rightts of Persons with Disabilities: A Commentary (Springer, 2017) 195 - 212

4 Article 24: the challenge of education inclusion

4.1 Introduction

Theorising inclusion as a transformational project encompassing institutions and communities and focused on increasing society's capacity to accommodate diversity,[252] this section offers a contextualized, socio-legal reading of the CRPD's article 24 (education). Within this reading education is presented as 'a pre-requisite to the exercise of many other rights,'[253] an idea which represents education as a social good which functions as a multiplier in terms of the other goods it can give rise to.[254] The argument being proposed in this chapter is prefaced on the claim that the work of education – of which schools are but one part, however prominent – is to recognise and support the innate learning capacity of every human and that this means embracing equality as the fundamental ethic around which successful, progressive education coheres. The argument itself is that by engaging with the dynamic of an expressly human rights perspective on education, specifically one grounded in article 24, the Irish education project – and, indeed, society itself – can be re-imagined and beneficially transformed. However, absent engagement with this perspective, phrased here as an inclusion imperative, education is theorised as a mechanism of exclusion.[255] This latter potential is discussed in this chapter as perhaps particularly oppressive in the lives of disabled persons. In a specifically Irish context the continued existence of special schools,[256] a dearth of creative policy and legal frameworks to effectively underpin educational inclusion and, indeed, a perceived imprecision about what inclusion means in practice might all be said to work systemically to impede the effective implementation of article 24.

---

[252] Anne-Lise Arnesen, Pavlina Hadzhitheodoulou-Loizidou, Cézar Bîrzéa, Miquel Angel Essomba, Julie Allan *Policies and practices for teaching sociocultural diversity* (Council of Europe, 2009)

[253] Charles O'Mahony Education Rights in Irish Law (Thomson Roundhall, 2006) 18. This point is also made by the OHCHR in describing the key role played 'in the full and effective realization of other rights' by realizing the right to education; see OHCHR (2013) para 9

[254] see, for example, Amartya Sen *Development as Freedom* (Oxford University Press, 1999) who contends, *inter alia*, that the enhanced education of mothers reduces child mortality rates

[255] Paulo Freire *Pedagogy of the Oppressed* (Penguin, 1993)

[256] Camille Latimier Jan Šiška *Children's rights for all! Implementation of the United Nations Convention on the Rights of the Child for Children with Intellectual Disabilities* (Inclusion Europe, 2011)

4.2 The Irish legislative, policy and constitutional context

4.3 The Education Act

In terms of policy and legislative initiatives, if not rhetoric, Ireland has been described as 'a latecomer to inclusion.'[257] Although a 'certain minimum education' is provided for in the Irish Constitution[258] - with free primary education specifically guaranteed[259] - a commitment to providing free second-level education only came in 1967,[260] and a statutory framework for education was only established for the first time in the *Education Act 1998*.[261] However, with specific reference to the entitlements of persons with disabilities, charitable responses remained the dominant trope right through Ireland's 20th Century, with, for instance, a 1984 government Green Paper opining that '[t]he most important thing which any disadvantaged minority needs is good-will and understanding.'[262] Hence, the importance of the 1998 Education Act in its signalling of an inclusion perspective by ensuring that every reference concerning people availing of education is followed by the phrase 'including [those] who have a disability or other special education needs.'[263] In itself, this phrase, uttered legislatively on the cusp of a new century, represents a significant development in Irish educational entitlement.

Although relying on an entirely medical model descriptor of disability,[264] the *Education Act 1998* guarantees to each person in the state 'support services and a level and quality of education appropriate to meeting the needs and abilities of that person.'[265] Although this legislation does

---

[257] Brian McGilla Phadraig Towards inclusion: the development of provision for children with special education needs in Ireland from 1991 to 2004 26 3 (2007) Irish Educational Studies at 289

[258] Bunreacht na hEireann (1937) Art 42.3.2

[259] ibid, Article 42.4; see also its interpretation in *Crowley v Ireland* [1980] IR 102 (SC); *O'Donoghue v Minister for Health* [1996] 2 IR 20 (HC); *O'Shiel v Minister for Education* [1999] 2 ILRM 241 (HC); and *Sinnott v Minister for Education* [2001] 2 IR 545 (SC).

[260] Bunreacht na hEireann (1937) Article 42.4

[261] Education Act 1998, as amended by Education (Admission to Schools) Act 2018

[262] Green Paper on Services for Disabled People (1984) at 112

[263] Education Act 1998; per S 2 of the Act the phrase 'special education needs' is strictly construed and 'means the educational needs of students who have a disability and the educational needs of exceptionally able students'

[264] Education Act 1998 S. 2(1) defines disability thus: '(a) the total or partial loss of a person's bodily or mental functions, including the loss of a part of the person's body, or (b) the presence in the body of organisms causing, or likely to cause, chronic disease or illness, or (c) the malfunction, malformation or disfigurement of a part of a person's body, or (d) a condition or malfunction which results in a person learning differently from a person without the condition or malfunction, or (e) a condition, illness or disease which affects a person's thought processes, perception of reality, emotions or judgement or which results in disturbed behaviour.' This medical model approach to defining disability is also used in the two pieces of legislation which provide for Ireland's non-discrimination framework, the *Employment Equality Act 1998* and the *Equal Status Act 2000*

[265] Education Act 1998 S 7 (1) (a)

not provide specifically for an entitlement to inclusive education for persons with disabilities,[266] and remembering that in the main it focuses on schools as such,[267] there is a commitment that the education needs of disabled people are identified and provided for,[268] that school inspectors will assess the implementation and effectiveness of any programme of education devised for persons with disabilities and special education needs[269] and that school boards of management shall use resources to make reasonable accommodation and provision for such persons.[270] The Act also established the National Council for Curriculum and Assessment (NCCA), its designated role, *inter alia*, being to advise the Minister of Education 'on the requirements, as regards curriculum and syllabuses, of students with a disability or other special educational need.'[271] Given a 1993 government review[272] which recommended that children with special education needs be integrated into mainstream schools, the net effect of these provisions is to raise an, albeit cautious, inference that mainstream schools are envisaged as the preferred environments in which pupils of all abilities and characteristics are to be educated.[273]

4.4 Education for Persons with Special Education Needs Act

A less taciturn – but by no means decisive - assertion of this, however, had to await the *Education for Persons with Special Education Needs Act 2004* (EPSEN). EPSEN alters the definition of

---

[266] indeed, the words inclusion and inclusive do not appear in the Act

[267] The 1998 Act provides generally for primary, post primary, adult and continuing education and vocational education and training; however, the great bulk of the Act is directed at the functioning of, and other matters pertaining to, primary and post primary schools, such establishments being defined in S 2 as those which '(a) provides primary education to its students and which may also provide early childhood education or (b) provides post-primary education to its students and which may also provide courses in adult, continuing or vocational education or vocational training'. S 2 excludes from this definition 'a school or institution established in accordance with the Children Acts, 1908 to 1989, or a school or institution established or maintained by a health board in accordance with the Health Acts, 1947 to 1996, or the Child Care Act, 1991'

[268] Education Act 1998 S 9 (a)

[269] Education Act 1998 S 13(3)(III)

[270] Education Act 1998 S 15(2)(g)

[271] Education Act 1998 S 41(2)(f)

[272] Special Education Review Committee (SERC) 1993 Department of Education and Science (DES); in particular, the committee had been asked to look at the processes for determining special education need and the appropriate level of mainstream educational provision to be made for children with special educational need as well as suggesting appropriate in-school support systems and those supporting linkages which would be necessary to develop between DES and other government departments

[273] the number of children in Ireland coming within this designation has increased considerably over the last two decades and is now believed to represent a quarter of the school-going population: see Selina McCoy, Michael Shevlin, Richard Rose, 'Secondary School Transition for Students with Special Educational Needs in Ireland' (2019) 35 (2) European Journal of Special Needs Education 154; focusing solely on disability prevalence the figure has been estimated at between 14 – 18% of the overall SEN estimate, see National Council for Special Education (NCSE) *Implementation report: Plan for the phased implementation of the EPSEN Act 2004* (NCSE, 2006)

disability contained in the 1998 Act[274] and imposes very specific responsibilities on school principals and teachers in respect of meeting the needs of children with disabilities, 'enunciat[ing] more rights than were evident prior to its enactment.'[275] The Act defines special educational needs as meaning, in relation to a person:

> a restriction in the capacity of the person to participate in and benefit from education on account of an enduring physical, sensory, mental health or learning disability, or any other condition which results in a person learning differently from a person without that condition[276]

Asserting that children with special education needs have the same entitlement to education as those children without these needs, the Act holds that a child with special educational needs:

> shall be educated in an inclusive environment with children who do not have such needs unless the nature or degree of those needs of the child is such that to do so would be inconsistent with— (a) the best interests of the child as determined in accordance with any assessment carried out under this Act, or (b) the effective provision of education for children with whom the child is to be educated.'[277]

EPSEN requires that school principals respond to an indication that a child has special education needs by arranging that an assessment be carried out, commencing not less than one month after this indication arises and concluding not less than three months from its commencement.[278] Such an assessment is to be carried out in line with such guidance as may be issued by the National Council for Special Education (NCSE), a statutory body established under the Act.[279] Where such an assessment confirms the presence of special education needs, and their nature and extent, the Act requires that an education plan then be produced for the

---

[274] Education for Persons with Special Education Needs Act 2004 S 52 amends S 2(1) of the *Education Act 1998* and substitutes the following: ''disability' means, in relation to a person, a restriction in the capacity of the person to participate in and benefit from education on account of an enduring physical, sensory, mental health or learning disability, or any other condition which results in a person learning differently from a person without that condition and cognate words shall be construed accordingly.''

[275] Mary Shine Thompson, Ann-Katrin, Lena Svaerd, 'Unintended consequences of special-needs law in Ireland and Sweden' (2019) 48 (2) Kybernetes 333, 337

[276] *Education for Persons with Special Education Needs Act 2004* S 1; it is submitted that this definition is flawed in that not all learning difficulties are prefaced on the presence of an impairment and nor are all impairments going to result in learning difficulties

[277] *ibid* S 2

[278] *ibid* S 3

[279] *ibid* S 19. S 20 sets out the functions of the Council

child not more than one month after this confirmation.[280] The Act also requires that this plan, reviewable annually, be produced in consultation with, and subsequently furnished to, parents and to the school's area special education needs organiser (SENO),[281] this person being an employee of the NCSE and whose functions are set out under the Act.[282] EPSEN also sets out the responsibilities of school boards of management[283] - inclusive of the responsibility to inculcate a school-wide awareness of the needs of those with special education needs – and of the Health Service Executive (HSE), specifically in relation to providing schools with appropriate support services. [284] The Act also provides for an appeals and mediation function, this envisioned to provide an alternative disputes resolution mechanism rather than recourse to the courts.

However, while EPSEN represents a significant and positive policy intervention for the lives of children with disabilities and their families it is important to note that large portions of it remain un-commenced.[285] Important individual rights such as a statutory entitlement to an assessment, to an education plan and its annual review, to planning for future educational need and to the provision of an appeals and mediation mechanism are not, at present, operative, nor does the duty on the part of boards of management to build a school community's awareness of and responsiveness to the special education needs of children with disabilities.[286] An EPSEN implementation strategy was produced in 2006.[287] Moreover, the necessity for children with disabilities to be provided with individualised education plans has been emphasised by the CRPD Committee.[288] However, current thinking, as articulated on behalf of Government in the Dáil in

---

[280] *ibid* S 3, subsections 5 and 9

[281] *ibid* S 3, subsection 9

[282] *ibid* S 26. At present NESC employs some 80 SENOs

[283] *ibid* S 14

[284] *ibid* S 16

[285] these un-commenced sections cover, as follows: S.3 Preparation of education plan by the school (including steps preliminary to such preparation); S.4 Assessment of child by or on behalf of Health Board or Council; S.5 Mode of assessment under section 3 or 4; S. 6 Appeals in relation to assessment; S 7 Provision of services; S 8 Preparation of education plan at direction of Council; S 9 Content of education plan; S 10 Designation of school; S 11 Review of education plan; S 12 Appeals in relation to education plans; S 13 Duty of Minister and Minister for Health and Children to make resources available; S 14(1) (*d*)[the responsibilities of boards of management to] ensure that all relevant teachers and other relevant employees of the school are aware of the special educational needs of students; (*e*) ensure that teachers and other relevant employees of the school are aware of the importance of identifying children and students who have special education needs, and (*f*) inculcate in students of the school an awareness of the needs of persons with disabilities; S 15 Planning for future education needs; S 16 Implementation of relevant policies by health boards; S 17 Liaison officers; S 18 Delegation of functions of principals etc; S 38 Provision of mediation in certain cases; S 39 Duty of health boards

[286] arguably, were such a duty commenced it would be a close fit with the requirements of CRPD article 8 (awareness raising)

[287] National Council for Special Education (2006) Implementation Report: Plan for the Phased Implementation of the EPSEN Act 2004

[288] CRPD Committee General Comment no 4 at para 32

2018 appears to be that, as presently constituted, the un-commenced portions of the EPSEN Act may not be implemented on either a phased or age-cohort basis. [289]Rather, schools are encouraged to voluntarily comply with the spirit of the Act – specifically, in terms of implementing individual education plans – through a non-statutory mechanism comprising of Department of Education Circulars and NCSE guidance documents. Where this voluntary compliance is unforthcoming and if the NCSE advises the Minister for Education that insufficient provision exists in a given area for the education of children with special needs powers exist under the *Education (Admission to Schools) Act 2018* whereby *a* school can be compelled to make such provision available.[290] However, the process through which this power might be used can be justly described as cumbersome.

4.5 National disability strategies and the special school

EPSEN is described as forming an integral part of the Irish Government's 2004 *National Disability Strategy*[291] which, itself, can be traced back to *A Strategy for Equality*, a report by the Commission on the Status of Persons with Disabilities.[292] The Commission, established by Government in 1993, adopts an explicit social model approach to disability and recommends, *inter alia*, a constitutional amendment to Article 42 to guarantee the right to education for people with disabilities, equality within education and access to all levels of education.[293] Asserting that rates of participation and success in education are, of themselves, measures of how advanced a society is in terms of actualising equality and recognising the direct correlation between a comprehensive access to education and disabled persons' later life opportunities, the report, however, stops well short of exhorting the State to re-consider the existence of segregated schooling. Rather, acknowledging the existence of two separate education systems

---

[289] Dail Eireann 16 January 2018 written answer to Louise O'Reilly TD from Minister for Education and Skills

[290] Education (Admission to Schools) Act 2018 S 8

[291] Comprising, legislatively, the Equal Status Acts 2000-2011, EPSEN and the Disability Act 2005, the Strategy also involves a statutory requirement that sectoral plans be produced by government departments covering employment, environment and housing, health and disability services, social welfare, transport and communications and a commitment to a multi-annual disability investment programme

[292] Commission on the Status of People with Disabilities *A Strategy for Equality. Report of the Commission on the Status of People with Disabilities* (1996)

[293] it was only in 1983 that an official report acknowledged that children described as 'severely and profoundly' learning disabled were educable; see Minister for Education and Minister for Health and Social Welfare *The Education and Training of Severely and Profoundly Mentally Handicapped Children in Ireland: Report of a Working Party to the Minister for Education and the Minister for Health and Social Welfare* (Stationery Office, 1983); moreover, it was only in 1996 that Hanlon J found that the article 42.4 duty to provide free primary education to all children extended to children identified as having severe and profound learning difficulties; see *O'Donoghue v Minister for Health* [1996] 2 IR 20

– the special school system and the mainstream system – the Commission argues instead for an inclusive Education Act which 'should enshrine and stimulate further progress towards inclusion while increasing support for special schools…. [and] facilitate co-ordination between mainstream and specialist schools.'[294] Despite adapting this dualist approach, the Commission does, nonetheless, contend that students with disabilities should be 'offered an appropriate education in the environment of their choice,'[295] that '[l]egislation must create a strong presumption that students will be placed in the least restrictive environment'[296] and, further, that 'appropriate education for all children with disabilities should be provided in mainstream schools.'[297] However, utilising language subsequently mirrored in the 1998 Act, the Commission also provides that this latter aspiration be subject to the caveat that integration shouldn't happen 'where it is clear that the child involved will not benefit through being placed in a mainstream environment, or that other children would be unduly and unfairly disadvantaged.'[298] Thus, it can be argued that this suggests that the educational equality being aspired to is purely formal rather than substantive. Indeed, the *Equal Status Act 2000* permits that no discrimination occurs in circumstances where 'compliance with any of its provisions in relation to a student with a disability would, by virtue of the disability, make impossible, or have a seriously detrimental effect on, the provision by an educational establishment of its services to other students.' [299]

The current *National Disability Inclusion Strategy 2017 - 2021*[300] identifies education as one of its key themes.[301] However, notwithstanding identifying itself as the operational means to 'advance the aims and principles of the CRPD'[302] the Strategy does not address inclusive education as an operational imperative, let alone as a human right. Nor, indeed, does it reference special schools. This (in)convenient silence contrasts with other European jurisdictions, most notably Italy where all special school provision ceased in 1977.[303] However,

---

[294] *A Strategy for Equality. Report of the Commission on the Status of People with Disabilities* (1996) at 42
[295] *ibid*
[296] *Ibid* at 43
[297] *ibid* at 41
[298] *ibid* at 41
[299] s 7(4)(b) the *Equal Status Act 2000*; see also s 4(4)
[300] Minister of State for Disabilities *National Disability Inclusion Strategy 2017 - 2021*
[301] there are eight such themes: education, employment, health and well-being, person-centred disability services, housing, transport and accessible places, equality and choice and joined-up services.
[302] Minister of State for Disabilities *National Disability Inclusion Strategy 2017 – 2021* at 6
[303] for a comprehensive insight into Italy's near 50-year commitment to inclusive education see Delia Ferri, The Past, Present and Future of the Right to Inclusive Education in Italy. In Gauthier de Beco Shivaun Quinlivan Janet E Lord (eds.) *The Right to Inclusive Education in Human Rights Law* (Cambridge University Press, 2019) 547 - 579

in Ireland the number of special schools recognised by the Department of Education and Skills has actually increased from some 118 in 2010 to some 130 in 2022.[304] Moreover, all of these are designated as *primary* schools, notwithstanding concern that a significant number of students transfer to special school provision at or before post-primary school age.[305]

4.6 A Constitutional perspective

At the inception of the Irish State in 1922 there was scant educational provision specifically available for children with disabilities. Moreover, that little which did exist was largely outside the official system and entirely provided for by charitable and voluntary sources. Hence, Ireland's first special school, founded for blind boys by the Carmelite Brothers in Drumcondra, Dublin in 1870, and gaining formal recognition as a primary school in 1918 received no State funding until 1952.[306] There is a sense of disabled children slowly emerging out of the shadows, the aspiration of 'cherishing all the children of the nation equally'[307] finding little purchase in terms of educating those with special education needs. Indeed, this was particularly true of children with learning disability. Griffin and Shevlin quote the words of the Irish National Teachers Organisation's General Secretary in 1952:

> [o]ne of the greatest crimes of our system is the callous disregard for subnormal and backward children. Many of these are condemned as fools and dunces according to our conventional academic standards. They are the victims of those who define education as a matter of books and words.[308]

Persuaded to the view that disability was a medical issue, many disabled children were consigned to widespread institutionalisation, wherein the emphasis was often more on rote training than on education. Indeed, a 1936 report emphasises that the education of disabled children in a mainstream setting could only serve to damage the education of 'normal' children.[309]However, slowly, and with increasing impetus from the 1960s on, a more systematic

---

[304] https://www.gov.ie/en/organisation-information/c8ff3-special-schools/

[305] National Council for Special Education *The Future Role of Special Schools and Classes in Ireland: Policy Advice* (NCSE, 2011)

[306] *Department of Education Report of the Special Education Review Committee* (The Stationery Office, 1993)

[307] Proclamation OF THE Irish Republic, 24 April 1916

[308] Sean Griffin, Michael Shevlin, *Responding to Special Educational Needs: An Irish Perspective* (Gill Education, 2011) 39

[309] *Commission of Inquiry into the Reformatory and Industrial School System 1934 – 1936* [the Cussen Report] (The Stationery Office, 1936)

approach to educational provision develops, albeit largely in the segregated setting of the special school.[310] However, in 1977, on the cusp of a highly influential UK policy document, the *Warnock Report*[311] - which introduces the phrase *special education needs* into common usage and which favours mainstream education provision for all those but the minority of children who have quite complex impairments – a Department of Education circular 'proposes that children with a mild general learning disability could be accommodated in special classes in ordinary schools.'[312]

Following the lead set by the *Warnock Report* a clear Irish statement affirming the education needs of severely and profoundly disabled children came in 1983 with the so-called 'Blue Report.'[313] Although its language now presents as pejorative and patronising, this report, drawing on American and British findings, clearly acknowledges that no disabled child is ineducable. However, a pilot project apart, the necessary investment to meet the consequences of this acknowledgement fails to materialise.[314] Of course, again, the education proposed here is not inclusive but, rather, segregated. Nonetheless, asserting the principle that *all* children can learn and that education is a benefit to *all* children is an important marker in the State's on-going evolution towards a full engagement with the education rights of disabled children. That this evolution has a certain stop-start quality is evinced in two cases which expound a constitutional interpretation of article 42.4 – an article with 'a prima facia relevance to demands for inclusive education.'[315] Initiated by parents of severely disabled children both cases expose the lack of monetary investment in educational services for children in this category.

4.7 O'Donoghue v Minister for Health and others

The first of these cases, *O'Donoghue v Minister for Health,*[316] resultes in the High Court clarifying the constitutional obligations owed by the State under article 42 to children with disabilities. Having acquired significant and permanent brain damage as a result of contracting Reye's

---

[310] see *Report of the Commission of Inquiry on Mental Handicap* (The Stationery Office, 1965)

[311] *Report of the Committee of Enquiry into the Education of Handicapped Children and Young People* [the Warnock Report] (Her Majesty's Stationery Office, 1978)

[312] Sean Griffin Michael Shevlin *Responding to Special Educational Needs: An Irish Perspective* (Gill Education, 2011) 43

[313] *The Education and Training of Severely and Profoundly Mentally Handicapped Children in Ireland* (The Stationery Office 1983)

[314] Sean Griffin Michael Shevlin *Responding to Special Educational Needs: An Irish Perspective* (Gill Education, 2011)

[315] Gerry Whyte 'Litigating the Right to Inclusive Education under Irish Law' in de Beco G, Quinlivan S, Lord JE, (eds) *The Right to Inclusive Education in International Human Rights Law* (Cambridge University Press, 2019) at 500

[316] *O'Donoghue v Minister for Health, The Minister for Education, Ireland and the Attorney General* [1993] IEHC 2; [1996] 2 IR 20

Syndrome as a baby it was the State's claim that Paul O'Donoghue was, by reason of being profoundly mentally and physically disabled, ineducable, other than in relation to some basic training in respect of bodily function and movement. The State further contended that this training could not be construed as falling within the article 42 guarantee of free primary education, asserting that this only applies to that type of conventional education exemplified in the National Schools curriculum. Finally, having offered Paul day care services, inclusive of transportation provision, with a local charity – albeit subsequent to the initiation of legal proceedings against the State – it was also contended that Paul's claims were now moot, the relief being sought having now been provided. In his judgement O'Hanlon J. rejects the State's assertions, citing O'Dalaigh C.J. in *Ryan v Attorney General*[317] who held education to be 'the teaching and training of a child to make the best possible use of his inherent and potential capacities, physical, mental and moral'.[318] Finding this definition a fit with emerging best practice insights about the educational capacities of persons with even quite significant learning disability, including as found in comparative legal developments in other jurisdictions and within recommendations to the Irish government contained in State-sponsored reports, including the Blue Report, O'Hanlon J finds that Paul was educable. As to the nature of primary education and its suitability in the instant case, O'Hanlon says:

> there is a constitutional obligation imposed on the State by the provisions of Article 42.4 of the Constitution to provide for free basic elementary education of all children and that this involves giving each child such advice, instruction and teaching as will enable him or her to make the best possible use of his or her inherent and potential capacities, physical, mental and moral, however limited these capacities may be. Or, to borrow the language of the United Nations Convention and Resolution of the General Assembly -- "such education as will be conducive to the child's achieving the fullest possible social integration and individual development; such education as will enable the child to develop his or her capabilities and skills to the maximum and will hasten the process of social integration and reintegration.''[319]

---

[317] *Ryan v Attorney General* [1965] IR 294

[318] *ibid* at 350

[319] *O'Donoghue v Minister for Health, The Minister for Education, Ireland and the Attorney General* [1993] IEHC 2; [1996] 2 IR 20 at 65

The judge continues:

> This process will work differently for each child, according to the child's own natural gifts, or lack thereof. In the case of the child who is deaf, dumb, blind, or otherwise physically or mentally handicapped, a completely different programme of education has to be adopted and a completely different rate of progress has to be taken for granted, than would be regarded as appropriate for a child suffering from no such handicap.[320]

Accepting that heretofore the State has met its constitutional obligations in respect of many disabled children, Hanlon J. maintains that this is not true in relation to children such as Paul, that is, those children whose impairment brings them within the severe and profound range of learning disability. But Hanlon J. is in no doubt that the State owes such children the same constitutional duty, asserting that the duty arises once it becomes clear that severe and profoundly disabled children can derive educational benefit from the school environment:

> But once that has been established - and my conclusion is that it has been established on a world-wide basis for many years past - then it appears to me that it gives rise to a constitutional obligation on the part of the State to respond to such findings by providing for free primary education for this group of children in as full and positive a manner as it has done for all other children in the community.[321]

As to whether such education properly comes within the scope of 'primary education' as provided for in article 42 – the State contending this to be an activity which is scholastic in nature – Hanlon J. takes a broader view, concluding that the breath of research and evolving educational practice permits a finding that the types of educational redress which Paul is claiming does constitute primary education. Finally, on the issue of Paul's claim being moot the judge rejected this on three grounds. First, the provision of a place within a day service was determined to be an act of 'grace and concession'[322] and, so, inevitably precarious if not recognised as an outright legal entitlement. Second, it was not clear that the day-service placement provided by the charity met the duty imposed on the State by article 42. Indeed, on this point, Hanlon J. appears to suggest that the constitutional duties owed to children in Paul's

---

[320] *ibid*

[321] *ibid* at 65-66

[322] *ibid* at 66

circumstances may be *higher* than those owed to children in the mainstream population.[323] Third, the placement did not obviate Paul's entitlement to damages for loss pursuant to the State's failure to discharge it's constitutional duties to him.

The matter for determination in *O'Donoghue* does not go to the issue of inclusive education *per se*. However, the case, *inter alia*, is very important in terms of context setting, specifically, in what it offers about the education entitlements of children with disabilities. In particular, it clarifies that the constitutional right to free primary education extends to all children in the State, placing the onus on the authorities to make whatever modifications which may be necessary to accommodate disabled children, including those whose impairments are within the severe or profound range. As a direct consequence of *O'Donoghue* a number of educational initiatives were put in place, including the introduction of a policy which invested in new resource teacher posts[324] and enhanced in-class ratios.[325] For the first time too, children with autism were recognised as having special education needs such that an enhanced pupil-teacher ratio would apply.[326] But notwithstanding these proactive developments the question of what limits might apply to a disabled person's entitlement to avail of education provision – one which implicitly does go to the heart of inclusion – was not addressed in *O'Donoghue.* This question was, however, central to *Sinnott v Minister for Education*,[327] wherein an exercise in statutory interpretation was deployed to probe the meaning both of 'primary' and 'education' as these words appear in the Constitution.

4.8 Sinnott v Minister for Education

From the age of four months the co-claimant in this case, Jamie Sinnott, had begun to display signs of severe autism. Both he and his mother, Kathy, initiated proceedings claiming declarations as to their rights, damages for breach of constitutional and statutory rights and a mandatory injunction compelling the Minister for Education to discharge the State's obligation to provide education for Jamie. Transitioning from the High Court to the Supreme Court, the Chief Justice accepted as fact a summary of Jamie's circumstances as stated in the High Court by Barr J. including that '[no]o programme was devised for [Jamie's] education and training until halfway through the trial when a grossly defective one was gathered together in haste which was roundly condemned by the experts - even those called on behalf of the defence,' that

---

[323] for an elaboration on this see Gerry Whyte *Social Inclusion and the Legal System. Public Interest Law in Ireland* (IPA, 2015) at 310
[324] Department of Education and Skills Circular 8 of 1999
[325] Department of Education and Skills Circular 9 of 1999
[326] Department of Education and Skills Circular 8 of 1999
[327] *Sinnott v Minister for Education* [2001] 2 IR 545

Jamie's had had less than three years 'meaningful education and training so far in 23 years of existence' and that that Jamie's loss can never be fully restored because:

> education now is arriving too late in his life to achieve optimum results. Progress is more difficult and potentially more stressful for him than would have been the case if he had been educated from an early age. At best he has suffered through lack of educational training a diminution in the quality of his life which has been substantial up to now but which will also continue significantly into the future – even if he derives major benefits from the education and training now proposed for him. It is probable that he will have a lifelong need for ongoing basic education and training consistent with his requirements as they emerge in the future.[328]

Approving the education definition found in *O'Donoghue*, Barr J. rejected the State contention that this definition created a tortious claim only and, as such, only operative from the date of O'Donoghue's determination. Instead, Barr J. held that rather than creating a new right *O'Donoghue* simply emphasised an existing one:

> In *O'Donoghue*, O'Hanlon J. did not create a new right but declared that the obligation of the State to provide for primary education under Article 42.4 of the Constitution applies to all citizens and that those who suffer from severe or profound mental handicap are not excluded from the constitutional benefit of appropriate primary education. That right has existed from the enactment of the Constitution in 1937 and failure to honour it has sounded in damages at least from the early 1970's when expert opinion widely accepted that those who suffer grievous mental disablement are capable of and would derive benefit from appropriate primary education.[329]

Contending that the right to free primary education is intended to confer a benefit on individuals *and* their families and applying article 41.2 of the Constitution Barr J. found a breach of duty to Jamie and his mother, such that the State had failed to protect them both. Further, by virtue of article 40.1, Barr J. identified a failure to respect and vindicate the rights of the claimants. Finding the declarations sought to be valid and awarding damages, the High Court judgement's most

---

[328] *ibid*

[329] *Ibid* at 586

significant finding was that it required the State to provide life-long education for persons with severe and profound learning disability.[330] Whyte elaborates further important dimensions of the judgement thus:

> Barr J's decision that Article 40.1 of the Constitution required that the Sinnott family should not have been deprived of basic advantages provided by the State to others also raised the interesting prospect of the guarantee of equality being prayed in aid in order to extend State social services. His decision was also further evidence of the willingness of some Irish judges to attempt to remedy systemic defects in the operation of State agencies by providing for ongoing judicial review of developments after judgement had been delivered and by threatening recalcitrant administrators with punitive sanctions, in this case, punitive damages.[331]

The State's appeal to the Supreme Court turned on three issues.[332] First, was primary education a life-long right in respect of people with severe and profound learning disabilities? Second, was Kathy Sinnott the holder of a derivative legal claim by virtue of an infringement of her son's right to free primary education?[333] Third, was it within the courts' power to grant a mandatory injunction against the State in cases such as this and to require a review of the award of damages and the mandatory injunction?[334]

Addressing the issue of primary education as a life-long entitlement in circumstances of severe or profound disability, the majority Supreme Court view resiled from the expansive interpretation of primary education espoused by Barr J. Hence, for Denham J. the essential question was not about delineating the nature of primary education but rather

---

[330] Gerry Whyte *Social Inclusion and the Legal System. Public Interest Law in Ireland* (IPA, 2015)

[331] *ibid* 317

[332] the particular seriousness of these issues might be reflected in the fact that this case involved all seven Supreme Court Judges sitting for the first time

[333] in respect of this second issue the Supreme Court rejected the contention that a family member could claim compensation for a breach of another family member's constitutional rights; its discussion falls outside the scope of this present chapter

[334] in respect of this third issue the State's contention was that the form of relief granted in the High Court, other than the financial compensation for breach of rights up to the time of the hearing, violated the doctrine of the separation of powers in that the Court took to itself the prerogative on how monies would be allocated; as such, this argument falls outside the scope of the present chapter

> [w]hether the right to the provision of free primary education under Article 42.4 of the Constitution of Ireland is a right given to children or to all citizens irrespective of age.[335]

For Denham J. answering this question was straightforward. Article 42.4 does not relate to adults, maintaining it 'reasonable to take the age at which society treats a young person as an adult as the age when the right [to free primary education] ceases to exist.'[336] Nor, in the same judge's view, did much of Jamie Sinnott's support and training to date fall within article 42.4's ambit; it being 'not the teaching of anything new but rather continued practice so that he may retain the skills he has learnt.'[337] Per Murphy J., interpreting 'primary' to reference education of a basic and fundamental kind, the entitlement ceased at age twelve and excluded the type of 'assistance from therapists, teaching staff, paediatricians, consultant psychiatrists, social workers, family therapists and psycho therapists' required by Jamie Sinnott. [338] For Murray J. the definition of primary education in its ordinary and natural meaning 'is at once both inclusive and exclusive. It relates to the teaching of children only.'[339] Rationalising that the duty to provide for free primary education could not be presented as qualitatively different to any other State duty and could not be open-ended in nature, Hardiman J. agreed that, even if somewhat arbitrary, eighteen years represented the latest point 'at which a person could, with any element of reality, be regarded as a child.'[340] Only Keane C.J. held that Jamie Sinnott's entitlement to free primary education did not expire on attaining eighteen years of age.[341] Having drawn attention to certain structural and presentational difficulties in the State's appeal the Chief Justice lay out a variety of ages at which certain legal milestones become operative, asking:

> Where in this spectrum can it be said with any semblance of truth that the first plaintiff passed from childhood to adulthood? So far as the evidence in this case goes, virtually none of these stages is of any significance in his case. He [Jamie Sinnott] is one of a relatively small category of people in our society who, because of their mental handicap, can never enjoy life in all its diversity and richness but to whom at least a measure of happiness may be available. The uncontested evidence in this case is that, to attain even that low

---

[335] *Sinnott v Minister for Education* [2001] 2 IR 545 at 652
[336] *ibid* at 655
[337] *ibid* at 655
[338] *ibid* at 674
[339] *ibid* at 682
[340] *ibid* at 696
[341] *ibid* at 639

> plateau, the first plaintiff requires continuing access to what, in his case, is education, as defined by O'Dálaigh C.J., albeit often extremely basic in character. No principled basis exists either in law or in the evidence for the contention advanced by the defendants that a person in his position ceases to be in need of primary education at age 18, at age 22 or at any age in the future which can now be identified with any precision.[342]

Several of the Supreme Court judgements drew attention to statutory remedies which Sinnott might have – and in the Court's view *should* have - relied on. Indeed, the provisions of the *Education Act 1998* (which as this chapter has already outlined makes loud its mention of disabled persons), taken in conjunction with the *Equal Status Act 2000* and the *Education (Welfare) Act 2000*, were noted by Hardiman J. to be possibly broader than those provide for in the Constitution.[343] But such provisions are constrained by reference to available recourses.[344] However, article 42.4 was indicated not to be so constrained, such that it was submitted that it imposed an unqualified duty on the State and was unaffected by 'consideration of limitation of means, policy choices, competing demands, or alternative priorities.' [345] However, Hardiman J. contended this assertion to be erroneous, maintaining that the article 42 duty is endorsed by a

> legislature and executive who must necessarily have a wide measure of discretion having regard to available resources and having regard to policy considerations of which they must be the judges.[346]

If the High Court judgement in Sinnott might be thought of as the high-water mark in judicial activism and public interest litigation in respect of children with learning disability, what is to be made of the Supreme Court ruling in the same case? Arguably, it can be read as a re-assertion of a traditional and dated understanding of disability which lacks modern nuance, turning more on (thinly veiled) neoliberal economic concerns than on concern for vindicating the practical

---

[342] *ibid* at 639

[343] *ibid* at 685 and 697

[344] hence, for example section 7(4) of the *Education Act 1998* which says that '[i]n carrying out his or her functions, the Minister: (a) shall have regard to - (i) the resources available ... '; moreover, section 2(1) of the *Education (Welfare) Act 2000* specifically draws attention to the interrelatedness of primary education with a tightly defined age range, to the effect that 'child' is defined as 'a person resident in the State who has reached the age of 6 years and who – (a) has not reached the age of 16 years, or (b) has not completed 3 years of post-primary education, whichever occurs later, *but shall not include a person who has reached the age of 18 years*' (emphasis added)

[345] *Sinnott v Minister for Education* [2001] 2 IR 545 at 694

[346] *ibid* at 695

citizenship rights of disabled people. Chronology appears to trump competence; retaining gains in personal ability appears to matter less than sketching dubious assertions about the moral value of adulthood.

4.9 Article 24's lineage

Among its many innovations, the CRPD is identified as the first internationally binding instrument to give legal effect to the concept of inclusive education.[347] Article 24 (education), reflects the CRPD's article 3 principle requiring states to respect disabled people's entitlements to '[f]ull and effective participation and inclusion in society'[348] but also touching, *inter alia*, on issues of autonomy,[349] non-discrimination,[350] respect for difference[351] and accessibility.[352] Further, in its explicit conceptualization of inclusive education as a human right, the CRPD positions exclusion from a general – that is, mainstream - education system as undermining the human dignity of persons with disabilities. More, the Convention also recognizes the role an inclusive education experience can play in the development of an individual sense of dignity and self-worth.[353]

In formally and explicitly asserting the right of persons with disabilities to education and lifelong learning the CRPD builds on a long UN tradition of recognising the importance of framing education access within a human rights context.[354] Within this tradition the UDHR,[355] the ICESCR,[356] ICERD,[357] CEDAW[358] and the CRC[359] all affirm the right to education, with the UDHR asserting that '[e]ducation shall be free, at least in the elementary and fundamental stages.'

---

[347] Andrea Broderick 'The Right to Inclusive Education: Article 24 of the UN Convention on the Rights of Persons with Disabilities and the Irish Experience' in De Londras F, Mullally S, (eds) *The Irish Yearbook of International Law Vol 9 2014* (Hart Publishing, 2017) 25-60; the recognition of education as the right of every individual is contained in article 26, the *Universal Declaration of Human Rights* UN General Assembly 10 December 1948 217 A (III)

[348] CRPD art 3(c)

[349] CRPD art 3(a)

[350] CRPD art 3(b)

[351] CRPD art 3(d)

[352] CRPD art 3(f)

[353] CRPD art 24(1)(a)

[354] Within a specifically European context see also article 2 of Protocol No 1 to the European Convention on Human Rights; article 17(2) of the (Revised) European Social Charter; articles 13 and 14 of the Framework Convention on the Protection of National Minorities; article 8 of the European Charter for Regional or Minority Languages; article 14 of the European Convention on the Legal Status of Migrant Workers; article 14 EU Charter of Fundamental Rights

[355] UDHR art 26

[356] ICESAR art 13

[357] ICERD art 5

[358] CEDAW art 10

[359] CRC art 28 and 29

Further, the CRC reminds state parties that in addition to the development of an individual's personality, talents and mental and physical abilities[360] education must also be directed to 'the development of respect for human rights and fundamental freedoms.'[361] Moreover, the UN's education agency, UNESCO[362] has adopted two conventions on education, the *Convention against Discrimination in Education*[363] and the *Convention on Technical and Vocational Education*,[364] the former representing the first international instrument in the area of education to have binding force in international law. Referring to educational provision of all types and levels,[365] the *Convention against Discrimination in Education* requires state parties 'to abrogate any statutory provisions and any administrative instructions and to discontinue any administrative practices which involve discrimination in education.'[366]

The CRPD also builds on a progressive international tradition of soft law initiatives, in particular, the *World Declaration on Education for All* (the Jomtien Declaration),[367] the *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities*[368] and the *Salamanca Statement*.[369] Although not referencing inclusion *per se*, the *Standard Rules* provide for integrated education, contending that only where a general school system does not *yet* adequately meet the needs of all persons with disabilities might special education be

---

[360] Reprised in CRPD art 1(b)

[361] CRC art 29(1) (b); this is reprised in CRPD 1(a)

[362] The United Nations Education Scientific and Cultural Organisation has a threefold mission, building peace, eradicating poverty and achieving sustainable development. Its mandate in terms of all aspects of education extends to responsibility for leading on the achievement of the UN's Transforming Our World 2030 sustainable development goal 4, to ensure inclusive and equitable quality education and promote lifelong learning opportunities for all

[363] UNESCO Convention Against Discrimination in Education adopted 14 December 1960

[364] UNESCO Convention on Technical and Vocational Education adopted 10 November 1989; it is noted that this Convention has a very low ratifications number

[365] *Convention Against Discrimination in Education* art 1(2)

[366] *Convention against Discrimination in Education* art 3(a); under the definition provided in article 1.1 discrimination does not identify disability per se but instead refers to discrimination arising from 'race, colour, sex, language, religion, political or other opinion, national or social origin, economic condition or birth.' However, given that its preamble references the UDHR affirmation that *every person* has the right to education it would seem appropriate to indicate that this list can be treated as non-exhaustive. The second UNESCO instrument, the Convention on Technical and Vocational Education, does make reference in article 2(4) to 'the special needs of the handicapped and other disadvantaged groups.'

[367] Inter- Agency Commission *World Declaration on Education for All* adopted by the World Conference on Education for All – Meeting Basic Education Needs 9 March 1990 available at https://unesdoc.unesco.org/ark:/48223/pf0000097551

[368] The *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities* (UN, 1993); rule 6 requires that '[s]tates should recognise the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings' and that 'the education of persons with disabilities is an integral part of the education system.'

[369] The *Salamanca Statement and Framework for Action on Special Needs Education* (UNESCO, 1994)

considered.[370] Thus, the *Standard Rules* envision segregated education not as an immutable but, rather, as acceptable only in terms of preparing students for education in the general school system.[371] But whereas the *Standard Rules* may be said to provide for inclusion implicitly, the *Salamanca Statement* does so explicitly. Indeed, this latter document is directed exclusively at the idea of inclusion and invites states to 'adopt as a matter of law or policy the principle of inclusive education, enrolling all children in regular schools, unless there are compelling reasons for doing otherwise.'[372] Although non-binding, at a policy level the *Salamanca Statement* reflects an early official perspective – the declaration having been signed by representatives of 92 governments – that the phenomenon of special schools segregating according to specific disability types is not, in the main, an appropriate means of educating children with disabilities.[373] While permitting recourse to separate education arrangements on a case-by- case basis, and then only as an infrequent exception to a continuum of support model,[374] the *Salamanca Statement* emphasises that '[i]nclusive schooling is the most effective means for building solidarity between children with special needs and their peers.'[375] Indeed, as represented in this 'principled approach to education'[376] this solidarity, while including persons with disabilities, is best understood as referring, more properly, to a wider rights perspective encompassing *all* those – children and adults – who experience barriers to educational participation.[377]

4.10 Requirements under article 24

However, despite the sustained international focus on developing inclusive education, including a Human Rights Council resolution in 2014,[378] the problems faced by disabled persons in achieving it remain considerable. Discriminatory practices that exclude or segregate continue in many states' education systems. Indeed, as elaborated on in the next section, article 24's

---

[370] The *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities* (UN, 1993) rule 6

[371] *ibid*

[372] The *Salamanca Statement and Framework for Action on Special Needs Education* (UNESCO, 1994) at para 3

[373] Ann Cheryl Armstrong, Derrick Armstrong, Illektra Spandagou, *Inclusive Education: International Policy and Practice* (Sage, 2010)

[374] this model is described in terms of 'ranging from minimal help in regular classrooms to additional learning support programmes within the school and extending, where necessary, to the provision of assistance from specialist teachers and external support staff;' see the Salamanca Statement at para 32

[375] The Salamanca Statement at para 8

[376] Mel Ainscow Tony Booth and Alan Dyson *Improving Schools, Developing Inclusion* (Routledge, 2006) 2

[377] Tony Booth Mel Ainscrow *Index for inclusion: developing learning and participation in schools* (CSIE, 2002)

[378] UNHCHR *Thematic study on the right of persons with disabilities to education. Report of the Office of the United Nations High Commissioner for Human Rights* Human Rights Council Twenty-fifth session 18 December 2013

drafting was itself heavily debated, with the CRPD's eventual explicit guarantee of inclusive education for disabled people much contested[379] – partly expressed in terms of a *need* to retain some form of separate, special educational provision, even while accepting the principle of inclusion.[380] While sometimes framed in terms of parental and children's choice,[381] it has also been argued that the educational needs of some disabled persons cannot be adequately provided for outside a special school setting.[382]

That said, in the ordinary course of events a refusal on the basis of disability to enrol a child in a mainstream school[383] - or an adult in a tertiary, vocational, adult education or life-long learning context[384] - is a discrimination prohibited by the CRPD both in terms of article 24(2)(a) and article 5(2) (equality and non-discrimination). Further, article 24(2)(a) provides that disability shall not be a barrier to disabled persons' access to 'free and compulsory primary education' and secondary education. In this, article 24(2)(a) clearly links to article 9 (accessibility) which, in line with the general principle found in article 3, requires states to ensure equal access to the physical environment, to transportation and to information and communications technologies for persons with disabilities.[385] Disabled persons must also receive reasonable accommodation[386] and individualised supports consistent with maximising academic and social development.[387] The CRPD Committee clarifies that this accommodation may, for example, require 'changing the location of a class, providing different forms of in-class communication, enlarging print, materials and/or subjects in sign, or providing all handouts in an alternative format, providing students with a note-taker, or a language interpreter or allowing students to use assistive technology in learning and assessment situations.'[388] Examples of other forms of

---

[379] Rosemary Kayess Jennifer Green Today's Lesson is on diversity. In Peter Blanck Eilionóir Flynn (eds.) *Routledge Handbook of Disability Law and Human Rights* (Routledge, 2017) 53 - 71

[380] see Gauthier de Beco Comprehensive Legal Analysis of Article 24 of the Convention on the Rights of Persons with Disabilities. In Gauthier de Beco Shivaun Quinlivan Janet E Lord (eds.) *The Right to Inclusive Education in Human Rights Law* (Cambridge University Press, 2019) 58 - 92

[381] Garry Hornby *Inclusive special education: Evidence-based practices for children with special needs and disabilities* (Springer, 2014); the principle of a parent's right to choose their child's school is found in art 26(3) UDHR and elsewhere such as in art 13(3) ICESCR and art 28 CRC; however, it is noted the CRPD is silent on this matter

[382] see, for instance, Marie Therese Doherty, 'Inclusion and deaf education: The perceptions and experiences of young deaf people in Northern Ireland and Sweden' (2012) 16 (8) International Journal of Inclusive Education 791; Mary Warnock, Brahm Norwich, *Special Education Needs: A New Look* (Continuum, 2005)

[383] the terms 'mainstream school' 'ordinary school' and 'general school' are used here interchangeably

[384] CRPD art 24(5)

[385] CRPD art 9(1)

[386] CRPD art 24(2)(c), 24(5)

[387] CRPD art 24(2)(d), 24(2)(e)

[388] CRPD Committee General Comment No 4 25 Nov 2016 CRPD/C/GC 4 at para 29

accommodation may require permitting a student more time, reducing levels of background noise or replacing an element of the curriculum.[389] It should also be noted that the requirement to provide reasonable accommodation is immediately applicable (*ex nunc*) and cannot be subject to progressive realisation[390] and nor can it impose a cost on the person requiring it.[391]

Under article 24(3) states are required to 'enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community.' Measures deemed appropriate to this end include facilitating the learning of, *inter alia*, Braille[392] and sign-language[393] as well as promoting orientation and mobility skills and facilitating peer support and mentoring.[394] There is a particular emphasis on the promotion of 'the linguistic identity of the deaf community,'[395] which is also referenced in Article 30(4) (participation in cultural life, recreation, leisure and sport). In addition, there is also a specific mentioning of children who are blind, deaf or deafblind in terms of a state's responsibility to ensure that these children's education 'is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximise academic and social development.'[396] This specific reference is taken to emphasise that children with these specific impairments must not be excluded from education but it is also taken, if tacitly, to endorse the appropriateness of special schools for children falling into these three categories of impairments.[397] Sometimes referred to as the 'sensory exception'[398] Gauthier de Beco phrases the tension in article 24(3) thus, reading it to mean that people with sensory or communication impairments 'should be allowed to be educated in special school, although this option should not prevent them from asking to be able to participate in the general education system.'[399] Of course, a natural question presents here as to why an exception is proffered –

---

[389] *ibid*

[390] CRPD Committee, General Comment No 2 on Article 9: Accessibility CRPD/C/GC/2 (22 May 2014) at para 26

[391] CRPD Committee, General Comment No. 6 on equality and non-discrimination CRPD/C/GC/6 (26 April 2018) at para 26(f)

[392] CRPD art 24(3)(a)

[393] CRPD art 24(3)(b)

[394] CRPD art 24(3)(a)

[395] CRPD art 24(3)(b)

[396] CRPD art 24(3)(c)

[397] Valentina Della Fina 'Article 24 [Education]' in Valentina Della Fina Rachele Cera Giuseppe Palisano (eds) *The United Nations Convention on the Rights of Persons with Disabilities* (Springer, 2017) 439 - 470

[398] Joseph J. Murray, Maartje De Meulder, Delphine le Marie, 'An Education in Sign Language as a Human Right? The Sensory Exception in the Legislative History and Ongoing Interpretation of Article 24 of the UN Convention on the Rights of Persons with Disabilities' (2018) 40 (1) Human Rights Quarterly 37

[399] Gauthier de Beco, 'The Right to Inclusive Education According to Article 24 of the UN Convention on the Rights of Persons with Disabilities: Background, Requirements and (Remaining) Questions' (2014) 32 (3) Netherlands Quarterly of Human Rights 263, 285

assuming it is – in respect of some impairment types and not others.[400] An answer, at least in relation to deaf people, is commonly phrased in terms of deafness not being presented as an impairment but rather as a cultural identity.[401] Within this understanding, attempts at educational normalization, as with medical interventions such as those involved with 'curing' deafness, are associated with the undermining of sign language as the central signifier of this important identity.[402]

In terms of shaping a normative institutional shift towards inclusivity in schools (and wider education providers) article 24(4) is of particular importance. Here, state parties are required to ensure the employment of teachers qualified in sign language and/or Braille – this, an indication in the overall phrasing of the section, perhaps suggesting that whatever the provision of special schools envisaged in article 24(3)(c) this might be regarded as temporary.[403] But more, there is a requirement that 'professionals and staff at all levels of education' be trained in disability awareness 'and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.' Add to this the expectation, also referenced in the paragraph, that appropriate steps be taken to employ teachers with disabilities and it can be argued that what is imported here into the Convention is a clear recognition that until teaching and support staff become more diverse, both in their persons and their skills, schools and other educational institutions will struggle to become comfortably and confidently diverse places. The CRPD Committee has also usefully elaborated on article 24(4)'s full implementation by noting that '[s]tates parties must ensure that all teachers are trained in inclusive education and that that training is based on the human rights model of disability.'[404] Indeed, with specific reference to teachers with disabilities the

---

[400] a possible answer lies in the political power of well-organised representative bodies such as the World Blind Union and the World Federation of the Deaf, both of which were represented at the art 24 drafting process

[401] see, for instance, Shelley Bartlett, 'Disabled or Deaf? Investigating mental health clinicians' knowledge of and attitude towards Deafness as a culture' (2018) 11 (4) International Journal of Culture & Mental Health 437; Paddy Ladd *Understanding Deaf Culture: In Search of Deafhood* (Multilingual Matters Ltd, 2003)

[402] Dirksen L Bauman Joseph J Murray Deaf Studies in the 21st Century: 'Deaf-Gain' and the Future of Human Diversity' in Lennard J Davis (ed) *The Disability Studies Reader* (Routledge, 2017) 242 - 255

[403] for a vigorous refutation of this idea see Joseph J. Murray, Kristin Snoddon, Maartje De Meulder, Kathryn Underwood, 'Intersectional inclusion for deaf learners: moving beyond General Comment no. 4 on Article 24 of the United Nations Convention on the Rights of Persons with Disabilities' (2020) 24 (7) International Journal of Inclusive Education 691

[404] CRPD Committee General Comment No 4 Article 24: Right to Inclusive Education CRPD/C/GC/4 (25 November 2016) at para 36

Committee promotes the recruitment and ongoing education of teachers with disabilities, saying:

> This includes removing any legislative or policy barriers requiring candidates to fulfil specific medical eligibility criteria and the provision of reasonable accommodations for their participation as teachers. Their presence will serve to promote equal rights for persons with disabilities to enter the teaching profession, bring unique expertise and skills into learning environments, contribute to breaking down barriers and serve as important role models.[405]

Implicit in both these comments is the Committee's recognition that, just as with students, teachers with disabilities can be excluded from the mainstream education domain.[406] Moreover, intriguingly, what is hinted at too is an expansive education milieu in which the 'alternative modes, means and formats of communication, educational techniques and materials'[407] are *generally* available to all learners. This could mean that braille and sign language, for instance, become part of the curriculum not as an activity reserved to disabled students but rather as a subject accessible by *all* students. Such an approach might be prefigured as a pedagogical act of social justice,[408] a recognition that within a truly inclusive educational model it becomes important that a mode of universal design attach to practices too.[409] Within this construct, special school expertise becomes available to resource and support mainstream

---

[405] *ibid* at para 37

[406] see, for example, Noa Tal – Alon, Orly Shapira – Lishchinsky, 'Ethical dilemmas among teachers with disabilities: A multifaceted approach' [2019] 86 Teaching and Teacher Education; Gila Vogal, Varda Sharoni, ''My success as a teacher amazes me each and every day' – perspectives of teachers with learning disabilities' (2011) 15 (5) International Journal of Inclusive Education 479

[407] CRPD article 24(3)(c)

[408] for an exploration of this idea of pedagogical social justice see Carolyn Williams, Steve Wilson, 'Pedagogies for social justice: did Bernstein get it wrong?' (2010) 14 (4) International Journal of Inclusive Education 417

[409] The CRPD arguably supports this expansive understanding of universal design, defining it in art 2 as referring to 'the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design;' see, also, Gauthier de Beco, 'Transitions to Inclusive Education Systems According to the Convention on the Rights of Persons with Disabilities' (2016) 34 (1) Nordic Journal of Human Rights 40

inclusion,[410] the very notion of special and mainstream schools as diametrically opposite points on a continuum becoming absorbed into what one scholar calls 'flexible interacting continua.'[411]

4.11 Inclusion i: approaching an normative account

It is contended that the understanding of what inclusion means in an educational context varies across jurisdictions.[412] This, in itself, can be no surprise, nor that the CRPD is silent as to providing a normative account of inclusion. Kayess and Green report the contentious nature of the inclusion ideal within debates attending the CRPD's transition from conception to realisation. Surveying the draft text produced by the working group charged with progressing the CRPD, Kayess and Green remind that much of the working group's proposals persist in article 24 – the goals to which education should be directed, the provision of support and a prohibition on excluding disabled children from compulsory education.[413] But the permissibility of continuing segregated education on the basis of parental and student choice was also a strong feature of the working group's text, the CRPD's status as an implementation convention being interpreted to mean that it 'should not derogate from or apply a lower standard to that of existing norms and standards.'[414] Hence, for de Beco article 24 is a compromise, its text 'a clear example of negotiated ambiguity.'[415] On its face, article 24 does not speak conclusively to an ambition that there be *only* an inclusive education system nor of compelling states to eradicate special school provision. Instead, the wording suggests a rather less assertive requirement that states 'shall ensure an inclusive education system at all levels and lifelong learning.'[416] In addition to the so-called 'sensory exception' attention is given, for instance, to article 24(2)(e) where the phrase 'environments that maximize academic and social development' might also be interpreted as

---

[410] Carol McKinstry, Elena Wilson, Kerryn Bagley, Amanda Kenny, 'Designing and Rating Options for Special School Expertise to Support Mainstream Educational Inclusion' (2020) 44 (1) Australasian Journal of Special and Inclusive Education 15

[411] Brahm Norwich, 'What future for special schools and inclusion?' Conceptual and professional perspectives' (2008) 35 (3) British Journal of Special Education 136

[412] Bronagh Byrne, 'How inclusive is the right to inclusive education? An assessment of the UN convention on the rights of persons with disabilities' concluding observations' (2019) 26 (3) International Journal of Inclusive Education 301

[413] Rosemary Kayess, Jennifer Green, 'Today's Lesson is on diversity' in Blanck P, Flynn E, (eds) *Routledge Handbook of Disability Law and Human Rights* (Routledge, 2017) 53

[414] *ibid* 61

[415] Gauthier de Beco Comprehensive Legal Analysis of Article 24 of the Convention on the Rights of Persons with Disabilities' in de Beco G, Quinlivan S, Lord JE, (eds) *The Right to Inclusive Education in Human Rights Law* (Cambridge University Press, 2019) 66

[416] CRPD art 24(1); in this, the art 24 provisions arguably present as weaker than those cited above in *the Convention Against Discrimination in Education at note 363*

endorsing special schools, albeit in limited circumstances whereby the envisaged '[e]ffective individualized support measures' are provided 'consistent with the goal of full inclusion.'[417]

But all this said, the CRPD Committee has been forthright in offering an account of inclusion which seeks to draw out article 24's normative content. Attaching the right to inclusive education firmly to the individual learner – and in the case of minors explicitly acknowledging that parents' or guardians' rights are subordinate to that of the individual child – the Committee situates its exploration of the inclusion paradigm within a distinction between it and the concepts of exclusion, segregation and integration. It is useful to briefly explore these three phenomena in turn. To this end the Committee notes that:

> *[e]xclusion* occurs when students are directly or indirectly prevented from or denied access to education in any form. *Segregation* occurs when the education of students with disabilities is provided in separate environments designed or used to respond to a particular or various impairments, in isolation from students without disabilities.[418]

The concept of exclusion utilised here by the Committee is, arguably, too restrictive. Indeed, in its recourse to the idea of exclusion as residing in the denial of access to education *in any form* the definition might even be read as an endorsement of special school provision rather than as a recognition that the existence of such provision is itself fundamentally exclusionary. Yet, it can also be noted that in its phrasing of the meaning of segregation – a concept not found in the CRPD – the very scenario the Committee describes is that very educational environment which the 'sensory exception' is intended to permit.[419]

However, a wider engagement with the exclusion concept draws attention to ways in which education as a system and, perhaps, school in particular, is constructed and stratified within a complex interplay of political, economic and organisational forces, often overlaid with issues of class, race, gender and culture.[420] Within this interplay, three fundamental inequalities can be

---

[417] Gauthier de Beco, 'The Right to Inclusive Education According to Article 24 of the UN Convention on the Rights of Persons with Disabilities: Background, Requirements and Remaining Questions' (2014) 32 (3) Netherlands Quarterly of Human Rights 263

[418] 418 CRPD Committee General Comment No 4 Article 24: Right to Inclusive Education CRPD/C/GC/4 (25 November 2016) at para 11 (italics in original)

[419] see Joseph J Murray, Maartje De Meulder, Delphine le Maire, 'An Education in Sign Language as a Human Right? The Sensory Exception in the Legislative History and Ongoing Interpretation of Article 24 of the UN Convention on the Rights of Persons with Disabilities' (2018) 40 (1) Human Rights Quarterly 37

[420] see, for instance, John Smyth Robert Hattam *'Dropping out', Drifting Off, Being Excluded: Becoming Somebody Without School* (Peter Lang, 2004)

identified: inequalities in opportunities to *access* education, inequalities in *experiences* of education and the post-education *outcomes* which individuals can access.[421] These inequalities undermine the idea of the school as an intrinsically democratic and meritocratic institution where academic ability and scholastic talent is measured and rewarded independent of any other consideration. Instead, perhaps, the image draws closer to Bourdieu's contention – perhaps echoing Friere - about how education provision can be relied upon to entrench the advantage of those already dominant in society.[422] According to his theory of social reproduction, Bourdieu contends that education works to legitimise and perpetuate privilege, ensuring that certain cultural codes and practices which have the capacity to secure a valuable return to their holders are transmitted inter-generationally.[423] This touches keenly on issues of curriculum, giving, for instance, priority to 'narrowly defined knowledge, which focuses on the majority culture's traditional definitions of what is important to learn.'[424]

4.12 Inclusion ii: approaching a republican view

Applying a republican lens and examining this from the specific perspective of disability, if it is true that schools reproduce rather than reduce or redress social inequalities the resolve around ensuring access for disabled students become potentially problematic. On the one hand, it seems axiomatic that a properly resourced inclusion of non-typical students in the general school system is the only ethically meaningful way of promoting social justice as an education norm. However, if the prevailing general school emphasis remains about measuring and promoting a narrow understanding of academic success – this being central to maintaining and advancing the interests of the traditionally privileged and bolstering the school's *reputation* – then actual *practices* in schools can never be inclusive and the presence of disabled students, among other non-typical learners, will be inevitably tokenistic. Hence, what can arise is a de facto separation masking as an integration; one where the question of access is apparently resolved but the actual quality of disabled students' experience is poor. Instead, often marked by the presence of separate classrooms (often called the special class or the special unit) and discreet teaching arrangements, the integration model permits a certain sort of segregation

---

[421] this taxonomy is taken from Caroline Sarojini Hart, 'Education, inequality and social justice: A critical analysis applying the Sen-Bourdieu Analytical Framework' (2019) 17 (5) Policy Futures in Education 582

[422] Pierre Bourdieu Cultural reproduction and social reproduction. In Brown R, (ed) *Knowledge, Education and Cultural Change: papers in the sociology of education* (Tavistock, 1973) 71 – 112;

[423] Pierre Bourdieu Jean-Claude Passeron, *Reproduction in Education, Society and Culture* (Sage Publications, 1977)

[424] Jonathan Rix Christopher Walsh John Parry Rajni Kumrai 'Introduction Another point of view' in Rix J, Nind M, Sheehy K, Simmons K, Walsh C, (eds) *Equality, Participation and Inclusion 1: Diverse Perspectives* (Routledge, 2010) 2

perhaps no less invidious than that engendered by the special school model. Indeed, Engsig and Johnstone capture well the tension implicit in the integration model when they observe that:

> when we discuss the fundamental differences between the thoughts and practice of integration versus inclusive education today, it is significant to note that the term integration was used in relation to the process of integrating people with special needs into societal systems – such as schools – and expecting them to adapt.[425]

Similarly, the Committee observes that integration 'is a process of placing persons with disabilities in existing mainstream educational institutions, as long as the former can adjust to the standardized requirements of such institutions.'[426]

In contrast, inclusion is inherently dialectical. This means change and development happening at all the levels and across all the processes of a school community and beyond. Hence, for some educational theorists, inclusion is less about persons with disabilities – or any other coterie of non-typical learners – than it is about re-engineering education itself, reforming schools and re-ordering societies and societal priorities.[427] In this reading, inclusive education has an 'insurrectionary heritage' and it 'presses us to consider the ontology of special and regular; presses us to resist such a bifurcation as redundant in democratic education.'[428] Such interpretations fit neatly with the broad human rights ethos of the *Salamanca Statement* which emphasised the role of inclusive education in overcoming societal prejudices, contending that:

> [r]egular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all.[429]

But as for shifting this rhetoric towards realisation – especially, perhaps, in terms of producing meaningful *outcomes* which disabled people might want and value – this begins in realising that inclusive education is not the end in itself. Rather, as envisioned within the CRPD, inclusive

---

[425] Thomas T. Engsig, Christopher J. Johnstone, 'Is there something rotten in the state of Denmark? The paradoxical policies of inclusive education – lessons from Denmark' (2015) 19 (5) International Journal of Inclusive Education 469, 472

[426] CRPD Committee General Comment No 4 at para 11

[427] see, for instance, Roger Slee Inclusive Education: A Framework Reform. In Woon Hueng Vivian King Mel Ainscow (eds.) *Inclusive Education: A Framework for Reform. Proceedings of the International Conference on Inclusive Education* (Hong Kong Institute of Education, 2003) 58 - 67

[428] Roger Slee 'Inclusive Schooling as an Apprenticeship in Democracy?' in Lani Florian (ed) *The Sage Handbook of Special Education. Volume 1* (Sage, 2014) at 222

[429] Salamanca Statement at viii

education is the necessary prerequisite to an inclusive, democratic citizenship. Thus, having a precise definition of inclusion comes to matter less than promoting an ever widening understanding that inclusion exists, flourishes or fails in its subjective *effects* for individuals. This is often summarised as a sense of belonging, a reality itself shaped (or denied) by the socio-spatial contexts in which people live together.[430] Mirroring an awareness of disability as constructed in the interplay of individual, environmental and socio-economic factors[431] this ecological understanding of inclusion draws together the individual, the interpersonal, the organisational, the community and the socio-political as distinct yet always connected vantage points from which that which enhances or inhibits inclusion in a person's lived experience can be evaluated.[432]

The CRPD Committee taps instinctively into this ecological perspective in its theorising as to how inclusive education is to be achieved, offering extensive insights, including the need for 'an in-depth transformation of education systems in legislation, policy, and the mechanisms for financing, administration, design, delivery and monitoring of education.'[433] In addition, by way of providing assurance 'that segregation or integration is not happening either formally or informally'[434] the Committee draws attention to the importance of focusing on what is happening in individual schools, in effect providing a self-assessment tool and advising that these discrete institutions be regularly monitored and evaluated, including by people with disabilities. Hence, among other core features of inclusive education, the Committee lists the importance of an individual student focus, flexible curricula, supported teachers, including teachers with disabilities, an environment where diversity is respected and valued and, perhaps most important of all, one where acceptance and friendship is promoted.

Indeed, friendship, of itself, is an important republican marker. Going back to Aristotle and Cicero there is a sense that friendship is the supreme prototype for civic cooperation, friendship

---

[430] Edward Hall, 'The entangled geographies of social exclusion/inclusion for people with learning disabilities' (2005) 11 (2) Health & Place 107; Edward Hall, 'Spaces of social inclusion and belonging for people with learning disabilities' (2010) 54 (1) Journal of Intellectual Disability Research 48

[431] see, for example, Ruth Luckasson, Robert L Schalock, 'Defining an applying a functionality approach to intellectual disability' (2013) 57 (7) Journal of Intellectual Disability Research 657

[432] see, for example, Stacy Clifford Simplican, Geraldine Leader, John Kosciulek, Michael Leahy, 'Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation' [2015] 38 Research in Developmental Disabilities 18; more generally, see Uri Bromfrenbrenner *The Ecology of Human Development* (Harvard University Press, 1979)

[433] CRPD Committee General Comment No 4 at para 9

[434] CRPD Committee General Comment No 4 at para 12 (i)

being one of the highest goods, teaching mutual respect, selflessness and care for the other. [435] Thinking about schools – and, indeed, early years settings too - as forums in civil society, as places 'where *the question of being together is posed*'[436] the capacity to nurture friendships as open, generous, curious explorations of self and others is, I suppose, fundamentally conditioned on how the school conceptualises itself. In this, Freire posits that schools have two options, either to promote conformity to the logic of the present system or to embrace the freedom to critically and creatively transform the world.[437]

Taking respect for human diversity, non-discrimination and the promotion of human dignity as the core values underpinning inclusive education and notwithstanding that article 24 provides for at least some element of specialist schooling to be maintained in certain specific circumstances,[438] it now becomes useful to say something about the challenges which the Irish State appears to face in making inclusive education the national norm.

Again, focusing in particular on the primary and secondary school systems, that there are many children and young people with disabilities in mainstream educational settings is not in doubt. However, there are also many children and young people with disabilities in special schools, a model of provision which continues to thrive. That these two systems run in parallel – with all of the myriad consequences this has, *inter alia*, for funding, teacher-training, student experience and the delivery of targeted resources, particularly, perhaps, in terms of providing reasonable accommodation – registers as a matter of concern. Moreover, the very existence of a widespread special school sector implicitly undermines the rationale of article 24 in that it may dis-incentivise general education providers to fully embrace their moral responsibilities, create confusion for parents and undermine disabled young people's confidence about what they have a right to expect and receive from educational providers and the state.

Arguably, this capacity to dis-incentivise and confuse exists and operates at multiple levels across the State apparatus. For example, according to Cosgrove *et al*., the difficulties associated with implementing EPSEN in full derive from a number of sources, including the inability of mainstream school structures, as currently designed, to provide for the therapeutic and medical

---

[435] see Gregory Bruce Smith *Political Philosophy and the Republican Future* (University of Notre Dame, 2018)

[436] Gunilla Dahlberg Peter Moss Alan Pence *Beyond Quality in Early Childhood Education and Care* (Routledge, 2013) at 86 (italics in original)

[437] Freire (n 255)

[438] CRPD art 24(3)(c)

needs of children with disabilities. [439] Such provision – which some educationalists believe may require separate legislation to make it work [440] - is likely to be central to enabling disabled children's education, social and care needs to be met in ways which do not implicitly undermine their presence in an inclusive school setting.[441]

In addition, appetite for substantive educational reform seems variable in the Irish system, perhaps exacerbated by the considerable autonomy traditionally granted to schools.[442] Within this autonomy, the enduring structural practice of the special class as a type of stand-alone offering may, at its extreme, be accurately represented in the idea that at the heart of the inclusion project is ’the promotion of the delusion that being present in a school equates with being socially and educationally included.’[443] Evidence of disabled students within mainstream settings being subject to systematically reduced timetables[444] and the exponentially increased provision of human supports to disabled children in the form of (the, perhaps, unfortunately named) special needs assistants (SNAs)[445] are but two markers of difference which, arguably, may suggest the student adapting to the school rather than the other way around.[446] Within this context, perhaps the very concept of the special class is inherently an undermining of those entitlements associated with a human rights perspective, with the word 'special' operating as a code for a medical model bifurcation which emphasises otherness rather than inclusiveness.[447] By way of contrast, for disabled students as for every member of the human family, the markers of inclusion are experiential. For a young person, feelings of peer-group belonging, of being

---

[439] Jude Cosgrove, Caroline McKeown, Joseph Travers, Zita Lysaght, Orla Ni Bhroin, Peter Archer *Educational Experiences and Outcomes of Children with Special Educational Needs: Phase 2 – from age 9 to 13. A Secondary Analysis of data from the Growing Up in Ireland Study* NESC Research Report Number 25 (NESC, 2018)

[440] Jackie Jones *Second opinion: Interagency work doesn't have a hope without legislation* Jan 19th Irish Times, 2016

[441] William Kinsella, Joyce Senior, 'Developing Inclusive Schools: a Systemic Approach' (2008) 12 (5–6) International Journal of Inclusive Education 651

[442] see, for instance, Amanda Keddie, 'School Autonomy, Accountability and Collaboration: a Critical Review' (2015) 47 (1) Journal of Educational Administration and History 1

[443] Paul Cooper Barbara Jacobs *From Inclusion to Engagement. Helping Students Engage with Schooling Through Policy and Practice* (Wiley, 2011) 6

[444] Deborah Brennan Harry Browne *Education, Behaviour and Exclusion: the Experience and Impact of Short School Days on Children with Disabilities and Their Families in the Republic of Ireland* (Technological University of Dublin/Inclusion Ireland, 2019)

[445] there are now some 14,877 SNAs working within schools according to Department of Education and Skills *Education Indicators for Ireland* (DES, 2019)

[446] with specific reference to students' experience of SNAs see Anita Prunty, Maeve Dupont, Rory McDaid, 'Voices of students with special education needs (SEN): views on schooling' (2012) 27 (1) Support for Learning 29; Michael O'Keefe, 'Students with Moderate General Learning Disabilities Speak of Their Experiences in Mainstream Schools' (2011) 25 (1) REACH Journal of Special Needs Education in Ireland 39;

[447] Sarah Arduin, 'Implementing Disability Rights in Education in Ireland: An Impossible Task?' [(2013] 36 Dublin University Law Journal 93, 114

accepted and valued and of being able to participate in the life of the school and, especially, the experience of having friends are central.[448] Absent these common experiences it is suggested that students with disabilities are denied important opportunities to practice and extend real-time capacities for autonomy, citizenship and self-discovery. Absent these experiences students are denied opportunities to share in and learn from human diversity.

Turning from the special class to the special school itself, it is suggested that this model is explicitly demeaning to young people with disabilities, the very transitions by which most educational continuums are marked denied them because it has been decided they are *special*. It speaks too, perhaps, to an implicit sub-text that some schools are too academic to be able to properly accommodate students with special education needs and, even, that it would be unfair to *those* children to include them in a school which – unlike the special school – has no expertise in helping them learn. As NESC has phrased it:

> Parents accept this reality and move to other schools which have a more inclusive ethos. The result is that certain schools are perceived as inaccessible to students with special educational needs and these schools are not held accountable. [449]

Mc Keon theorises how some schools deploy references to their culture and their academic reputations as 'soft barriers' to including disabled children among their student cohort, suggesting the effect is debilitating, particularly in the post-primary sector.[450]

Underpinning all this, of course, are the legislative references to 'other students' and their putative disadvantage. It is suggested that these legislative pronouncements act as a control on disabled children, suggesting an ontological and hierarchical ordering of whose interests takes precedence. This dichotomy appears again in EPSEN where the entitlement of a child with special education needs to be educated in an inclusive environment is correlated negatively if, even in its *proposed* exercise, it interferes with 'the effective provision of education for children

---

[448] see, for instance, Cynthia Pinto, Ed Baines, Ioanna Bakopoulou, 'The peer relations of pupils with special educational needs in mainstream primary schools: The importance of meaningful contact and interaction with peers' (2019) 89 (4) The British Journal of Educational Psychology 818; Michael O'Keefe, *The Rarely Heard Voice: Students with Moderate General Learning Disability Speak of Their Experiences in Mainstream Schools* Doctoral Thesis (unpublished 2009); Mairin Kenny, Michael Shevlin, 'Normality and Power: Desire and Reality for Students with Disabilities in Mainstream Schools' (2007) 19 (2) Irish Journal of Sociology 105

[449] National Council for Special Education *Regulatory Framework on School Enrolment* (NESC, 2011) at 3

[450] David Mc Keon 'Soft barriers' – The impact of school ethos and culture on the inclusion of students with special educational needs in mainstream schools in Ireland' (2020) 23 (2)Improving Schools

with whom the child *is to be* educated' (emphasis added).[451] Arguably, the missing component indicated here is a sufficiently clear distinction – both at policy level and within the wider discourse – between inclusion and integration and, in particular, the identification of inclusion as a human right.[452] Were such an identification present, the emphasis shifts from competing rights to valuing human diversity, from perceptions of deficit to conditions of worth.

Yet, that much school –based education can often seem to invoke exclusion has long been a concern to educational theorists.[453] With its adult-centric, neoliberal focus on replicating what the teacher knows rather than on engaging creatively with what the student wants and needs to know, this form of education reinforces dominant ideologies and protects existing power structures and runs counter to the interests and potential of the underprivileged, the weak and the vulnerable.[454] Arguably, this is the form of education which the Supreme Court turned to and upheld in its majority view in Sinnott, a form which, it is submitted, is inimical to the diversity, non-discrimination and dignity ethos of the CRPD's article 24. That said, as Whyte theorises, the capacity of the Irish Constitution to sustain an individual claim for inclusive education is in doubt given that so much of the Irish education infrastructure is owned and controlled privately such that 'a decision by such a school to refuse to admit a student with disability may not come within the scope of the constitutional principle of equality.'[455]

This form of education constrains freedom; it is, in itself, oppressive.[456] The inclusion imperative – that is, conceptualising education for disabled people as a human rights issue – fundamentally challenges the existence of a dual educational system – the general and the special – on the basis that it rests on jaded notions of dependence and on stereotypical conceptions of disabled people as *other*. By its nature, a dual system is discriminatory and anti-republican, enshrining a particular form of un-freedom. It is prefaced on protecting privilege rather than on expanding opportunity and it constrains the moral capacity of the entire community to share in an ever-

---

[451] EPSEN S 2(b)

[452] Sarah Arduin 'Implementing Disability Rights in Education in Ireland: An Impossible Task?' [2013] 36 Dublin University Law Journal 93, 114

[453] see, for instance, John Holt *How Children Fail* (Pitman Publishing Company, 1964); Ivan Illich *Deschooling Society* (Penguin, 1973); Paulo Freire *Education for Critical Consciousness* (Seabury Press, 1973); Paulo Freire *Pedegogy of Freedom. Ehics, Democracy and Civic Courage* (Rowman & Littlefield, 1998)

[454] Paulo Freire *The Politics of Education. Culture, Power and Liberation* (Bergin & Garvey, 1985)

[455] Gerry Whyte 'Litigating the Right to Inclusive Education under Irish Law' in de Beco G, Quinlivan S, Lord JE (eds) *The Right to Inclusive Education in International Human Rights Law* (Cambridge University Press, 2019) at 500

[456] Freire (n 255)

expanding, ever-deepening understanding of education as fundamental to the practices of freedom.

5 Article 27 - Work and employment

5.1 Introduction

As well as in several regional human rights instruments, such as the European Social Charter[457] and the Additional Protocol to the American Convention on Human Rights,[458] the right to work is recognised as a fundamental human right in international documents such as the UDHR,[459] as subsequently affirmed in in the ICESCR,[460] and in CEDAW.[461] The underlying rationale in this might be said to seem quite simple. Having a job is an access point, *inter alia*, to having individual resources, to experiencing enhanced opportunities for social connectedness and personal agency in terms, for instance, of where one lives and how one lives. Employment prospects link clearly to educational attainments and can also confer cultural and political power, not least because the person who has secure employment may be thought of as the prototypical citizen who has the time and incentive to be actively engaged in civil society.[462] Viewed through a perhaps more intimate lens, freedom to work - that is to freely sell one's labour - is both a value in itself and the source of other societally esteemed values, such as those emblematised in having money, in having social respect, in having opportunities to learn intellectual and physical proficiencies and in this to experience both individual satisfaction and the respect of peers. To be a worker, a member of the workforce, is to, potentially, own one's own image as a productive, adult, useful, valued member of society. To be employed is to be in the world as a socially connected entity, it is to be among the included, it is to be *normal*. The sharp edge to this, however, is that, conversely, those adults who do not work may be regarded as lazy, parasitical, *abnormal*.

Emblematic of their exclusion, people with disability are significantly under-represented in the workforce.[463] In part because of this, both poverty and extreme poverty rates are considerably

---

[457] European Social Charter (revised) (ETS No. 163) Council of Europe; entry into force 1/7/1999

[458] Additional Protocol to the American Convention on Human Rights In The Area of Economic, Social and Cultural Rights 1988 ('Protocol of San Salvador')

[459] UDHR art 23

[460] ICESCR art 6

[461] CEDAW art 1

[462] Iain Wilkinson, 'Ulrich Beck' in Ritzer, G, Stepnisky J, (eds) *The Wiley-Blackwell Companion to Major Social Theorists*, vol 1 (Blackwell, 2011).

[463] Adrienne J Colella, Susanne M Bruyère 'Disability and Employment' in Zedeck S, (ed) *APA Handbook of Industrial and Organizational Psychology* Vol. 1 (American Psychological Association, 2011) 473–504

higher, globally, for persons with disabilities.[464] Hence, the economic argument, say, for instance, in the context of the United Nations Sustainable Development Goals,[465] for creating pathways to employment for persons with disabilities would seem unassailable.[466] However, employment is often also about much more than just monetary advantage. Within the inclusion paradigm the participation of persons with disability in employment, properly constituted and appropriately supported, yields to a panoply of individual and social goods, including reduction in social isolation, improved health,[467] diminished stress, individual fulfilment and an enhanced sense of agency and self-worth.[468]

The CRPD brings disabled people into a wider discourse on work and working conditions that has been at the heart of international efforts to create a more just society since the 1919 foundation of the International Labour Organisation (ILO), now embraced within the United Nations structure. Although not then utilising the language of human rights – notwithstanding that the ILO's inaugural Convention on reducing the working day to eight hours could clearly be framed in such terms[469] - there is a value in briefly situating the discussion of the CRPD's article 27 within the context of how work has already been articulated as a human rights issue. At international level, work has evolved as a complex issue and, perhaps more than any other right in the CRPD, there is need to contextualise article 27 within this wider frame. I do this particularly with reference to the more recent decent work agenda. I then proceed to theorise work and disability within a capitalist frame before discussing aspects of reasonable accommodation, citing an Irish case of some significance. I end this section with a republican perspective.

5.2 Main duties under article 27

In being required to recognise the right of persons with disabilities to work on an equal basis with the not yet disabled the state is enjoined to ensure equal labour rights and to address creatively those many barriers which, traditionally in modernity, act negatively against disabled people's work ambitions and deny so many the freedom to work. Based on equality and the

---

[464] World Health Organization. (2011). World Report on Disability

[465] United Nations Department of Economic and Social Affairs (2016) Global Sustainable Development Report

[466] this economic argument extends to benefits for employers too

[467] Esther Curnock, Alastair H Leyland, Frank Popham 'The impact of health on employment and welfare transitions for those receiving out-of-work disability benefits in the UK' (2016) 162 Social Science and Medicine 1

[468] Ernesto Castaneda, Casey Chiapetta, Laura Guerrero, Alma Hernandez, 'Empowerment through work: the cases of disabled individuals and low-skilled women workers on the US-Mexico border' (2019) 34 (3) Disability & Society 384

[469] ILO Hours of Work (Industry) Convention, Convention No. 1, 28 November 1919

prohibition of discrimination, what is expected of the state is no small task: the creation of a labour market and work environment that is 'open, inclusive and accessible to persons with disabilities.'[470]Applying to both the public and private sectors, and addressing discrimination in a wide-ranging way to include conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe working conditions,[471]this prohibition of discrimination is understood to have immediate effect as does the provision of reasonable accommodation.[472] In addition, the article references 'just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value' as well as, *inter alia,* protection from harassment, the redress of grievences, trade union rights, general technical and vocational guidance and career advancement and self-employment opportunities. States must also ensure that 'persons with disabilities are not held in slavery or in servitude and are protected, on an equal basis with others, from forced or compulsory labour.' [473] The provisions – eleven in all – are supported by other articles in the Convention, most notably article 9 (accessibility) which requires the removal of barriers to accessibility, inclusive of physical impediments to workplaces, transportation, communications and information technologies and housing.

5.3 The right to work within the general UN schema

The right to work, within the United Nations human rights framework, operates from two interdependent normative principles, that people have a right to work as a source of livelihood and that work is an inherent means of advancing individual dignity and self-actualisation. To meet the first principle, the UDHR ties this dignity to having access to the type of work which provides a just and favourable remuneration with equal pay for equal work.[474] As to enlarging dignity, this derives from being able to freely chose an employment wherein, moreover, there are just and favourable conditions and protections against unemployment, [475] equal opportunities for promotion, based solely on seniority and competence, as well as rest provisions, including paid holidays. [476]

---

[470] CRPD art 27(1)

[471] CRPD art 27(1)(a); for an account of the extensive nature of the discrimination covered see Marco Fasciglione, 'Article 27 of the CRPD and the Right of Inclusive Employment of People with Autism' in Valentina *and Employment* (Springer, 2015) 145 - 170

[472] see Andrea Broderick, Della Ferri *International and European Disability Law and Policy* (Cambridge University Press, 2019)

[473] CRPD art 27(2)

[474] UDHR art 23

[475] UDHR art 23

[476] ICESCR art 7

Among all of the United Nation's human rights instruments the most extensive treatment of work as a human right is found in the ICESCR,[477] not least because the rights therein contained are neither restricted to a specific group[478] nor are they reliant on the presence of discrimination in order to be triggered.[479] Hence, article 6 of the ICESCR recognises the right to work of 'everyone,' inclusive of the right to gain a living by work which is freely chosen or accepted. Article 6 also places a responsibility on state parties to take appropriate steps to ensure the full realisation of this individual right, including via the provision of 'technical and vocational guidance and training programmes, [and] policies and techniques to achieve steady economic, social and cultural development and full and productive employment under conditions safeguarding fundamental political and economic freedoms to the individual.' Article 7 fleshes out the right in terms of the 'just and favourable conditions' concerning work which should be experienced and article 9 recognises the right of everyone to social security, including social insurance. The special protection needs of mothers for a reasonable period of, preferably paid,[480] leave before and after childbirth is recognised in article 10(1) as are, in article 10(3), the needs of children in respect of being safeguarded from work that might damage their normal development.

5.4 The decent work agenda

While the 1994 General Comment of the Committee on Economic, Social and Cultural Rights (CESCR) addresses specific barriers disabled people face in respect of work,[481] the same Committee's General comment 18, adopted in 2005, represents the most authoritative interpretation to date of the ICESCR article 6 right to work, its scope and its content.[482] Taken together, these two General Comments are crucial in understanding the broader decent work context in which CRPD article 27 must be situated and from which it draws resonance.

Focusing on its normative content and describing that in its interpretation of article 6, the General Comment 18 intends to lay down 'specific legal obligations rather than a simple

---

[477] a much more restricted range of important labour rights also appear in ICCPR: prohibitions on slavery (art 8(1)) and on servitude (art 8(2)) and on forced labour (art (article 8(3)) and freedom of association, including the right to form and join trade unions (art 22)

[478] such as those contained in the CRC or in the Migrant Workers Convention

[479] as in respect of CEDAW or ICERD

[480] ICESCR art 10(2)

[481] CESCR General Comment No.5: Persons with Disabilities. Adopted 9 December 1994

[482] CESCR General Comment No. 18: The Right to Work (article 6 of the Covenant). Adopted 24 November 2005

philosophical principle'[483] the Committee assert that the work specified in the article 'must be decent work.'[484] Asserting that the right to work is fundamental, the Committee says it should not be interpreted as an absolute and unconditional right to obtain employment. Rather, the General Comment reminds state parties of their obligation to assure individuals their right to freely choose or accept work, including the right not to be unfairly deprived of work or in any way forced to take up employment. Further, the right is both simultaneously individual and collective, this latter dimension being provided for in the ICESCR's article 8 in respect of the right to join trade unions and the right to strike. The Committee recognises the gateway status of article 6, acknowledging that the right is central to an individual being able to live in dignity and, 'insofar as work is freely chosen or accepted, to his/her development and recognition within the community.'[485]

The General Comment lays out the normative content of the right to work in the overarching context of there being an obligation on state parties to ensure that the work specified in article 6 must be decent work. Decent work is defined as 'work that respects the fundamental rights of the human person as well as the rights of the workers in terms of conditions and of work safety and remuneration.'[486] Decent work also 'provides an income allowing workers to support themselves and their families' and it is consistent with 'respect for the physical and mental integrity of the worker in the exercise of his/her employment.'[487] In this context too, the Committee references other international instruments, in particular ILO Convention No. 29 (concerning forced or compulsory labour), article 4 of the UDHR and article 8 of the ICCPR (both on the prohibition of slavery), and article 4 of ILO Convention 158 concerning termination of employment and, specifically, the requirement to provide valid grounds for dismissal and provision of legal redress in respect of unlawful dismissal. The responsibilities to provide adequately for decent work and not merely *any* work are further elaborated in terms of the Committee's recognition of a duty on state parties to disrupt, legislatively and otherwise, the existence of their economies' informal sectors – the unregulated nature of these being such that workers forced by circumstances into participating in them are without lawful protections. As a corollary to this, note is taken of the Committee's endorsement of the view[488] that the right of everyone to the opportunity to gain a living by work which is freely chosen is not realised 'where

---

[483] *ibid* at para 2

[484] *ibid* at para 6

[485] *ibid* at para 1

[486] *ibid* at para 6

[487] *ibid* at para 7

[488] expressed in CESCR General Comment No. 5: Persons with Disabilities (adopted 9 Dec 1994) at para 21

the only real opportunity open to disabled workers is to work in so-called 'sheltered' facilities under substandard conditions.'[489]

Having set the context, the General Comment next turns to elaborating on the right in greater detail, asserting that the exercise of work 'in all its forms and at all levels' requires three essential and interdependent elements, 'implementation of which will depend on the conditions present in each state party:' availability, accessibility and acceptability and quality.[490] Availability references the onus on state parties to have specialised services in place to assist and support individuals in identifying and finding available employment, supporting the progressive realisation of the exercising of the right to work, adopting measures, as quickly as possible, aimed 'at achieving full employment.'[491] In further expanding on this general legal obligation the Committee is conscious, that, from state to state, there are inevitable constraints arising from limited resources on reaching this goal. However, the existence of such limited resources cannot function as a defence against doing nothing. Hence, the Committee reminds states of General Comment No 3[492] and its assertion that the onus on state parties to 'take steps' towards a right's progressive realisation means doing so in a timely, deliberate, concrete and clear manner - inclusive of legislative action – and, crucially, 'targeted towards the full realisation of the right to work.'[493]

The accessibility requirement has three dimensions, all interlinked in respect of opening up access to the labour market. First, states must prohibit discrimination in access to and maintenance of employment across the range of grounds set out in articles 2(2) and 3 of the Covenant.[494] Requiring states to proactively design and implement appropriate national policies to promote equality of opportunity and eliminate work-based discrimination,[495] the Committee notes that such initiatives, including legislative initiatives, are unlikely to have more than minimum resource implications. Moreover, the Committee also reminds, in this context, again

---

[489] *ibid* at para 17

[490] ibid at para 12

[491] *ibid* at para 19

[492] CESCR General Comment No. 3 The Nature of State Parties' Obligations (article 2, para 1 of the Covenant)

[493] CESCR General Comment No. 18: The Right to Work (article 6 of the Covenant) at para 19

[494] *ibid* at para 12(b)(i); the full range of grounds as set out in the ICESCR are as follows: race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation or civil, political, social or other status where such discrimination has the intention or effect of impairing or nullifying exercise of the right to work on a basis of equality.

[495] here the Committee references ILO Convention No. 111, Concerning Discrimination in Respect of Employment and Occupation

consistent with General Comment No 3, that there is a particular requirement on states – regardless of even severe resource constraints – that 'disadvantaged and marginalised individuals and groups must be protected by the adoption of relatively low-cost targeted programmes.'[496] Second, accessibility has a particular meaning in respect of persons with disabilities and, in this respect the General Comment references General Comment No. 5 and, in turn, its citing of the ILO insight that the physical barriers which inhibit the employment participation of persons with disabilities exist both within and beyond workplaces, encompassing not just inadequate workplace design but also to be found in areas such as housing and transportation.[497] Third, the Committee is clear that the concept of accessibility includes 'the right to seek, obtain and impart information on the means of gaining access to employment,' this requiring that stares must set up data networks and other information sharing facilities in respect of access to the employment market at local, regional, national and international levels.[498]

The acceptability and quality element of the right to work, as further elaborated in articles 7 and 8 of the Convention, again relates to the decent work requirement referencing the right to just and favourable conditions of work, inclusive of safe working conditions, the right to form trade unions and the right to freely choose and accept work.

Each of these three normative elements to the right to work - availability, accessibility and acceptability and quality – and the need for state parties to be particularly aware of their application in respect of particularly vulnerable groups in society – are further underscored by the Committee's invocation of the standard obligations typology used in relation to fundamental human rights: to respect, protect and fulfil (this latter obligation meaning to provide, to facilitate and to promote).[499] Hence, the Committee describes a state's respecting the right to work as a function of not denying or limiting equal access to decent work for all persons, particularly those who belong to especially disadvantaged and marginalised groups. There is an especial onus in this regard for states to take 'effective measures, in particular legislative measures, to prohibit labour of children under the age of 16' and states 'must adopt effective measures to ensure that

---

[496] CESCR General Comment No. 18: The Right to Work (article 6 of the Covenant) at para 12(b)(i)

[497] CESCR General Comment No. 5: Persons with Disabilities (adopted 9 Dec 1994) at para 22

[498] CESCR General Comment No. 18: The Right to Work (article 6 of the Covenant) at para 12(b)(iii)

[499] associated with the moral philosopher, Henry Shue - who analyses the duties owed collectively to each person's basic human rights in terms of avoidance of a violation, protection and aid, claiming no right could be fully guaranteed unless all three duties are met – the typology's adaption as the respect, protect and fulfil categories has become foundational in economic and social rights jurisprudence. See Henry Shue *Basic Rights: Subsistence, Affluence and U.S. Foreign Policy* (Princeton University Press, 1996); see also Jack Donnelly *Universal Human Rights in Theory and in Practice* (Cornell University Press, 2013)

the prohibition of child labour will be fully respected.'[500] The obligation to protect imposes on states a duty to effectively intervene to ensure non-state actors are prohibited from engaging in discriminatory or exploitative work-based practices. In addition, protection also encompasses taking positive action to ensure equal access to work and training and 'to ensure that privatization measures do not undermine worker's rights.'[501] Again, the prohibition on forced or compulsory labour is mentioned in this context but, interestingly, so too is the requirement that state actions designed to increase the flexibility of labour markets 'must not render work less stable or reduce the social protection of the worker.'[502]

The obligation to fulfil the right to work when individuals or groups, for reasons beyond their control, lack the capacity to directly realise the right themselves requires the state to take wide-ranging actions. The state must formulate and implement a comprehensive and sufficiently resourced employment policy in line with the requirements of ILO Convention 122, in 'stimulating economic growth and development, raising levels of living, meeting manpower requirements and overcoming unemployment and underemployment.' [503] The right to work must be recognised in national legal systems and a national policy must be adopted on the right. Compensation systems for the loss of employment must be set up and adequate resources put in place to reduce the unemployment rate, in particular unemployment 'among women, the disadvantaged and the marginalised.'[504] Further, a national mechanism to 'monitor implementation of employment strategies and national plans of action'[505] should be established, these to contain numerical targets, specific timeframes and provisions for the involvement of civil society, including experts on labour issues, the private sector and international groups.

The General Comment addresses globalization with quite a significant suggestion that states 'should recognise the essential role of international cooperation'[506] in respect of realising the right and 'should endeavour to promote the right to work in other countries as well as in bilateral and multilateral negotiations.'[507] Indeed, the inference here seems to be that to enter into an agreement with other states, international organisations or private actors which is inconsistent with international obligations in respect of the right is a violation of the right.[508] More, for those

---

[500] CESCR General Comment No. 18: The Right to Work (article 6 of the Covenant) at para 24
[501] CESCR General Comment No. 18: The Right to Work (article 6 of the Covenant) at para 25
[502] *ibid*
[503] ILO Convention 122 Employment Policy 1964 article 1
[504] CESCR General Comment No. 18: The Right to Work (article 6 of the Covenant) at para 26
[505] *ibid* at para 38
[506] *ibid* at para 29
[507] *ibid* at para 30
[508] see Colm O'Cinneide The Right to Work in International Human Rights Law. In Virginia Mantouvalou (ed) *The Right to Work, Legal and Philosophical Perspectives* (Hart Publishing, 2015) 100 - 122

states in a position to influence the policies and practices of international financial institutions such as the World Bank or the International Monetary Fund, the Committee contends that this influence should be exercised in ways consistent with protecting and expanding the right to work. Further, any state which either by omission or commission, is not operating to realise the right to the maximum of their available resources is in violation of the right.

5.6 Capitalist culture and disability

Work's place as 'a central axis of the social order' [509] is clearly attested to and supported in General Comment No. 18. However, the Comment does not engage with wider questions such as whether the decent work it espouses can really be provided in the contemporary global economy, at least in the type of sufficient amount necessary. Moreover, by asserting the right in international law that work be available, accessible and decent– and by suggesting that this standard cannot be relaxed even in times of economic crisis - the Comment could be read to impute a corresponding right not to be forced to accept *indecent* work. Indeed, whether or not this is true, even in theory, the Comment is very clear that the right to freely choose or accept work implies 'not being forced in any way whatsoever to exercise or engage in employment.'[510] The ILO defines forced work as work 'exacted from any person under the menace of any penalty and for which the said person has not offered himself voluntarily.'[511] Hence, this aspect of the right to work may mean that governments that seek to incentivise employment take-up by tying job refusal to, say, the removal of unemployment benefit are in breach of the right.[512] Given the onus on states to ensure work is available there seems an obvious tension here: 'states must adopt, as quickly as possible, measures aiming at achieving full employment.'[513]

By setting the bar at a concept of decent work, what is being signalled to is something important about the interplay between employment standards and the core of human dignity, as experienced in and expressed through the medium of work. But, as a universal norm, the degree to which choice is a viable construct in separating out decent from non-decent work is dubious, not least when the choice is really between having, say, the precarious economic advantage a

---

[509] Gary Mundlak Working Out the Right to Work in a Global Labour Market. In Virginia Mantouvalou (ed) *The Right to Work, Legal and Philosophical Perspectives* (Hart Publishing, 2015) at 292

[510] CESCR General Comment No. 18: The Right to Work (article 6 of the Covenant) at para 6

[511] ILO Convention No. 29 Concerning Forced or Compulsory Labour art 2

[512] Nicolas Bueno, 'From the right to work to freedom from work: introduction to the human economy' (2017) 33 (4) International Journal of Comparative Labour Law and Industrial Relations 463. Of interest here, by way of analogy, may be the concern shown by the Committee in concluding observations about labour duties being included as part of prison sentences, see, for instance, CESCR Concluding observations on the 3rd periodic report of Japan (10 June 2013) para 14

[513] CESCR General Comment No. 18: The Right to Work (article 6 of the Covenant) at para 19

job in the informal sector can confer and having no job at all, especially in states where the welfare model is under-developed or inadequate. These are people caught up in liminality, living in what Beck describes as 'the political economy of instability.'[514] The dilemma here turns on the stark fact that ours is a world where so many millions of people, the great majority of them in the world's poorest places, are experiencing what little work they may have or aspire to have as, perhaps, at best, an unfulfilling necessity and, at worst, a relentlessly destructive drudgery. Marx's concept of alienation may offer something helpful here and his image of the worker degraded to 'the level of being an appendage to the machine.'[515] Marx conceptualises work as much more than merely instrumental in character but, rather, as *the* quintessential human activity – a deep need, the fulfilment of which, in its natural state, brings meaning and contentment to the individual worker. But all this changes when, through the machinations of capitalist industrialisation, the worker no longer sees work as 'the satisfaction of a need but a mere means to satisfy needs outside itself.'[516] In this reworking of the natural, the worker now experiences work only as something dehumanised and appropriated for (another's) profit. Within this understanding, work becomes dominating and oppressive rather than liberating. The worker is alienated or estranged not just from the activity of work and what work produces but also from other human beings and from that shared human essence which Marx terms 'species being.'

Marx uses 'species being' to differentiate human kind from all other life, summarised as the rich textures of possibility and potential which human beings embody and express in their capacity, given freedom of choice, to consciously and creatively respond to their environment by making things which satisfy individual and collective need. In this conceptualisation labour, then, is not just what humans *can* do; it is what humans *must* do. Labour is how humans find meaning, how they express empathy and build community. Labour is how 'human beings interact and shape their world and in turn shape their humanity.'[517] But this vision of generative labour is swept aside by highly mechanised industrialisation and, indeed, the neoliberal project. Instead, what occurs is an inversion of reality: value comes to reside in things rather than in people. As Marx puts it, the worker 'is no longer the principle agent of the production process: he exists alongside it.'[518]

---

[514] Ulrich Beck *The Brave New World of Work* (Polity Press, 2000) 2

[515] Karl Marx *Capital. A Critique of Political Economy* volume 1 (Vintage, 1977) 799

[516] Karl Marx *Economic and Philosophical Manuscripts* vol 3 (International Publishers, 1975) 274

[517] Timothy Weidel The 'ugliness' of economic efficiency: technology, species-being and global poverty 8 1 Ethics & Global Politics (2015) no page

[518] David McLellan *Marx's Grundrisse* (Paladin, 1973) at 165

The value to this discussion of Marx's thoughts on alienation of labour and, in particular, his thinking about species being is amplified by Morgan who characterises capitalism as 'systemically weird' because we rarely stop to consider 'just how weird it is that the knowledge, skills and resources exist to do something and yet we say that it cannot be done because a system that operates according to the distribution of tokens carrying notional monetary value tells us we cannot do that something.'[519] In this context species being functions as 'a reminder that there is a human who can flourish or be harmed and the systemic weirdness of capitalism fundamentally means that human well-being is not an explicit concern of capitalism in general.'[520]

Taking this human being to be a person with disabilities, capitalist culture, perhaps, particularly in circumstances of neoliberalism, has not been kind. The capitalist ethic produces specific forms of social relations which can be summarised in terms of the productive and the unproductive person. Identified, in many instances, as the latter and pathologised in terms of their perceived inability to meet the demands of waged labour, modern industrialised capitalism starts to institutionalise disabled people. Indeed, Stiker describes only one overarching institution impulse: the rehabilitative. Rehabilitation seeks to return the disabled person 'to ordinary life, to ordinary work.'[521] Of course, the conceit here is that disabled people are not already – and always have been – part of ordinary life and, indeed, for most of human history, part of ordinary work.

That disabled people are not *now* part of ordinary work is, however, another matter. Ireland's National Disability Authority (NDA) – drawing on the 2016 Census data - report that while 72.8% of people without a disability aged twenty to sixty four are in work, the comparable figure of persons with a disability is 36.5%. Within this figure, only 17.3% or one in six of people with an intellectual disability have a job.[522] In respect of persons with vision impairment their labour market experience is startlingly similar to that of the general population of disabled people with half of those vision impaired people who are able to work not being in paid employment.[523]

Worldwide, disabled people have a significantly lower presence in the employment statistics and what slight variation there is may likely be accounted for in terms of data collection

---

[519] Jamie Morgan, 'Species Being in the Twenty-First Century' (2018) 30 (3) Review of Political Economy 385

[520] *ibid* 391

[521] Henri-Jacques Stiker *A History of Disability* (The University of Michigan Press, 1999) 128

[522] see www.nda/Resources/Factsheets

[523] Jim O' Leary *The Labour Force Status of People with Visual Impairment* (ChildVision, 2019)

anomalies or the type of definitions in use. An Organisation for Economic Co-operation and Development (OECD) report on thirty two states finds that one in four of disabled people with high support needs and one in two persons with moderate support needs are in employment and that, taken together, the employment rate for disabled people is 27 percentage points lower than for non-disabled people. More, this figure has remained relatively consistent for the last decade.[524]

For Oliver and Barnes this exclusion of disabled people from the world of paid work links directly to the onset of industrial capitalism and the perceived inability of disabled workers to submit to the highly disciplined, heavily mechanised processes now in use.[525]Like Stiker, they trace the mass institutionalisation of disabled people to industrial capitalism, separating people with disabilities from their own class and communities and segregating them away as social and educational problems.

5.7 Reasonable accommodation

Of profound importance in advancing the human rights model of disability is the idea of reasonable accommodation,[526] a concept which makes its first international law appearance in the CRPD.[527] The concept is defined in CRPD article 2 (definitions) to mean

> necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

As it relates to employment and work, Broderick advises that while there is no duty on states to ensure provision of all sought accommodations the use of the word ‘appropriate’ indicates that measures deemed *effective* in allowing the enjoyment or exercise of human rights are likely to come within the ambit of the duty.[528] As to further clarifying effectiveness, Broderick suggests

---

[524] Organisation for Economic Development and Co-operation *Disability, Work and Inclusion: Mainstreaming in All Policies and Practices* (OEDC, 2019)

[525] Michael Oliver, Colin Barnes, *The New Politics of Disablement* (Palgrave Macmillan, 2012); for a contrast with more agrarian societies see Eda Topliss *Provision for the Disabled* (Blackwell, 1979)

[526] Anna Lawson Duties to Make Adjustments and Human Rights. In Anne Lawson (ed.) *Disability and Equality Law in Britain: The Role of Reasonable Adjustment* (Hart Publishing, 2008)

[527] Janet E Lord Rebecca Brown ‘The Role of Reasonable Accommodation in Securing Substantive Equality for Persons with Disabilities: The UN Convention on the Rights of Persons with Disabilities’. in Rioux MH, Basser LA, Jones M. (eds) *Critical Perspectives on Human Rights and Disability Law* (Martinus Nijhoff Publishers, 2011) 273 - 307

[528] Andrea Broderick *The Long and Winding Road to Equality and Inclusion for Persons with Disabilities* (Intersentia, 2015)

of paramount concern will be that a measure promotes equality and eliminates discrimination and, further, that it 'cater for the inherent dignity of a disabled individual.'[529] Broderick continues:

> [h]uman dignity is concerned with integrity, empowerment and self-respect. In considering the extent to which a particular accommodation promotes full participation and maximises inclusion in society, account must be taken of such factors as privacy, autonomy, comfort and self-esteem. [530]

Of course, the dignity of a duty-bearer is also of significance and, so, assessments as to any possible burden on a putative employer must 'be sensitive to the particular circumstances' of that employer.[531] This said, the proven inability to bear one burden – which may or may not be monetary – is not necessarily, the end of the matter. The idea of ongoing dialogue between claimant and employer is central and the employer must remain open to exploring other, less onerous, options to accommodate the disabled person.[532] Thus, unlike the accessibility principle – which is a duty on state parties – reasonable accommodation arises in the context of an individual person and has to engage at that intimate level. Nonetheless, as Lawson reminds

> the more accessible an environment or organisation is, the less likely it is that aspects of its structure or functioning will place a disabled person at a disadvantage that calls for reasonable accommodation.[533]

Notwithstanding that the CRPD Committee has made many recommendations that national legislatures enshrine reasonable accommodation legislatively at local level and, where this already exists, to ensure its efficacy it has not often sought to guide how the provision be implemented in workplaces themselves.[534]

---

[529] *ibid* 162

[530] *ibid* 163

[531] Anna Lawson Reasonable Accommodation in the Convention on the Rights of Persons with Disabilities and Non-discrimination in Employment: Rising to the Challenges? In Charles O'Mahony Gerard Quinn (eds.) *Disability Law and Policy: An Analysis of the UN Convention* (Clarus Press, 2017) 363

[532] see, for instance, Lucy-Ann Buckley, Shivaun Quinlivan, 'Reasonable accommodation in Irish equality law: an incomplete transformation' (2021) 41 (1) Legal Studies 19

[533] Anna Lawson Reasonable Accommodation in the Convention on the Rights of Persons with Disabilities and Non-discrimination in Employment: Rising to the Challenges? In Charles O'Mahony Gerard Quinn (eds.) *Disability Law and Policy: An Analysis of the UN Convention* (Clarus Press, 2017) at 366

[534] see, for instance, Ilias Bantekas Facundo Pennilas Stefan Tromel Article 27 Work and Employment. In Ilias Banktekas Michael Ashley Stein Dimitris Anastasiou (eds.) *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 764 - 800

5.6 Irish case law

In Irish legislation, reasonable accommodation (or appropriate measures) has a pre-Convention presence by virtue of section 16 of the Employment Equality Acts 1998 – 2015. However, in *Re Article 26 and the Employment Equality Bill*[535]a requirement that the costs of reasonable accommodations be borne by employers was considered by the Supreme Court and deemed an affront to the constitutional rights of employers. This required the Bill to be substantially altered such that the scope of permitted accommodations could now only impose a nominal cost on an employer, overturning a previous test which required 'undue hardship.' This reference to 'nominal' was subsequently replaced in 2004 with a reference to 'disproportionate burden' – this change arising from a requirement under EU law, specifically the Equality Directive 2000.[536]

The *Employment Equality Acts* 1998 - 2015 set out nine grounds, including disability, under which an employer cannot discriminate against an employee or potential employee. In respect of reasonable accommodation, the most significant case to date is the Supreme Court judgement in *Nano Nagle v Daly*.[537] A heavily litigated case, the facts are that Maire Daly, a Special Needs Assistant (SNA) employed by the Nano Nagle school[538] suffered a serious injury while on holiday which resulted in her becoming a wheelchair user. Following an intensive period of rehabilitation, Ms Daly sought to return to her work whereupon the school's board of management – having reviewed a series of medical reports – determined that Ms Daly no longer had the capacity to discharge or any future prospect of discharging her SNA duties and they terminated her employment. Ms Daly framed a claim to the (then) Equality Tribunal claiming a violation of her right to reasonable accommodation ('appropriate measures') under section 16 of the Employment Equality Acts.

The Equality Tribunal (now the WRC) found in favour of the school but Ms Daly's appeal to the Labour Court was upheld in her favour on the basis that her employer, the board, had not given sufficient consideration to a redistribution of tasks and duties among the school's entire SNA cohort sufficient to remove those aspects of the role Ms Daly could no longer fulfil. Appealed to the High Court on a point of law, Noonan J endorsed the Labour Court finding but a further appeal to the Court of Appeal sided with the school, setting aside the Labour Court

---

[535] *Re Article 26 and the Employment Equality Bill* [1997] 2 IR 321

[536] Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation; note that this change applies in the employment context only, the 'nominal cost' test still applies to goods and services

[537] Nano Nagle School v Daly [2019] IESC 63

[538] it may be interesting to note that the Nano Nagle school was a special school for children with disabilities

determination. Drawing a distinction between 'tasks' and 'duties' the Court of Appeal held that while an employer had to consider a redistribution of the former no such duty existed in respect of the latter, 'duties' being identified as essential functions. Were this where the case ends it is likely that a very restrictive reading of section 16 would now be in force, one focusing perversely on a disabled person's inabilities rather than on her abilities subject to the provision of reasonable accommodation. Such an interpretation would appear to run 'counter to the purpose of introducing this legal duty into Irish employment equality law.'[539]

A further appeal to the Supreme Court clarifies that the Court of Appeal's interpretation of section 16 is an overly restrictive and narrow reading, the Supreme Court holding that there is a positive (that is, mandatory) duty on employers to provide reasonable accommodation and that the only limiting factor is if doing so would impose a disproportionate burden on the employer. The supposed distinction between tasks and duties is held by MacMenamin J. to be an irrelevance, stating that in providing reasonable accommodation there is no prohibition on an employer redistributing – or, indeed, eliminating - core 'duties' or non-core 'tasks.' That said, the Court opines that to completely redesign a job to facilitate a claimant would likely constitute a disproportionate burden, the relevant test being reasonableness and proportionality. Further, the Court recognises that while the absence of consultation with a disabled employee cannot constitute, of itself, discrimination in terms of assessing what may or may not be reasonable accommodation, to have such consultation would be prudent and indicate transparency and fair procedure. In taking the view that dialogue with a disabled claimant is a good thing the Court partially endorses a CRPD Committee finding that reasonable accommodation includes dialogue with the disabled person concerned.[540] As an addendum to this case it is noted that the CRPD does not entail any qualification to reasonable accommodation by way of reference to essential job functions, indicating that the judgement is likely to be cited widely beyond Ireland.[541]

5.7 A republican reading

Within the contemporary republican canon, employment has become a particular area of interest, including genres focusing on workplace democracy[542] and a specifically socialist

---

[539] Shivaun Quinilvan, Charles O'Mahony, 'The Irish Supreme Court Judgement in Nano Nagle v Marie Daly: a Saga of Litigation' (2019) 70 (4) Northern Ireland Legal Quarterly 505

[540] UN Committee on the Rights of Persons with Disabilities, *General Comment No 6: Equality and Non-discrimination* (2018) CRPD/C/GC/6 at para 26(a)

[541] see Desmond Ryan, Mark Bell, 'Disability, Reasonable Accommodation and the Employer's Obligation: Nano Nagle School v Daly' (2020) 83 (5) Modern Law Review 1059

[542] see Daniel Jacob, Christian Neuhauser, 'Workplace Democracy, Market Competition and Republican Self-Respect' [2018] 21 Ethical Theory and Moral Practice 927

republican theorising.[543] It is straightforward to understand why. Workplaces are inherently sites where domination is likely. Indeed, Gourevitch fashions a compelling narrative around a strand of activist labour republicans, originating from within America's 19th Century slave culture, who shake off dependence and 'transform themselves into agents capable of collective action.'[544] In the process, Gourevitch also brings to awareness how the contemporary republican vision of freedom maps easily onto the concerns of modern industrial capitalism both as a practice which alienates labour in general and relegates disabled people to an inferior status. Gourevitch's idea here of 'structural domination' is useful and I return to it below.

Concern with work as a macro (read economic) issue is not unique to communists, socialists or, for that matter, republicans. Arguably at odds with current Western economic reality, and neoliberalism in particular, Rawls' vison of liberalism's just society is one in which an elite are prohibited from controlling the economy – and, thus, politics too – by ensuring that wealth and ownership of the means of production are dispersed widely, ever mindful 'to assist those who lose out through accident or misfortune.'[545] This contrasts notably with Pettit's position, which holds that, of itself, an unequal property system is not a source of domination.[546] Pettit contends that while such inequality may very well restrict people in terms of what they might want to do - 'under the existing property regime you have more opportunities than me to enjoy our common status as free citizens'[547] – this restriction does not mean the wealthier person is in a position to dominate another. That said, there is recognition that in circumstances where there is a glut of possible workers there may have to be a way of equalising the playing field so that an employee could not fall foul of an arbitrary decision by an employer to terminate employment.[548]

Here, from Pettit's perspective, the key issue is that of socioeconomic independence, an argument developed by him and others in the context of promoting a basic income.[549] Access to such a basic income permits un-dominated choice on the part of the worker, the theory goes, on the basis that its existence serves as counterweigh to an employer's arbitrary abuse, perhaps

---

[543] see, for instance, James Muldoon, 'A Socialist Republican Theory of Freedom and Government' (2022) 21 (1) European Journal of Political Theory 47; Tom O'Shea, 'Socialist Republicanism' (2020) 48 (5) Political Theory 548

[544] Alex Gourevitch *From Slavery to the Cooperative Commonwealth* (Cambridge University Press, 2015) 183

[545] John Rawls *Justice As Fairness: A Restatement* (The Belknap Press, 2001) 139

[546] Philip Pettit 'Freedom in the Market' (2006) 5 (2) Politics, Philosophy & Economics 131

[547] *ibid* 140

[548] Philip Pettit A Republican Right to Basic Income? (2007) 2 (2) 2007 Basic Income Studies 1

[549] see *ibid*; David Casassas 'Basic Income and the Republican Ideal? Rethinking Material Independence in Contemporary Societies' (2007) 2 (2) Basic Income Studies

particularly at the point of contract negotiation. Indeed, Pettit contends that in order to ensure a resilient freedom access to a basic income must be unconditional (although he also argues that such an income must not be so generous that it distorts the market and disincentives workers to work). Gourevitch takes issue here, however, with Pettit. Introducing the concept of structural domination, Gourevitch suggests that the existence of private property is, inevitably, a source of un-freedom for those who, in their *necessity*, are commodified by the system. Hence, the argument that

> the labourer is not a product of his situation vis-à-vis a *specific* employer, but rather of his dependence on *some* employer or another for livelihood.[550]

So, while Pettit envisages a worker eschewing domination by simply up-stakes and moving to another job or availing of a universal basic income safety net, labour republicans see a systemic problem that axiomatically visits un-freedom on workers and makes 'them vulnerable to minimal shocks – illness, loss of a family member, a reduction in production needs.'[551]

Intuitively, the labour republican view here seems more of a fit with modern capitalism. Indeed, it also seems to better situate the circumstances of so many people with disabilities both within and on the periphery of today's labour market. The problem, as I construe it, is that absent a sufficient number of employers not just willing but *vying* to employ disabled people those disabled people wishing to work could well find themselves in situations of precarity and dependence. A basic income– assuming it exists – does nothing for these people except, perhaps, offer some compensation for an institutionalised discrimination that permits employers *not* to employ disabled persons. Thus for disabled people, the more pressing questions from a republican perspective must be as follows. How might the state dis-incentivise employers from practicing an institutionalised discrimination while, at the same time, working with disabled people to create the sorts of solidarities that permitted 19th Century American slaves to act within a collective dignity to free themselves from the structural, psychological and attitudinal dimensions of domination and recast themselves as entitled workers? In essence, there is in this a call for a muscular ethic of virtue, an invitation to find ways to incentivise self-interested employers to act virtuously and to consciously break the taboos that keep so many people with disabilities outside the labour market. This is likely to also embrace welfare to

---

[550] Alex Gourevitch 'Labour Republicanism and the Transformation of Work' (2013) 41 (4) Political Theory 591, 602

[551] Fausto Corvino 'Republican Freedom in the Labour Market: Exploitation Without Interpersonal Domination' (2019) 66 (158) Theoria 103, 108

(decent) work initiatives, embracing short-term policy interventions alongside the need for well-thought through long-term structural reforms, including a wide provision of personal assitance. In terms of both, a republican perspective is posited to be valuable, for instance in terms of justifying positive discrimination approaches underwritten by cogent law.

But, while this law must recognise the particular disadvantages disabled people face in terms of employment it must, also, be alive to the realities of a neoliberalism which universalises worker vulnerabilities in its deification of the market as the ultimate determinant of worker freedom. Within the neoliberal frame, this freedom is not compromised by economic necessity – say, that the worker's family is starving - any more than it is by a natural disaster.[552] The idea of the *free* person and the *free* market merge and the role of the state becomes

> to propel the 'willing' and coerce the 'unwilling' into adopting, practicing and regulating their *individual* behaviour in favour of 'free' market competition.[553]

If freedom is not compromised by necessity – indeed, if necessity is repackaged as a spur, a drive to achieve economically – values of participation, representation and inclusion, all central to the realisation of the Convention, become subsumed too into a perspective that the moral worth of the individual is, essentially, caught up with – and expressed through - the economy. Hence, neoliberalism's disdain for any form of solidarity which might seek to presume on the market's indulgence. The free market replaces the free *polis* as the ultimate determinant of the common good and egalitarian ambitions and structures fall away just as the powers and privileges of the economic elite expand, invariably at the expense of the poorest, including persons with disabilities.

In circumstances of neoliberalism, living labour is commodified. In such circumstances, workers become invisible, the dominant economic system 'depicting them as passive and adaptive.'[554] Accepting the social model logic that disability connotes a relationship between impairments and the restrictions society places on individual bearers of impairment, a materialist analysis indicates that, arguably, this invisibility manifest, first, in terms of workers with impairments. Reasonably well placed to function as workers in agrarian society, the rise of capitalist industrialisation pushed many people with impairments out of paid employment. Neoliberalism

---

[552] see Friedrich A Hayek *The Constitution of Liberty* (University of Chicago Press, 1978)

[553] Karen Soldatic, Helen Meekosha, 'Disability and Neoliberal State Formations' in Nick Watson Alan Roulstone Carol Thomas (eds) *Routledge Handbook of Disabilities Studies* (Routledge, 2012) 197

[554] Lucia Pradella Beyond Improvishment: Western Europe in the World Economy. In Lucia Pradella, Thomas Marois (eds) *Polarising Development* (Pluto Press, 2015) 15

takes this banishment to a new level. In a system that disdains workers as individuals and that openly seeks to equate citizenship and its benefits with fiscal productivity, the (now) disabled worker is particularly disadvantaged, even onto an effective exclusion from the *polis*. That this is happening even as the political community attests to the values of the CRPD is no less bizarre than the idea that a system which *exploits* mass labour for the enrichment of the few is as good as it gets.

Republicanism must engage with the neoliberalist rationality and its 'undoing of democracy and a democratic imaginary.'[555] Positing it as a discourse about market freedom that seeks to undermine and deny diversity and human freedom, neoliberalism is a domination corrosive of human development and freedom, reminiscent, in ways, of aspects of fascist totalitarianism. These regimes were murderously disposed towards disabled people and, of course, millions of other dispossessed and marginalised peoples. That these butchered people were first were made invisible reminds that disabled people's presence in the community, in schools, workplaces and in ordinary homes, not alone undermines ableist domination but also performs an important protective function. In restoring disabled people to the (Western) world that early capitalism effectively expelled them from, there is an important acting out of freedom, an assertion of the legitimacy of all people to be in the world and of the right to have rights co-equal with everyone else.

6 Article 19 – Living Independently and Being Included in the Community

6.1 Introduction

This section theorises the CRPD's approach to independent living and community inclusion as a matter of self-determination. The section offers a contextualisation which suggests that institutionalisation – once the standardised form of provision for many people with disabilities – remains a potent and destructive force in the Western imaginary, even though certain forms of physical institutions are in decline. Taking the view that while behaviours towards disabled people may be modified even as certain forms of prejudiced attitudes remain entrenched, this section pays particular attention to those forms of institutionalisation which can exist *beyond* the physical institution and which can hamper and impede the practical implementation of article 19, contributing, even, to what might be termed the tyranny of the normal.

Paradigm shifting as it is, the CRPD is not self-fulfilling. Its realisation means forming partnerships and alliances that are generative of a shift in values, in part by being alive to the

---

[555] Wendy Brown *Undoing the Demos* (Zone Books, 2015) 76

reality that institutionalisation can take many forms, including in circumstances where a disabled person may live in a community without being meaningfully a part of that community. To that end, perhaps a comprehensive shift to an independent living model is best understood as a product, first, of a keen understanding of the nature of institutionalisation since only by promoting this can it become possible to begin to understand how disabled people comprehend their social position within a society that is inherently ableist and discriminatory towards disabled people.

6.2 The non-radical demands of article 19

Prefaced on 'the equal right of all persons with disabilities to live in the community, with choice equal to others,' Article 19 imposes a duty on State parties to 'take effective and appropriate measures' to facilitate full enjoyment of this right, as well as a duty to ensure 'full inclusion and participation in the community.' Under article 19(a) the State must further ensure that disabled people have the opportunity to choose where and with whom they live and that they are 'not obliged to live in a particular living arrangement.' Pursuant to article 19(b) the State is required to provide access by persons with disabilities to 'a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community and to prevent isolation or segregation from the community.' Finally, article 19(c) articulates the expectation on the State to ensure that community services and facilities for the general population 'are available on an equal basis to persons with disabilities and are responsive to their needs.' Article 19 links clearly with article 12 (equal recognition before the law). Article 12 underpins a disabled person's legal capacity to make decisions, including decisions as to where and with whom the person lives. In turn, living in the community facilitates and potentially enlarges the scope within which legal capacity is exercised. In this, living in the community contrasts with an accommodation model for persons with disabilities still prevalent in Ireland, that is, various forms of institutional living, including living in what are known as congregated settings.

Rooted in the social model of disability, article 19 is to be understood as a central expression of the Convention's commitment to the principles of equality, non-discrimination and equality of opportunity.[556] More, the article 19 juxtaposing of 'living independently' with 'being included in the community' speaks to its rationale being about a positive experience of empowering people

---

[556] Giuseppe Palmisano Article 19 [Living Independently and Being Included in the Community]. In Valentina Della Fina Rachele Cera Giusseppe Palmisano (eds) *The United Nations Convention on the Rights of Persons with Disabilities. A Commentary* (Springer International Publishing, 2017) 353 - 373

to live full, socially engaged lives of their own choosing. In this context, then, it becomes clear that living independently does not necessarily mean living without interdependence, assuming, in modernity, that such a thing is even possible.[557] This is an important point. Article 19 addresses personal autonomy and the practical means of supporting it as measures to reduce the kind of dependency which corrals personal choice and freedom rather than increasing it. But the article is clearly not a traducing of dependency in all its forms nor can it be read to suggest living independently equates with living alone or being able to carry out daily activities unaided.[558]

As to the boundaries within which 'independently' functions the article is silent here, as it is about what amounts to appropriate and effective measures. However, in CRPD General Comment Number 5 independent living/living independently is described as meaning 'that individuals with disabilities are provided with all necessary means enabling them to exercise choice and control over their lives and make all decisions concerning their lives.'[559] The General comment continues:

> Personal autonomy and self-determination is fundamental to independent living, including access to transport, information, communication and personal assistance, place of residence, daily routine, habits, decent employment, personal relationships, clothing, nutrition, hygiene and health care, religious, cultural and sexual and reproductive rights.[560]

Constituting one of the most wide ranging and intersectional articles in the Convention, article 19 refers to both civil and political[561] as well as economic, social and cultural rights.[562] As such, the former fall to immediate enforcement whereas the latter are understood to be progressively applicable.[563] Hence, article 19(a) which refers to the opportunities to be afforded to disabled people to choose their place of residence and where and with whom they live is an immediately applicable civil and political right. Article 19(b) and (c) referencing, respectively, access to

---

[557] see, for instance, Mike Oliver Disability and Dependency: a Creation of Industrial Societies? In Len Barton *Disability and Dependency* (The Falmer Press, 1989) 6 – 22; see also the Universal Declaration of Human Rights 1948, article 29(1) which recognises that 'everyone' has duties to the community and that it is the community 'in which alone the free and full development' of a person's personality is possible

[558] CRPD General Comment No 5 2017 at 16(a)

[559] *ibid*

[560] *ibid*

[561] CRPD art 19(a)

[562] CRPD art 19(b) and 19(c)

[563] ICESCR art 2(1)

support services and availing of community services and facilities, are economic, social and cultural entitlements requiring the state to progressively realise them in the lives of disabled persons. That said, however, progressive realisation always commences in the now, meaning 'the immediate obligation to design and decide upon concrete strategies, plan of actions and [to] allocate resources to develop support services as well as making existing as well as new general services inclusive for persons with disabilities.'[564] As Quinn puts it, progressive realization means that '[t]here must be some positive dynamic in place—it must be measurable, and it should lead to positive results within a reasonable time frame.'[565]

As to article 19's wider intersectional and cross-cutting character, many of the Convention's provisions connect with living independently and participating in the community. These provisions include the universal design obligations imposed on States by article 4(f), article 5 (equality and non-discrimination), article 8 (awareness raising), article 9 (accessibility), article 20 (personal mobility), article 24 (education), article 26 (habilitation and rehabilitation), article 27 (work and employment) and article 28 (adequate standard of living and social protection). In addition, rich conceptualisations of what it means to participate in a society's political and public life (article 29) and in its cultural, recreational, leisure and sporting activities (article 30) inevitably draw on understandings of being included in the community which require attitudes of prejudice, stigma, ableism and intolerance to be effectively challenged. Hence, whether it be marked as protectionism, perhaps often well-meaning, or manifest hostility – at its extreme perhaps expressed as hate crime[566] - there are barriers to the realisation of article 19 which remind that living independently and feeling included is about much more than simply the provision of appropriate housing. This perspective suggests that article 19 should, more precisely, be understood best as a gateway to other rights – indeed, that other rights can only manifest fully and resiliently when article 19 is properly realised.[567]

---

[564] n 558 at para 39

[565] Gerard Quinn, 'The United Nations Convention on the Rights of Persons with Disabilities: Toward a New International Politics of Disability' (2009) 15 (1) Texas Journal of Civil Liberties & Civil Rights 44

[566] see, for instance, Anna Novis 'Disability hate crime; a campaign perspective' in Alan Roulstone Hannah Mason-Bish (eds) *Disability, Hate Crime and Violence* (Routledge, 2014) 118 – 125; Katharine Quarmby *Scapegoat* (Portobello Books, 2011)

[567] see *Olmstead v L.C.* 527 U.S. 581, 587 1999

6.3 Building towards article 19

A common refrain about the Convention is that it creates no new rights but, rather, simply codifies rights already in existence.[568] Generally, versions of this argument surface in concerns about 'rights inflation'[569] and about an (alleged) inevitable undermining of the universal applicability of human rights if some groups are holders of entitlements perceived to be solely available to them.[570] However, whatever the relative merits of these concerns, it remains true that international human rights treaties are the product of often intense political – and politically pragmatic - haggling such that the idea of an underlying conceptual coherence seems vain, especially in circumstances where the nascent rights present as controversial.

In terms of what eventually emerges as article 19 the drafting history reveals the report presented in December 2003 by the Chair of the Working Group[571] - charged with initial preparatory work for 'a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities'[572] - proposes a (then) article 17 titled the 'right to live and be a part of the community.'[573] Of particular interest in this article 17 is an explicit reference to states taking all necessary measures to ensure that 'no person with a disability is institutionalised.' Moreover, the right of disabled people 'to choose their own living arrangements' 'includes the right not to reside in an institutional facility.'[574] However, by the next phase in the drafting process – January 2004, with article 17 now becoming article 15 – the

---

[568] Rosemary Kayess, Philip French, 'Out of Darkness into Light?' Introducing the Convention on the rights of persons with disabilities (2008) 8 (1) Human Rights Law Review 1

[569] see, for instance, Dominique Clement, 'Human rights or social justice? The problem of rights inflation' (2018) 22 (2) The International Journal of Human Rights 155

[570] for an interesting view on this idea in the context of the United States' non-ratification of the United Nations Convention on the Rights of the Child 1989 see Anne L Alstott, 'Neoliberalism in U.S. Family Law: Negative Liberty and Laissez-Faire Markets in the Minimal State' (2014) 77 (4) Law and Contemporary Problems' 25 and, also, in respect of the claims that such ratification would, *inter alia*, undermine parental rights, see Shulamit Almog, Ariel L. Bendor, 'The UN Convention on the Rights of the Child Meets the American Constitution: Towards a Supreme Law of the World' (2004) 11 (3) International Journal of Children's Rights 273

[571] the working group was set up at the second session of the Ad Hoc Committee (itself set up in December 2001 by the General Assembly following a proposal from Mexico for what would become the UNCRPD) to prepare a draft text. Consisting of twenty-seven governmental representatives designated by regional groups, twelve representatives from NGOs and one representative of a National Human Rights Institution the working group examined numerous putative draft texts submitted by States and others; see United Nations Department of Economic and Social Affairs *The United Nations and Disability: 70 Years of the Work Towards a More Inclusive World* (DEPA, 2018)

[572] United Nations Department of Economic and Social Affairs *The United Nations and Disability: 70 Years of the Work Towards a More Inclusive World* (DEPA, 2018) at 14

[573] Giuseppe Palmisano Article 19 [Living Independently and Being Included in the Community]. In Valentina Della Fina Rachele Cera Giusseppe Palmisano (eds) *The United Nations Convention on the Rights of Persons with Disabilities. A Commentary* (Springer International Publishing, 2017) 355

[574] *ibid*

title changes to 'living independently and being included in the community' and the strong onus on a State to ensure that no person is institutionalised is diluted. Instead, article 15 says that persons with disabilities 'are not obliged to live in an institution or in a particular living arrangement.'[575] Even at this, however, some members of the Working Group held to the view that even this less strict obligation would be too onerous on States 'to guarantee this obligation without exception.'[576] That said, given the phrasing – which survives in a slightly altered form into the present article 19 – that '[p]ersons with disabilities have the equal opportunity to choose their place of residence and living arrangement' other members of the Working Party were of the opinion that the reference to *not* being obliged to live in an institution becomes redundant.[577]

Feala-Butora *et al*. report that the particular differences in the Working Party around article 15 (hereafter article 19) derive from cultural differences. For instances, some members preferred the concept of integration to that of inclusion while others asserted that the words 'living independently' did not reflect the cultural norms in many countries and could be read to mean that a person would be separated from their families.[578] The significance of this latter point, perhaps, is drawn out further by the fact that in many parts of the Global South and the Middle East the inadequacy or absence of facilities-based or community programmes means that children and adults with disabilities can often find themselves ostensibly included in the community but essentially institutionalised within the home, the effect of poverty and stigma meaning they can stay hidden away, their presence perhaps both an embarrassment and an economic impediment to the family.[579] By contrast, other Working Party members, notably Israel and the International Disability Caucus, argued that the phrase 'living independently' should not be included in the article since its connotation of being able to live without assistance might actually undermine the freedom aspirations of, say, severely disabled people, becoming,

---

[575] Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities Working Group January 2004 Annex 1 20

[576] *ibid* at n52

[577] *ibid*

[578] Janos Fiala-Butora Ari Rimmerman Ayelet Gur Living Independently and Being Included in the Community. In Ilias Bantekas Michael Ashley Stein Dimitris Anastasiou (eds) *The UN Convention on the Rights of Persons with Disabilities* (Oxford University Press, 2018) 530 - 558

[579] see, for example, Hashem N Alsharif, 'The Models of Disability in Saudi Arabia' (2019) 6 (1) The Indonesian Journal of International & Comparative Law 3; Judith Anne Mckenzie, Roy McConkey, Colleen Adnams, 'Intellectual disability in Africa: implications for research and service development' (2013) 35 (20) Disability and Rehabilitation 1750

as it were, an eligibility criteria to justify continued institutionalisation.[580] In the end, the decision not to remove the phrase 'living independently' in the title to article 19 – but not, however, in its chapeau - turned on the majority view within the Working Group that its retention reinforces the dignity and autonomy of persons with disabilities and emphasises the centrality of choice and freedom to choose.[581]

6.4 Choice and control as model for living independently

However, put another way, the core of the Israeli objection to the article 19 use of 'independently' as a descriptor is that *living* comes in many forms. Hence, just as the descriptor might be used to justify curtailing a form of living so too might it appear that there is some sort of *giving* of independence to disabled people, rather than it being persons with disabilities themselves who are solely the ones who must make their own choices and decisions about whether to live independently or not.[582] As to this latter dimension two cases from the United Kingdom may be cited as illustrative of circumstances in which a conception of independence could be said to be used by domestic courts to coercively impose a particular living arrangement on disabled people. In *A NHS Trust v DE* (2013) [583] independence – and the deleterious effects on it of the perceived need to constrain a sexual relationship – was held decisive in the decision to compel DE, a 37 year old man with a reported ability to consent to sexual relations, to undergo a forced vasectomy. In *A Primary Care Trust v P (2009)*[584] 'the advantages of 'independent living'[585] are referenced as conclusive in the decision to remove a 24 year old disabled man from a living arrangement of over seventeen years which he wished to remain in. Notwithstanding what was acknowledged as the 'superficial rationality of his views'[586] the court felt that 'his expressed wishes are by no means the whole story'[587] and that his rationality was 'conditioned by the actual poverty of his experience.'[588]

---

[580] Ad Hoc Committee UN Convention on the Human Rights of People with Disabilities – Daily Summaries Seventh Session 20 January 2006; available https://www.un.org/esa/socdev/enable/rights/ahc7sum20jan.htm

[581] Giuseppe Palmisano Article 19 [Living Independently and Being Included in the Community]. In Valentina Della Fina Rachele Cera Giusseppe Palmisano (eds) *The United Nations Convention on the Rights of Persons with Disabilities. A Commentary* (Springer International Publishing, 2017)

[582] Fourth Session, Proposed Modifications to Draft Article 15, Israel

[583] *A NHS Trust v DE* [2013] EWHC 2562 (Cop)

[584] *A Primary Care Trust v P & Others [2009] EW Misc 10 (EWCOP)*

[585] *ibid* per Mr. Justice Hedley at 64

[586] *ibid* at 70

[587] *ibid* at 69

[588] *ibid* at 70

A significant factor in the decision in *A Primary Care Trust v P* was the opinion formed by the court that P's views had been distorted by 'the dominating effects of an obsessive and smothering relationship,'[589] suggesting that a relational conceptualisation of mental capacity is vital.[590] However, arguably what both these cases speak to is an outside-in perspective of what independence and living independently means - or can be allowed to mean - for disabled people within the wider society. In this sense, every-day conceptions of independence prove unhelpful. To live independently as a disabled person is unlikely to mean being able to function in a completely self-reliant sense. It is unlikely to mean not needing others and the care they can provide, at least at some point in the life-cycle. Rather, disability activists contend that living independently means exercising choice and control over one's own living arrangements – it is, in essence, about the disabled person, if needing help, having real agency over how and from whom that help comes.[591] This idea sits at the heart of the independent living movement, a social movement of disabled people, originating in the US and which is there, sometimes, styled the modern disability rights movement.[592] In practical terms, the disabled person's ability to live in their own home rather than in some institutional arrangement becomes about her having the financial resources to be supported to do so. Various models exist, including in some US states, Nordic countries, Australia, Canada and the UK where money, for example, to employ personal assistants, goes directly to the disabled person themselves (or to an agent, broker or trust acting on the disabled person's behalf) to be spent as they wish.[593] While promising, these schemes – which can, broadly, be subsumed under the heading of the personalisation of care and supports – are not without risks[594] and they can be administratively difficult to access.[595] Nor do they operate securely beyond funder interference[596] nor, indeed, is the value of their extension to

---

[589] *A Primary Care Trust v P & Others [2009] EW Misc 10 (EWCOP)* per Hedley at 64

[590] Camilla Kong *Mental Capacity in Relationship: Decision-Making, Dialogue and Autonomy* (Cambridge University Press, 2017)

[591] John O'Brien, 'Downstairs That Are Never Your Own: Supporting People with Developmental Disabilities in Their Own Homes' (1994) 32 (1) Mental Retardation 1

[592] Andrew I Batavia, 'Disability Rights in the Third Stage of the Independent Living Movement: Disability Community Consensus, Dissention and the Future of Disability Policy' (2003) 14 (2) Stanford Law & Policy Review 347

[593] for an early investigation of this approach see Theresia Degener *Personal Assistant Service Programs in Germany, Sweden and the USA: Differences and Similarities* (LLM Thesis, 1992) available at https://eric.ed.gov/?id=ED347720#?

[594] see, for example, Jaromir Junne, Christian Huber, 'The risk of users' choice: exploring the case of direct payments in German social care' (2014) 16 (7-8) Health, Risk & Society 631

[595] see Christopher Alan Griffiths, Emily Ainsworth, 'Personalisation: Direct Payments and Mental Illness' (2013) 18 (1) 'International Journal of Psychosocial Rehabilitation' 69

[596] Colin Slasberg, Peter Beresford, 'Independent living: the real and present danger' (2020) 35 (2) Disability & Society 326

other housing scenarios such as community housing and residential care well theorised.[597] Of particular concern, however, is the suggestion that those disabled people in higher socio-economic groups may derive greater benefit from personalisation than those in lower socio-economic groups.[598]

But if choice and control are to really become the *modus operandi* by which the increasing international trend towards personalisation is to be measured then disabled people resiliently securing article 19 rights will require more than just government and administrative commitment. It needs to be acknowledged that the goals of equality and inclusion which the independent living movement and the Convention espouse do not correspond with a widespread popular demand in the general population.[599] Within society, understandings of what inclusion and participation demand are inadequate[600] and Lang *et al.* suggests that, notwithstanding political discourses to the contrary, public awareness of disability as a human rights issue is poor.[601] Hence, the context within which the proper, principled enactment of article 19 in terms of the choice and control element can be elusive, the 'do things for' rather than 'do things with' effects of a long-established paternalistic care culture continuing to cast its shadow.[602] As one campaigner puts it:

> The tendency to see disabled people as objects rather than complete people leads to the view that they are less than human. That obviously

---

[597] Lorraine Williams, Stefanie Ettelt, Margaret Perkins, Raphael Wittenberg, Daniel Lombard, Jackie Damant Nicholas, Mays Will, 'Direct Payments Make Adult Residential Care more Personalized? Views and Experiences of Social Care Staff in the Direct Payments in Residential Care Trailblazers' (2017) 51 (7) Social Policy Administration 1060

[598] Gemma Carey, Brad Crammond, Eleanor Malbon, 'Personalisation schemes in social care and inequality: review of the evidence and early theorising' (2019) 18 (1) International Journal for Equity in Health 1

[599] Tim Clement, Christine Bigby *Group Homes for People with Learning Disabilities: Encouraging Inclusion and Participation* (Jessica Kingsley Publishers, 2010)

[600] see, for example, within the education field Mireille Krischler, Justin J. W. Powell, Ineke M. Pit-Ten Cate, 'What is meant by inclusion? On the effects of different definitions on attitudes toward inclusive education' (2019) 34 (5) European Journal of Special Needs Education 632; Claes Nilhorm, Kerstin Goransson, 'What Is Meant by Inclusion? An Analysis of European and North American Journal Articles with High Impact' (2017) 32 (3) European Journal of Special Needs Education 437

[601] Raymond Lang, Maria Kett, Nora Groce, Jean-Francois Trani, 'Implementing the United Nations Convention on the Rights of Persons with Disabilities: Principles, Implications, Practice and Limitations' (2011) 5 (3) Alter 206

[602] See, for example, Sharon Walsh, Eamon O'Shea, Tom Pierse, Brendan Kennelly, Fiona Keogh, Edel Doherty, 'Public preferences for home care services for people with dementia: A discrete choice experiment on personhood' [2020] 245 Social Science & Medicine 1

> affects the way disabled people - and the “stick ‘em in a home attitude – are treated[603]

6.5 Institutionalisation in Ireland: a topographical account

In Ireland a 2011 Health Service Executive (HSE) report, *Time to Move on from Congregated Settings*[604] identified some 4,000 people (described as ‘residents’) living in 72 such places. Excluding residential services for people with autism and ‘intentional communities,’[605] the report defines a congregated setting ‘as living arrangements where ten or more people share a single living unit or where the living arrangements are campus-based.’[606] The report makes for distressing reading, describing as among the 4,000 people ‘a high proportion of people with severe and profound intellectual disabilities, considerable levels of challenging behaviour and high levels of multiple disabilities.’[607] Confirming that most of the people in the institutions had multiple disabilities and that many were aging - and some experiencing dementia - increasing levels of significant dependency were noted. Staff surveys indicated that over 70% of the 4,000 people needed help with dressing themselves, about a third needed help with eating and almost 90% needed help to wash. Further, 40% of the residents were described as unable to walk independently and only 35% were reported as capable of speaking in sentences.[608] In terms of living conditions just over half of residents were identified as having a single bedroom and a ‘quarter of residents were living with 4 or more to a bedroom, while one in 10 were living with 12 or more people to a bedroom.’[609] In terms of community engagement, the report continues:

> [t]he picture of daily life that emerges from the survey is of people whose lives are largely confined to the centres where they live, few of whom take part independently in mainstream community activities outside the centre.[610]

---

[603] Mark Brown *Disabled people are to be ‘warehoused.’ We should be livid*. The Guardian 25 January 2017

[604] Report of the Working Group on Congregated Settings *Time to Move on from Congregated Settings: a Strategy for Community Inclusion* (Health Service Executive, 2011)

[605] citing the reports own explanation at 25 “ ‘an intentional community’ is a planned residential community designed to promote a much higher degree of social interaction than other communities. The members of an intentional community typically hold a common social, cultural, political or spiritual vision. They also share responsibility and resources. Intentional communities include co-housing, residential land trusts, communes, eco- villages and housing co-operatives.’(www.wikipedia.org). In the Irish context, intentional communities include Camphill Community and L’Arche Community.”

[606] *ibid* at 25

[607] *ibid* at 38

[608] *ibid* at 40

[609] *ibid* at 41

[610] *ibid* at 42

Welcomed as an important official acknowledgement of the need to radically re-imagine disability service provision and as a milestone strategy for moving to community living, the report committed the State to end congregated settings by 2018. However, by 2018 some 2,580 people were still living in such institutions.[611] By 2019 this figure had settled at 2,000 people with a mere 132 people scheduled to move in 2020.[612]

The history of sequestering disabled people in Ireland in large part mirrors that process of exclusion, medicalisation and institutionalisation whereby the 'personal troubles' of impairment became the 'public issues' of disability.[613] Indeed, Albrecht talks of the commodification of disabled peoples' bodies, describing an industrialised approach providing employment to great armies of workers in the rehabilitation industries.[614] By the mid-nineteenth century Ireland's movement to mass institutionalisation was impressive, if only from a bureaucratic perspective. Having already become the first country in Western Europe to have a comprehensive system of public asylums (for so-called lunatics) - ten by 1835[615] - a tradition of public, community-based medicine witnessed the building of a hundred fever hospitals by 1845 and six hundred dispensaries by 1840.[616] Factor into this the foundling hospitals[617] and 123 workhouses which existed by 1845 (and a police constabulary charged, from time to time between 1845 and 1877, with submitting a census of 'lunatics, idiots, imbeciles and epileptics' *not* in institutions[618]) then the scene is set to begin to separate out different types of disability for distribution among different forms – new forms – of institutions. Hence, Durkheim describes how '[t]he insane and the sick of certain types, who were heretofore dispersed, [were] banded together from every province and every department into a single enclosure.'[619] Many of these enclosures, particularly in post-colonial Ireland, fell to the control of the Roman Catholic church. Thus, for example, under the auspices of the Catholic Institute for the Deaf the Dominican Sisters open

---

[611] Inclusion Ireland *Deinstitutionalisation in Ireland: a failure to Act* (Inclusion Ireland, 2018)

[612] Inclusion Ireland press release 2018

[613] Anne Borsay, 'Personal Trouble or Public Issue: Towards A model of Policy for People with Physical and Mental Disabilities' (1986) 1 (2) Disability, Handicap & Society 179

[614] Gary L Albrecht *The Disability Business: Rehabilitation in America* (Sage, 1992)

[615] Markus Reuber Moral Management and the 'Unseen Eye': Public Lunatic Asylums in Ireland 1800 – 1845. In Greta Jones Elizabeth Malcolm (eds) *Medicine, Disease and the State in Ireland 1650 – 1940* (Cork University Press, 1999) 208

[616] F S L Lyons *Ireland Since the Famine* (Harper Collins, 1985)

[617] as places for abandoned infants the foundling hospitals have an especially awful history; see Joseph Robins *The Lost Children: a study of charity children in Ireland 1700 – 1900* (Institute of Public Administration, 1980)

[618] Patrick McDonnell *Disability and Society: Ideological and Historical Dimensions* (Blackhall Publishing, 2007)

[619] Emile Durkheim *The Division of Labour in Society* (first published 1893, The Free Press, 1964) 188

St. Mary's School for Deaf Girls in 1846 and the Christian Brothers open St. Joseph's School for Deaf Boys three years later. In 1857 the (non-religious) Stewart's Institute for Idiotic and Imbecile Children opens, in 1884 the Carmelite Brothers open St. Joseph's School for Blind Boys (having previously operated an asylum for blind men). In 1885 members of the St. John of God Brothers begin working with people with mental health problems (including, in the understanding of the times, people with intellectual disability),[620] as had members of the Brothers of Charity two years before, although uniquely among Irish institutions (including schools and hospitals) mental asylums persisted as 'one of the few areas of Irish social intervention that remained predominantly secular in its administration.'[621]

With Ireland's independence from Britain the church's involvement in the provision of disability services continued at an increased pace, the fledgling's state's paucity of resources and its political commitment to Roman Catholic social teaching meaning that across the health and social care continuum institutions operated with little or no state regulation or oversight.[622] Indeed, in the period 1925 to 1955 four religious orders came to dominate national provision for people who were then referred to as mentally handicapped.[623] Further, memoranda of the Department of Health from the 1950s demonstrate that in respect of this cohort of citizens the State's preference was not only for the Catholic church to continue to provide for them in institutional settings but to encourage religious orders already working in this area to expand their involvement and to ask these orders leaders to personally 'induce' other orders to follow suite.[624] With specific reference to intellectual disability, the report of a government inquiry from 1965 is illustrative of how dependent the state became on institutionalisation as a service model and on non-state actors to deliver this model, chief among these Catholic religious orders. Referring to 'mental handicap' as 'one of the gravest problems' and a 'great loss to the nation through lack of productivity' the report[625] identifies 3,130 residential places available for intellectually disabled persons spread nationally across eighteen designated residential centres, all but 29 of these places being occupied as of 31st December 1964. Thirteen of these centres

---

[620] see, for example, John Sweeney, Duncan Mitchell, 'A challenge to nursing: an historic review of intellectual disability nursing in the UK and Ireland' (2009) 18 (9) Journal of Clinical Nursing 2754

[621] Damien John Brennan *A Sociology of Institutionalisation of the 'Mentally ill' in Ireland* (PhD Thesis, unpublished, Trinity College Dublin, 2006) 147

[622] Ruth Barrington *Health, Medicine and Politics in Ireland 1900 – 1970* (Dublin Institute of Public Administration, 1987)

[623] John Sweeney, 'Attitudes of Catholic religious orders towards children and adults with an intellectual disability in post-colonial Ireland' (2010) 17 (2) Nursing Inquiry 95

[624] Annie Ryan *Walls of Silence: Ireland's Policy Towards People with a Mental Disability* (Red Lion Press, 1999) 46

[625] Department of Health Commission of Inquiry on Mental Handicap (Government of Ireland, 1965) xiii

are identified as being in the care of five religious orders, accounting between them for 2,571 places. [626] 1,237 of the people occupying these places are revealed to be under sixteen years of age. Of the remaining five residential centres, the smallest is that run by the Church of Ireland (19 occupied places) and the largest is Stewarts Hospital (290 occupied places); the other three, run by two lay organisations, accounting for 90, 67 and 64 occupied places.[627] Further, the report notes that 3,900 people with intellectual disability are in the care of the Health Authorities, 2,700 'mainly' in District Mental Hospitals and 1,200 in County Homes. It is suggested that what these figures indicate is an extraordinary commitment to a rigorous institutional incarceration of disabled persons.

By 2012, sixty agencies were providing residential services to 8,500 people with disabilities in 1,200 locations ranging from large institutional settings to small group home environments and supported independent living arrangements.[628] But, given the figures cited at the beginning of this section concerning the 2011 report this means that while the number of non-congregated settings around the state were considerably more, they only provided housing to some 4,500 people – just over half of all of the disabled people then availing of a residential service. Proposing a person-centred rather than a services-centred model – funding people rather than places - the 2012 report also indicates that while most people with a physical disability are not in a residential facility, living instead 'independently, with family and community support' slightly more than half of persons with an intellectual disability live in some form of institutional care.[629]

6.6 Institutionalisation, drawing on Goffman

The institutionalising of people with disabilities – what has been poignantly described as the warehousing of disabled people - still continues in many countries in Europe and beyond. Indeed, in North America the institutionalisation model that flourished up to the late 20th Century has been identified as central to public policy. Described by Higgins as 'a pen of

---

[626] Hospitaller Order of St. John of God, three centres of respectively 217, 371 and 189 places; Brothers of Charity, two centres of respectively 247 and 101 places; Sisters of Charity of St Vincent de Paul, five centres of respectively 503, 267, 232, 35 and 90 places; Sisters of Charity of Jesus and Mary, two centres of respectively 120 and 74 places; Congregation of the Daughters of Wisdom, one centre of 125 places

[627] Cork Polio and After-Care Association, two centres of respectively 90 and 60 places; St. John's Unit, Peamont Hospital, 64 places

[628] Department of Health Value for Money and Policy Review of Disability Services in Ireland (Department of Health, 2012)

[629] *ibid* 140

inutility'[630] Goffman speaks of the 'total institution' as an enclosed and formally administered way of living that is cut off from the wider society for an appreciable time. But more, total institutions are

> the forcing houses for changing persons; each is a natural experiment on what can be done to the self.[631]

For Goffman, the institutional arrangement is marked by four main characteristics. The first is 'batched living.' The very antithesis of independent living, to be batched refers to those significant portions of daily life that are required to be carried out in the company of a large group of others, all of whom are treated alike and all of whom are required to do the same. Batched living is a life lived under surveillance where rules and regulations dominate and choice is absent. The second characteristic is binary management. This is demonstrated by the presence of two distinct groups of people, those who manager and those who are managed: '[t]wo different social and cultural worlds develop, jogging alongside each other with points of official contact, but little mutual penetration.'[632] The power of the manager is expressed in social distance and in controlling access to information. Third, Goffman talks of the inmate role, a debilitating, stigmatised, disempowering identity, the very existence of which reinforces the staff's sense of superiority. Finally, feeding into and out of all this is the institutional perspective, expressed and reinforced in a thousand daily ways – the special tone of voice used, the language employed, the stereotypes referenced, the drab environment, the poor food, the lack of human feeling.

6.7 Institutionalisation as the charity model of disability

Institutionalisation represents the turning into bricks and mortar of new ideas and regimes about how disabled people should be treated, the buildings often constructed on a grand scale to reflect their imposing moral purpose.[633] Yet, in a seminal study of British asylums, Scull contends that the altruistic arguments for humane treatment on which these institutions were increasingly prefaced, the arguments advanced in this instance by medical professionals, soon

---

[630] Winton Higgins To him that hath . . . : the welfare state. In Richard Kennedy (ed) *Australian Welfare History: Critical Essays* (Macmillan, 1982) 202

[631] Erving Goffman *Asylum: Essays on the Social Situations of Mental Patients and Other Inmates* (Penguin Books 1991) 22

[632] *Ibid* 20

[633] this issue of architecture as it applies to buildings for people with mental health needs is well explored in Tom Burns *Our Necessary Shadow: the Nature and Meaning of Psychiatry* (Allen Lane, 2013)

gave way to a darker reality of coercion and control.[634] That the doctors had held themselves out – and continued to be esteemed – as moral arbiters despite their institutions failing to uphold the principles on which they were founded speaks, perhaps, to an unspoken complicity in the mainstream society that the people incarcerated in these institutions deserved no better. Indeed, Robins quotes an inspector of one asylum in the west of Ireland who decried the folly of 'erecting palaces for the permanent accommodation of worthless and slavering idiots.'[635]

In Ireland the ideal of moral treatment being consistent with the increasing institutionalisation of disabled people also takes on a particular sectarian content. At a time when Roman Catholicism was in the ascendant in the national consciousness - triumphant in the aftermath of that period of Irish history stretching from reformation to emancipation - there was concern, certainly, that disabled Catholic children might be vulnerable to proselytising. McDonnell illustrates this point with reference to deaf children who were though particularly susceptible.[636] But as wider issues of social control[637] and government of the body[638] came to dominate, the more pressing issue of entrenching a Catholic hegemony emerged naturally out of a widespread conviction that true, muscular, Irishness and catholicity were synonymous.[639] This meant leaving no public space, physical or discursive, unmediated by the church. Asylums and Homes for the disabled became just one more reference point on an intricate, and predominantly Catholic moral grid. So, the increasing surveillance of the prurient Catholic gaze comes to fall gradually upon more and more of Irish society, including those marked out as different or deviant or deformed in body and mind. This, then, is institution building as an act of control, revealing less about the needs of the disabled people within than about the societies wherein which, for so long, they thrived.[640] Indeed, despite the soft optimism implicit in the use of words like 'school' and 'asylum' and 'home' as part of the title of many institutions – suggesting learning,

---

[634] Andrew Scull *The Most Solitary of Afflictions: Madness and Society in Britain 1700 – 1900* (Yale University Press, 2005)

[635] Joseph Robins *Fools and Mad: History of the Insane in Ireland* (Institute of Public Administration, 1986) 159.

[636] Patrick McDonnell *Disability and Society: Ideological and Historical Dimensions* (Blackhall Publishing, 2007)

[637] see, for instance, Joseph A. MacMahon, 'The Catholic Clergy and the Social Question in Ireland 1891 – 1916' (1981) 70 (280) An Irish Quarterly Review 263

[638] Tom Inglis *Moral Monopoly: the Catholic Church in Modern Irish Society* (Gill and Macmillan, 1987); Tom Inglis, 'Origins and Legacies of Irish Prudery: Sexuality and Social Control in Modern Ireland' (2005) 40 (3-4) Eire-Ireland 9

[639] see, for instance, Joseph Nugent, 'The Sword and the Prayerbook: Ideals of Authentic Irish Manliness' (2008) 50 (4) Victorian Studies 5887; for an opposite view from the other side of the border see Joe Lee *Ireland 1912 – 1985: Politics and Society* (Cambridge University Press, 1989)

[640] David Rothman *Discovery of the Asylum: Social Order and Disorder in the New Republic* (Little Brown, 1971)

development and, above all, safety – these places were also often represented in the wider society in terms of their role in protecting *normal* people from those with disabilities.[641] This, then, is the construction of the disabled person as deviant, as dangerous – as needing to be sequestered away.

Important as it was that these new and increasingly grandiose institutions were presented as moral places, as safe places, it was also important that they be thought of as charitable places, operating independent of state interference.[642] Displaying disabled people, particularly, perhaps, children and, again, perhaps especially those with sensory and physical disabilities produced valuable publicity for the institutions, especially in the context of there being an emerging Catholic middle class eager to support Catholic works.[643] Indeed, it is reported that '[t]he charitable crusade to "save" the deaf/dumb and blind became America's first experience with collective benevolence.'[644] The outward show of charity marks out its institutional dispensers as good people, caring and concerned and because of it, deserving of public approval and support. As is only too evident in Ireland's modern history, being thought to be godly confers great power, including political power. Whereas the workhouses and public asylums were parts of the (colonial) state apparatus, the creation of disability-specific institutions within a charity sphere elevates paternalism into a newly exalted place, worthy of generous public support while giving free reign to those in charge of these institutions to do as they saw fit, even if this meant practices which denied people autonomy, such as forced medication and ritual humiliations. Hence, analogous to the borstals,[645] reformatory schools[646] and Magdalen homes,[647] institutions for disabled children and adults that may have outwardly displayed themselves as places of rehabilitation, training and even refuge are now notorious in the Irish psyche for having been sites of unimaginable suffering, abuse and neglect.[648]

---

[641] Rita Rhodes 'Mental Retardation and Sexual Expression: An Historical Perspective' (1993) 8 (2) Journal of Social Work & Human Sexuality 1

[642] for an analogous account in respect of religious run reformatories and industrial schools in Ireland see Paul Sargent *Wild Arabs and Savages* (Manchester University Press, 2014)

[643] see, for instance, Maria Luddy Gender and Irish Society. In Alvin Jackson (ed.) *The Oxford Handbook of Modern Irish History* (Oxford University Press, 2014) 193 - 213

[644] Sheila C Moeschen, 'Suffering Silences, Woeful Afflictions: Physical Disability, Melodrama and the American Charity Movement' (2006) 40 (4) Comparative Drama 434

[645] see Conor Reidy *Ireland's 'Moral Hospital': The Irish Borstal System 1906 – 1956* (Irish Academic Press, 2009)

[646] see Mary Raftery, Eoin O'Sullivan *Suffer the Little Children: The Inside Story of Ireland's Industrial Schools* (New Island Press, 1999); Bruce Arnold *The Irish Gulag* (Gill & Macmillan, 2009); The Commission to Inquire into Child Abuse (The Ryan Report) (Government of Ireland, 2009)

[647] Frances Finnegan *Do Penance or Perish: Magdalen Asylums in Ireland* (Oxford University Press, 2001)

[648] Arie Rimmerman *Disability and Community Living Policies* (Cambridge University Press, 2017)

6.8 Institutionalisation as (mis)reading the body

Institutionalisation demonstrates a shift from the individual life to the collective existence. This analysis fits with a modernisation consistent with a move to what Foucault describes as biopower (or biopolitics).[649] This conceptualisation of power, which Foucault tracks to the late eighteenth century and the rise of capitalism, contrasts with the Hobbesian epitome of power residing in a sovereign entity. Instead, Foucault describes a 'decapitated and dethroned power, an anonymous, multiple, pale, colourless power,'[650] a form of governing which is both about being governed and governing oneself. The object of this power is the body, *all* bodies. Whereas practices of repression, seizure, torture and death – often by way of public spectacle – are represented as typifying a classical sovereign's power ('the right to *take* life or *let* live'),[651] within the biopower construct a very different dynamic pertains. Foucault contends that the State abandons stark public punishments when their spectacle no longer serves a useful purpose because, within biopower, 'regulation of behaviour becomes a matter of internalization – the tendency of citizens to police one's own behaviour at the behest of the state.'[652]But because power is now diffused across so many and diverse actors preserving the integrity and cohesion of the social group against individualism becomes vital; hence, Foucault talks of 'a *society of normalisation.'*[653]

In contrast to thinkers like Agamben,[654] Foucault talks of biopower as 'a power that exerts a positive influence on life, that endeavours to administer, optimize, and multiply it, subjecting it to precise controls and comprehensive regulations.' [655] Focusing along two axis, the individual (the body, maximised and integrated into efficient systems) and the collective (the species itself), the theory of government now proposed is one where

---

[649] Michel Foucault *The Will to Knowledge. The History of Sexuality 1* (Penguin, 1998) at 140; in respect of the terms 'biopower' and 'biopolitics' according to Mills the former term has, in contemporary debate, now been largely abandoned with the latter being used as a general term to encompass both state and non-state actors; see Catherine Mills *Biopolitics* (Routledge, 2018). However, for the purposes of this work biopower is taken as a more viscerally communicative word.

[650] Michel Foucault cited in Stuart Elden *Foucault: The Birth of Power* (Polity, 2017) 115

[651] Michel Foucault *The Will to Knowledge. The History of Sexuality 1* (Penguin, 1998) 136 (emphasis in the original)

[652] David T Mitchell *Neoliberalism, Ablenationalism and Peripheral Embodiment* (University of Michigan Press, 2015) 225

[653] Michael Foucault Two Lectures. In Colin Gordon (ed.) *Power/Knowledge: Selected Interviews and Other Writings 1972-1977* (Vintage Books, 1980) at 107 (emphasis in original)

[654] for a contrast between the two see, for instance, Katia Genal The Question of Biopower: Foucault and Agamben (2006) 18 (1) Rethinking Marxism 43

[655] Michel Foucault Right of Death and Power over Life. In *Biopolitics: A Reader* Timothy Campbell Adam Sitze (eds) (Duke University Press, 2013) 42

> governing people is not a way to force people to do what the governor wants; it is always a versatile equilibrium, with complementarity and conflicts between techniques which assure coercion and processes through which the self is constructed or modified by himself.[656]

Within this construction, tracking phenomena which impact on the quality of life becomes central. Hence, biopower describes a complex technology of measurement and information gathering so that norms – and, crucially, deviations from the norm – 'become the primary means by which people are individualized, come to be understood scientifically and even come to understand themselves.'[657] Hence, where power in the old dispensation rests on shows of punishment it now becomes regulatory, mundane. For Foucault, this transformation in the mechanics of power does not replace the more traditional forms of top-down authority but rather supplements them from below, permitting the creation of dispersed networks operating at 'the level of life' itself.[658] At this level of life the multiplication of institutions for disabled people contributes within the biopower thesis by taking on the discursive management of those, for example, whose 'health and productivity'[659] deviates from the norm.

Biopower allows the body to be read as an epistemological object but in a way which is about much more than merely understanding the biological functions of life. Rather, the political purpose is to render bodies - in both their capabilities and conduct as populations *and* individuals – docile, compliant and self-governing.[660] Hence, in respect of people with disability, biopower operates at the level of formal segregation but also it is about people *themselves* knowing where they belong and acting accordingly – including, perhaps, responding to paternalism by assuming a posture of gratitude for the charity received or promised. In turn, this is charity as a transforming of people into deserving objects of the help being offered, of the disabled person as indebted. Viewed from this perspective, as Tremain has it, biopower is the exercising of those:

> practices, procedures, and policies [that] have created, classified, codified, managed, and controlled social anomalies through which

---

[656] Michael Foucault About the Beginning of the Hermeneutics of the Self: Two Lectures at Dartmouth 21 2 1993 Political Theory 204

[657] Shelley Tremain *Foucault and the Government of Disability* (University of Michigan Press, 2015) 14 -15

[658] Michel Foucault *The Will to Knowledge.The History of Sexuality 1* (Penguin, 1998) at 137; elsewhere Foucault terms these networks the *dispositif,* see Michel Foucault *Security, Territory, Population: Lectures at the College de France 1977 -78* (Palgrave Macmillan, 2009)

[659] Dan Goodley *Disability Studies* (Sage, 2017) 131

[660] Michael Foucault *Discipline and Punish. The Birth of the Prison* (Penguin, 1991)

> some people have been divided from others and objectivised as (for instance) physically impaired, insane, handicapped, mentally ill, retarded, or deaf.[661]

Thinking again of 'a *society of normalisation*' this emphasises Foucault's intuition that normalisation is the great project of biopower.[662] Legitimised by scientific measurement and statistical data, to be normal is to belong 'in a homogeneous social body (a "population") and serve[s] to distinguish subjects from each other, to classify them, and to rank them in a host of hierarchies.'[663] Moreover, the institution, emblematic of the type of civil society entity now charged with stepping in for the state as it seeks to draw 'a new relation between ethical citizenship and responsible community fostered, but not administered, by the state,'[664] assumes responsibility for ordering these hierarchies in respect of disabled people. In effect, what results - indeed, increasingly, perhaps, in the context of neoliberalism - is what McRuer describes as an narrative of compulsory able-bodiedness.[665] Within this narrative the non-disabled body is recognised as natural, as the 'corporeal standard,' as 'species-typical' and as 'essential and fully human.'[666] Hence, the institutionalising discourse draws attention to this problematizing of the non-standard body, legitimising the way difference is used to authorise people being treated as less, for example as objects of pity, deserving of charity and as bearers of a diminished citizenship. Biopower reinforces ableism – the notion that able-bodiedness and able – mindedness is an objective reality and that, therefore, impairment is inherently negative, meaning the goal becomes to ameliorate disability, cure it or, even, eliminate it.[667] Moreover, in this telling, biopower serves to subjugate disabled persons by constructing them as dependent while, simultaneously, constraining them in ways which ties them to their assigned 'disabled' identities.

---

[661] Shelley Tremain *Foucault and the Government of Disability* (University of Michigan Press, 2015) 14

[662] Michael Foucault *Security, Territory, Population: Lectures at the Collège de France, 1977-78* (Palgrave Macmillan, 2007); Michel Foucault The Subject and Power. In Hubert L Drayfus Paul Rabinow (eds) *Michel Foucault: Beyond Structuralism and Hermeneutics* (University of Chicago Press, 1982) 208 - 226

[663] Shelley Tremain Feminist Philosophy of Disability: A Genealogical Intervention 51 1 2019 The Southern Journal of Philosophy 149

[664] Nikolas Rose 'Community, Citizenship and the Third Way' (2000) 43 (9) American Behavioral Scientist 1395, 1398

[665] Robert McRuer *Crip Theory: Cultural Signs of Queerness and Disability* (New York University Press, 2006) 2

[666] Fiona A K Campbell 'Inciting Legal Fictions: "Disability's" Date with Ontology and the Ableist Body of Law' 10 1 2001 Griffith Law Review 42, 44

[667] Fiona A K Campbell 'Exploring internalized ableism using critical race theory' (2008) 23 (2) Disability & Society 151

In this context, biopower presents as an incisive lens for seeing again the eugenics movement.[668] Originating in the work of Francis Galton,[669] eugenics came to a particular prominence in the United States in the very early twentieth century[670] before migrating, reinvigorated, to Scandinavia,[671] Britain[672] and other countries, attaining its most virulent, populist and darkest epitome in Nazi Germany.[673] With its uncomfortable insistence on the optimization of life, biopower aligns with the dangerous central conceit of eugenics: that through careful scientific study and precise measurement human perfection can be attained. That the political application of these theories of genetic worth and racial improvement involved compulsory sterilizations[674] and, ultimately, institutional mass murder[675] is well known. But that long after the horrors of the Nazi era had passed that eugenics continued to exert a social and scientific appeal is perhaps less apparent, as may be the reality that doctors and other institutional players were the pioneers rather than the pawns of the eugenic movement.[676]

Eugenics targeted those whose social value was regarded as questionable, those whose status as citizen was insecure. Indeed, Schweik writes of 'eugenic charity.'[677]In terms of American

---

[668] see Philippa Levine *Eugenics: a Very Short Introduction* (Oxford University Press, 2017)

[669] Francis Galton 'Hereditary Talent and Character. Parts I and II' (1865) 12 (68) 1865 Macmillan's Magazine 157-166, 318-327; Francis Galton 'The Possible Improvement of the Human Breed Under Existing Conditions of Law and Sentiment' [1901] 64 Nature 659-665; Francis Galton Eugenics: its Definition, Scope and Aims. In *Sociological papers* (Macmillan, 1905) 45-50

[670] Gerald V O'Brien *Framing the moron: the social construction of feeble mindedness in the American eugenic era* (Manchester University Press, 2015)

[671] Gunnar Broberg, Nils Roll-Hansen, *Eugenics and the Welfare State: Norway, Sweden, Denmark and Finland* (Michigan State University, 2006)

[672] see, for instance, Bradley W. Hart, Richard Carr, 'Sterilization and the British Conservative party: rethinking the failure of the Eugenics Society's political strategy in the nineteen-thirties' (2015) 88 (242) Historical Research 716

[673] Giorgio Agamben *Homo Sacer: Sovereign Power and Bare Life* (Stanford University Press, 1998)

[674] As many as 70,000 forced sterilizations are believed to have happened in the USA in the 20th Century and in the first two years of Nazi Germany's 1933 *Law for the Prevention of Hereditarily Diseases in Future Generations* some 200,000 sterilizations were initiated: this law mandating compulsory sterilization in cases of 'congenital mental defects, schizophrenia, manic-depressive psychosis, hereditary epilepsy, severe alcoholism, hereditary blindness and Huntington's chorea;' see, respectively, Adam Cohen *Imbeciles: the Supreme Court, American Eugenics and the Sterilization of Carrie Buck* (Penguin Books, 2017), Richard J Evans *The Third Reich in Power 1933 – 1939* (Penguin Books, 2005); see also, Friedemann Pfafflin, 'The Connections Between Eugenics, Sterilization and Mass Murder in Germany from 1933 to 1945' (1986) 5 (1) Medicine and Law 1

[675] Brigitte Bailer Juliane Wetzel (eds) Mass Murder of People with Disabilities and the Holocaust (Metropol Verlag, 2019); Michael A Grodin, Erin L Kelly, Johnathan I Kelly 'The Nazi Physicians as Leaders in Eugenics and "Euthanasia": Lesson for Today' (2018) 108 (1) American Journal of Public Health 53; Mark P Mostert, 'Useless Eaters: Disability as Genocidal Marker in Nazi Germany' (2002) 36 (3) The Journal of Special Education 155

[676] see, for instance, Robert N Proctor Eugenics in Hitler's Germany. In Donna F Ryan John S Schuchman (eds) *Deaf People in Hitler's Europe* (Gallaudet University Press, 2002) 32 - 48

[677] Susan M Schweik *The Ugly Laws: Disability in Public* (New York University Press, 2009) 48

jurisprudence the high water-mark of this perspective is summarised in the Supreme Court decision of *Buck v Bell*,[678] a case not yet formally overturned. The decision to uphold a State law asserted to permit the surgical sterilization of Carrie Buck – whose mother and child were also identified in the proceedings as 'feeble -minded'[679] – was delivered on behalf of the majority by Oliver Wendell Holmes:

> We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes… Three generations of imbeciles are enough.[680]

The removal of so many inconvenient people to institutions might be said to represent a slowed down eugenics, yet no less destructive; a shutting away of those who sap the strength of the state. As Dolmage has it, '[p]eople with disabilities have been removed from their families and from society, allowing or forcing many to pretend that they do not exist at all.'[681] On this reading then it would seem axiomatic that if the institutions cease to be, the inevitable increased visibility of disabled people's presence on streets and in communities will ameliorate issues of exclusion and isolation. Yet, as the next section suggests, institutionalised thinking may be so entrenched in modern society that institutionalisation – even in the absence of physical institutions – remains a potent delimiter of disabled people's rights and entitlements. Prefaced on the 'ongoing cultural authority and ubiquity,'[682] of the term *normal* - that is, its continuing

---

[678] *Buck v Bell* 274 US 200 (1927)

[679] this 'diagnosis' is strenuously rebutted in Paul Lombardo *Three Generations, No Imbeciles: Eugenics, the Supreme Court and Buck v Bell* (John Hopkins University Press, 2008)

[680] at https://supreme.justia.com/cases/federal/us/274/200/; although Carrie Buck was the first person to forcibly undergo sterilization under Virginia's sterilization law some 8,300 Virginians were similarly victimised before the programme was brought to an end nationwide in the 1970s

[681] Jay Timothy Dolmage *Disability Rhetoric* (Syracuse University Press, 2014) 271

[682] Peter Cryle Elizabeth Stephens *Normality: A Critical Genealogy* (The University of Chicago Press, 2017) 354

influence in the Western imaginary – the claim is that normative assumptions about disability still serve to promote the subjugation of the disabled body.[683]

6.9 Institutionalism without walls and the power of normalisation

Agamben's analysis is useful here in that his representation of contemporary biopower suggests 'a politics that is fundamentally dependent on the domination, exploitation, expropriation and, in some cases, elimination of the vital existence of some or all subjects over whom it is exercised.'[684] Hence, what begins as an exercise in establishing supposedly statistically validated objective norms rapidly transmutes into an imposition of moral norms and then into the pathologising of those who 'violate' those norms.[685] The institution – charitable or otherwise – is in this sense, then, a profoundly adverse environment for a person with disabilities. The institution's implicit rationale is disciplinary, formulated as practices of containment, surveillance, treatment and training which coalesce in a dynamic intended to alter conduct and correct defect.[686] At the heart of these practices, the subtext appears to be about leading people with disabilities to an essentialist acceptance of who they *are*. This then, according to Hardt and Negri, is the particular achievement of biopower, the way it functions as 'a control that extends throughout the depths of the consciousnesses and bodies of the population – and at the same time across the entirety of social relations.'[687] Hence, even as institutional walls crumble and the traditional institution ceases to be, institutional thinking persists, undermining actual inclusion while reinforcing what Bolt describes as rhetorical inclusion.[688] Within this reading, the language used to describe disability may soften but in the wider consciousness exclusionary practices persist because dominant tropes endure whereby disability remains understood as a problem to be overcome rather than as just another expression of human diversity deserving of respect and, even, celebration.[689] This formulation casts light on two very public – yet arguably veiled - social phenomena that are posited here as challenging to the proper inclusion of people with disabilities in the community. The first, derived from a theoretical approach known as

---

[683] see, for instance, Lennard J Davis *Enforcing Normalcy: Disability, Deafness and the Body* (Verso, 1995)

[684] Paul Rabinow Nikolas Rose 'Biopower Today' (2006) 1 (2) BioSocieties 198

[685] see, for instance, Michael Feely, 'Disability studies after the ontological turn: a return to the material world and material bodies without a return to essentialism' (2016) 31 (7) Disability & Society 863

[686] Foucault (n 660)

[687] Michael Hardt Antonio Negri *Empire* (Harvard University Press, 2000) 24

[688] David Bolt 'Disability and the Rhetoric of Inclusive Higher Education' (2004) 28 (4) Journal of Further and Higher Education 353

[689] see, for example, Leslie Swartz, Jason Bantjes, Faine Bissett, 'Fitting in and looking pretty: experiences of students with visual impairment participating in 'inclusive' ballroom dance classes' (2018) 33 (7) Disability & Society 1087; Lennard J Davis *The End of Normal: Identity in a Biocultural Era* (The University of Michigan Press, 2013)

normalisation[690] or, in its later format, social role valorisation (SRV),[691] has a long history in disability discourse; the other, known as inspiration porn or super crip[692] is a relatively recent concept in the disability literature.[693]

Emerging as a coherent formula in Sweden in the late 1960s[694] the normalisation construct was, originally, conceptualised only in terms of people with intellectual disability, the intention being to make ‘available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society.’[695] Dated as this language is now, in its time, particularly in the context of a bleak and unproductive institutionalisation, the idea that people with intellectual disabilities might live lives that approximate to those of people without disabilities was startling. Yet, nonetheless, certainly in its earliest formulations, normalization rested on a prefiguring of disabled people as deviant – a word, indeed, which litters the early work of normalisation’s best known and most influential proponent, Wolf Wolfensburger.[696] Persuaded to the view that the traditional human care services approach to people with disabilities was designed to perpetuate the existence of large groups of dependent and devalued people, Wolfensburger not only moved the theory beyond the confines of intellectual disability (something which also happened in the Scandinavian

---

[690] Wolf Wolfensberger *The Principle of Normalization in Human Services* (National Institute on Mental Retardation, 1972)

[691] Wolf Wolfensberger *A brief introduction to Social Role Valorization: A high-order concept for addressing the plight of societally devalued people, and for structuring human services* (Plantagenet, 2014); Susan Thomas Wolf Wolfensberger An Overview of Social Role Volorization. In Robert J Flynn Raymond A Lemay (eds) *A Quarter Century of Normalization and Social Role Valorization: Evolution and Impact* (University of Ottawa Press, 1999) 125 - 159

[692] the use of the word ‘crip’ in this context relates to crip theory, a radical, activist, critique of the concept of normativity. Short for ‘cripple’ the use of the word crip is meant to be provocative, a deliberate appropriation of a term which is derogatory and cruel as an emblem of pride and positivity; see Lotta Lofgren-Martenson “Hip to be Crip?” About Crip Theory, Sexuality and Intellectual Disabilities (2013) 31 (4) Sexuality and Disability 413; to borrow from another – but related – field of studies, crip theory substitutes ‘the narrative of abjection’ with the ‘narrative of attack;’ Heather Sykes, ‘The qBody Project: from Lesbians in Physical Education to Queer Bodies In/Out of School’ (2009) 13 (3) Journal of Lesbian Studies 238, 250

[693] Robert McRuer *Crip Theory: Cultural Signs of Queerness and Disability* (New York University Press, 2006)

[694] Bengt Nirje Introduction. In Bengt Nirje (ed.)*The Normalization principle papers* (Uppsala: Centre for Handicap Research, Uppsala University, 1992); Bengt Nirje The Normalization principle and its human management implications. In Robert B Kugel Wolf Wolfensberger (eds.) *Changing patterns in residential services for the mentally retarded* (President's Committee on Mental Retardation, 1969)

[695] Bengt Nirje The Normalization Principle and Its Human Management Implications. In Robert B Kugel Wolf Wolfensberger (eds) *Changing patterns in residential services for the mentally retarded* (President's Committee on Mental Retardation, 1969) at 181

[696] see, for instance, Wolf Wolfensberger *The Principle of Normalization in Human Services* (National Institute on Mental Retardation, 1972); but in the same text at 28 Wolfensberger also acknowledges that ‘deviancy is, by definition, in the eyes of the beholder,’ noting how the visible presence of a hearing aid may be more detrimental to a person’s employment prospects than being ‘hard of hearing.’

context[697]) but also sought to 'North Americanize, sociologize and universalize the Scandinavian formulations.'[698] Moving away from the more rights-based character of its Scandinavian version,[699] Wolfensburger now proposed a refined definition of normalisation as the '[u]tilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible.'[700]

For Wolfensburger the 'norm' is a statistical device rather than a moral one, hence the issue is not about mimicking a notional 'normal' person but, rather, about recognising that there Is something profoundly *abnormal* about the circumstances in which many disabled people live. Understood best as an inductive theory[701] and building on a perceived consensus about what the good things in life are – such things as friendship, dignity, respect, acceptance, participation, home and family – proponents of normalisation most naturally find themselves aligned against institutionalisation. In Wolfensburger's normalization construct institutionalisation (and, by implication, the isolation of many disabled people in their own families) is a product of a welfare system which actively promotes congregated living.[702] For Wolfensburger institutions are places of *deindividuation*, the singular vulnerabilities of residents being operated on by regimes of fear and dependence which, exacerbated by the time spent in the institution and the resident's perception of her circumstances as hopeless, results, as intended, in a person *becoming* institutionalised.[703] As for the many professionals and others who work in these institutions and in other forms of 'societally sanctioned roles'[704] Wolfensberger contends that they too – and

---

[697] see, for example, Burt Perrin The original "Scandinavian" Normalization principle and its continuing relevance for the 1990s. In Robert J Flynn Raymond A Lemay (eds) *A Quarter Century of Normalization and Social Role Valorization: Evolution and Impact* (University of Ottawa Press, 1999) 181 - 196

[698] Wolf Wolfensberger A Brief overview of the principles of Normalization. In Robert J Flynn Kathleen E Nitsch (eds) *Normalization, Social Integration and Community Services* (University Park Press, 1980) 7

[699] see, for instance, Burt Perrin The original "Scandinavian" Normalization principle and its continuing relevance for the 1990s. In Robert J Flynn Raymond A Lemay (eds) *A Quarter Century of Normalization and Social Role Valorization: Evolution and Impact* (University of Ottawa Press, 1999) 181 - 196

[700] Wolf Wolfensberger *The Principle of Normalization in Human Services* (National Institute on Mental Retardation, 1972) at 27

[701] see, for instance, Bengt Nirje How I Came to Formulate the Normalization Principle. In Robert J Flynn Raymond A Lemay (eds) *A Quarter Century of Normalization and Social Role Valorization: Evolution and Impact* (University of Ottawa Press, 1999) 17 - 50

[702] Wolf Wolfensberger Human Services Policies: the Rhetoric versus the Reality. In Len Barton (ed) *Disability and Dependence* (Falmer, 1989) 23 - 42

[703] Miriam McNown, Johnson Rita Rhodes, 'Institutionalization: A Theory of Human Behavior and the Social Environment' (2007) 8 (1) Advances in Social Work 219

[704] Wolf Wolfensberger *The Principle of Normalization in Human Services* (National Institute on Mental Retardation, 1972) at 1

perhaps especially those who see themselves as benevolent servants of disabled people - are, in a sense, institutionalised. He writes:

> [t]hey see their clients as free agents, free to accept or reject the offered service. Their self-concept – in part due to the indoctrination received during training – is frequently incompatible with action perceived as controlling, directing or dictating client behaviour. Yet here it is where so many human service workers deceive themselves because their roles are not only almost always socially sanctioned, but in an endless array of encounters between the server and the served, the server is the interpreter of and agent for the intents of society, and wields a truly amazing amount of power and control, even if he may not consciously perceive himself as so doing.[705]

Role perceptions have always been central to Wolfensberger's concept of normalisation, in terms of how professionals see themselves (and are seen) and in relation to how labels, stereotyping and negative role expectations can force disabled persons into complying with these restraints. Hence, for Wolfensberger, the essence of the problems faced by disabled people is that 'they have been cast into devalued roles.'[706] Therefore, by re-positioning it as social role valorisation (SRV) Wolfensberger may reveal a sensitivity to claims that normalisation is about making disabled persons *normal* while also seeking to place the theory on a firmer empirical, scientific basis. Further, with the opportunity to re- structure a refined understanding of normalisation around SRV there develops an overt ideological dimension marked by a significant production of teaching and training programmes and materials designed to entrench normalisation as the preeminent approach to working with disabled people.[707] The purpose of these trainings is to re-orientate service providers to concentrate now on developing methods which reverse the negative status of disabled people by encouraging them to take on socially valued roles. Cocks summarises the implications of these training interventions thus:

---

[705] Wolf Wolfensberger *The Principle of Normalization in Human Services* (National Institute on Mental Retardation, 1972) at 1

[706] Jack Yates The North American formulation of the principle of Normalization. In Robert J Flynn Raymond A Lemay (eds) *A Quarter Century of Normalization and Social Role Valorization: Evolution and Impact* (University of Ottawa Press, 1999) at 117

[707] see, for example, Wolf Wolfensberger Susan Thomas, *PASSING (Program Analysis of Service Systems' Implementation of Normalization Goals): Normalization criteria and ratings manual* (National Institute on Mental Retardation, 1983)

> SRV provides a set of rationales in support of the social integration of devalued people in valued participation with valued people in valued activities which take place in valued settings.[708]

Wolensberger defines SRV as '[t]he application of what science can tell us about the enablement, establishment, enhancement, maintenance, and/or defence of valued social roles for people.'[709] As more people became trained in the theory, normalisation quickly became highly influential in Western thought, particularly among professionals working with disabled people. At policy level its reach is emblematised by the United Nations describing normalisation as a precursor of its 1993 *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. In part, this influence may be prefaced on the intuitive simplicity of the construct, namely that people with disabilities should have access to the normal routines and rhythms of the culture within which they live, living 'ordinary' lives as fully participating citizens. Yet, as normalisation/SRV came to greater social prominence, an number of criticisms of the model began to emerge. For some, the Wolfensberger model is authoritarian, with particular behaviours associated with particular impairments identified, for instance, as needing to be eradicated because their presence in a person's presentation of self might devalue that person in the eyes of others. By the same logic, some normalisation/SVR practitioners have argued that visible hearing aids and grab rails in public washrooms can devalue a disabled person and, so, should be avoided.[710] Within this reading of Normalisation/SRV the image the disabled person provides to the world is perceived as all important to their *fitting in*, such that the concept of a 'coercive normalizing' has been invoked to suggest 'a tutelary knowledge that disciplines and governs, rather than liberates.'[711] Indeed, suggesting a prizing of the professional status not dissimilar to the kind of pre-eminence which the medical model affords, Wolfensburger writes:

> a [disabled] person's image depends greatly on the actions of those who exercise 'managerial' controls over him, and therefore the manager should take steps to minimise the probabilities that the person for whom he has responsibility presents himself to the public in a fashion

---

[708] Errol Cocks 'Normalisation and 'Social Role Volorisation: Guidance for Human Service Development' (2001) 11 (1) Hong Kong Journal of Psychiatry 12, 15

[709] Wolf Wolfensberger The SRV training package (unpublished, 1995)

[710] Burt Perrin The original "Scandinavian" Normalization principle and its continuing relevance for the 1990s. In Robert J Flynn Raymond A Lemay (eds) *A Quarter Century of Normalization and Social Role Valorization: Evolution and Impact* (University of Ottawa Press, 1999) 181 - 196

[711] Barry Allen Foucault's Nominalism. In Shelley Tremain (ed) *Foucault and the Government of Disability* (University of Michigan Press, 2015) 97

> that is apt to lower what we might call 'the perceived deviancy threshold.'[712]

By encouraging a notional disabled person to play a role supposedly palatable within the wider society Wolfensberger has been criticised for devaluing the whole person.[713] Moreover, the model never questions the legitimacy of the social norms it holds up for emulation,[714] never engaging with the idea that norms – let alone disability itself - are social constructs.[715] The privileging of the professional gaze reproduces the power asymmetries which, traditionally, have denied disabled people their freedom as dignified, autonomous beings, in the process contributing not to disabled people's freedom but, rather, to their continuing oppression.[716] In the same vein, Culham and Nind contend that 'the assimilationist aspects of normalisation/SRV' conflicts with the empowerment strategy validated by other devalued groups in society 'who have instead glorified their differences and openly congregated.'[717] Instead, the theory may be said to conform to traditional ideas about normality and its desirability. In shoring up a comforting ableist binary, it keeps professionals in control[718] and in its promoting of a particular kind of inclusion it never requires engagement with the hard questions of why disabled people experience exclusion in the first instance.

Yet, despite these and other criticisms it is suggested that normalisation/SRV continues to exercise considerable salient influence in the wider public discourse. As Wolfensberger might have it, normalisation intuitively represents common sense. According to him all people relate to each other evaluatively, hence in Wolfensberger's view normalisation/SRV offers people with disabilities – perhaps particularly those with intellectual disabilities – an unprecedented opportunity to *fit in* and, in doing so, to be valued, if not for themselves, then, at least, for the roles they inhabit. But this fitting in is, axiomatically, always in the gift of the so-called able-bodied against whose *normality* the efforts of the disabled person are measured and rated. It is in this context then that the 'inspiration porn' phenomenon comes to light. The term is

---

[712] Wolf Wolfensberger *The principle of normalization in human services* (National Institute on Mental Retardation, 1972) at 33

[713] Anne Louise Chappell From Normalisation to Where? In Len Barton, Mike Oliver (eds) *Disability Studies: Past, Present and Future* (The Disability Press, 1997) 45 - 62

[714] John Hattersley The future of normalisation. In Steve Baldwin John Hattersley (eds) *Mental Handicap: Social Science Perspectives* (Tavistock Routledge, 1991)

[715] Hilary Brown Helen Smith 'Whose "ordinary life" is it anyway?' (1989) 4 (2) Disability, Handicap and Society 105

[716] Michael Oliver *Understanding Disability* (Palgrave Macmillan 2009)

[717] Andrew Culham, Melanie Nind, 'Deconstructing normalization: Clearing the way for inclusion' (2003) 28 (1) Journal of Intellectual & Developmental Disability 65, 71

[718] see, for instance, Dan Goodley Disability Studies: An interdisciplinary introduction (Sage, 2011)

attributed to disability activist Stella Young and captures the way non-disabled people objectify and use disabled people’s mundane acts and ordinary achievements to gratify themselves about the superiority of their own lives, whatever their defects and difficulties. Young says:

> [l]et me be clear about the intent of this inspiration porn; it's there so that non-disabled people can put their worries into perspective. It's there so that non-disabled people can look at us and think "well, it could be worse. I could be that person.”[719]

Stories of how inspirational some disabled people are – what might be termed ‘in spite of’ stories – feed into the myth of the super crip and can be understood as part of the wider normalisation culture which denies disabled people the legitimacy of their own mundanity. Disability becomes an *it* which some unfortunate people have. But, some of these people with *it* are adjudged to have the right attitude, *they* are patient and accepting of their lot in life, making the best of it, cheerful and, often, appreciative of any help offered or received. Such people are often described in heroic terms – theirs is a story of ‘triumph over adversity’ or of having ‘defeated the odds.’ By contrast, other disabled people may be represented as tragic figures, victims of a condition, an *affliction*, over which they have no control.[720] But, at root, what both of these stereotypes have in common is the perception that disability is a bad thing, an negative. This too, at root, is, arguably, what the normalisation/SRV methodology holds. The intention to normalise confronts disability as something to be cancelled out or concealed, the very same dynamic powering the now closed institutions. Stiker’s observation seems apt:

> [b]ut when it is a question of showing “what society is doing” or how the disabled are situated within it, it is only and always normalcy that is represented. Deficiency will always be concealed so that the image projected and retained by the spectator or auditor will always be agreeable, not be aggressive and, above all, not stigmatize any social wound. Our Western culture of the moment can no longer tolerate deformity.[721]

---

[719] Stella Young https://www.abc.net.au/news/2012-07-03/young-inspiration-porn/4107006

[720] See, for instance, Mark Sherry Reading me/me reading disability. In Brenda Jo Brueggemann Martin E Lupo (eds) *Disability and/in Prose* (Routledge, 2008) 153 - 165

[721] Henri-Jacques Stiker *A History of Disability* (The University of Michigan Press, 1999) 146

Stiker says: 'I do not say that normalization ought to be challenged: I say that it ought to be recognised for what it is.'[722] The theory never questions the legitimacy of prevailing theories of normality[723] and some critics have even identified normalisation as a contributor to disabled people's marginalisation and oppression.[724] As a supposedly scientific way of working which takes integration as one of the most significant corollaries of normalisation, Wofensberger warns that for people with disabilities:

> integration is only meaningful if it is social integration; i.e. if it involves social interaction and acceptance, and not merely physical presence.[725]

6.10 Isolation in the community

Indeed, physical presence in a community may not merely not result in disabled people's integration but may exacerbate individual isolation and cultural marginalisation. In circumstances where ideological notions of normality dominate and where, in the culture, 'impairment literacy'[726] is low, it is submitted that people with disabilities, post deinstitutionalisation, may often find themselves living *in* the community but not *of* the community. On such views, the quality of life envisaged in article 19 can prove illusory. Worse, persons with disability may find themselves vulnerable to victimisation. Within social care scholarship, the literature on the mistreatment of people with disability tends to focus on abuse occuring within institutional settings.[727] However, less robust information is available in terms of the abuse experiences of people with disability living in the community,[728] partly, perhaps, because disabled people may not recognise the abuse as criminal or because they do not know where to report it or, if reported, do not believe it will be taken seriously.[729] But what is clear is

---

[722] *ibid*

[723] see, for instance, Colin Barnes Geoff Mercer *Exploring Disability* (Polity, 2010)

[724] Mike Oliver Capitalism, disability and ideology: a materialist critique of the normalization principle. In Robert J Flynn Raymond A Lemay (eds) *A Quarter Century of Normalization and Social Role Valorization: Evolution and Impact* (University of Ottawa Press, 1999) 163 - 174

[725] Wolf Wolfensberger *The principle of normalization in human services* (National Institute on Mental Retardation, 1972) 48

[726] Deborah Marks 'Some Concluding Notes – Healing the Split Between Psyche and Social: Constructions and Experiences of Disability' (2002) 22 (3) Disability Studies Quarterly 46, 48

[727] see, for instance, Aras Attracta Swinford Review Group *What Matters Most* (HSE, 2016); UK Department of Health *Transforming Care. A National Response to Winterbourne View Hospital. Department of Health Review Final Report* (Department of Health, 2012)

[728] Chih Hoong, Sin Annie Hedges, Chloe Cook, Nina Mguni, Natasha Comber, *Disabled people's experiences of targeted violence and hostility* (Equality and Human Rights Commission, 2009)

[729] see, for example, John Clayton, Catherine Donovan, Stephen J MacDonald, 'A critical portrait of hate crime/incident reporting in North East England: The value of statistical data and the politics of recording in an age of austerity' [2016] 75 Geoforum 64; Chih Hoong Sin, 'Making disablist hate crime visible. In Alan Roulstone Hannah Mason-Bish (eds) *Disability, Hate Crime and Violence* (Routledge, 2015) 146 – 165; Chih

that whether the adverse events people with disabilities are experiencing manifest as hate crimes[730] – that is crimes, violent and non-violent, motivated by bias and prejudice[731] – or 'mate crimes' perpetrated by putative friends or family members[732] or in a myriad other ways such as abusive language, bullying, discourtesy or expressed contempt the common thread is that they all can have significant impact on disabled people's confidence and participation in society.[733] What also appears clear is a corollary between the targeting of disabled people in these sorts of undermining and destructive ways and the increasing visibility of disabled people in communities and public spaces.[734]

Prejudice is a significant impediment to disabled people's full and meaningful inclusion in society and the enfleshing of article 19 in individual lives. Chakraborti and Garland suggest that the victimisation of disabled people is a complex issue.[735] While it may arise because disabled people are perceived as easy or soft targets – less likely to defend themselves or report victimisation – 'boredom, jealousy or unfamiliarity with 'difference'' also plays a part, as does socio-economic factors, age and the sorts of areas victimisers and victims live in together. [736] That said, however, intimations that vulnerability is axiomatically associated with disability is denied by other theorists, who claim that this type of argument orientates disabled people's experiences of hate crime away from a policing and legal response and, instead, towards a paternalistic social care intervention.[737] Nonetheless, whether or not the difference represented by impairment

---

Hoong Sin, Annie Hedges, Chloe Cook, Nina Mguni, Natasha Comber, *Disabled people's experiences of targeted violence and hostility* (Equality and Human Rights Commission, 2009) https://www.equalityhumanrights.com/en/publication-download/research-report-21-disabledpeoples-experiences-targeted-violence-and-hostility

[730] for the purposes of this discussion a useful definition of hate crime is provided by Wolfe and Copeland, thus: '[v]iolence directed towards groups of people who generally are not valued by the majority of society, who suffer discrimination in other areas and who do not have full access to remedy social, political and economic injustice.' Leslie Wolfe Lois Copeland *Violence Against Women as Bias Motivated Hate Crime* (Centre for Women Policy Studies, 1991)

[731] Nathan Hall *Hate Crime* (Routledge, 2013); for Hall the word *hate* is problematic, preferring instead the much more expansive concept of prejudice to explain the complex web of emotions which lead to some people victimizing others

[732] see Pam Thomas Hate crime or mate crime? In Alan Roulstone Hannah Mason-Bish (eds) *Disability, Hate Crime and Violence* (Routledge, 2015) 135 - 146

[733] Neil Chakraborti, Jon Garland, Stevie-Jade Hardy *The Leicester hate crime project: Findings and conclusions* (University of Leicester, 2014)

[734] Edward Hall 'A critical geography of disability hate crime' (2019) 51 (2) Area 249

[735] Neil Chakraborti, Jon Garland 'Reconceptualising hate crime victimization through the lens of vulnerability and difference' (2012) 16 (4) Theoretical Criminology 499

[736] *ibid* at 510

[737] see, for instance, Katharine Quarmby Media reporting and disability hate crimes. In Alan Roulstone Hannah Mason-Bish (eds) *Disability, Hate Crime and Violence* (Routledge, 2015) 64 – 79; Katharine Quarmby *Scapegoat: why we are failing disabled people* (Portobello Books, 2011); Mark Sherry *Disability Hate Crimes: Does Anyone Really Hate Disabled People?* (Ashgate, 2010)

connotes vulnerability *per se*, it is emphasised by Perry as key to understanding hate crime. Mirroring Said's conceptualisation of the *Other*,[738] Perry draws attention to how normalising narratives indicate some in society as believing themselves superior and others inferior, the violence and/or intimidation perpetrated on one victim being intended to convey to other disabled people that they do not belong.[739] As Perry describes it:

> '[i]t is a means of marking both the Self and the Other in such a way as to re-establish their 'proper' relative positions, as given and reproduced by broader ideologies and patterns of social and political inequality.'[740]

In the mundane micro-spaces of everyday living, fear of violence and aggression can making living independently in the community a frightening experience for some disabled people. As Hall and Bates note, encountering hostility from others, whether in the form of hate crime or what are termed micro-aggressions,[741] can result in '[i]solation, self-exclusion and absence, and feelings of vulnerability and precarity.'[742]

In Ireland, disability hate crime is under-theorised,[743] although this might be seen in the context of an institutional lag in addressing hate crime in general.[744] Indeed, as of yet, Ireland has no comprehensive hate crime legislation. The nearest relevant legislation is the *Prohibition of Incitement to Hatred Act 1989* [745] but, in general terms, this is of very limited application and

---

[738] Edward Said *Orientalism* (Penguin Books, 2003)

[739] Barbara Perry The sociology of hate: Theoretical approaches. In Barbara Perry (ed.) *Hate Crime Volume One: Understanding and Defining Hate Crime* (Praeger, 2009) 55 – 76

[740] Barbara Perry *In the Name of Hate: Understanding Hate Crimes* (Routledge, 2001) 10

[741] the concept of micro-aggression has entered the literature to describe those types of veiled and seemingly minor verbal and behavioural engagements which, while often deniable and even unconscious, serve to remind a target person of their marginalized status and, thus, reproduce disadvantage. Hence, for Natilier micro-aggressions are those 'discriminatory and undermining interactions that articulate and reinforce social hierarchies and power differentials.' Kristin Natilier 'Micro-aggressions, single mothers and interactions with government workers: The case of Australia's child support bureaucracy' (2017) 53 (2) Journal of Sociology 622, 623; see also Derald Wing Sue Lisa Beth Spanierman *Microaggressions in Everyday Life* (Wiley, 2020); Derald Wing Sue (ed) *Microagreesions and Marginality* (Wiley, 2010)

[742] Edward Hall, Ellie Bates 'Hatescape? A relational geography of disability hate crime, exclusion and belonging in the city' [2019] 101 Geoform 100, 106

[743] However, see Claire Edwards, Nicola Maxwell *Disability and the Creation of Safe(r)Spaces* (UCC, 2019)

[744] James Carr, Amanda Hayes, Jennifer Schweppe 'Hate crime: an overview of relevance and significance to Irish sociology' (2017) 25 (1) Irish Journal of Sociology 73

[745] the Act's genesis was intended to discharge Ireland's responsibilities under international human rights instruments and in particular the ICCPR, article 20.2 of which requires that 'any advocacy of national, racial or religious hatred that constitutes incitement to discrimination, hostility or violence shall be prohibited by law.' As the Bill proceeded through the Oireachtas, its provisions were extended to include the Traveller community and sexual orientation – in the latter case, three years before the state removed the criminal sanction on homosexuality; the other groups protected under the Act are determined in terms of race, colour, nationality, religion and ethnic or national origins

regarded as particularly deficient in a number of respects.[746] Indeed, the Act makes no mention of disability, perhaps indicating the relative invisibly of disabled citizens at the time the legislation was enacted or a benign belief on the part of legislators that the offence of incitement to hatred had no application in respect of disability.

6.11 A republican reading: visibility and voice

Republican theory is concerned with exclusion, as any cohesive political theory must be. But, the particular emphasis republicanism places on freedom as non-domination draws an especial attention to the corrosive societal damage exclusion represents. To be unfree in the republican sense is to live a partial life, one constrained by another's power – or, indeed, a corporate entity's power - to intervene inappropriately in that life at will. Hence, this particular focus on freedom emphasises how for people with disabilities there is the domination of being subject to a particular kind of disparaging or patronising attitude, likely across a range of areas, including education, work and independence. Within the domination context, this exclusion shapes a restricted social world and feeds into stereotypical tropes that further oppress disabled people. This lowers expectations about people with impairments in general while, at the same time, creating space to extol those disabled people labelled 'exceptional' or 'inspiring.' This bifurcation, perhaps, further serves to alienate the great majority of disabled people.

Republicans are particularly sensitive to any form of paternalism. Indeed, what is the benign slave owner or the indulgent but ultimately controlling husband if not a reminder of the insidious ways in which apparent kindness can mask domination and serve to pervert another's ability to assert their own choices for how they want to live their life? By its very definition, paternalism creates problems for persons with impairments. In its most common usage – that of treating an adult like a child – it is clear why paternalism is a problem. But, libertarians, for instance, also rail against the state for enforcing laws that they deem paternalistic, such as those which arise in respect of prohibiting smoking indoors or criminalising recreational drug use, the libertarian claim being that this is state over-reach. Thus, Bok quotes Constant:' [l]et [government officials] confine themselves to being just. We shall assume the responsibility for being happy for ourselves.'[747] However, for their part, governments display this type of paternalism as a token of an appropriate state concern that people should be protected from their own – and others' - harmful inclinations.

---

[746] see, for instance, Jennifer Schweppe Amanda Haynes James Carr *A Life Free from Fear: Legislating for Hate Crime in Ireland: An NGO Perspective* (University of Limerick, 2014); Seamus Taylor *Responding to Racist Incidents and Crime: An Issues Paper for the Equality Authority* (Equality Authority 2011)

[747] Derek C Bok *The Politics of Happiness* (Princeton University Press, 2010) 46

Of course, in circumstances where physical or cognitive impairment are taken as markers for invoking particular forms of interventionist regimes, such as institutionalisation, paternalism takes on a different hue again. Here, liberals and libertarians, republicans and authoritarians are likely, perhaps, to fall foul of the same assumptions, the same sort of taken-for-granted thinking that may throw considerable light on why there are mainstream schools and special schools operating in tandem and why so few disabled people are in remunerated employment. Rooted in a deficit model of impairment, these assumptions may be taken as social *facts* – impairment equates almost inevitably with dependence, whether on special educational provision, on welfare arrangements rather than work or on certain forms of living arrangements rather than on independence and community inclusion. Within such a social understanding, independence is presented as the precise antonym of dependency, even as within the wider critical disability discourse dependency is theorised as entirely the product of an ableist society.[748] Nonetheless, these social facts percolate persuasively through the culture, even in circumstances where government policies may favour – even strongly articulate for – mainstream education, work rather than welfare (or some amalgam of the two) and social inclusion. The strain of paternalism now in play is moved by charity or pity or, perhaps, disguist, fear or prejudice or, indeed, a medley of these and other feelings and thoughts. The net result is a confused social and political perception, a form of doublethink where it seems possible to be for and against something simultaneously.

Within this context, what might the appropriate republican response be? On the one hand, I have indicated that republicanism naturally disdains paternalism. However, I am also conscious that within the republican rubric not all forms of interference are axiomatically dominating. Thus, an interference is not arbitrary – and, therefore, non-dominating – if it tracks the common avowable interests of a person or persons, whether in terms of *dominium* or *imperium*. [749] In relation to disability, the common categorisation of many disabled people as being in some supposedly fatal ways incapable of managing their own freedom puts them beyond full or proper agentive participation in the republican (and liberal) paradigm. This disrupts discerning the common avowable interests of disabled people and, in turn, all but invites paternalism. Indeed, a whole, intricate industry has grown up providing care and services to people with disabilities in all sorts of ways, including, perhaps, some new forms of institutionalisation, the broad purpose of which is to operate *for* disabled people but yet run by and staffed by people who are not, in the main, disabled. How can a large swathe of contemporary republican

---

[748] see Oliver and Barnes (n 198)

[749] Philip Pettit *A Theory of Freedom: From the Psychology to the Politics of Agency* (Polity Press, 2001)

theorising leave *this* paternalism unstudied? How can a theory concerned with countering worries about majoritarian tyranny be disinterested in circumstances where the world's largest minority is inadequately represented within the polity; where, drawing on but one example, SRV requires disabled people to *fit in* with majoritarian ways of being? How can a theory that promotes dignity and social diversity be seemingly untroubled by the exclusion of people with disabilities from mainstream schools and workplaces? More, what of the violence and fear of violence disabled people report being subject to, perhaps especially where this correlates with moves towards realising the article 19 goal of living in the community?

How might *these* social facts be incorporated into a more expansive, disability-friendly republican ethic, one that extends its parameters to include all disabled people? How might *all* of contemporary republican theorising be encouraged to fully embrace disabled people's agency, including those Pettit identifies as not 'abled-minded?'[750] An attempt to answer these questions has already been offered in chapter two. There, drawing, in particular, on Nussbaum's prominent placing of dignity within her reading of the capabilities paradigm, I have suggested that to exclude disabled people from full involvement in the community violates human dignity. Here, briefly, I seek to undergird this point with reference to two elements which I believe are central to helping broad republicanism make this imaginative realignment, both of which are also pivotal in enabling the CRPD take root in the wider social consciousness: *visibility* and *voice*.

Visibility goes to the heart of the article 19 ambition. The institutional approach to dealing with great swathes of disabled people within the Western system was prefaced, in part, on the idea of keeping disabled people out of sight, sequestered away from *normal* people and promoting (the fiction of) 'a sanitised norm of human behaviour and experience.'[751] The beliefs, myths and practices that constitute ableism find easy purchase in a world where difference is, largely, hidden away. It becomes straightforward equating citizenship and its benefits with a particular type of body and a particular type of mind, a stratification that places impairment on the margins of society and of pressing political concern. Being *seen* – that is, being seen other than as anything more than their impairment – becomes the great emancipatory struggle for disabled people: an urge to freedom of a type consistent with (and just still as uneven as) the ending of slavery and the enfranchisement of women. As Agamben reminds, those who have only 'bare life' are easily marginalised and oppressed, their experiences without currency in the wider

---

[750] see Pettit (n 122) 75

[751] Bill Hughes Civilising Modernity and the Ontological Invalidation of Disabled People. In Dan Goodley Bill Hughes Lennard Davis (eds) *Disability and Social Theory* (Palgrave Macmillan, 2012) 17

politics.[752] Hence, the huge importance of the 'nothing about us' agenda of the disability activists and the Independent Living Movement in aligning the directly expressed freedom wants of disabled people with the need to dismantle an ableist culture largely unseen by those who are not yet disabled. That said, others express concern that while ramps and disabled parking spaces – and rights talk – proliferate, of itself, an increasing (if slow) visibility of disabled people is insufficient to tackle the inequalities which still exist in terms, say, of employment rates or local housing options or properly inclusive education. Indeed, Reeve claims that today 'disabled people live in an age where exclusion and inclusion can and do exist in many areas of their lives,' rendering it very difficult to successfully challenge disablism. [753]

So, the question again is how might contemporary republicanism track the common avowable interests of disabled people and so include them fully in the republican research project. The increased visibility of disabled people in contemporary society is important. But, we can see that this is hampered by segregated schooling (including *within* mainstream schools), the low rates of employment among disabled people and, in a problem common to an increasing number of citizens – and, so, pointing to a particularly potent point of praxis - a shortage of suitable housing in local communities.

A key question thus becomes determining what a common avowable interest is. Pettit understands this question in terms of *voice*.[754] For Pettit, democratic voice enables the state to understand what policies and strategies it must prioritise in order to increase the range of non-dominated choices available. So too does voice enables private and domestic relationships to be appropriately regulated. This perspective fits well with the CRPD's article 29 (participation in political and public life), article 8 (awareness raising) and article 19 itself. It also fits with the general obligation imposed on states under article 4(3) that in the development and implementation of legislation and policies to implement the Convention - and in other decision-making processes - disabled people, including children, be actively consulted and involved.

At least as it applies to the not yet disabled, this notion of voice is well developed in Pettian theory.[755] Within this schema, democratic electoral systems are necessary but they are not

---

[752] Giorgio Agamben *The Open: Man and Animal* (Stanford University Press, 2004)

[753] Donna Reeve Biopolitics and bare life: does the impaired body provide contemporary examples of *homo sacre?* In Kristjana Kristiansen Simo Vehmas Tom Shakespeare (eds.) *Arguing About Disabilities* (Routledge, 2010) 213

[754] Pettit (n 749) 159

[755] see, for instance, Philip Pettit Republican Freedom and Contestatory Democratisation. In Ian Shapiro Casiano Hacker-Cordon (eds.) *Democracy's Value* (Cambridge University Press, 1999) 163 - 190; Philip

sufficient. Something else is required to contest decisions between electoral rounds and to ensure 'that only matters of common avowable interest shape what happens in and at the hands of government.'[756] This something else Pettit identifies as rights of democratic contestation, that is voicing dispute in a structured, democratically provided-for, fine-grained way. Extending this to disabled people, De Wispelaere and Casassas contend that

> [c]ontestation mechanisms importantly shift the balance of decision-making back to a state where disabled people are not mere recipients of policy, as in the social welfare model, but are instead regarded as genuine political partners in policy design and delivery. Democratically speaking, being able to challenge decisions is an apt way of making oneself visible (and audible), and therefore rightly regarded as amongst the most important political rights. In addition, effective contestation ensures that public policy, and state action more generally, remains firmly grounded in the avowable interests of disabled citizens by introducing a politics of presence into disability policy and legislation.[757]

Thus, De Wispelaere and Casassas point to a finely-tuned, sensitive arrangement wherein the common interests of disabled people are discernible in entirely the same way as they are for the rest of the citizenry: by finding ways of dignified listening for them. In terms of article 19 and inclusion generally, what is described here is of practical utility. It posits an eminently achievable goal of disabled people welcomed into clubs and residents associations and community groups and councils and local political pressure pop-ups and parliaments not simply as disabled people *per se* but as people whose life insights are important to creating as comprehensive a democratic contestation as possible in the interests of reducing domination and building up liveable communities. In ensuring disabled people's robust entry into the public sphere, disabled people help shape the norms under which interpersonal and political life in the community are regulated, their insights and contributions valued as those of fellow citizens in a resiliently republican polity. Moreover, in such a dispensation, the continued use of institutional arrangements to accommodate disabled people – of whatever type – or the expectation that disabled people can only live in communities at the sufferance of service providers or that they conform within a range of normalised behaviours become visible as issues for the *entire* political

---

Pettit Deliberate Democracy and the Discursive Dilemma (2001)11 (1) 2001 Philosophical Issues 268 - 299

[756] Pettit (n 749) 16

[757] Jurgen De Wispelaere David Casassas 'A life of one's own: republican freedom and disability' (2014) 29 (3) Disability & Society 402, 411

community. So too for the idea that disabled people might experience elevated levels of harassment or violence – this also becomes a matter of communal rather than sectional concern.

The fundamental communal ethic of republicanism at work here is that it is in *everyone's* benefit to reduce domination in both private and public spheres, that tracking common avowable interests ensures that in the protection of the weakest is found strong legitimation for the republican argument in its entirety. This being so, the lack of attention paid to disabled people within much of contemporary republican theorising is troubling; but it is not fatal. Silvers' positioning of disabled people as having been arbitrarily deprived of opportunities to contribute as citizens is helpful here and, of itself, simply delineates another domination.[758] Citing the emancipatory struggles in the US of women and black people and the challenges this represented to prevailing political and legal norms, Silvers reminds that there were strong – and entirely erroneous - arguments within these norms which equated women and black people as naturally inferior and incapable of political involvement by virtue of 'their differences in talent and character.'[759] The net effect was to damage the polity by not recognising sooner 'the facts of human diversity rather than the fiction of a homogeneous humanity.'[760] Moreover, in delaying justice's embrace of difference the polity denied itself access to a 'profound diversity of potential co-operators.'[761]

In accepting that disability manifests as an area entirely consistent with what republican norms seek to achieve, the inclusion of disabled people as equals within the contestatory process is itself a protective, non-dominating act. Conversely, not to do so runs the clear risk of increasing domination within a society by permitting that there will be citizens subject to norms they have not been able to contest.

7 Conclusion

This chapter offers, respectively, a contextualised account of the CRPD's articles 4 (general principles), 24 (education), 27 (work and employment) and 19 (living independently and being included in the community). In particular, in individually juxtaposing these accounts with a republican commentary I seek to contend not alone that contemporary republicanism is a

---

[758] Anita Silvers Formal Justice. In Anita Silvers David Wasserman Mary B Mahowald (eds) (Rowman & Littlefield Publishers, 1998) 13 - 110

[759] *ibid* at 15

[760] Anita Silvers No Talent? Beyond the Worst Off! A Diverse Theory of Justice for Disability. In Kimberley Brownlee Adam Cureton (eds.) *Disability and Disadvantage* (Oxford University Press, 2009) 192

[761] *ibid* at 199

political theory of depth and wide applicability but also that by placing the Convention in direct dialogue with republicanism strong points of cohesion are revealed.

Chapter Four:

Methodology and Methods

‘Because we are in the world, we are condemned to *sense*’[1]

1 Chapter overview

The sections herein offer an account of the methodological choices underpinning this dissertation’s critical stance as well as describing the particular methods employed in the instant research.

2 Introduction

In this dissertation’s opening chapter, I reference republicanism’s natural methodological stance as indicating a fit with the broad critical theory approach. I then reference aspects of a critical phenomenology which provides me as researcher with the tools I – in my particular circumstances – require to hold true to the demands of facilitating a discussion of the data which is empowering and emancipatory. I further indicate that this approach necessitates me interrogating myself and my world so that I may better attune to the experiences of those who participate in this research and their worlds. In adapting such a perspective my interest can be said to be ‘not ‘what is out there’ but what is meaningfully present within a human context’.[2]

In this chapter, I seek to make explicit two dimensions. First, as a matter of methodology I seek to present critical theory and, more specifically, aspects of a critical phenomenology, as underpinning the claim that I am producing emancipatory and empowering research. Second, as a matter of method, I extend a particular species of critical phenomenology to demonstrate the methodological promise in its application to the instant research. As devised by Dahlberg *et al.,*[3] this approach is called the reflective lifeworld method and is prefaced on the assertion that the supposed fissure between description and interpretation represents an ultimately erroneous epistemological gap. As represented in the phenomenological canon, describing lived experience is the goal of those practicing in the Husserlian tradition, which Heidegger and his follows eschew in favour of *interpretation*. However, Dahlberg and Dahlberg contend that the purported objectivity of the one and the supposed subjectivity of the other can be usefully

---

[1] Maurice Merleau-Ponty *Phenomenology of Perception* (Routledge, 2014) at xxxiv; in some editions of this book ‘*sense*’ is translated as ‘meaning’ (italics in original)

[2] Thomas Sheehan ‘Dasein’ in Hubert L Dreyfus Mark A Wrathall (eds) *A Companion to Heidegger* (Blackwell Publishing, 2005) 197

[3] Karin Dahlberg Nancy Drew Maria Nystrom *Reflective Lifeworld Research* (Studentlitteratur, 2001)

reconciled to enable scientifically rigorous and reflectively open research approaches that are 'capable of making a change.'[4]

3 Critical theory

Coalescing around a scepticism about the veracity of perceived truths, critical theory refers to a specific movement first identified with the neo-Marxist Institute for Social Research, colloquially (and universally) known as 'the Frankfurt School.'[5] Established in the inter-war years and inter-disciplinary in nature, those intellectuals who came together within the Frankfurt School were self-consciously political in their ambitions to change society, the cornerstone of critical theory being a commitment to emancipation.[6] Looking about at a world where authoritarian forces were increasingly in the ascendant, both on the left and the right, members of the school viewed facts not as objective and neutral depictions of reality but as fungible entities, their meanings contingent on the individual values, exigencies and social forces which shape the culture within which they emerge.[7] Although not formally a critical theorist, Gramsci's ideas are useful here. Gramsci, himself a person living with disability, employs the idea of hegemony to describe a subtle, yet pervasive level of societal control whereby an exploiting class makes its beliefs and ideas seem natural and even necessary, including to those subjugated by them.[8]Gramsci contends that through this hegemony the exploited become unwitting accessories in their own exploitation, in thrall to culturally mediated 'capitalist mystifications' rather than, as once, to fear of a repressive state.[9] As Williams has it – describing something resonant with experiences of disability - this hegemony represents

> a whole body of practices and expectations, over the whole of living: our senses and assignments of energy, our shaping perceptions of ourselves and our world. It is a lived system of meanings and values –

---

[4] Helena Dahlberg, Karin Dahlberg 'Open and Reflective Lifeworld Research: A Third Way' (2020) 26 (5) Qualitative Inquiry 458, 463

[5] among the leading figures associated with the school were Max Horkheimer, its first director, Theodor W. Adorno, Eric Fromm, Herbert Marcuse, Walter Benjamin and Jurgen Habermas; see David Ingram *Critical Theory and Philosophy* (Paragon, 1990); Stephen Eric Bonner *Of Critical Theory and Its Theorists* (Routledge, 2002); Stuart Jeffries *Grand Hotel Abyss* (Verso, 2016)

[6] see, for instance, Helen Meekosha Russell Shuttleworth What's so "Critical" about Critical Disability Studies? In Lennard J Davis (ed.) *The Disabilities Studies Reader* (Routledge, 2017) 175 – 194; Max Horkheimer *Critical Theory Selected Essays* (Continuum, 2002)

[7] see, for instance, Dino Franco Felluga *Critical Theory. The Key Concepts* (Routledge, 2015)

[8] Antonio Gramsci *Selections from the Prison Notebooks* (International Publishers, 1971)

[9] Perry Anderson *The Antinomies of Antonio Gramsci* (Verso, 2020) at 63

> constitutive and constituting – which as they are experienced as practices appear as reciprocally confirming.[10]

As with hegemony, critical theory offers a particular perspective on the layered ways in which humans are dominated in modern societies, including ways in which the genuine needs and interests of people are obfuscated and repressed. Convinced that liberal systems of government can give birth to totalitarian regimes – exemplified in the Third Reich's replacement of the Weimar Republic – two first generation members of the Frankfurt School, Horkheimer and Adorno, address a world in which people are reduced to *things*, subjugated and manipulable.[11] Thus portrayed, the person becomes just an instrumental entity and the whole world presents merely as a collection of resources to be exploited. These two ideas, characterised, respectively, as reification and alienation, prefigure a contemporary world not progressing but regressing. More, that this may appear otherwise is a product of a false consciousness, generated in no small part by a homogenised, industrialised mass culture which is in the service and control of capitalist monopolies.[12]

Kantian in essence, the *critical* in critical theory refers to methodical doubt, albeit extending this out to embrace modern areas of interest such as how relationships of power and dominance are socially encoded.[13] With its rationale of interdisciplinary social research, this interest in exploring the way domination functions in the world appears from the very inception of the Frankfurt School. Originally, this research took two broad but closely related forms: analysis of the hegemony of bourgeois ideology and culture and a focus on the failure of the Marxist revolutionary vision to take hold across Europe.[14] However, as already suggested, over time the research interests which come to the fore could be described as explorations about the nature of conformity, including the ways in which popular culture functions to endorse the status quo and to shield people from an awareness of the actual reality of the lives they are living. This concern with illusion – in essence, how that which purports to be liberation can really represent oppression – means that the critical theorist is always interested in researching social phenomena from the perspective of the power relations that shape them. For Strydom, this focus is summarised as being attentive to 'the pathological deformation of reason in the historical process of its actualisation and realisation.'[15]

---

[10] Raymond Williams *Marxism and Literature* (Open University Press, 1977) 110

[11] Max Horkheimer Theodor W Adorno *Dialectic of Enlightenment* (Stanford University Press, 2002)

[12] *ibid*; see also Theodor W Adorno *The Culture Industry* (Routledge, 1991)

[13] see, for example, Immanuel Kant *Critique of Pure Reason* (first published 1781, Penguin Classics, 2007)

[14] Gregory Claeys *Marx and Marxism* (Nation Books, 2018)

[15] Piet Strydom Contemporary Critical Theory and Methodology (Taylor and Francis, 2011) at 114

Within such an urgent context, the critical theorist is called, as Marx has it, not merely to interpret the world but to change it. Thus, simultaneously, a critical theory is required to be explanatory of what is wrong with the existing social reality, practical in its identification of the social actors capable of effecting change and normative in its provision of 'both clear norms for criticism and achievable practical goals for social transformation.'[16] As Buchanan puts it:

> critical theory is interested in why human society has (in its eyes) failed to live up to the promise of the enlightenment and become what it is today, unequal, unjust and largely uncaring.[17]

As practiced today, critical theory is best understood as a broad tradition rather than a strict system or set of proscriptions. Though long extant, the Frankfurt School remains influential, its former trenchant neo - Marxist ideology now largely distilled into a defence of liberal democracy, a shift today particularly associated with the work of Jurgen Habermas.[18] Remaining central, however, is the tradition's emphasis on radical social change, expressed in terms of promoting transformational democratic freedom. Within the disability consciousness critical theory is practised with specific reference to critical disability studies, a broad but coherent field that has emerged across Western academia, committed in the main to intra –disciplinary and multidisciplinary research and to working closely with disability activists to bring about change.[19]

3.1 Finding a critical phenomenology

Both phenomenology – as understood here - and critical theory work to de-familiarise the familiar, so that a phenomenon might be perceived anew. Hence, the aim here is not to deny the reality of the world but rather to make it more accessible to research inquiry, it being likely that what is taken for granted passes un-noticed. With specific reference to researching the experiences people have of disability in the world – whether direct or indirect – arguably a taken-for-granted stance is, inevitably, detrimentally at play. Such a stance permits that hearing is superior to not hearing, that not seeing is inferior to sight, that there is a normal way in which a brain or a limb or a mood must present if that brain or limb or mood is not to be ontologically deemed abnormal or deficient or defective. Within this binary, potential harm is ever-present.

---

[16] James Bohman Critical Theory (Stanford Encyclopedia of Philosophy, 2005) at https://plato.stanford.edu/entries/critical-theory/

[17] Ian Buchanan *Oxford Dictionary of Critical Theory* (Oxford University Press, 2018) 106

[18] see, for example, Jurgen Habermas *The Theory of Communicative Action. Vol 1 Reason and the Rationalization of Society* (Polity Press, 1981); Jurgen Habermas *Beween Facts and Norms* (MIT Press, 1993)

[19] Helen Meekosha Russell Shuttleworth What's so "Critical" about Critical Disability Studies? In Lennard J Davis (ed.) *The Disabilities Studies Reader* (Routledge, 2017) 175 – 194

Hence, Hughes' observation that while for most people it goes without saying that they are human beings, for many disabled persons 'it has to be said.'[20]

This focus on taking nothing for granted, a prizing of methodological doubt, is clearly a feature of both critical theory and phenomenology (and, I contend, of a critical republicanism too). However, it is not the only point of contact between the two methodologies. For example, both traditions promote an non-reductive view of what it is to be human, alongside an interest in how meaning is constructed within the pivotal significance of the intersubjective experience.[21] Indeed, on this latter point, Beauvoir writes: '[m]an can find a justification of his own existence only in the existence of other men.'[22]

Beauvoir is emblematic of an emerging synthesis which derives from the view - by no means universally shared - that 'phenomenology is increasingly understood as a form of politically and ethically engaged critique capable of analysing and illuminating contemporary socio-political phenomena.'[23] Indeed, Guenther argues that critical phenomenology is distinctive in its 'methodological and ethical commitment to attend to the ways that power and history shape lived experience'.[24] Describing critical phenomenology as a hybrid method, Gunther contends that its strength lies in the capacity to be pluralistic and open-ended, generative and experimental, borrowing conceptual tools and practices from across a range of possibilities, including from critical race theory, postcolonial theory, feminism and critical disability studies.

This then is the methodological fusing proposed in the instant research, an interdisciplinary, eclectic borrowing from a critical phenomenology informed by Merleau-Ponty's work on the body, and a utilising of the conceptual tools provided by the Frankfurt School and by the critical disability studies movement. Adapting, in part, a research posture indicated by Mladenov,[25] I conceptualise the macro – the world of politics, policy and, in this case, the CRPD – as being in methodological tension with the micro – the everyday experiences of disability. In this dissertation, the macro is presented as consisting of law, domestic and international, and the policy decisions and practices in place in the polity. The micro is represented by the lived

---

[20] Bill Hughes 'Being disabled: towards a critical social ontology for disabilities studies' (2007) 22 (7) Disability & Society 673, 677

[21] See, for instance, Alexi Procyshyn Phenomenology and Critical Theory. In Daniele De Santis Burt C Hopkins Claudio Majolino (eds) *The Routledge Handbook of Phenomenological Philosophy* (Routledge, 2021) 670 - 683

[22] Simone de Beauvoir *The Ethics of Ambiguity* (Citidel Press, 1976) 72

[23] Johanna Oksala 'The method of critical phenomenology: Simone de Beauvoir as a phenomenologist' (2023) (1) 2023 European Journal of Philosophy 137, 137

[24] Lisa Guenther 'Six Senses of Critique for Critical Phenomenology' (2021) 4 (2) Puncta. Journal of Critical Phenomenology 5, 6

[25] Teodor Mladenov *Critical Theory and Disability* (Bloomsbury, 2016)

experiences of the research participants as leavened by relevant literature. In the perceived gap which is hypothesised between these two domains, that is, between what might be characterised as the rhetoric and the reality is the space of *unknowing* but also the space of *becoming*. This, I contend, is the space where a recalibrated republicanism might provide the bridging necessary to reflexively connect dispirit thoughts and (mis)understandings – for instance about the real strength disabled people have and the frailty of the supposedly able body – using freedom as an ethic to advance a shared rights agenda. Given this dissertation's interest in notions of shared human vulnerability perhaps this might be usefully conceptualised as the phenomenologist Jan Patocka has it, as opening the way for a 'solidarity of the shaken.'[26]

3.2 Charting a critical phenomenological approach

For Husserl, phenomenology's core task is grasping something's essence such that to describe this essence is to illuminate the essential character of the phenomenon being studied. Hence, for Husserl essences are not esoteric concerns. Rather, essences are everywhere about us in the everyday experiencing of the world. However, 'people interpret them away.'[27] To mitigate this, Husserl describes researchers' need to consciously attend to their own presuppositions, using the methodological device of bracketing – of cordoning off one's own biases and presuppositions - so that the phenomenon might be viewed anew.

On the other hand, Heidegger's commitment is premised on the concept of Dasein, that is, literally, *being-there* or (human) being-in-the-world.[28] Dasein is the being for whom its own being can be in question, the being whose understanding is bounded by an awareness of finitude and death. Yet, as a being which authors itself – and lives either in an authentic or in-authentic way - Dasein vibrates with the possibilities of the world. [29] Whereas in Husserl's though there appears to be a clear demarcation between subject and object, Dasein represents a radically different research orientation. Dasein is intimately caught up in a process of meaning-making, both shaping and being shaped by the world. Thus, the world exists only if Dasein exists and only if the world exists is there understanding of Dasein. Hence, '[s]elf and world belong together in the single entity, the Dasein'.[30] Moreover, in using the concept to signal *meaningfulness*, Heidegger's interest can be said to be 'not "what is out there" but what is meaningfully present

---

[26] Jan Patocka *Heretical Essays in the Philosophy of History* (Open Court, 1996) 135

[27] Edmund Husserl *Ideas Pertaining to a Pure Phenomenology and to a Phenomenological Philosophy* (Kluwer Academic Publishers, 1998) 41

[28] Martin Heidegger *Being and Time* (Blackwell, 1962)

[29] J. Jeremy Wisnewski *Heidegger: An Introduction* (Rowman & Littlefield Publishers, 2013)

[30] Martin Heidegger *The Basic Problems of Phenomenology* (Indiana University Press, 1982) 297

within a human context'.[31] Hence, Heideggerian hermeneutics becomes much more than just a theory of interpretation. Rather, in social research terms, it becomes about appreciating that

> to understand someone, we must understand their lifeworld and look at the way the world has influenced them and been influenced by them.[32]

Hence, the researcher stance requires

> a constant back and forth between our culture, our background, our past, present and future experiences – all combining to make sense of our life world.[33]

3.3 Translating this to method: the Reflective Lifeworld approach

As practiced by Dahlberg *et al.* the reflective lifeworld method that I draw on in this research proceeds on the basis of an openness to what research participants describe, indicating that a researcher should always be both available to being surprised and sensitive to the unexpected.[34] Inhabiting the world as a place of wonder and being open to that wonder means seeking to connect with 'the world as we immediately experience it.'[35] This is the primary goal of phenomenological research, to capture *lived experience* as it is given. Emphatically it is not about validating preconceived ideas or individual bias.

Within the reflective lifeworld schema, bracketing (or bridling as Dahlberg *et al.* reference it) is central. But this is not as traditional Husserlian phenomenologists perceive it, that is, a strict setting aside of the researcher's own beliefs and a priori assumptions. Rather, the bridling which the Dahlberg method requires accepts that the researcher's own being-in- the world cannot simply be turned off: 'the world cannot be investigated from a distance, as though it were lying on the other side of a window.'[36] This means that while pre-understandings and personal knowledge is corralled, it is not put entirely beyond use. Instead

---

[31] Thomas Sheehan Dasein. In Hubert L Dreyfus Mark A Wrathall (eds.) *A Companion to Heidegger* (Blackwell Publishing, 2005) 197

[32] Lorna Chesterton, Kirsten Jack, 'Using Heidegger's philosophy of dasein to support person-centred research' (2021) 29 (4) Nurse Researcher at 29

[33] Lesley Dibley Suzanne Dickerson Mel Duffy Roxanne Vandermause *Doing Hermeneutic Phenomenological Research* (Sage, 2020) 31

[34] Dahlberg, Drew and Nystrom (n 3); Karin Dahlberg Helena Dahlberg Maria Nystrom *Reflective Lifeworld Research* (Studentlitteratur, 2008)

[35] Max van Manen *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy* (Routledge, 2016) a 9

[36] Dahlberg and Dahlberg (n 4) 460

> [t]hrough bridling, researchers are aware of their involvement in the world so that they can restrain their pre-understanding from preventing them from uncritically analysing data and forcing meanings to appear.[37]

As to what Dahlberg *et al.*'s method brings to data analysis and presentation a number of points are pertinent. Drawing on other phenomenological scholars, Dahlberg *et al.* advise that interview transcripts are approached with an almost meditative reverence, reading and rereading them, identifying what they call *meaning units* that can then be grouped together into clusters of meaning.[38] At this point, the only theory relied on is epistemological and ontological, as the researcher tries to balance and resist the pull to either describe (broadly, be objective) or interpret (be subjective), or, to put it another way, between detachment and immersion. Such a dichotomy undermines the idea of inseparability, the notion that just as the world cannot be investigated from a distance so too must the researcher accept that in fact one cannot choose to be *either* wholly objective or wholly subjective.

Recognising, however, that 'meaning is infinite' and that 'there is always more to uncover in the analysis of empirical data'[39] a move to the method's next stage is indicated when, as researcher, I am comfortable that external inputs – other theory as a source of data – can now usefully be introduced. The purpose of bringing theory (from whatever source) into play in this way may be that a fuller analysis of the phenomenon or its context requires it or it assists in helping turn one's results into some form of practice. However, Dahlberg and Dahlberg warn that adjudging the right time to introduce this theory is crucial, theory 'representing a strong voice that runs the risk of silencing the soft and less articulate voice of the lifeworld.'[40]

4 Methods

4.1 Introduction

In engaging with it as a research method, critical phenomenology presents not merely as a methodological choice among other choices. Rather, it presents as a profoundly radical way of encountering the social world and the distilled experiences of people living in it, operating not so much in the realm of *what* is seen but, specifically concerning itself with *ways* of seeing. Thus,

---

[37] Cheryl Tatano Beck *Introduction to Phenomenology* (Sage, 2021) 58
[38] Dahlberg, Drew and Nystrom (n 3)
[39] Dahlberg and Dahlberg (n 4) 462
[40] *ibid*

the importance of having a sound working sense of the philosophical underpinnings of critical phenomenology as a method.

This radical nature of a critical phenomenology is captured in the sense that it is inherently vocational, that is, as method it is required not just to amass and describe data but also to exemplify a commitment 'to repair the world, encouraging generosity, respect and compassion.'[41] In this, it exemplifies a baseline requirement for research with persons with disabilities and their families, namely that any method employed be inherently emancipatory. Within its strongest meaning in modern disability research 'emancipatory' refers to a close tie between research and political activism. Indeed, Oliver has argued that the only research that merits doing in relation to people with impairments is that which directly improves lives by removing social and economic barriers.[42] Others, however, refute this narrowly focused activist requirement, holding that research with disabled people can be no less emancipatory for focusing on hearing positive stories, unconnected explicitly to a political agenda.[43] Critical phenomenology is comfortable with both these perspectives.

As this applies to the instant research this means, in summary, that the research is collaborative in nature and wishes to contribute to advancing the individual and socio- political liberation of disabled people.[44] Because – at one with all species of critical theory – critical phenomenology aligns itself with the oppressed and the marginalised, its core concern is with revealing the multifaceted ways in which power 'moves through our bodies and our lives.'[45] Uncovering this power, particularly as it relates to domination and un-freedom, is, therefore, central to the way critical phenomenology is deployed in this dissertation, drawing, for instance, on a phenomenological empathy and an inter-subjectivity to draw attention to and combat insidious ideas and representations disempowering to disabled people, including the notion of *compulsory able-bodiedness*.[46] As explained by McRuer compulsory able-bodiedness goes to the idea that the paradigmatic body is the healthy, whole body and that so entrenched is this notion that the effective equation of the able body as the *normal* body goes un-interrogated.

---

[41] Gail Weiss Ann V Murphy Gayle Salamon 'Introduction' in Gail Weiss Ann V Murphy Gayle Salamon (eds) *50 Concepts for a Critical Phenomenology* (Northwestern University Press, 2020) at xiv

[42] Mike Oliver 'Changing the Social Relations of Research Production?' (1992) 7 (2) Disability, Handicap & Society 101

[43] see, for example, Tom Shakespeare *Disability Rights and Wrongs Revisited* (Routledge, 2014)

[44] see, for instance, Ronald J Berger Laura S Lorenz 'Disability and Qualitative Research' in Ronald J Berger Laura S Lorenz (eds) *Disability and Qualitative Inquiry* (Routledge, 2015) 1 - 10

[45] Gail Weiss Ann V Murphy Gayle Salamon Introduction. In Gail Weiss Ann V Murphy Gayle Salamon (eds) *50 Concepts for a Critical Phenomenology* (Northwestern University Press, 2020) at xiv

[46] Robert McRuer *Crip Theory: Cultural Signs of Queerness and Disability* (New York University Press, 2006)

In the case of the instant research, this means understanding experiences as lived by three distinct cohorts of people. In the first section comprising this chapter, I introduce these three cohorts and offer a contextualisation as to why research with these cohorts is valuable. I describe how research participants have been recruited and the practices used to ensure a high ethical standard in relation to their protection and well-being. I do this in the context of also bringing to the fore my own status in relation to each of these cohorts, particularly in respect of cohort three. I commence the second section, with an outline of the particular phenomenological research method I use, the reflective lifeworld approach. An eclectic model – fusing diverse aspects of pre-existing phenomenological insights into its workings - I use this method as a structuring approach, particularly in terms of sifting through, ordering and analysing interview data. In the remainder of section two, I offer some thoughts on my commitment to emancipatory research and I discuss how through utilising a specific focus on dignity, a phenomenological empathy and, in a particular way, through using bridling as a reflexive tool I have personally invested in honing what I hope are my emerging skills as a phenomenological researcher. Drawing on Merleau- Ponty I view this engagement with emancipatory research as no esoteric, rhetorical stand. Rather, it is prefaced on two core convictions: the idea that freedom is a value shared – and shareable – between diverse research participants and myself as researcher, and that, being of the same flesh, 'the world of each opens upon that of the other.'[47]

4.2 Introducing the research participants

A number of general remarks to begin. In total, my research involved interviewing fifty eight research participants. Having secured an informed consent, each of these interviews were taped and transcribed, both the audio and transcripts being stored securely in password protected files in accordance with the ethical undertakings given as part of the application for permission to proceed with the research and as contained in the plain language statements.

The research participants for this dissertation comprise of three cohorts; professionals working with persons with disabilities, parents of children with disabilities and, the final cohort, persons living with impairments, specifically blind and vision impaired people. In going on now to introduce these three cohorts I will offer a rationale for why I decided on these three distinct – but clearly multiply interconnected – groups and provide some contextualising remarks which I believe are important.

---

[47] Maurice Merleau-Ponty *The Visible and the Invisible* (Northwestern University Press, 1968) 141

4.3 Cohort one: persons working with people with disabilities

This first research cohort is composed of people who work in what is known as the disability sector or, even, the disability industry. Despite what this nomenclature might imply – and hereafter I use only the former – what is being referenced here is an area of economic activity in which 'disability is the area of work specialisation, not an expected characteristic of the workers'. [48] This said, there are, of course, persons with impairments working in organisations providing services to - or in other direct ways involved with – disabled persons. However, the purpose of the disability sector itself is not, in the main, to serve as a vehicle for employing disabled people. Nor should organisations within the disability sector be confused with Disabled Persons Organisations (DPOs).[49] DPOs are representative groups composed *of* persons with disabilities; that is, they are civil society organisations that are led, directed and governed by persons with disabilities and which embody a strong focus on human rights realisation.[50]

Organisations within the disability sector are organisations *for* persons with disabilities, operating to business models and likely to have formal contractual ties with the state, most likely with the HSE in the form of an annually reviewed Service Level Agreement (SLA). Within Ireland disabled people who avail of services provided by disability sector organisations are often referred to as 'service users', 'clients' or, less commonly, as 'leaders' or 'customers.' None of these descriptors is recognised as value-free; each is reductive, speaking to power relations that may also be stigmatising.[51]

The Irish disability sector is quite diverse in its composition, embracing charitable, statutory, for-profit and not-for-profit entities and ranging in size from small single-issue advocacy groups to large umbrella organisations.[52] Most of the organisations within the disability sector offering

---

[48] Anna Revillard 'Disabled People Working in the Disability Sector: Occupational Segregation or Personal Fulfilment?' (2022) 36 (5) Work, Employment and Society 875, 876

[49] DPOs have a special status under the CRPD: article 4.3 requires that '[in] the development and implementation of policies to implement the present Convention, and in other decision making processes concerning issues relating to persons with disabilities, State Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations.' See also CRPD article 33.3, which provides for the prioritising of disabled persons and their representative bodies in the national monitoring process concerning the implementation of the Convention. Both of these articles are further elaborated on in General Comment No. 7 (2018)

[50] see The National Disability Authority *Engaging and consulting with disabled people in the development and implementation of legislation and policy* (NDA, 2022)

[51] it is acknowledged that each of these terms is problematic in the way they can characterise the relationship and power dynamic between disability service providers and the people that avail of the services provided; see, for example, Hugh McLoughlin 'What's in a Name: 'Client', 'Patient', 'Customer', 'Consumer', 'Expert by Experience', 'Service User'—What's Next?' (2009) 39 (6) British Journal of Social Work 1101

[52] the sector is, in the main, regulated by the Health Act 2004

direct services to persons with disabilities are segregated according to impairment types and, taken together, they represent a significant exchequer spend. Hence, for example, residential places for persons with disabilities accounted for 62% of the 1.8 billion euro budget allocated to disability services in 2018.[53] This proportion rises to 80% when day service places are included.[54] By contrast, only 5% of the same budget was allocated to the provision of personal assistants and home supports directly to persons with disabilities.[55]

Theorising people employed to work in the disability sector as pivotal to the quality of many disabled people's lives, this dissertation identifies the participants interviewed in this research - social care workers, teachers, tutors, nurses, therapists, early years staff and service administrators – as powerful agents. Coextensive with the casual power which comes with being intimately involved in disabled peoples day-to-day lives, I also theorise these professionals as participants in what, following Foucault, can be termed the *governmentality* of people with disabilities. [56] For Foucault, governmentality is a complex system, described as

> [t]he ensemble formed by institutions, procedures, analysis and reflections, calculations, and tactics that allow the exercise of…..power that has the population as its target, political economy as its major form of knowledge, and apparatuses of security as its essential technical instrument.[57]

In his formulation, Foucault's conception of government encompasses varied phenomenon, tracing a continuum from government of self to government of others.[58] Objectifying processes emerge that make this immense task of government manageable, processes that divide, classify and order, new technologies which shape and are shaped by a new understanding of power, one focused directly on the body: *bio-power*. Unlike the entirely repressive and coercive power of earlier (pre-modern) human histories, bio-power - modern, expansionary and insidious – is productive, seeking to discipline the body in order to optimise its capabilities and potentialities and increase its usefulness.[59] Alongside this focus on the individual body runs a requirement to

---

[53] Deirdre Collins, Tara Featherstone, Patrick Moran *Spending Review 2021 Social Care for People with Disabilities: Trends in Expenditure and Delivery of Services* (Government of Ireland, 2021)

[54] *ibid*

[55] *ibid*

[56] Michel Foucault 'Technologies of the self' in Luther H Martin, Huck Gutman, Patrick H Hutton (eds) *Technologies of the Self: a Seminar with Michel Foucault* (University of Massachusetts Press 1988) 16-49

[57] Michel Foucault 'Governmentality' in James D Faubian (ed) Michel Foucault: Power. Essential Works of Foucault 1954 – 1984 Volume 3 (Penguin Books, 2000) at 219 - 220

[58] see Thomas Lemke *Foucault's Analysis of Modern Governmentality* (Verso, 2019)

[59] Michel Foucault *Discipline and Punish: The Birth of the Prison* (Penguin Books, 1991)

assert control over the *species-body*, through 'the regulation and tracking of birth rates, death rates, fertility rates, economic and poverty statistics, infant mortality, longevity and disease.'[60] As Tremain sees it, out of this insistent measuring comes a new type of medicine, focused on public hygiene and the coordination of care, with charitable institutions and other institutional arrangements such as insurance and social welfare created to address specific anomalies.[61]

From a critical perspective, I hypothesise the professionals involved in the instant research as part of this institutional response to impairment and the anomalous bodies impairment creates. Outside of their direct role responsibilities, often involving intervention techniques, including habilitation and rehabilitation specialisms, most of them belong to professions which either are or are soon to be regulated by law and subject to protection of title, codes of ethics and fitness to practice mechanisms.[62] This increasing regulation can be read as itself a mark of increasing professionalism.

On a more intimate or individual level, deciding to interview people who work in the disability sector turns on a number of additional points. Consistent with the phenomenological emphasis on the embodied experience of everyday life, I wanted to hear what these research participants had to say about their own lived understanding of freedom. I wanted to juxtapose their practices of – and ambitions for – freedom in their own lives with their thoughts about freedom in the lives of those with whom they are employed to work. MacPherson characterises freedom in terms of the extent to which an individual is proprietor of her own person and capacities.[63] This idea - which I believe in a semi-structured interview format presents as a reasonable proxy for exploring areas pertinent to the notion of republican freedom becomes, perhaps, particularly pertinent in relation to professionals working in institutional settings.

The breakdown of the professions in this cohort are found in Table 1

---

[60] Vernon W Cisney Nicholas Morar Introduction: Why Bio-power? Why Now? In Vernon W Cisney Nicholas Morar (eds) *Biopower. Foucault and Beyond* (The University of Chicago Press, 2016) at 5

[61] Shelley Tremain Foucault, Governmentality and Critical Disability Theory Today. In Shelley Tremain (Ed.) *Foucault and the Government of Disability* (University of Michigan Press, 2015) 9 - 23

[62] for instance, under the Health and Social Care Professionals Act 2005 which establishes CORU as a multi-regulator

[63] Crawford Brough MacPherson *The Political Theory of Possessive Individualism: Hobbes to Locke* (Oxford University Press, 2010)

Table 1.

Profession	Number
Nurses	3
Physiotherapists	1
Occupational Therapists	2
Speech & Language Therapists	2
Administration	3
Teachers	2
Tutors	4
Social Care Workers	5
Early Years Practitioners	3
Total	**25**

Cohort two: parents of persons with disabilities

Table 2

Parents of	Number
Preschool age children	8
School age children	6
Adult	3
Total	**17**

Cohort three: persons with a vision impairment

Table 3

Adults	Number
Total	16

4.4 Parents of persons with disabilities

In seeking to interview parents I was aware of a number of tensions to which I needed to be sensitive, not least that mix of nebulousness and publicness whereby parenting is simultaneously a very intimate, private activity and one subject to significant public gaze. A pivotal social function, yet one for which there is usually no formal training, parenting, in the modern idiom, is conceived in terms of providing for children's health, development, emotional and protection needs. Where these are deemed to fall below a certain minimum standard public opprobrium and, possibly, criminal sanction, may ensue.

Bearing all this in mind, in conceptualising the instant research the participation of parents of persons with disabilities always presented as an important component. Here too this mix of the nebulous and the public asserts itself. Characterising parents' of children with disabilities as providing voices from the margins, Green talks about such parents as being 'betwixt and between.'[64] To begin, archetypically, families represent the first social environment in which persons with disabilities – and other members, including parents themselves – often come to experience impairment as lived, embodied reality. As such, parents' role, *inter alia*, in mediating their child's experiences and needs,[65] in advocating for their inclusion,[66] in obtaining necessary services,[67] in enhancing potential and in futures planning[68] marks them out as people whose traditionally patterned, expected caring role is likely to be significantly expanded once disability becomes part of a family ecosystem. In addition, there may be related tensions, for instance, in terms of ensuring sufficient parental availability to non-disabled siblings,[69] in terms of stress within the intra-parental relationship,[70] in terms of the economic well-being of the family itself[71] and in terms of life-course change.[72] There may also be exposure to the phenomenon Goffman describes as courtesy stigma, whereby the prejudicial practices associated with one person's

---

[64] Sara E Green Staying True to Their Stories: Interviews with Parents of Children with Disabilities. In In Ronald J Berger Laura S Lorenz (eds.) *Disability and Qualitative Inquiry* (Routledge, 2015) at 58

[65] see, for example, Hege Lundeby, Jan Tossebro 'Exploring the Experiences of ''Not Being Listened To'' from the Perspective of Parents with Disabled Children' (2008) 10 (4) Scandinavian Journal of Disability Research 258

[66] see, for example, Ruth Jeanes, Johnathan McGee 'Social Exclusion and Access to Leisure in Northern Ireland Communities: Examining the Experiences of Parents with Disabled Children' (2010) 33 (2) Loisir et Société / Society and Leisure 221

[67] see, for example, Tonje Gundersen 'Human dignity at stake - how parents of disabled children experience the welfare system' (2012) 14 (4) Scandinavian Journal of Disability Research 375

[68] see, for example, Ruth Walker, Claire Hutchinson 'Care-giving dynamics and futures planning among ageing parents of adult offspring with intellectual disability' (2019) 39 (7) Ageing & Society 1512

[69] see, for example, Seonaid Mulroy, Laila Robertson, Karina Aiberti, Helen Leonard, Carol Bower 'The impact of having a sibling with an intellectual disability: parental perspectives in two disorders' (2008) 52 (3) Journal of Intellectual Disability Research 216

[70] see, for example, Young Ran Tak, Marilyn McCubbin 'Family stress, perceived social support and coping following the diagnosis of a child's congenital heart disease' (2002) 39 (2) Journal of Advanced Nursing 190; Annette Primdal Kvist, Helena Skyt Nielsen, Marianne Simonsen 'The importance of children's ADHD for parents' relationship stability and labour supply' [2013] 88 Social Science & Medicine 30

[71] see, for example, Matilda Sorkkila, Kaisa Aunola 'Risk Factors for Parental Burnout among Finnish Parents: The Role of Socially Prescribed Perfectionism' [2020] 3 Journal of Child and Family Studies 648

[72] see, for example, Tova Band-Winterstein, Hila Avieli 'The Experience of Parenting a Child With Disability in Old Age' (2017) 49 (4) Journal of Nursing Scholarship 421

impairment – for instance, exclusion, rejection, blame or diminishment – attach to those linked with the disabled person.[73] Hence, in a very concrete way an individual diagnosis of impairment can have family-wide consequences. Some of these consequences can be deeply intimate including, perhaps, parents' grieving of envisioned hopes and expectations for their child,[74] as well as fear, shock, denial, anger and self-blaming. [75] Hearing the voices of these parents and incorporating their narratives into this dissertation strengthens it, perhaps not least because many of these parents will have encountered disability and all its complexities and consequences for the first time *through* their child, almost in a sense of a curtain parting to reveal something perhaps not properly glimpsed before.

It also presented as important that parents participating in this research not be confined by reference to any one impairment type but, rather, that they might represent a wide range of experiences across the disability demographic, inclusive, indeed, of parents who are themselves disabled.[76] In this way, as with cohort one, the research opens itself to opportunities to explore commonalities and inconsistencies – even contradictions - across the disability experience.

The number of parents interviewed, laid out according to their children's age range is laid out in Table 2.

4.5 Vision impaired persons

My decision to restrict my research among disabled persons to adults who share the characteristic of vision impairment, inclusive of blindness (some of whom also have additional, non-cognitive, impairments), merits some brief discussion.

Although disability is common, it is never commonplace. Indeed, in my Research Ethics Committee (REC) proposal I contended that so vast are the range of impairments, impairment circumstances and impairment effects that it is epistemologically dubious, at best, to suggest

---

[73] Erving Goffman *Stigma. Notes on the Management of Spoiled Identity* (Penguin Books, 1990)

[74] Kenneth Denton, Betty Coneway, Michelle Simmons, Malvika Behl, Mikyung Shin 'Parents' voices matter: A mixed-method study on the dyslexia diagnosis process' (2022) 59 (11) Psychology in the Schools 2267

[75] Melinda Haley, Helen Hammond, Lawrence Ingalls, Merranda Romaro Marin 'Parental reactions to the special education individual education program process: Looking through the lens of grief' (2013) 16 (3) Improving Schools 232–243

[76] parents of disabled children who are themselves disabled are particularly absent from research agendas although there is some engagement in respect of parents who have become impaired due to ageing. However, the paucity in research of people with impairments or disabilities who become parents may betoken the widespread prejudice that such people are more naturally the *recipients* of care rather than the providers of it. For a valuable contribution to remediating this perception, see Richard Olsen Harriet Clarke *Parenting and Disability. Disabled Parents' Experiences of Raising Children* (Bristol University Press, 2022)

that persons with disability can be researched meaningfully as a discreet category (Appendix 2). Since submitting the REC proposal I have entrenched this view considerably. I now believe it to be undermining of the unique individuality and unique dignity of each person with a disability to postulate the existence of – to reluctantly employ a deeply flawed yet all too common phrase - 'the disabled' as if a signifier of some supposedly objective, empirically verifiable reality. That many among the (so-called) able-bodied assume that this phrase represents an embodied reality and that governments draw on it as an administrative category does nothing to confer legitimacy. Rather, in my view, the putative presenting of people with disability as a homogenous group is implicitly a (further) negation, an ontological cordoning off which conveys the stigma of being *less than*, an inevitable othering. All too often, as one writer suggests: 'to see a phenomenon as…a disability is to see something wrong with it.' [77] Hence, as I consider it, conjuring up 'the disabled' further *disables* people.

In this context then, I encountered the idea of interviewing widely among people with different impairment types as likely to infer support for this purely colloquial, essentialist notion of disability as somehow seemingly *one* knowable thing. More, in seeking to pursue a category of people who are widely (if erroneously) assumed to exist, I would also implicitly undermine the critical phenomenological requirement that I engage with phenomena as they reveal themselves rather than that I impose preconceived ideas on them. Thus, I explicitly reject the view that people with disabilities are a homogenous group. However, this is not to claim that it is not possible for research to produce data which, while always only a snapshot in time, may resonate in socially useful ways with other disabled peoples' experiences. Thus, I identify vision impaired people as sharing many of the adverse experiences and challenges in modernity and postmodernity that many others identified or self-identifying as disabled persons face. These range to include difficulties in accessing education opportunities,[78] in securing remunerated, good quality employment[79] and in finding both appropriate accommodation and accepting communities in which to belong.[80] However, none of this is to suggest that I accept that those who come within the designation of vision impaired are a homogenous group either.

---

[77] H Tristram Engelhardt Jr *The Foundations of Bioethics* (Oxford University Press, 1996) 197

[78] Heidi Lourens Leslie Swartz ''It's Better if Someone Can See Me for Who I Am': Stories of (in)Visibility for Students with a Visual Impairment within South African Universities' (2016) 31 (2) Disability & Society 210

[79] Graham Douglas, Rachel Hewett 'Views of Independence and Readiness for Employment amongst Young People with Visual Impairment in the UK' (2014) 20 (2) The Australian Journal of Rehabilitation Counselling 81; Ralph Fevre, Amanda Robinson, Duncan Lewis, Trevor Jones 'The Ill –Treatment of Employees with Disabilities in British Workplaces' (2013) 27 (2) Work, Employment and Society 288

[80] John Percival, Julienne Hanson, Doroto Osipovic 'A Positive Outlook? The Housing Needs and Aspirations of Working Age People with Visual Impairment' (2006) 21 (7) Disability & Society 661

5 Recruiting the three research cohorts

Having submitted two separate Research Ethics Committee forms , one in respect of cohort one and the other in respect of both cohorts two and three and having been granted approval to proceed I set about fine-tuning what I hoped would be appropriate recruitment approaches, each calibrated to encourage participation and re-assure would-be participant.

A different recruitment strategy was employed in respect of each of the three research cohorts. In respect of cohort one I used the DCU template to produce a plain language statement (PLS) which I then circulated to a number of professionals working with persons with disabilities, asking them in turn to distribute copies on my behalf to other professionals known to them and whom they thought might be interested in participating in the research. Through employing this non-probability, snowballing approach I was able to reach out beyond the range of professionals known to me – almost all of whom work in one specific service context – and to engage the involvement of a much wider group.

The PLS laid out the details of the project, including an indication of the type of areas I would intend to discuss, as well as offering ethical assurances in respect of the secure storage of data. It also provided contact details of my supervisors and DCU's data protection officer.

In respect of cohort two I engaged a friend of mine, a professional working in the area of disability and herself the mother of a child with a disability to act on my behalf in the recruitment of a number of parents from her own quite diverse circle, in part comprised of parents who meet regularly as part of a support group. In addition, a number of parents who had learned of my research personally contacted me directly and asked me if they could participate. As for my friend, she suggested that it would be useful in terms of her recruitment role, in addition to circulating the relevant PLS, if she could indicate something of the sort of interview style I might adopt. Wanting, anyway, to pilot the parent's interview format, I was happy to do so.[81] In turn, my friend said that being able to say she had herself participated in the interview was reassuring for those she would seek to recruit in helping them decide to participate.

Turning now to cohort three and its recruitment strategy I begin by naming the most salient challenge faced in relation to this cohort's recruitment. Ireland's vision impaired population is

---

[81] this piloted interview is not included in the research. I did, however, receive some very useful feedback, for instance in terms of asking pithier questions and leaving more time for people to develop their answers. I feel this piloting also enabled me to commence this cohort's interviews with an enhanced confidence

relatively small – smaller still in terms of meeting the inclusion criteria for this present study[82] – and, as someone who has worked in a disability organisation specifically offering services to blind and vision impaired young people for in excess of three decades, I was naturally concerned that no would-be research participant might feel compelled in any way to participate because of any prior existing relationship with me. In order to allay this ethical concern, I approached a person of considerable standing in the vision impaired community, this person agreeing to act as gatekeeper in relation to cohort three. I provided the gatekeeper with an extensive guidance note which set out the way in which gatekeeper duties would be performed, including the important proviso that would-be participants would be assured that in no circumstances would I ever know who might have declined to participate (see appendix 5). I also supplied the gatekeeper with alternative format PLSs – specifically in large print and braille versions – so that the gatekeeper could ensure that the most appropriate version was given to each possible participant. In addition, the gatekeeper undertook to record an audio version of the PLS for completeness, this being available on the gatekeeper's phone for ease of dispatch if required.

6 Fine tuning an interview format: a focus on dignity

It is useful here to reprise this dissertation's research question. It is as follows:

> *Drawing on a contemporary republican perspective, prefaced on an understanding of vulnerability as a universal human feature and explored in the context of both the CRPD and the Irish polity, what value is derived from a robust understanding of freedom for disabled people, disabled people's families and those working with and for disabled people?*

Having earlier laid out the salient aspects of republicanism's unique perspective on freedom I acknowledge here some initial difficulty in crafting semi-structured interview questions in which I could have confidence as being supple and nuanced enough to draw out data on research participant's perceptions of freedom. Earlier in this section, I mentioned MacPherson's characterisation of freedom in terms of the extent to which an individual regards themselves to be proprietor of her own person and capacities. Certainly I felt there was no issue in taking MacPherson's lead, as it were, in respect of cohort one and just asking people to extemporise on their perceptions of what freedom means in their own individual lives – and, indeed, in the

---

[82] specifically, that would-be participants be aged between 23 and 70 at the time of contact, that, as far as can be reasonably ascertained, there is no co-presence of intellectual disability and that, again as far as reasonably ascertainable that participation in the research not be a source of stress for the would-be participant

lives of those disabled people they each work with. The problem as I came to work through it began to present itself in terms of how to ask about freedom and its antonym in ways that did not just yield trite answers, and which, it seemed increasingly clear, would, most likely, fail to address the research question. I think I found an answer by focusing anew on dignity.

Tomlin talks about how even in a cynical age freedom remains an idea which inspires devotion, energy and sacrifice.[83] Indeed, pursuing the instant research would have been pointless without the presumption that the ideal of freedom is vivid in the human psyche. By this I suggest that near everybody has some connection to the notion of freedom, even, perhaps, though that connection may be vague or taken-for-granted or cynical or, even, experienced as a sense of loss or as an inchoate absence. This dissertation being about a particular formulation of freedom – what I am now calling the *ethic* of non-domination – it became a central concern of this work to invite research participants to reflect on and share what freedom feels like in their lived experiences. In this, a phenomenological encountering of human dignity introduces a crucial additional, indispensable, element, particularly in permitting the sorts of synergies and interdependencies between the three research cohorts to reveal themselves and to be *seen*.

Consistent with what has already been offered in this dissertation concerning the role of dignity in the lived experience of disability, including its invocation within the human rights discourse as pivotal to creating a better world for persons with disabilities, the recognition of the dignity of each of the research participants in this work is foregrounded. Going to self-esteem, self-respect and recognition, non-fungible and non-tradable, dignity – with law being an important element in its protection – has its first unfolding with the individual and the individual's nascent sense of autonomy, but, also, I suggest, the individual's sense of their own fragility.[84]

In this sense, then, dignity is clearly amenable to critical – and critical phenomenological - investigation. Hence, the Universal Declaration on Human Rights opening reference to *all* human beings being born free and equal in dignity and rights becomes the basis for a way of discerning how freedom and dignity is actually *experienced*, regardless of individual differences, lifestyles or presumptions. In holding this, I draw inspiration from the cautionary insight that:

> [e]mancipation begins when we challenge the opposition between viewing and acting; when we understand that the self-evident facts that

---

[83] Graham Tomlin *Bound To Be Free* (Bloomsbury, 2017)

[84] see, for instance, Paul Ricoeur *Oneself as Another* (University of Chicago Press, 1992)

> structure the relations between saying, seeing and doing themselves belong to the structure of domination and subjection.[85]

Reminding that what counts as activity and passivity changes place over time, Ranciere talks of the practices of theatre in ways which in my view transfer to practicing critical research as a way of trying to structure interview questions with emancipatory intent. Hence, when he encourages 'that theatre assigns itself the goal of assembling a community which ends the separation of the spectacle' I see precisely the same ambition falling to critical phenomenology: that I must remain ever open in the moment of interview to the fact that I am in a relationship which must *not* be dominating. I am not *apart from* but *part of* - otherwise, how might I elicit anything of value about freedom or derive insight worth sharing?

Hence, as I engaged more with phenomenological texts and strove to better understand phenomenological uses I came to realise that the struggle to access the perfect question and structure the best *semi-structured* interview was really getting in the way of my properly entering into the relationship each interview encounter was. I was distracting myself from seeing the phenomenon, the *essence*. Certainly, many of my earliest interviews – all of them cohort one – would have been much better had I entered into them as moments of relationship rather than just trying to stick to a question sheet. Reflecting on this later, now better understanding Dahlberg *et al.'s* insight that phenomenological interviews 'do not occur in a vacuum but in a world vibrating of meanings'[86] it struck me that something significant I missed was the effect my own professional status was bringing to bear on these interviews. Professional to professional, perhaps eager to impress, to sound erudite, to pass over carelessly what I perhaps thought I knew as well as anyone, I was, doubtless, at times so distracted that I was not even attending to the most obvious things about myself in these interviews. That being so, what chance had I of seeing the phenomenon as revealed? What chance of honouring the dignity of the other person with my complete attention?

Vagle describes the phenomenological research approach as a means by which Western philosophy can 'get out of its own head' and 'out into the interconnectedness of human relations among human beings and with the things of the world.'[87] Charting this capacity from within the phenomenological research tradition means placing this phenomenon called 'freedom' in view as a thing that is lived and experienced as dignity. The critical researcher is not interested in

---

[85] Jacques Ranciere *The Emancipated Spectator* (Verso, 2009) 13

[86] Dahlberg, Dahlberg and Nystrom (n 34) 172

[87] Mark D Vagle *Crafting Phenomenological Research* (Routledge, 2018) 30

trying to co-habit other people's minds nor in trying to 'join chemists, biologists, mathematicians, and physicians in finding more precise ways to explain how things work.'[88] Thus, the goal is not to highlight human consciousness – as Descartes does, the mind thinking about itself – nor to study the individual herself. Rather, the purpose is to connect with freedom's experiential immediacy as something which is either present or is not present in a person's lived experience. Moreover, because the individual dignity is always, in the critical phenomenological understanding, in a rich inter-subjectivity with others – what is described as a cross-generational and cross-cultural humanity, 'the streaming living present'[89] - the individual experience permits the first-person narrative to inform and identify 'generalities and typical features of the experience as such,'[90] but while not taking from the individual dignity.

7 Data engagement; empathy and bridling

All this speaks to the inevitable slowness of pace with which the phenomenologist researcher must approach data. For a phenomenologist, data is always emergent. This means that the researcher brings a reverence to the stories shared. Committed to bridling, my responsibility, as researcher, is to keep empathy alive throughout the description process while also being present to how data changes during this process too.

Seeking to immerse myself in the participants' narratives – now in textual form – I strive to leave no detail un-noticed, respecting the supposedly mundane just as much as the supposedly profound. Merleau-Ponty is helpful here, advising that:

> [a]t each moment, my perceptual field is filled with reflections, sudden noises, and fleeting tactile impressions that I am unable to link to the perceived context and that, nonetheless, I immediately place in the world without ever confusing them with my daydreams.[91]

This reminds that the world is always already there, before reflection begins, and that the bridling to which I am committed is not about denying my own 'being in the world' – what Heidegger terms *Dasein*[92] - signifying that the world is not external to me but that I and the world are inextricably connected. Rather, instead of renouncing the world and 'the certainties

---

[88] *ibid* 23

[89] Janet Donohoe *Husserl on Ethics and Intersubjectivity: From Static and Genetic Phenomenology* (University of Toronto Press, 2016) 21

[90] Linda Fisher The Illness Experience. In Kristin Zeiler Lisa Folkmarson Kall (eds.) *Feminist Phenomenology and Medicine* (SUNY Press, 2014) 28

[91] Merleau-Ponty (n 1) xxiv

[92] Martin Heidegger *Being and Time* (Blackwell, 1962)

of common sense' I am enjoined to refuse 'to be complicit with it…or again, to put it out of play.'[93] Throughout, the goal is always 'to render visible what is invisible because of its very familiarity.'[94]

Throughout, too, empathy must be preserved. Rogers warns that one's availability to the other in empathy is conditional on keeping a clear boundary in place; feeling with the other as if one is the other 'but without losing the as-if condition.'[95] Yet, Stein's phenomenological schema suggests another understanding. Hence, following Stein, an empathetic understanding of another is intrinsically caught up with a deeper understanding of myself, the one being a precondition of the other:

> openess is the mark of a true willingness to listen, see and understand. It involves respect, and certain humility towards the phenomenon, as well as sensitivity and flexibility.[96]

Second, bridling addresses understanding as a whole.[97] Contending that understanding is impeded by seeking to grasp a phenomenon too fast or too carelessly, bridling becomes a reiterative mechanism for encouraging me as researcher to understand differently.[98] It's 'essentially a sort of self-reflection, a continuous investigation of one's own point of departure, one's presumptions and presuppositions.'[99] Hence, bridling is not a once-off action – think, as Dahlberg intends, of using a bridle with a horse – but, rather, an immersion of oneself in the phenomenological attitude, slackening and tightening one's connection to the phenomenon and what is revealed about it, and ever careful not to make definite what is indefinite.[100]

---

[93] Merleau-Ponty (n 1) xxvii

[94] Katherine J Morris *Starting with Merleau-Ponty* (Bloomsbury, 2012) 14

[95] Carl Rogers A Theory of Therapy, Personality, and Interpersonal Relationships as Developed in the Client-centered Framework. In Sigmund Koch (Ed.), Psychology: A study of a Science, Vol. 3: Formulations of the Person and the Social context (McGraw Hill, 1959) 210

[96] Dahlberg, Drew and Nystrom (n 3) 97

[97] Karin Dahlberg 'The essence of essences - the search for meaning structures in phenomenological analysis of lifeworld phenomena' (2006) 1 (1) International Journal of Qualitative Studies on Health and Well-Being 11

[98] Dahlberg, Drew and Nystrom (n 3)

[99] Helena Dahlberg, Karin Dahlberg 'The question of meaning—a momentous issue for qualitative research' (2019) 14 (1) International Journal of Qualitative Studies on Health and Well-Being 1, 4

[100] Helen Dahlberg, Karin Dahlberg 'To Not Make Definite What is Indefinite: A Phenomenological Analysis of Perception and its Epistemological Consequences in Human Science Research' (2003) 31 (4) The Humanistic Psychologist 35

8 Openness to a phenomenon

The openness which bridling supports is a research posture in which nothing is taken-for-granted. This is not to suggest that the reflective lifeworld approach does not yield conclusions; it does. However, the approach reveals that the concept of data saturation – the alleged point at which engagement with research data can be discontinued because all new meaning has been mined – is a fallacy. Instead, 'meanings are viewed as infinite, always expanding so meaning saturation cannot exist.'[101] But this does not impede the likelihood that, if approached the right way, the phenomenon will give itself to the researcher, that is, that its essence will be revealed. The work of the researcher, at every element of the research process right up to publication, is to make space not alone for the essence to present itself, emerging out from all the multitudinous features and correlations that crowd around it, obscuring it. Bridling is also about informing how best to structure a research study, how to frame engagements with research participants and how to analyse and present data.[102] This comprehensive, adventurous openness begins with immersing one's researcher-self in the richness of the phenomenon, in all its aspects and nuances, embracing the world and what it can offer.

9 Bridling as seeing myself

In thinking about the application of all this as method in my research, I suggest that there is a useful synergy between Dahlberg *et al.*'s open, respectful research posture and Merleau-Ponty's conception of the body. To begin, if bridling is to mean anything of value to my method I must confront thoughts that trouble my professional identity and which disturb my personal equilibrium.

For me, *qua* researcher, chief among these troubling thoughts is captured in the ages-old trope shorthanded by Goodley as 'bodies that matter.'[103] I have worked – that is, been paid to work – for several decades now with young people with disabilities and their families. In those years, this involvement has enriched my life. I have found a career and established a professional reputation. I have acquired close friendships with disabled persons and other professional friendships. I have set up valuable working relationships across the disability sector, including many across Europe. I have been able to participate in numerous international projects and working partnerships. I have been sponsored to study and, in turn, have had the opportunity to

---

[101] Cheryl Tatano Beck *Introduction to Phenomenology: Focus on Methodology* (Sage, 2021) 59

[102] Helena Dahlberg 'Balancing at the Beginning of Words – Revisiting the Idea of Open Awareness in Qualitative Research' (2022) 28 (10) Qualitative Inquiry 1019

[103] Dan Goodley Dis/Entangling Critical Disability Studies 28 5 2013 Disability & Society at 634; see also Judith Butler Bodies That Matter. In Janet Price Margrit Shildrick (Eds.) *Feminist Theory and the Body: A Reader* (Routledge, 1999) 235 - 245

teach, including university courses on disability. I have been a Ministerial appointee and have been proud to represent my profession on State bodies. I have been invited to speak at national and international conferences. I have become a body that matters.

That said, in the last number of years, this body of mine has also become prey to certain impairments. However, while at one with a central motif of this dissertation that in current social conditions *not* to be disabled is a temporary circumstance for a human, I do not perceive that these impairments have disabled me. They have, at times, slowed me down. They have impacted on my stamina. They have induced anxiety. They have brought certain infirmities and intimate more to come. But they are hidden and, so far, they are treatable. There are no outward signs of the type with which the social model is concerned. There is nothing, as yet, which serves to identify my body as non-normative. Thus, I continue to appear a body that matters.

The suggestion that disabled bodies matter less is a stark one. It does not fit with the Western liberal ethos. It does not fit with my reasoning, preferred self. Yet here I am, having worked with and been socially connected to disabled people practically all of my adult life and required now, as a matter of method, to engage reflectively with one pivotal question: what is it that I have to bridle?

I have to bridle my *gratitude* that my impairments are treatable; that they have not brought me into a world that I am comfortable to work in and make my living from but not one in which I am ready yet to publically live. I have to bridle what I have had to occlude from myself. That I make a good living despite the fact that the people I ostensibly work *for* are dramatically less likely to acquire a good education or be employed or not be socially isolated. That while I am appreciated and even praised for the work I do with disabled people, many disabled people are stigmatised as lazy, incapable, workshy or welfare scroungers. That I am a paid employee of a charity sector whose very existence implicitly endorses an iconography of disability which relies on disempowering tropes captured in words such as ‘vulnerable’, ‘deserving’, ‘in need’, ‘tragic’ and ‘inspiring’. I have to bridle that the impulse to charity and the impulse to pity are often so close to each other that they can appear indistinguishable. I have to bridle that, like contempt, pity also hierarchizes. I have to bridle my entitlement as a body that matters and the cognitive dissonance that permits me hold contradictory views ordinarily untroubled by reflection.

Phenomenology’s rubric of making the familiar unfamiliar so that it might be seen anew invites a further teasing out of this dissonance and a sense – contrary to my own direct experience – that living with impairment precludes or is harmful to living a good human life; that it imperils dignity and respect. That it is a fundamentally *unhappy* state. But how then to reconcile this with my own direct experience? Are my friends who appear to live well with disabilities outliers? Have they mobilised something in themselves that feels they must *prove* themselves to me and all those who are not yet disabled? Or, is my fear a function of my own ageing and the ailments aging brings? A fear that I will no longer be a body that matters? Intuitively there is a connection between the notion of my aging self and a dread of fragility, a species of shame, perhaps, at not being capable, of becoming noticeably dependent on others. That the body that was free is now encumbered. This engenders the question as to whether I have fallen into perhaps the most insidious of all traps; the subliminal association of disability with personal disaster and death? All this too I must bridle.

In making sense of all of this, Merleau-Ponty's conception of the body is helpful. His quest is to demonstrate the unity between the objective and the subjective. For him, the body is not a passive receiver of sensory inputs from the world but, rather, such is the body's tight, sensual relationship with the world that Merleau-Ponty talks of the body coupling with the 'flesh of the world'.[104] For Merleau-Ponty there is no inner/outer experience: to be human is to be embodied in the world such that my being does not end with my own skin but, rather, my being is interwoven with the world.[105] Thus, Merleau-Ponty's theory of embodiment is a rebuke to Cartesian dualism and its adverse effect on how the body, and, perhaps, the disabled body in particular, is represented in the culture. Within this Cartesian structure, it is the conscious mind, independent of the world of matter, which confers on me who me is.[106] However, in Merleau-Ponty's thought, embodiment is the recognition that minds and bodies are not separate entities, the former superior to the latter, the latter no more than a fleshy machine. Nor, by logical extension, is perception a purely cognitive exercise. Instead, Merleau-Ponty uses the phenomenological method to affirm that as people we do not *experience* ourselves as mind-body pairings or as substances *with* properties.[107] Rather, as Matthews summarises it:

> [o]ur relationship to the world of experience is not an external one; the world that I experience is, in an important sense, *my* world, a world that I "inhabit" rather than simply contemplate.[108]

---

[104] Maurice Merleau-Ponty cited in Dermot Moran 'Between Vision and Touch: From Husserl to Mearleau-Ponty' in Richard Kearney Brian Treanor (eds) *Carnal Hermeneutics* (Fordham University Press, 2015) at 231

[105] see Kevin A Aho *Heidegger's Neglect of the Body* (State University of New York Press, 2009)

[106] see, for instance, Robert Wilkinson *Minds and Bodies* (The Open University, 2002)

[107] see, for instance, Taylor Carman *Merleau-Ponty* (Routledge, 2020)

[108] Eric Matthews *The Philosophy of Merleau-Ponty* (Taylor & Francis Group, 2002) 68 (italics in original)

All this invites me to consider that my body is not an enclosed system in itself but the dynamic centre point of the world around me, the ground-zero from which I orientate everything and everyone within my awareness: 'an active, purposeful hub of perception embedded in its world'.[109] Simultaneously, my body experiences *and* makes the world.[110] It is '*the* place where self and society interact.'[111] In research terms, I am both the perceiver and the perceived.

10 Considering an impaired body

Merleau-Ponty indicates how a person 'reckons with the possible.'[112] In this reckoning, the possible 'acquires a sort of actuality' that does not infringe its status as possibility.[113] In this context, the constrained, non-normative, socially disabled body represents a disabling too of possibilities, or, at least, of positive possibilities. It is suggested that this, in part, happens because normative bodies are the paradigm around which the built environment and the wider social environment is designed. The blurred boundaries – arguably, the non-existent boundaries – which Merleau-Ponty indicates between body and world support a range of possibilities *only* if the body in question is one which can take itself for granted. By this I mean, Merleau-Ponty describes bodies whose component parts only make themselves apparent as and when necessary for a particular reason, 'as a posture towards a certain task, actual or possible'.[114] Persons with impairments, on the other hand, often have no choice but to be constantly aware of their bodies, expending more of them even in addressing ostensibly small tasks.[115] Those whose bodies are not yet impaired do not routinely have to think about their bodies, for example, noticing their heads only when headaches manifest. Hence, it occurs, for the purpose of the instant research, that the bridling required can also be, in a meaningful way, a *recoiling* from what I bridle; both a putting out of play and, simultaneously, a bringing into play. Noticing, as it were, that I *do not* notice and perceiving in that my privilege (still) as a body that matters.

---

[109] Kristin Vindhol Evensen, Øyvind Førland Standal '"I Guess that the Greatest Freedom ...": A Phenomenology of Spaces and Severe Multiple Disabilities' (2017) 17 (2) Indo-Pacific Journal of Phenomenology 1, 3

[110] Kevin Paterson, Bill Hughes 'Disability Studies and Phenomenology: The Carnal Politics of Everyday Life' (1999) 14 (5) Disability & Society 597

[111] Dan Goodley *Disability: An Interdisciplinary Approach* (Sage, 2010) 56 (italics in original)

[112] Merleau-Ponty (n 1) 112

[113] *ibid*

[114] *ibid* 102

[115] for an account of how debilitating this can be see Christine Miserandino *The Spoon Theory* at https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/; see also Fortesa Latifi *Spoon theory: What it is and how I use it to manage chronic illness* 14 January 2023 The Washington Post at https://www.washingtonpost.com/wellness/2023/01/14/spoon-theory-chronic-illness-spoonie/

11 Conclusion

In this chapter, I introduce and contextualise each of the three research cohorts and describe the recruitment processes used and the processes in place to demonstrate ethical sensitivity. In addition, I discuss both methodology and method as separate but intimately connected dimensions of practicing worthwhile social research. Connecting critical theory with a critical phenomenology, I indicate my use of a reflective lifeworld approach as requiring me to practice a reflexivity that situates me in tension with – but never apart from – the people and phenomena being researched. Throughout the chapter I seek to suggest that the instant research is prefaced on core values, specifically, a prizing of human dignity, and a commitment to an emancipatory practice.

Chapter Five:
Findings and discussion

'A Republic deals with the necessities of life'[1]

1 Chapter overview

This chapter seeks to honour and critically engage with the data, juxtaposing themes from the data with a contemporary republican commentary. In adopting this approach the intention is to draw out resonances between research participants' views and experiences and the republican ethic and to suggest how, in drawing on this ethic, the lived realities of the research participants involvement in the modern polity might be better understood and creatively responded to.

2 Introduction

Sitting at the heart of contemporary republicanism is the ethic of non-domination; the idea that the most robust – the most resilient - form of freedom is found in the absence of uncontrolled interference, whether this control be actual or merely possible, acted upon or perhaps not even within a powerful other's contemplation to act upon. Situated in the context of relationships of dependence, this idea goes considerably beyond that negative liberty favoured within the liberal project, namely that freedom consists in the absence of another's actual interference. In this formulation, the onus falls on protecting a private sphere against interference, including state interference. Straightforward and, at first glance, intuitively sufficient, this negative phrasing of freedom seems to capture all there is to say about the nature of un-freedom. Except, of course, that it does not, a point I seek to make in this dissertation with particular reference to the lived experience of disabled persons, the parents of disabled persons and professionals working in the disability sector.

In broad scope, I commenced this research with certain assumptions. These were that

- engaging with people who make their living in the disability sector (research cohort one) would allow me consider how people with disabilities in Ireland are enfolded into systems and how the people working within these systems perceive people with disabilities and whether they regard freedom and, indeed, the CRPD – which I conceive of as a freedom charter - as useful perspectives through which to view disabled people's entitlements to liberty, for instance, in terms of the ability to shape the opportunities under which their lives are lived;

---

[1] Michael D Higgins, President of Ireland, The Late Late Show, RTE 26/5/2023

- listening attentively to parents (research cohort two) would help me incorporate their sense of past, present and future into my republican theorising, particularly in terms of their unique roles as advocates and
- by adopting an emancipatory research posture I might be permitted to enter into the lifeworlds of people with vision impairment (research cohort three), acknowledged as experts in their own experience, with a particular aspiration to better understand, from within an insider vantage point, the ways freedom might be constrained or contested.

This research privileged me with the opportunity, across these three cohorts, to speak with almost sixty people. As a practical matter doing justice to the volume of data gleaned from so many research participants requires a considerable degree of paraphrasing and annotation, while at the same time striving to be true to the ideas and thoughts encountered. To this end – and grouping themes together - for ease of presentation I amalgamate the voices from the three cohorts, intertwining a critical republican commentary. However, in this first section, discussing freedom, I take the opposite approach. I do so for a number of reasons. Freedom is the central concern of this dissertation, positioned as both motif and measure of (or at least the beginnings of) the good life as perceived within contemporary republicanism. On this basis alone, making a defined space for each of the three cohorts to evince what freedom means within their worldviews is important. However, to reiterate, republican freedom and liberal freedom are not the same thing, the latter requiring only an absence of interference, the former, in its fullness, requiring an institutional, communal order of a particular depth and breadth if the personal choices which embody freedom, in the every-day, are to be relied on. Hence – perhaps as something formed, perhaps something partial or something elliptical – striving to derive what freedom means, cohort by cohort, is about, in part, attempting to clarify whether freedom might appear to be a group-specific concept or whether there is an intra-cohort cohesion. Enfolded in this is a wish to explore if there is a sense of freedom as a given, a property of persons rather than as something held in common, or as something which might form the basis of a shared political task.

Thereafter, however, the headings can be read as serving the broad goal of directing the reader to themes that, while not necessarily cleanly homogeneous, are strongly present in the data and strongly interconnecting, all of them speaking, ultimately, to the overarching theme of freedom. Deriving many of the headings under which this data is grouped from either quotes or analogies offered by the research participants – and, thereby, further representing the deeply personal nature of this data – some of the themes are presented through a few voices, while others draw on a wider range. In part, this is because some individual stories speak of injustices so egregious that the detail of their telling draws stronger attention to the (sometimes casual) injustices and un-freedoms encountered by many, many disabled people. As to the themes drawing on many participants experiences in particular, there is a special attention given to education issues, not least because whether describing their present or their past this is an area where participants had a lot to say, much of this conveyed with a palpable emotion. But also, education represents an area of especial intersectionality, drawing together overlapping and interdependent questions of disadvantage, discrimination and, indeed, distress that resonates powerfully throughout the other themes identified in the data.

3 Encounter i: freedom - the professional cohort

Each of the research participants, regardless of cohort, were asked questions concerning their own conception of freedom and how that operates as a construct in their own lives. In the main, people working in the disability sector offered confident, articulate answers, many of them phrased in terms of self-agency and autonomy. Asked how they experienced freedom in their own lives, the following quotes, each from a different person, are representative of the responses provided:

'*Freedom is everything really. You know, when you think about it. I suppose why would I leave the bed in the morning if I wasn't feeling my life is where I make my own choices, my own decisions?*'

'*It's a very philosophical question. Freedom means for me that I am able to make decisions, good and bad, for myself and my family; that I have the freedom to leave my job and apply for another job, that I have the freedom to sell my house and buy another house, I've the freedom, you know, to drink five bottles of wine if I want to.*'

'*Choice and decision making is really what freedom means to me. I have autonomy and the rights to do what everybody else can do in society.*'

'*For me it's the right to speak up, to be heard, to have my voice heard.*'

Across all of the respondents in this cohort, freedom had a clear personal meaning, nonetheless a meaning that displayed a remarkable degree of unanimity. This was so even though several of these respondents indicated that freedom was not something often (or ever) thought about – rather it was '*taken for granted,*' '*just there*' or '*part of [my] life, thankfully*.' Nor did any of the respondents in this cohort link freedom to a politico-historical or civil context, although one did suggest a contextualisation of their own individual freedom by way of a comparison with how '*Ireland must have been in my parents time, when they were my age, what with the Church's* *control of morality and everything*.' From a republican perspective, this was the only response that offers any intimation of a sense that freedom might be compromised by alien control, in this instance by an institution that was perceived by the respondent to have once had real social control over public mores. Indeed, if anything, the invocation of an organisation which, while still prominent in Irish society, is clearly viewed by the respondent as of merely historical or marginal significance now might suggest that the respondent understands that Ireland today is a society in which freedom is unmediated and robustly available. Only one respondent referenced human rights as a ground of individual freedom. This respondent provided no further elaboration.

None of this cohort suggests any ambivalence about their own freedom being a good thing, articulating it as an important underpinning of lives that are authentically their own. That this authenticity is expressed in large part in terms of personal examples relating to owning property, employment options, recreational activities, social connections and, even, by mistake-making (perhaps the five bottles of wine), speaks to a (seemingly shared) awareness rooted in the immediate contingencies of a postmodern social ordering. Remembering Lyotard's foundational assertion that the postmodern subsists in an 'incredulity towards metanarratives'[2] there is a consistency in the way the research participants being cited here seem to understand freedom very much in terms of personal self-determination. Moreover, in speaking of their freedoms what is described is a freedom that is intimate, personal. It is also a freedom that, while containing slight elements of republican freedom and the positive freedom claim to self-actualise, in the main appears to conform to the liberal negative freedom norm, appearing untroubled, serene, existing in the absence of an interfering agent – a freedom of quiet certainty. After all, as one participant in this cohort put it, there is little call to analysis the nature of freedom too minutely since '*we live in a free society*.' However, where this shifts is when these same participants are asked to consider freedom with reference to people with disabilities, specifically those people with whom the participants in this research cohort work with and for.

Universal across this professionals cohort, there is an identifiable ambivalence in relation to how freedom is thought about as it may apply to disabled people. To this extent then, the freedom which is '*just there*' is now something of an abstraction and is talked about, sometimes, by analogy: '*not everyone who wants to be a pilot will be a pilot*' and '*everyone knows you can't eat chocolate all day*' are but two examples of quite reductionist ways this important ideal is referenced when the object under discussion is a notional disabled person. The shared

---

[2] Jean Francois Lyotard *The Postmodern Condition: A Report on Knowledge* (Manchester University Press, 1984) xxiv

communalities of living together in a modern, democratic society – such republican staples as equal standing before the law, effective access to justice, reliable and transparent public services, the right to vote – none of these are referenced or alluded to, although nor were any such themes explicitly referenced either when the professionals were talking directly of their own freedom.

As to the practices of freedom – and focusing, in particular on the baseline issue of personal choice -one participant talked about disabled persons known to them as '*having the illusion of choice*' rather than real, substantive, choices. Indicating that this illusion has to be indulged, even though '*we* [staff] *hate it*' and even though '*when it comes down to it they* ['service users'] *know deep down'* that freedom of choice is, often, illusionary: '*everybody plays this game, you know*.' The suggestion here is that playing this game is perceived as a form of kindness, the same professional describing a young women whose ambition is to have five children: '*but yet she can't dress herself and when she is asked who is going to dress the kids oh, mummy will help me*.' Elaborating on this the following is added:

'*I don't know, we* [staff colleagues] *were talking about it today and we were saying, like, is it because that fantasy is so unrealistic there's comfort in it because it can never become a reality? Is it that she's just saying that because if she was to think about a possibility like, maybe, living independently or having a partner or having a part-time job those things are kind of feasible but yet they're a bit too scary*.'

From a republican perspective, this issue of freedom as illusion is deeply troubling. It speaks to a practice – perhaps even in instances a systemised practice – which might be thought to consciously ignore or casually negate or otherwise subvert what disabled persons are saying, acting in effect to displace what is being said rather than engaging with it and, perhaps, thereby, arriving at a clearer distillation. Contemporary republicanism is presented as a resilient form of dignity and as a mode of respect. For Pettit, the onus on political philosophy is that it be practical and focused on achievable, sustainable outcomes. Pettit regards – as do I – that it is eminently possible to put in place, at every level of structured human engagement, systems that enable us all to deal with each other without feeling foolish, or condescended to or tricked into thinking we are being listened to and taken seriously, systems which place the practices of dignity at their core. Playing games of the type referenced here, manipulations even if kindly meant, is anathema. Usefully here, Pettit describes republicanism as anti-utopian, meaning, *inter alia*, that freedom interests are not served by domination-reducing initiatives that cannot survive, since this way lies inevitable 'disenchantment and disorder.'[3] The call, then, is to find – or, perhaps more properly, forge - these initiatives in all the circumstances of disability.

3.1 A republican insight: civility

By way of elaborating on this call I return to the '*not everyone who wants to be a pilot will be a pilot*' remark, a remake which played on my mind a lot in the wake of encountering it. This remark was made in the context of a person with significant sensory and intellectual disabilities expressing a desire to be something which presents as impossible to realise. Arguably, the non-utopian, realist and respectful engagement here is not to dismiss this out of hand – or worse, as appears to have happened, indulge it in the moment only subsequently, privately, to dismiss and, perhaps, ridicule it. If this is what happened, the indulgence indicates a form of toying with the weaker person, a misleading of sorts, offensive to republican values on a number of levels. The sense of security which living in a republican polity engenders is one prefaced on a deep trust. In a personal sense, this trust is understood as a confident reliance on the powerful, including a reliance that people will deal truthfully and with civility. To be clear, however, establishing and maintaining freedom as non-domination does not *depend* on civility. Indeed, one might perceive how civility could, in itself, be dominating in certain circumstances. Rather, for republicans the significance of civility is found in its status as a 'reinforcing structure,'[4] a means of practically demonstrating the values republicanism embraces. Civility is important because, *inter alia*, it shows respect. In this case, a person has trusted something – perhaps, something intimate (one cannot know) - to a powerful person, a dream of a hoped for future. Hopes are delicate, telling, things. In engaging this expressed desire truthfully head-on, there arises the possibility to tease out, hopefully, some respectfully mediated compromise that could be realistically achievable. From a republican standpoint, there is an obvious interest in promoting individual autonomy. In the person's reported ambition to be a pilot it is plausible to discern first, a desire to work or, at least, an interest in or openness to working. Perhaps from here there is the possibility of distilling down a range of jobs that happen in airports to which the person might be suited to or attracted. This is civility in the lived moment and I would contend that every opportunity to practice it should be consciously embraced. Indeed, Daly holds that civility within the republican ethic is best considered not as a vague, abstract virtue but as a set of practices, specifically, bodily and linguistic techniques, performed in both small

---

[3] Philip Pettit 'Political realism meets civic republicanism' (2017) 20 (3) Critical Review of International Social and Political Philosophy 340

[4] Philip Pettit *Republicanism: A Theory of Freedom and Government* (Oxford University Press, 1997) 266

and large human engagements.[5] Indeed, when Pettit (and others) theorises the kinds of laws a republican dispensation requires, it is always in the context of wider norms being societally inculcated, the idea being that a wider civility functions to ensure a citizenry that is concerned not alone with their own private matters but with the concerns too of their fellow citizens.[6] These wider social norms are the habits of virtue which every citizen must be given the opportunities to learn and practice. They do not constitute a republican society but they do concentrate the mind on virtue's value as productive of a way of harmoniously living together. Building up such a society is prefaced on viewing good citizenship not as 'internalised dispositions'[7] but, rather, as inter-linked and reiterative public expressions of what Kymlicka refers to as 'decency'[8] and what Pettit calls 'fidelity to civil norms as an exercise in overcoming the self.' [9]

Overcoming the self has an almost ethereal, spiritual tinge to it. Indeed, what is being referenced in this phrase has resonances with the phenomenologist practice of bracketing (or bridling as it is used in this dissertation). However, it is not just a getting out of your own way as, for example, research purposes. Rather, overcoming the self represents a conscious – and, potentially, profound - turning towards the *other*. Practicing a civility founded on denial of self re-orientates us and permits us 'to be recruited to other identities'[10] and enables us more deeply enter into the reality of 'the irrepressibly social nature of our species.'[11] It is a civility that lifts us out of the sectional and into the reality that a compromised freedom for any citizen is a diminished freedom for all citizens, that 'if we cherish our own citizenship and our own freedom , we have to cherish at the same time the social body in the membership of which that status consists.'[12]

3.2 Perceptions of *other*

In talking about the disabled people with whom they work, few among the professionals cohort appear to demonstrate the sense of civility as understood here. There are some slight references in the data indicating that some professionals have '*learned a lot from disabled persons*' but little to suggest in this that what is being referred to is anything of especial note. Indeed, I

---

[5] Eoin Daly 'Ostentation and republican civility: Notes from the French face-veiling debates' (2015) 14 (3) European Journal of Political Theory 297

[6] Pettit (n 4); Cass R Sunstein 'Beyond the Republican Revival' (1988) 97 (8) Yale Law Journal 1539

[7] Andrew Peterson *Civic Republicanism and Civic Education* (Palgrave Macmillan, 2011) 82

[8] Will Kymlicka *Contemporary Political Philosophy* (Oxford University Press, 2002) 300

[9] Pettit (n 4) 258

[10] *ibid* 257

[11] *ibid* 260

[12] *ibid*

venture a far stronger – and, regrettably adverse - impression subsists in a particular use of language which it is now apposite to draw attention to. I introduce it with a disclaimer of sorts, indeed, a phenomenological one.

From the vantage point of a critical phenomenology, it is important to endeavour not to allow phenomena under study to became abstractions, representations or theoretical models. Of noteworthy importance here, is the relationship of literature to bridling, such that 'the concern is that existing literature would end up settling matters before the study was even conducted.'[13] The risk is that new insights are snuffed out, that *seeing through* happens in place of *seeing.* The same concern arises in relation to practice models and cultures within organisations providing services to persons with disabilities. Particularly perhaps in organisations where the culture encourages staff members to think of their practice models as creative, person centred and progressive, the pull on individual professionals to validate this is likely to be strong, not least in the context of comparing themselves favourably with other organisations whose reputations may indicate lower standards.

As referenced previously, this is a concern I bring to researching professional staff members' experiences of working directly with persons with disabilities, not least given my own professional associations. Professional pride can run deep, perhaps especially in the context of an overarching national service provision profile which is highly segregated according to perceived *types* of impairments, with all the intonations of concepts like specialism and expertise such a stylised division of service brings. This then seems an appropriate context in which to offer the general observation that when asked directly about freedom as it relates to 'service users' many of the research participants in the professional cohort indicate that their service promotes independence and personal freedom '*as much as possible*' or '*up to a person's ability*' or '*within what's safe for the person*.' I also note that, without exception, all of the participants in the professional cohort fall immediately and repeatedly into the use of two pronouns when referencing the disabled people with whom they work or disabled persons in general: *they* and *them*. Such a uniform usage goes to questions of governmentality and the processes whereby an inclusive epistemology is, or is not, demonstrated. Perhaps it goes too to a mobilisation of concepts which remain rooted in notions of care, certainly, but notions that represent a binary perspective.

---

[13] Mark D Vagle *Crafting Phenomenological Research* (Routledge, 2018) 79

One of the strengths of a critical phenomenological analysis is its capacity to capture experiential immediacy and subjective perspectives.[14] In these two words –*they* and *them* - is adroitly captured the perceived and singular otherness of disability, even among those who have made working in the field of disability their chosen profession. Arguably, too, this otherness is so at a remove from a supposed standard of physical or cognitive *normality* that even people who might reasonably think of themselves as advocates for inclusion appear to unselfconsciously employ words which deny individuality and promote implicit notions of compulsory able-bodiedness and this othering of disabled people.

3.3 Invigilating choice, including economic choice

Services that do not offer meaningful opportunities for 'service users' to experience and practice choice are dominating in so far as, *per force*, these institutions limit rather than expand the horizon of choice available. Hence, the image presents of a disabled person not just denied opportunities to choose but, as important, denied the resources required for choice. A few professionals describe circumstances in which regimes of care are so tightly scheduled that respect for the dignity of the 'service user' is subordinate to getting to an appointment on time or moving efficiently through a task. In such circumstances – as described, often kindly meant - individual freedom is compromised, the will of a powerful other being inserted into the space where the 'service user's' choices should be operant. That what is in play here may be relatively innocuous choices and, more, that the less powerful person may not even be aware that their choice is being in some way invigilated is of no consequence, the domination is no less real, the freedom no less compromised. From the small ways of respect and mutual regard on to formal acts of deliberative democracy, that circumstances may arise where persons with disabilities are denied choice or the taking on of personal responsibilities, this is in a visceral way a denial of the equal citizenship that is a hallmark of republican freedom.

Indeed, regarding disabled peoples' citizenship – presented here as a distinct perspective on freedom – professionals' contributions were largely phrased in terms of a perceived disconnect with citizenship, with a number of participants in this cohort noting that disabled people can be '*passive*' when it comes to asserting their entitlements as citizens or '*waiting for things to happen to them*.' One participant attributes this inaction to the influence of parents who have not provided their children with the '*scaffolding to be independent*.' Another talks about the disconnect as being a learned behaviour which could be reversed but also seems to suggest that

---

[14] Linda Fisher The Illness Experience: A Feminist Phenomenological Perspective. In Kristin Zeiler Lisa Folkmarson Kall (eds.) *Feminist Phenomenology and Medicine* (SUNY, 2014) 27 - 46

what is being talked about here are formal processes such as voting rather than something more diffuse. Yet another speaks of a power imbalance that militates against disabled people in need of services from organisations, saying, as one put it, that in her experience persons with disabilities are unable to '*stand up to those service providers and advocate for themselves*.' More generally, service providers –state, statutory, charitable and private providers – are alluded to as inherently powerful organisations. Referencing what one participant called '*the hegemonic model of disability*,' this participant describes an attitude whereby service providers offer services which are within their competence and their strategic plan – an attitude of '*we will let you in*' – rather than seeking to offer perhaps more responsive, more individually calibrated – and, perhaps, less controlling - responses to their 'service user' groups. Encouraged to elaborate on a similar point, another participant indicates that service providers are micro versions of the society in which they operate. The suggestion here is that Irish society still seeks to control disabled people because '*there's a lot of un-explored fear there*' and that service providers may be '*more about making the non-disabled feel better, feel good*' than actually meeting the '*real needs*' of disabled people. However, one participant describes a different (nascent) model:

a lot of movement around now is taking that power away and giving that power back to the person and that's through finances say where there's personalised budgets and the person would be in control of their own life. And I would love to see that happening but I heard about this for the first time seven years ago and I've yet to see it.

As explained by government, the model – known as personalised budgets for people with a disability[15] - promotes choice and control for disabled persons in accessing services. Attesting to the value of such a model, the same participant continues:

But you know then, service providers would be begging, saying come on, come with us, we'll do this for you, we'll show you this and we'll provide you with this for x amount and we'll reduce our price but, instead, it's us [service providers] *with the power, us with the control…….and I'd love for it to be the other way around. They* [disabled persons] *should be consumers, consumers of our service that decide what they want from us and when they want it, so they can be the ones making the decisions and taking control over their own lives*.

This prefiguring of the disabled person as consumer opens up the possibility of a new social contract between the state and persons with disabilities, creating opportunities for a republican citizenship based on real economic power and independence. More, it offers the possibility of

---

[15] Government of Ireland *Towards Personalised Budgets for People with a Disability in Ireland* (Department of Health, 2018)

fundamentally recasting the disabled person as an employer in their own right. However, when the topic of personalised budgets was put to several of the professional participants, a number of them expressed concern that while people with physical or sensory impairments might find valuable opportunities here, people with cognitive disabilities might actually be harmed. Indeed, one person doubts that '*without the centrifugal force*' which a disability service organisation can provide whether introducing individual budgets would not be placing disabled people under considerable stress, including the possibility of disabled people falling foul of abuse. There is also expressed anxiety that anything that might be perceived as diluting the contribution of professional expertise would ultimately work against the interests of 'service users.' As one professional teases this out:

'*[t]he profession I belong to is just about to be registered, as many other professions in the therapies area and social work area already are. We've waited a long time for this – it means higher standards professionally, a better understanding of what we do, what we bring, all of that. Wouldn't it be a shame if people with no professional code of conduct and ethics could just get their hooks into disabled people now*?' [16]

There seems something of the proprietorial in this, perhaps particularly amplified in the '*get their hooks into*' phrasing. Again, the imagery invokes domination in that opportunities for choice are being juxtaposed with potential damage, including, it seems, putative damage to the soon to be regulated profession. There seems something almost transactional here. Indeed, arguably, this quote is mostly about professions and professional control and, arguably, only tangentially about persons with disabilities. Professionals *deserve* respect and recognition and this must not be undermined; the emphasis is on *their* status.

Yet, it seems intuitively axiomatic that a source of un-freedom in disabled people's lives is the absence of resources over which they have volitional control. Accepting that deliberative democracy – the idea that 'government is a public matter to be directed by members of the public themselves'[17] – can play a strong role in protecting freedom as non-domination, in a capitalist order the most basic spur to participation may well be the desire to protect and improve one's economic status. This is reflected in the ages-old Athenian linkage of economic independence to active citizenship. That said, the absence of widespread roll-out of personalised budgets continues, perhaps, to contribute to a trope whereby disabled people are

---

[16] the reference here to registration is in relation to the ongoing regulation of specified professions by Coru as provided for in the *Health and Social Care Professionals Act 2015*

[17] Richard Dagger 'Neo-republicanism and the Civic Economy' (2006) 5 (2) Politics, Philosophy and Economics 151, 153

consigned as welfare dependents rather than as net contributors to society. Indeed, I think this a good example of what Pettit references as

> structural domination in the sense in which this is not the product of intentional effort on the part of the powerful. However it emerges, it serves to expose the relatively powerless – those in one or another vulnerability class – to domination by others.[18]

This notion of disabled persons availing of the services of personal assistants becoming their direct employers and now, perhaps, being *free* to take up remunerated employment themselves, has a particularly strong appeal. Indeed, I suggest, this appeal must extend to classical liberals and to neoliberals alike, who have long hailed the paring back of restrictions on all sorts of contractual relationships as essential to advancing human freedom. On a different basis (and here we loop back to registration), it must appeal to republicans too – but, here, on the understanding that considerably more regulation is in place to protect against domination (on both sides of the contract). The pertinent issue at present, however, is that personal assistants (PAs), whatever the concern some professionals interviewed may represent, are a vanishingly small part of the care provision in Ireland. The proper introduction of a comprehensive PA programme would undoubtedly clearly increase the freedom quotient in the lives of many disabled people, not least in that it goes to so many CRPD rights, including the right to work, the right to exercise legal capacity and the right to live independently and be included in the community. PA provision is returned to again later in this chapter, this time in the context of one research participant's experience of the process of accessing the provision.

3.4 Encounter ii: freedom- parents

Earlier in this dissertation, I describe phenomenology as a research method operating on a more intimate scale, that of the individual's consciousness of her own lived experience. Hence, the phenomenological method begins in encountering the experience of things simply, in all their givenness, 'appearing to the subject, to consciousness.'[19] Taking that as the lodestone by which I must navigate, the almost at times single most overpowering awareness given to me – almost exclusively from parents and, in particular, mothers – is that of desperation and exhaustion: a sense, as one parent phrases it '*of being cast out, thrown out because I had a disabled child*.'

---

[18] Mark Haugaard, Philip Pettit 'A conversation on power and republicanism: an exchange between Mark Haugaard and Philip Pettit' Journal of Political Power (2017) 10 (1) 25, 29

[19] Dermot Moran 'Editor's Introduction' in Dermot Moran Timothy Mooney (eds) *The Phenomenological Reader* (Routledge, 2002) 5

The message is stark: *'I had a life. I had a future. I had great career prospects. I belonged. Now I live for my child and the fight.'*

Another parent participant offers:

'*I feel judged all the time. My child has a tantrum in a supermarket I'm judged. My child hits another child I'm judged. I'm judged for how my child behaves in school, in a playground, at a party, in McDonald's, in church. Everywhere, every day I feel judged.'*

Remembering the very moment they each realised that their child had a significant impairment – a moment of self-revelation or a diagnosis or even a remark from another - parents describe feelings of shock, of horror, of nausea, of anger, of grieving and of loss, not least the loss of their *hoped for* child. No one who spoke to me did not seem to *not* want to share how despairing and bleak that moment was. I never had to ask. I never would have asked. For some, it seemed to present as a relief to say the difficult, despairing thing out-loud; for others, it seemed to me as intended to suggest an important counterpoint to better situate what they were feeling now and how they and their child are coping now, to give the now solidity and credence perhaps. But, to be explicit about this one thing, it is that the triggering query was invariably about freedom and the ensuing answer was invariably about freedom lost.

At the heart of this freedom lost, in all of the accounts given by parents, is a state apparatus of supports inadequate to disabled children's needs and the needs of their families. Again and again, parents allude to a '*broken system*' which, as one parent says '*actively works against us, annoyed by us and telling us we should be more grateful for the little we get*.' Parents describe having '*to beg*' for services and of having to humiliate themselves and their children just to get someone in authority to perhaps listen. As one parent phrases it: '*why when you have a child with a disability does your life end, because our lives ended ten years ago*.'

The same mother talks of the stress placed on her and her partner's relationship caring for a non-verbal child with extremely high support needs without external help, saying '*it's very hard, it's very isolating…….we're not like a married couple, we're like two carers, tag teaming……it's no life*.' The child also manifests severe sleeping problems, meaning the child's parents describe themselves as 'exhausted all the time.' All attempts to get help for this are rebuffed:

'*every appointment we take him to we literally beg for help but the epilepsy nurse says I'm only here for epilepsy and the GP says you need to see a sleep specialist because the medication she prescribes doesn't knock a feather out of him, nothing. But then the sleep specialist doesn't want to know and says no point coming to me I can't help you. And in our exhaustion and frustration* *nurses and doctors and receptionists and social workers tell us 'to calm down' and 'not be so aggressive.' It's like we are the problem, not the complete refusal to help. And if you raise your voice or get upset or start crying - literally crying, like sobbing – they get uncomfortable and rush you out of the room*.'

Several other parent participants identify with this type of '*unending strain*,' one saying '*having a disabled child in Ireland is like a prison sentence, a life sentence*.' As another puts it '*it shouldn't be so hard, but the state pushes everything back on you to cope with on your own*.' Indeed, such is this sort of official disinterest that for some of the research participants a sense of agency in their own lives appears to distil down to desperately small things: '*I used see my life as being bigger than a sneaky coffee before going home with the shopping.*' Another mother says of her daughter '*she is my world now and I am hers but a lie-in, you wouldn't believe how much that means to me the rare time it happens*.'

3.5 A republican insight: objectionable dependency

Inadequate resources or the inability to access resources is a recurring theme in the data. Here it is referenced with specific recourse to the connection which is emphasised in the republican ethic between resources and resilient freedom. Pettit writes about the 'strategy of reciprocal power.'[20] Meaning a type of status whereby a person has – in its most likely formulation – the readily available means of responding to domination on the part of another, this strategy provides the damaged party with access to an effective punishment for that damage. However, Pettit recognises that such a strategy may limit instances of arbitrariness but is unlikely to eliminate arbitrariness (while, of course, also being, in itself, a form of domination). Hence, Pettit also talks about 'the strategy of constitutional provision.'[21] Unlike the former strategy, which might be characterised as a sword, this latter strategy is more akin to a shield, as understood in the estoppel sense. The presence of a constitutional authority – 'say, a corporate, elective agent'[22] – promises a capacity to wield a defensive and deterrent authority that aligns with the common good and with which it is in the general interest to comply. Such an authority confers a practical equality whatever other disparities might exist. As Pettit contends:

> Let the agents in question take against me; let me fail to be good at toadying to them; let me lose the cunning required to keep out of their way. None of this matters if I really enjoy non-domination: if I really

---

[20] Pettit (n 4) 67
[21] *ibid*
[22] *ibid* 68

> benefit from the reciprocal power or the constitutional provision required for non-domination……I will count by any criteria, then, as a relatively powerful individual: I do not have to depend on luck for avoiding the relevant sort of interference.[23]

Not, of course, losing sight of the data already presented, the practical value of this is distilled, in the main, in respect of the following data. A parent participant laments that her child has missed a possible '*intervention window'* for developing speech having only ever been given one block of six hours HSE-provided speech and language therapy when the child – now ten – was four. HSE staff shortages being cited for why nothing further materialised, the parent describes sourcing a private therapist and paying for this service entirely at her own expense – at a rate of a hundred euro an hour. However, without warning, and having commenced providing therapy, the private therapist subsequently advises that her company had changed its client criteria and, effective immediately, was now only providing therapy to '*high functioning*' disabled children. By way of a yardstick, they were told, any child attending a special school – that is, not in mainstream education provision - would, henceforth, automatically, be disqualified from availing of a therapy service from the company, even if already on the company's books. An alternative source of private speech and language supports has not been found. This parent understands this shift to represent '*the perfect storm*':

'*the HSE can't get or keep enough staff to meet need and the private providers can clean up, making money easier from easier cases than my child who probably could have learned to speak maybe just a little if we had a system that cared even a bit about equality. I used to pray maybe next year there could be a few words but now I've lost hope*.'

Another mother, referencing the toll of advocating for her daughter, says '*I find myself exhausted from the constant advocation for her, it's constant*.' Describing her daughter's life-limiting condition as a gene mutation resulting in intellectual and physical disabilities and the inability to '*walk, talk, sit, eat or urinate,*' the child has a catheter, is peg fed and is polypharmacy, meaning she is on '*a lot of medications every day just to function*.' Yet, despite her daughter's evident complexity in terms of need, the mother describes her '*battles*' with the authorities as divided into '*menial fights*' and '*the big fights*.' Among the former are

'*everything from supplies just to give her her medications, like syringes and things like that that you get from public health nurses, you almost have to argue that, yes I do need this amount of*

---

[23] *ibid* 69

syringes per month, yes I do need this amount of nappies and you have to quantify how many nappies a child who's doubly incontinent would need each day. Things like that, these are just menial fights.

As for the big fights, these are

'*like wheelchairs, or activity chairs or car seats. It's endless what you need like bathing aids, things like that so you can safely bathe your child with dignity and if that doesn't fit on a HSE contract list you don't get it and if you don't get it you pay for it yourself and if you pay for it yourself it's thousands, not hundreds, thousands of euros. So we are doing all this for [our child] to give her the best possible life and then in the background of that you're trying to give her everything a normal six year old would have, and when I say normal I use that term very loosely because she has a very complex life and we want her to have what any other six year old little girl would have walking down the road. I mean just going to school, being amongst her peers, having independence, she deserves independence. She doesn't need to be with her family 24/7.'*

Pettit maintains that republican states 'will be less sceptical of the possibility of state intervention and they will be more radical in their view of the social ills that the state ought to rectify,' describing the republican polity as 'politically more optimistic.'[24] I share no sense that this is a polity any of the parent participants interviewed would recognise theirs and their children's experiences as mirroring. Indeed, quite the reverse, as parents describe how precisely *who* their child can be has to vary from day to day, depending on who they need to convince or, more accurately '*try to persuade*' to offer the child a service. Hence – introducing a theme to be further reflected on below - parents describe getting advice from, variously, HSE officials, doctors and, in two instance, public representatives, as to how they must either '*really exaggerate, like lay it on with a trowel, how bad*' their child is so as to perhaps move up a service queue or get a scarce appointment. Conversely, parents report having to minimise behaviours and so forth so as to perhaps get a place on a special summer camp or even find a crèche or mainstream school placement. As one mother shares: '*you learn how to lie*.'

These narratives – mere snippets really – all speak to parents and children for whom the state, in particular, is '*a part of our problem*' rather than a supplier of support, variously '*just not caring and not caring we know that*,' '*mocking us*' and '*waving an abacus at drowning people*.' In Pettit's taxonomy, a state's embrace of contemporary republicanism serves to clarify the tension which can exist between contending views of who is owed what under the rubric of social justice.

---

[24] *ibid* 148

By enthroning the freedom as non-domination ideal a certain *sort* of dependency becomes an objectionable situation for any citizen to find herself in, perhaps reliant on charity or in some other way having to present as a deserving supplicant. For Pettit, contemporary republicanism operates on the 'inclusivist assumption that each is to count for one, none for more than one.'[25] This expresses an egalitarian ethic which disdains living at the mercy of another, including, I would contend, at the mercy of a therapist who might arbitrarily withdraw a service already commenced without making a proper arrangement for substitution or, at a minimum, reimbursement. Indeed, Lovett is very clear that such a situation where one is

> dependent on a person or group who has the power to arbitrarily withhold goods or services needed to meet one's basic needs, whose satisfaction one does not regard as optional, amounts to a domination.[26]

Looking more intently at the arbitrary withdrawal of a speech and language service already commenced, it is to be expected in this republican ordering that such an act would, at a minimum, be constrained, perhaps by an enforceable code of ethics which would seek to ensure no inference might arise that economic considerations trump the needs of vulnerable people. Remembering too that in specific circumstances omissions may be sufficient to ground domination the failure of the state to sufficiently regulate the provision of essential services to people desperately in need of them not only permits domination but, by its omission, promulgates injustice. As to what an explicitly republican justice requires, O'Shea observes:

> We should note that this conception of justice focuses not only on the actions or characteristics of individuals, but rather on the basic structure of society: its political constitution, economic order, legal system and other major social institutions. Justice within this basic structure is most fully realized when expected aggregate nondomination is maximised.[27]

An essential point underscoring my reading of republican theory is that the vulnerability to domination and to the un-freedom which flows from that, represents a unifying feature of the human condition, recognised in the republican tradition from its very earliest iteration. Hence, a political and legal system which recognises the necessity of instituting measures to resource

---

[25] *ibid* 110

[26] Frank Lovett *A General Theory of Domination & Justice* (Oxford University Press, 2012) 195

[27] Tom O'Shea Civic Republican Disability Justice. In Adam Cureton David Wasserman (eds) *The Oxford Handbook of Philosophy and Disability* (Oxford University Press, 2020) 217

its citizens to resiliently resist domination is, by its own internal logic, a system which cannot require disabled people hold to a lesser standard. The system so envisaged works or fails on the quality of its universal coverage. As a system of government which embraces pluralism and diversity the identity of someone as disabled goes only to the possibility of alerting to greater vigilance in protecting their dignity as persons entitled to enjoy freedom as non-domination. A state that requires desperately vulnerable people to provide it with regular book-keeping on nappy usage, is a state which fails to meet the republican need to ensure it is not, itself, oppressive and arbitrary. It is a state which has lost itself to abstraction, rather than affirming its solidarity with its weakest members, failing to protect and assert, in Laborde's phrase, 'the importance of *'we-ness'* to citizenship.[28]

3.6 Encounter iii: freedom – vision impaired persons

An unexpected feature of a number of the interviews among this cohort was how many of the research participants elect not to represent themselves as vision impaired or, at least, to elide vision impairment where possible. Indeed, some participants spoke of their impairments as if they were things extraneous to their bodies, employing phrasing like '*I didn't want to give in to it*' or *'I couldn't let it beat me.'* The broad sense is that disability is a *presence*, '*a thing that compromises your freedom to just be yourself*.' Dispelling this presence, denying it its power over the person or at least dissipating its negative effects becomes important to experiencing the freedom of belonging or, at least, '*to be free to not be excluded*.' As another participant puts it:

'*if I am interesting to people I don't want it to be because I don't see because that's not me – that's just their stereotypes of blind people. That's not interest in me; all that is is clichés*. *I don't want to be anyone's cliché*.'

3.7 Hiding in plain sight

For the participants within this sub-category the broad rationale is that the individual herself sees only personal disadvantage and un-freedom in self-identifying as disabled, including issues of compromised personal privacy. Hence, as one research participant says '*the word disability is not the term you want after you*.' This speaks to recurring themes within this entire cohort's contributions revealing prejudice, discrimination, mistrust, fear and, even, hostility and violence. However, for others, this decision speaks to a determination to be the arbiter of their own life-story. A determination not to have to persuade others of an ability or competence which would,

---

[28] Cecile Laborde *Critical Republicanism* (Oxford University Press, 2008) 247

most likely, just be taken for granted if the presence of an impairment was kept to oneself or, otherwise, not in evidence. ‘ *Look at you*,’ one mobility cane using participant quotes a stranger telling him on public transport – in a tone the participant took to indicate ‘*admiration but also astonishment*’ – ‘*you’re washed, dressed, blind and on a bus*.’

Another participant phrases this point thus:

‘*I’m not in that mind-set. I’ve always kinda been of the mind-set that it’s not going to stop me, it’s not going to be a barrier or something I need a label on sort of thing. Personally, I never zoned in on it so why should I let other people zone in on it?*’

As this participant continues, asserting the legitimacy of defining himself:

‘*I know what I have is a disability but I don’t categorise myself in that way, it’s very much a privacy thing. I sort of veer away from the whole disability thing. I’m a private person and disability is too public for me*.’

For another participant the issue is about not inviting comparison with clichéd representations of blindness and vision impairment: ‘*I’m me, not Mr. Magoo*.’[29] For a fourth participant, the issue of whether or not to reveal her vision impairment is described as ‘*strategic*’ and relates, in particular to job interviews:

‘*I would certainly be strategic about when I’d reveal it and that would usually be when you are going for a job because there is always this debate do you disclose a disability or not. Some employers will declare that they are equal opportunities employers but if you don’t get past a certain stage of the recruitment process you do wonder, you never really know. It’s a bit like estate agents when you’re buying a house and they tell you there’s another bidder. You’ll never know whether the disability you have declared had an impact on it or not. So I go in with a strategy*.’

Because of the precise nature of her vision impairment, this participant describes having ‘*been able to get fairly mainstream work.*’ This participant also describes going for quite a lot of interviews when she left college ‘*just to get used to them*’

‘*and I came to the conclusion that the best thing to do was go in, do the interview, see how it progresses and if they show an interest in you, that they appear to be heading in the direction that they might recruit you then you reveal your disability and I found in the early days that if*

---

[29] commencing in 1949 and popular throughout the 1960s, 70s and 80s, Mr. McGoo was a popular, syndicated American animated TV series, in which the eponymous character’s significant vision impairment , compounded by his inability or refusal to admit to it, resulted in continual mishaps

they asked questions about it then I usually got the job. If they didn't ask questions I would find that you wouldn't get the job, either because they were afraid of it, they didn't know what to do with it or whatever the case might be.'

Another says he has patterned his life on trying not to reveal his vision impairment except in exceptional circumstances, saying '*I've always known I have a disability but I was stubborn and I didn't want to give in*.' Referring to the '*very tight*' circle of people he has ever admitted his vision impairment to, one man says '*I like people to meet me, not a disability*.'

On several occasions vision impaired participants recalled '*the front of the class*' as a place to be avoided at all costs, even though each participant who referenced this added that they had known sitting there would have conferred an advantage in terms of better perceiving what was being taught, particularly maths. However, there seemed to have been an instinctive sense that what ever might have been gained, it was not worth the trade-off relative to what might have been lost. Nor was this just a feature of primary and secondary classrooms. A participant mentioned continuing to avoid the front row when studying to be a teacher himself:

'I didn't want to let on. At teacher training college it was all overhead projectors and I was afraid to say that I couldn't see them then because if you said you couldn't see the lecture notes you might be asked to leave.'

This participant explained that as part of his application process to become a teacher he – in common with all applicants at the time – had to prove '*I was sound of mind and body.'* This required him passing a medical examination. However, the doctor examining him had rejected his application on the basis of his eye sight. The teacher training college principal, a nun, '*intervened on my behalf*' and the medical assessment was overruled. Yet, even knowing that this support was there for him the participant still felt that throughout his time studying at the college he could not openly admit to his impairment. This was so even though sitting at the front during lectures and, in other ways being able to publically accommodate his needs would '*have made my life easier, but I just couldn't do it.'* The participant adds: '*they were the things that made you feel you had a disability. It was institutions made you feel it.*'

4 Invisibility, hatred, violence and unwanted help

One participant recalls examples of regret when '[I] *broke my rule and revealed the secret identity*' feeling it occasioned workplace condescension and even bullying. Another, now an academic herself, describes how she decided to share her inability to properly participate in seminars and staff training exercises without having handouts and notes in large print and so '*outed myself at a department meeting*.' Not only does she feel hoped-for promotions were adversely affected but also no particular benefit ensued in terms of accommodation from colleagues. She reflects '*I had not realised how difficult it is to get educators to accommodate just one person.*' She adds

'*from some people you just can't get help from them, they are just going to deliver* [their lecture] *and it doesn't matter to them if you get it or don't. Usually they are people who seemed to be successful and they just don't know what it is to struggle*.'

The overarching sense here is of a group of people for whom freedom – in its most basic articulation of feeling able to be yourself – is constrained. Indeed, this sense is further heightened by other participants who express the wish that they too could hide their identities. Particularly in terms of participants who are long cane users or who are guide dog users, it was distressing to hear how these symbols of disability could be contact points for unwanted and, in some cases, violent engagements. Several guide dog users report people interacting with their dogs in ways which disrespect the person for whom the dog is working. For instance

'*I've had people prevent my dog from guiding me safely across a road because they have a hold of the dog or are cuddling it or introducing their children to it, patting it and lifting its paws. It's like they don't see me.'*

Of the same type of intrusion another participant said:

'The dog is working; she's concentrating. Someone told me there is a sign in buses saying do not distract the driver. She is massive for my independence but people just seem to think I am out walking my pet but more she's walking me.'

The almost casual way in which a number of participants mentioned violence or the fear of violence suggests that this is not an uncommon experience. Hence, one participant mentioned how he has learned to be careful about when to produce his cane or to ensure that when the cane is not in use it should remain unseen:

'*oh, yeah, I've had some very bad experiences. The way my sight is I am ok in daylight but once it starts to go dark I need the cane. But people on the bus have told me off for pretending to be blind, telling me I should be ashamed of myself, that it's a money scam. Oh, you're one of those people who take from the government. I get it all the time. Sometimes I've been screamed at, spat at once. And these are people who see me on my bus all the time. I never know when it will happen*.'

One participant describes a similar situation, being careful *not* to put the cane away when she no longer needs it and to keep using it

'*kinda performing but it keeps me safer, I think, not having to explain myself or draw attention. I'd like to be freer, take the cane out, put it away, whatever. It would be better to kinda express myself, be myself but it's like the blindness is in the cane and that keeps me safer*. *The cane kinda makes sighted people happy*.'

Another participant describes how even in his thirties he was highly unwilling to use a long cane because of the attention it focused on him saying '*I would have walked into bins, into shop windows, into people. But after that I woke up to myself and said don't be so stupid.'* This participant also says '*I avoided going into town for about five years because I couldn't see…. I kind of introverted myself*.'

Another story begins with a participant describing being disorientated one evening in town and meeting '*a stranger who saw the cane and asked me if I needed help so I said I just needed to get to a place that I know*.' As the story continues, the participant describes folding his cane and taking the stranger's arm, setting off towards Temple Bar. The participant describes a pleasant, relaxed, easy conversation en route but then things went quickly awry:

'*we basically bumped into his girlfriend and when she spoke I looked in her direction. I could see her silhouette and all the rest. And he says 'you can see my girlfriend.' I said oh, yeah I can see her shadow and stuff like that and I can see lights. Then he pushed me. She spat at me and then he came over and punched me in the face and said 'you're a disgrace.' I just basically had to wait until he had left so I could get back up again. And I wouldn't mind but nobody came to my help.'*

The assault was not reported, the participant adding '*I've just come to terms with it that this is something that is going to happen in my life*.'

Accusations of being welfare cheats are also referenced several times in the interviews, with participants frustrated at the casual inferences that get drawn that people are masquerading at being disabled to cheat taxpayers – a status, according to one participant, that even some of her fellow workmates refuse to not believe she shares:

'*my big mistake was to tell someone in work about the blind pension. It's not a lot, it's means tested but anything extra when you have a disability helps because disability is expensive, you know? It costs you more to be disabled. But then the jokes – inverted commas - started and they never stopped. Mostly I pretend to laugh but they're really hurtful, you know?*'

There is also a sense, hinted at much more often than explicitly said, that if you are acknowledged to have a disability you should behave in certain ways appropriate to your circumstances. One vignette which perhaps captures something of both the liminality and the idiocy of this is shared by a blind cane using participant who, boarding a late-night bus home with his sighted boyfriend found himself accosted by the bus driver:

'*we just sat down together mid-way down the bus when I heard the driver screaming 'you have to move, you have to move, you can't sit there.' Hadn't a clue he meant me until suddenly he was on top of me, grabbing my arm and dragging me up the bus to the seat he said disabled people have to sit in. I was so shocked – shocked and embarrassed – I didn't move until we got to my stop. It really upset me*.'

Another blind participant describes the frequency with which he is '*accosted on the street*:'

'*I literally have had people pounce on me on the street, grabbing hold of me and dragging me across the road. I might be stopped for a million reasons and next thing I know I'm on the other side of a bloody road and I haven't a clue where I am anymore. And then people give out to me or say I'm rude because I haven't said thank you. I said to one woman 'give me your address and I'll bloody send you bloody flowers.'*

As a blind woman confides

'if someone is going to grab me I'm going to push them back. I'm not going to know what they are doing, whether they are mugging me or assaulting me. The instinct is to protect yourself. And then they get all hurt because you are not taking their help.'

This help when not sought is described, variously, '*as being treated like a child*,' as '*being used to make them feel virtuous,'* as '*an actual assault*' and, as perhaps, most tellingly as '*not seeing the person*.'

It is suggested that of the many insights these accounts offer in common, perhaps the most disturbing is a sense of the way in which disability - defined as functional limitation -works to harm the capacity of persons with disabilities to live their lives as citizens within systems that protect dignity and self-expression. Having been comprehensively *othered,* disability becomes performative, ritualised and medicalised. There are the deserving and the undeserving disabled, those who can be admired and those who must be challenged, held to account and, even, berated. And even among those who meet the stringent public test of legitimacy, these too may need reminding of where they stand – or sit. If disability really is, as the CRPD has it, an evolving concept, there is scant evidence in the accounts presented here that this evolution is occurring in the mind-sets of the not yet disabled, least of all, perhaps, in a sense of disability as a highly complex reality, with much to teach about shared human fragility and vulnerability. Instead, persons with disabilities are held to *be* their impairment and, on the evidence of the instant research, the *help* some not-yet-disabled people appear to feel inclined to give focuses entirely on engaging purposefully with that impairment. That this compromises bodily integrity and the disabled person's sense of safety and undermines individual dignity - perhaps even to the point of a de-personalising of the individual – appears not at all to enter in.

5 Education

This section draws on observations that highlight the complex, multidimensional and problematic experiences encountered in respect of education, whether at early years, mainstream or special school level.

5.1 The maximising/minimising dilemma

A sense of a paucity in state supports for children with disabilities is indicated from parent participants from all around Ireland. Nor is this sense confined to health and health related services. Several parent participants speak about mainstream pre-schools and schools as sites of exclusion, especially in respect of children who present with complex needs or multiple impairments. While several of the parent participants in this cohort actively advocate for the special school model as the most appropriate for their child, others tell stories of having to be very persistent and, perhaps, even disingenuous, in seeking to secure a mainstream school place for their child.

One mother references the seventeen letters she had received from primary schools in her own town and the next three nearest towns, each one a negative response to her efforts to secure a mainstream school place for her child. In the end, as the mother tells it, a Special Education Needs Organiser (SENO)[30] became aware that a school in the immediate local area had a place available and insisted that since this mother's child was next on the list that the place must be assigned to this child. However, as the mother elaborates, both she and the SENO were aware that at this point the child's diagnoses of a global developmental delay gave the school little practical room for refusal. However, both the SENO and the mother were also aware that a new cognitive assessment had been carried out since the application for school admission and that

---

[30] Operating under the authority of the National Council for Special Education - a statutory body formally provided for under the Education for Persons with Special Educational Needs Act 2004 – SENOs have a wide ranging role, including planning, co-ordinating and reviewing the provision of additional education supports to schools which enrol children with special education needs and providing advice and supports to parents

this had now reclassified the child's diagnosis to that of moderate intellectual disability. Anticipating that such a reclassification would almost certainly undermine the proposed placement the SENO agreed to delay forwarding this reassessment to the school authorities until the child was established in the school. The mother reports that while this tactic worked to assist her son, immediately thereafter the school principal commenced personally visiting all would-be students who had impairments before any school placement offer. The mother believes this change in procedure is directly intended to close any further possibility that delayed paperwork might '*saddle the school with a child they don't want*.' While grateful for the pivotal support of the SENO in this case, the same mother reports feeling guilt that while this particular manoeuvre directly benefited her child it has also served to possibly hardened this particular school community's attitude towards other children with moderate intellectual disabilities.

This opens up the issue of whether a child's best interests are served by either seeking to minimise or maximise the presenting features of a particular child's disability circumstances. A number of parent participants identify an interesting dichotomy here, which, broadly, equates as follows: for health and social care related services maximise; for education services minimise. The following four quotes exemplify the perceived imperative to maximise:

'*We're not comfortable with the maximising. But where I see ability the HSE has to see disability, the more extreme the better the chance of getting some sort of service, anything at all. So, we've become better at playing with words. There's no room for positivity*.'

'*You have to pick it out, big it up. If you don't emphasise – and you probably feel like you are emphasising the negatives, the defects if you know what I mean – but that's the system. There's no point in emphasising the pluses. That won't get you anywhere*.'

'*They told me in no uncertain terms, physio, speech and language, occupational therapy, you won't get any of that. 'He's only blind,' that's what they said. Then I argued it, saying blindness effects the way he plays and interacts, how he runs. We were having to put up a fight to get these extra things, chasing them and then being told 'oh, if he fitted into two boxes it would be better; if he had, let's say, the visual impairment and, let's say, another condition it would be much better because 'we don't know where to put ye.' So, they didn't put us anywhere*.'

'*God forgive me but it's like Britain's Got Talent for disabled children, you have to give a performance that impresses the judges or you don't get through to the next round*.'

These next four quotes represent the minimising tack:

‘*It’s fundamentally unjust but it’s across the board like, you have to decide which way to play it: if you need something from the system the system has to hear what it wants to hear*.’

‘*I can understand why people do minimise it* [the presenting features of impairment] *for the education part of it so you kinda have to jump between downplaying it and almost exaggerating what you need from other services hoping to getting something at all. You can’t just be. You have to tailor it to what the end goal is*.’

‘If teachers think it’s going to impact them and make their life harder, that the disability will just take over the classroom and cause them grief of course they are going to swerve it. So you have to calm things down, persuade them to see [the child] *not the disability*. *But if they are allowed medicalise her then bye bye mainstream*.’

5.2 Schools as places of power

A number of parents referenced how powerless and, even, cowed they felt when meeting mainstream school principals, being careful about what they felt they could say for fear ‘*one wrong word could destroy the hope of getting – no, being given – a school place*.’ Parents who describe the process of securing a local school place for their other children as straightforward, now describe feeling very distinctly that their disabled child was considered less worthy or less deserving and, even, ‘*distinctly unwanted*.’ A parent reports being told, in reference to her son: ‘*we already have a child like him, we couldn’t take two*.’

In particular, mainstream school principals are identified as quite adroit gatekeepers, wise to not transgressing the norms of inclusive discourse while, nonetheless, placing what one parent calls ‘*soft barriers’* in the way of children whom the principal determines is not a good fit with their school. As one parent says:

‘*They [school Principles] can make you feel very welcome when you visit. They can nod a lot and agree a lot and say how much they would love more disabled children in their school. They use the right words, soft words, even when they are telling you it wouldn’t be fair to the child or the parents because there’s only so much their school can give you and it’s so much less than the special school can give you*.’

Another parent contributes:

‘*They have way more power than they should have and can be very protective of their school, of its reputation and its status, behaving like they own it rather than just running it*.’

More, in circumstances where a mainstream place is secured, there can still be a feeling of being unwanted and this sense can transfer to how parents feel they themselves are regarded by school personnel and, indeed, by other parents. In respect of the latter, a participant describes being accosted at the school gate by another parent, a stranger, angry that the participant's child was, according to her, the reason her son was doing less well in school. When asked why this could possibly be thought, the stranger grew aggressive and shouted '*you know, you know*,' and, then, gesturing to the participant's child saying, '*sure just look at him*.' This participant asked that the school take some action about this incident but nothing ensued.

In respect of school personnel, another mother confides how a mainstream primary school principal's '*shoulders used to go down when he saw me*.' Describing herself as constantly researching, constantly seeking to persuade the school to innovate in her child's interests, and constantly fundraising for adaptive technologies – indeed, being pivotal to the first ipads being introduced to a school in the south of the country – this mother situates her motivation in a feeling that '*if I didn't keep the pressure on, my child would be forgotten about and to make sure they didn't forget him I had to make sure they couldn't forget me*.'

This idea of having to keep a child *present* to the school authorities reoccurs throughout the research. As suggested in the interview responses, this can be a finely judged balancing act. On the one hand, parents want to ensure that their child is deriving benefit from being in the school; that the child is being included and is regarded as being there by right, rather than under some kind of sufferance. On the other hand, however, a number of parent participants reference a concern that questioning a teacher or asking about some arrangement specific to their child may draw adverse attention to the child or attract some disadvantage. Teachers, in general, are seen as holders of considerable power and, in the main, not natural allies. A parent offers:

'*my son's teacher thinks I think that we are bonding when she says her own child has autism too but my son is non-verbal and doesn't sleep and can't be unsupervised for two minutes. Her son is in UCC*.'

Another parent suggests that teachers '*don't see what disability can do to a family, the impact. Support for parents isn't on the curriculum*.'

Hence, several participants feel that they must be cautious in exercising their parental entitlements to hold teachers to account and even sometimes to accept perceived discourtesy or tolerate unprofessionalism without challenge. By way of example, some concern is expressed that expected norms within which teachers communicate with parents (and by implication with their children) are slacker than they might be expected to be. Hence, some suggest that it is a good week when some teacher does not complain about their child. '*We all have headaches today*' a teacher told one parent when he came to collect his child, indicating that his daughter's behaviour was to blame. The father reports not feeling he could say how being told this really made him feel for fear it would rebound adversely on his daughter. However, in interview he continues:

'*I really resented that. It's a way of saying I'm the reason that teacher or that Special Needs Assistant had a bad day. Having our daughter in a school she is entitled to be in is literally a headache for the whole school. I'm a headache, my wife is a headache, our daughter is a really big headache*. *She's eight and that's what they think of her.'*

Given that the special school provision is widely available in Ireland it seemed appropriate to invite parents of children within mainstream provision to reflect on why they had opted to enrol their child within a mainstream school, particularly in the context of complex needs. One parent responded thus:

'[m]y experience of mainstream has been good for my child. He has sensory processing issues and is autistic so in many ways a special school could be a better choice and we were told that outright. But I just don't think it is. He's in a local school, not a maybe two hour bus journey away. He's [in] the same school as his older brother is. He's part of his community in a way he couldn't be if four hours of every day was on a bus. The school is doing its best, the resources aren't great but he's the only child there on the autism spectrum so he brings something to the other children and they bring something to him. *Yeah, sometimes he gets frustrated but I hope he's learning, I hope his classmates are learning, to be part of a diverse community.*'

Another parent participant explains her daughter's attending mainstream school in terms of the limited experiences she remembers having of people with disabilities in her own childhood, saying: '*Whatever future [she] has is going to be I don't want her invisible the way disabled people were when I was in school*.'

For another parent '*mainstream schooling isn't for everyone and, yeah, so far it's the biggest decision we've had to make as parents and we've certainly had our battles and asking still did we do the right thing* [opting for mainstream].'

Another puts it as follows: '*We've had great teachers and not so great and there's been a bit of bullying too, mostly exclusion and maybe more insensitivity and lack of awareness than deliberate bullying but not nice to deal with and tough for our son whose very innocent really.*

But in the end I have to hope that, even with the problems, he is learning more for his future than he would otherwise.'

Drawing a number of these themes together – for example, minimising, disinterested teachers, social connection, managing power relations - one blind participant reflecting on his own experience of mainstream schooling describes it as:

'*Good. Not academically good but brilliant socially. I went to Primary School in the early eighties and, yeah, everything really minimised by my parents to get me in. Then on to secondary in the early nineties, parents pulled the same stroke. But in all that time, no teacher, no Principal, no one ever brought me into the office and said 'what can we do for you?' or 'how can we help?' They gave me a Mickey Mouse computer course in first year but I wasn't allowed use my computer in school because no –one else had one and it wouldn't be fair. I t was all very disjointed. Some teachers would embrace the visual impairment, some teachers would just sit me up under the blackboard, even though I told them I still can't see the blackboard. Like my technical graphics teacher – me doing technical graphics was a kind of a joke in itself – but me telling him I can't see very well but he thought I said I couldn't hear so he'd stand very close and just shout at me, that went on for a year. But I wouldn't change it. Like if a teacher asked me to read what was on the board, I'd always say something smart like 'why? Can't you read it?' and he'd throw me out. Instead I'd get a laugh, be the class clown. It ended up in* [me] *going down a certain path but no way was I gonna say to everyone 'I can't see.' No way.'*

5.3 Inclusion or integration

Drawing on data from all three cohorts, there is concern that within mainstream school provision notions of inclusion and integration can create confusion, such that, sometimes, these quite separate concepts appear interchangeable. One blind adult, reflecting on his experiences of mainstream education, shares the following:

'*I was just so delighted to be in the local school it took me a while to realise I was like being protected almost from the other kids. I had a special room to eat my lunch in and to have free classes in. My SNA came to the yard with me. I'm certain it was meant to keep me safe and like it did in a way - who wants to hang out with the blind guy and his special adult? Teachers kept asking me was I okay, checking in with me all the time, offering help and willing to go over stuff again, even after class. I was a sort of school pet*.'

This sense of being physically in a school (integrated) but also of being kept apart from many of the common, mutually bonding experiences of the place (the experiences of inclusion) is indicated by a large number of participants, again across the three cohorts. Moreover, this part of yet apart from dichotomy is represented in the very earliest educational contexts. Describing how pleased she was when the Access and Inclusion Model (AIM) programme[31] came on stream – a government funded early years' initiative that offers supports to enable disabled children avail of the Early Childhood Care and Education (ECCE) free pre-school hours provision[32] - the mother continues:

'*he got a place in a mainstream crèche, the same one our other son is in and run on behalf of a government department for employees' children. But, after a little while they basically turned around and said to us we can't care for him any more than three hours a day. So, basically, they wanted to marginalise him. Every child that goes there goes for the full day. But they told us in no uncertain terms that they can't care for him outside of the three hours when they have extra help provided by the AIMS* [sic]. *But after the three hours all his peers would be remaining and he'd be the only child standing by the door and a parent collecting*. *So, for him thinking why am I different when all my friends are still getting to play together*.'

Describing an entirely different early years' provider, another parent offers a useful context here, suggesting a perhaps cynical motivation:

'*Offering the AIMS* [sic] *thing there's a legal obligation to do that, AIMS is government policy. But by saying all we can give you is AIMS they know, hundred per cent, very few parents can settle for just three hours what with jobs and other commitments. So, by meeting the law they know they won't probably even have to give you those three hours. It's almost clever they way they can play it to their advantage and your family's disadvantage. Covering themselves and using the law against you*.'

This idea, as it were, of sleight of hand, of appearing to offer a service while really demurring is referenced across a number of areas, including employment and accessing the community. But in all the data it is most prominently referenced in relation to mainstream school:

'*They* [mainstream school Principles] *can make you feel very welcome when you visit. They can nod a lot and agree a lot and say how much they would love more disabled children in their school. They use the right words, soft words, especially when they are telling you it wouldn't be*

---

[31] AIM offers a suite of targeted supports over seven levels; see Department of Children, Equality, Disability, Integration and Youth *AIM Rules* 2023/2024 at https://www.gov.ie/en/organisation/department-of-children-equality-disability-integration-and-youth/

[32] the ECCE scheme is available to children aged from two years and eight months for three hours a day, five days a week, thirty eight weeks a year; see https://www.gov.ie/en/publication/2459ee-early-childhood-care-and-education-programme-ecce/

fair to the child or the parents because there's only so much their school can give you and it's so much less than the special school can give you.'

This same sleight of hand tendency – described by one participant as '*giving you something while keeping more back*' - is exemplified in the following concerning what appears to be an not uncommon practice of subjecting disabled children, arbitrarily, to school days that are shorter than those available to peers:

'*The school introduced this bloody 'communication book.' Like every day these notes about what he did wrong, misbehaviours, broken rules, other children upset, on and bloody on. There were meetings too, asking us what we were doing to fix the behaviour. Then the penny dropped when the principle said we'd have to agree to be on stand-by to come and get [our child] at a minute's notice, you know, agree to shorter school days. The bloody communication book was about setting us up for a fall, leaving us feel we had no choice*.'

It is salient that the child in this example left mainstream for a special school environment and perhaps salient too that the child's parent says that the special school report no particular behavioural problems.

Another instance of arbitrariness derives from a parent participant who recounts an example of an offer of a mainstream school place that is subject to a condition which makes the offer one the parent cannot accept:

'*I had a meeting with the primary school in our area. But they weren't interested in her. She uses a PECS system.*[33] *The school said she was welcome but they said she couldn't use PECS. So they said she could still come; she just couldn't use her voice. So they met every legal requirement. They accepted her, she could still come, she was in the locality, but she couldn't communicate*.'

Incorporating a teacher perspective into this element of the data – and cognisant that only two teachers participated in the research – provides resonance to much of what has already been cited in respect of the tensions surrounding education inclusion. Hence:

'The theory about inclusion is great but so is the theory about a lot of things. Everyone learning together, learning from each other, breaking down barriers and all that good stuff. But what I'm seeing are overcrowded classes, poor resources, disruptive behaviours and parents of non-

---

[33] PECS – the Picture Exchange Communication System - is an expressive, picture based communications system used by people of all ages with a wide range of learning difficulties, including autism, allowing users to initiate communication relevant to their needs and wishes. PECS originated in the US in 1985.

disabled kids complaining if they think high-needs kids are stopping their Johnny or Julie getting the academic input and the learning environment they send their kids to school to get.'

The same teacher also offers:

'I have had blind students in my class. Not a problem. Once the books in braille are available or large print or on whatever device not a problem. But, do I have the skills to manage the kid with learning disability who gets overloaded because of noise or whatever and hits the kid sitting beside him? I don't. That's where the theory goes out the window. That's not what I'm in teaching to do.'

What appears to reveal itself here is twofold. First, there is indication of a hierarchizing of impairment. Within this, the teacher position is dominant, suggesting that teacher attitudes towards difference, if negative, can represent a significant barrier to the success of inclusionary practice. In this instance, the reference to '*what I'm in teaching to do*' juxtaposes with the image of '*parents of non-disabled kids complaining*' hinting at, perhaps, an un-reflected upon bias which presents teaching not as a part of a dynamic interplay of diverse social relationships within a school community but more as a pragmatic, contractual exchange structured along very traditional lines. Second, is the implication that children with impairments are, in the main, the problem unless they conform to some implied educative norm. Enfolded in this is a subjective, socially mediated labelling which identifies a problem – say, inadequate resources or disruptive behaviours – and situates that problem within the disabled child (or, indeed, the child's parents) rather than within the wider system.

By way of contrast, the second teacher represents a different perspective, drawing attention to issues of structural design as central to resolving the inclusion dilemma:

'*The two-systems approach doesn't work, I think. There are millions poured into special schools, smaller class sizes, special equipment, therapists on tap. So, yeah I'd close them and redirect all their resources and expertise into mainstream ed. It would be tough for a while but do the right planning and it would be better in the long-run, you know? As long as special schools exist there's the opt-out for mainstream school[s] to do inclusion properly*.'

5.4 Restricted imaginations

Almost all the parents who have their children in mainstream provision complain about a lack of resources, both material and in terms of what one participant calls '*restricted imaginations*.' Resource deficits are referenced across a range of issues, including delays in necessary grants for specialist equipment, the provision of accessible toilets, appropriate environment arrangements and inadequate staffing, including the availability of SNAs. All of the resource issues fall within the remit of the Department of Education. This, working through the NCSE, includes SNA allocation, although any complaints concerning allocation (more precisely, *non*-allocation) must first be directed to the individual school Principal and the school's board of management. [34] This is not a straightforward or responsive process as one parent explains, concerning her son who is in an autism spectrum disorder (ASD) class in a mainstream school:

'*there's six children in the class, one teacher, two SNAs. They've applied for an SNA every year and basically it doesn't go by need, it goes by the size of the class. So, they have sent report after report, he [my son] needs care needs, he needs someone with him all the time, he needs someone in the yard and, basically, he's hogging one when the others have one* [SNA] *between five*.'

This mother goes on to explain that the school now want '*to see the back of*' her son and that in an attempt to forestall this she has had to get a report from the National Education Psychology Service (NEPS) – also a service of the Department of Education – to bolster the case for additional SNA provision. However, notwithstanding a very salutary report, the only additional provision has been an extra SNA in the ASD class for two hours a day. The mother adds:

'*basically, it's a tick-box exercise. There's an ASD class, it doesn't matter about the need, they're not going by need, they're going by six children, one teacher, two SNAs, it doesn't matter about the needs of the child, of the children. Basically, it's one teacher, two SNAs, you aren't getting any more and they applied and applied and they just kept getting refused by the Department of Education. So, even though* [my son] *clearly needs one to one it doesn't really matter*.'

This mother now feels that there is little practical option for her son other than moving him to a special school. This is a move she does not want to make but she feels that from soon after her son commenced in the school it has been tacitly promoted by the school Principal and, indeed, the ASD class teacher. The mother continues:

'*basically, when I was collecting him every day the teacher comes in and it's nothing but giving out. He's done this, he's done that. He's shouting , he's disturbing the other students, he's wet himself four times*.'

The pressure to move this mother's son out continues in intensity until a formal meeting is called with the SENO. At this meeting the SENO stands by the child's right to remain in a school which has accepted him and enrolled him, insisting that the onus is on the school to adapt to the child's

---

[34] NCSE Special Needs Assistants (SNA) Scheme: Information for Parents/Guardians of Children with Special Education Needs at https://ncse.ie

needs. However, the mother reports that even with this support she sees no future for her child in the school, saying '*they* [the Principal and the class teacher] *will get their way, keep the pressure on, keep the resources low, we've mostly cracked already*.'

This links to the reference to 'restricted imaginations.' This too is explained as a resource issue but of the non-material kind, encompassing teacher-training, school policies and procedures - in particular, perhaps, codes of behaviour – and a lack of innovative practice. The parent who used the phrase explains:

'*Ah, what isn't it about really. Like, my child often gets a 'bad behaviour' label or a 'doesn't join in' label. But it's not those things, its emotional regulation, not deliberate. Teachers see bad behaviour because that's what they're trained to see, very limiting. Why aren't teachers better trained around disabilities? Why is it about my son fitting in and not about the school changing? If he can't sit there for the forty minutes without acting out that's not him disrupting the school. That's more like the school disrupting him*.'

Another parent participant makes a related contribution:

'*If we are ok with special schools then why do we have special classes in mainstream schools? I think that's just plain wrong. It's kind of cheating to me. I mean if inclusion means being in the mainstream school I think it's undermining to say but you and you and you go down the corridor to the special class. That's just being in the building, not being in the school*.'

All this goes to a wider sense among many of the participants – across all three cohorts – that when it comes to resource allocation there is '*lip service to everybody being equal*' but that '*really there are different kinds of equality*.' A view on this fall thus:

'*so when maybe the school wants to impress an inspector or get some extra funding for specialist equipment then my child is very equal. But then when nearly everyone in his class is in the school play he isn't included or when they are all going to support the school team he's back at base with the SNA*.'

5.5 The special school

By contrast, the parent participants interviewed who have children in the special school provision are, in the main, more homogenous in their experiences, generally reporting arrangements better calibrated to meet the needs of their children. Described among these are smaller classes, specially trained teachers, better equipment and what are deemed to be more appropriate educational environments. However, it would be an error to presume that the special school provision is not without its own organisational challenges. So, although the special school system is widespread across Ireland, parent participants who have opted for it reference a shortage of places within it and experiences of delay and disappointment:

'*I personally wasn't guaranteed a place. He – my son – has a constitutional entitlement to an education until he's eighteen but yet I still had to wait until he got a place instead of a place waiting for him. Like, he has lived through two census and I have made his needs clear in both. So they know where we live, they know his needs, they know he's coming. They know when. What's the point of the census? Something else that isn't for disabled people*.'

Thinking about special schools from the perspective of the vision impaired research cohort all but two of the participants in this cohort had had experience of special school, with a significant number having had experience of both special and mainstream education.[35] Their experience of attending special school was invariably as a boarder. Most of the participants commented favourably on the special school education they received but few were happy to have had to live away from their families. There was, however, a certain stoic sense in which several participants – particularly older participants – accepted that no other viable education alternative existed. However, almost all felt that the knock-on effects in terms of family were considerable. As one put it:

'*All my life I would have resented going to a special school. But, I don't blame my parents. The words that were used were they were told 'oh you've got to put him away.' I would have spent a lot of my life trying to regain my family.'*

Another says:

'*if I had not gone there I think life would have been different, probably in a more negative sense. I probably would have wound up like my brothers and sisters being put out to work at the age of fourteen in order to contribute to the meagre income of a family of eight kids. You know, it's a strange quirk or challenge of fate that actually put me on the inside. Without being blind I wouldn't have got the life chances I got. I was miserable in the school but I'm sure I would have been more miserable at home.'*

Another participant feels strongly that effectively being '*forced to move to Dublin for school*' was a form of discrimination, '*maybe the first of many.*' He continues:

---

[35] the circumstances which enabled this were peculiar to boys who attended a Dublin boarding school for vision impaired boys, wherein the primary element was part of the special school provision but the secondary element was provided within a local community school, a circumstance which pertained from the late 1970s; secondary provision for girls remained within the special school provision until the girls' school closed in the mid-1990s

‘*when I did get to school at home for the year I repeated the Leaving, it was great. I wasn’t the blind guy. I was my father’s son, my granda’s grandson. There was teachers there who taught both of them*.’

One participant poignantly sums up the isolation going to a special school caused him. Referring to summer holidays at home he simply notes ‘*I didn’t have friends. I had nieces and nephews*.’

Several of the vision impaired participants allude to friendships made in the special school setting, indicating, in some contributions, that these friendships still endure and remain very important to them. However, one participant describes having no ‘*real friends*’ outside a small vision impaired group. Questioned as to whether the vision impaired people were not real friends the reply came:

‘*Well, they’re not unreal obviously and don’t get me wrong I’m glad to have them. It’s just, well, I, maybe most people’s friends come from different parts of their lives, like college and work and where you live. It’s hard to make those kinds of friends, like a cross-section, if you’re blind and you grew up more or less separate from your home place your friends are the friends you had to make because you were all in a boarding school for the blind*.’

Another vision impaired participant offers:

‘I suppose in a way because I was in the system I had to leave home for a special school and I kind of moved away from my family and a sense of community and that was the beginning of an alienation from family. When you arrived home for the holiday you were the oracle come to pass judgement on ‘do you think your sister should go out dressed like that [name]*, what do you think?’ So you grew apart within the family*.’

6 Institutionalisation

As a vision impaired man contributes: ‘*I was away from them* [my family] *from such a young age I came to think I didn’t really belong there. That shocks me now. It is institutionalisation. The State institutionalised us and everyone thought that was fine*. *It wasn’t*.’

Another snapshot into institutionalisation comes in the form of a vision impaired participant describing a night spent in a rural mental hospital because he and four peers from the same general locality were put on a train a day sooner than they should have been for a school holiday. Arriving at their local train station and discovering no parents on the platform to meet them the group are taken into the protection of the local Garda who promptly delivers them to the hospital for the night, returning them to the platform the next morning. ‘*I don’t think at the time* *anyone of us realised how weird a thing was happening to us. They can't see, bring them to the mental hospital, it's all the same*,' he says.

Institutionalisation is an important theme for many of the vision impaired participants in this study, not least in terms of the sense that experiences at a young age (childhood and adolescence) has had life-long – and, in some instances, adverse – consequences. In this regard, some older participants talk of a concentration on a social training designed to '*get us to fit in with sighted people*' and, from a different participant, '*to try and make us not stick out*.' Variously described as training around such things as table etiquette and folding and hanging clothes and personal grooming '*the main thing was don't draw attention to yourself, don't look odd or people will avoid you or be bad to you, smile.'* As another participant has it: *'don't frighten children or the horses*. *Be clean and presentable. Don't chew with your mouth open*.' Again, older participants describe how aspects of daily living skills that they could or should have learned like cooking were unavailable, partly because of a perceived safety risk and partly because in the institution's architecture there was literally nowhere such a skill could be taught:

'*it promoted a learned helplessness though, for sure, a dependency on others to do something for me that I should have learned for myself*.'

Both older and younger vision impaired participants talk about difficulties reading social cues and, in some cases, how this has diminished their capacity for social participation and, in one case, is associated with what is described as '*life-long social phobia*.' Another participant speaks of '*social anxiety,*' making a link between this and an inability to secure paid employment:

'*I think in my own head it comes from being too solitary as a child and being left to it. I'm not saying the [special] school wasn't good, just it wasn't good for me. I feel very self-conscious outside the blind world, worried about how I look, what people will think*.'

7 Work and Employment

Within this section the presented data represents a mix between research participants' conception of work in terms of external forces productive of discrimination and oppression and as a discrete, individualised and internalised activity where a (notional) disabled person has to be careful how she publically constructs herself. In this latter context work's importance as a signifier of personal status and as a protection against social exclusion are clear sub-texts within the data. Interestingly, however, work's other public dimension, as it were, expressed in the debate as to its – successful or not – function as a protection against poverty does not arise in the instant data at all, other than in an occasional oblique reference. This may possibly be accounted for in terms of the reality that among the vision impaired research cohort there is a higher than the norm representation of disabled people in employment and, moreover, many of the jobs being done are in spheres of work that are reasonably well remunerated.

7.1 Cost

The responses around work divide into three broad categories. In the main, professionals are concerned that employers appear unwilling to make '*the necessary mind-set change*' to make employment opportunities more readily available to persons with disabilities either because they '*don't want to take a risk on the disabled*' or '*they are afraid it will cost them*.' Those parents of children with particularly complex needs – the majority of those who participated in this research - see employment as a marginal concern, talking instead about wanting to focus on quality of life issues, including social engagement and friendships. Vision impaired participants, however, have very diverse views and it is these contributions that I concentrate on here.

As one participant from this cohort puts it:

'*Work is everything to me. I love having a job, doing something I think is useful and worthwhile. I couldn't imagine not having a job. I'm very lucky*.'

Another says:

'*for me work is about self-respect, it's about financial independence, about being able to have a flat of my own and a life I can live the way I want to. Work makes you feel productive, that you are doing something of value. If you weren't working it would be very easy to fall through the cracks. I know lots of blind people who've never worked. Falling through the cracks is so easy to happen*.'

However, as another participant says

'I have worked my whole life but I have never once had a job that paid me. I do a lot of volunteering and I feel great about it but it would be nice to think I could earn money for it.'

Asked to consider what the main barriers against disabled people in the workplace are, participants discussed discrimination and prejudice as being at the root of the employability problem for disabled people.

7.2 Hiding disability

Mirroring a number of themes already mentioned, including being very careful to '*minimise the vision impairment*' or even to elide it, one participant spoke about how he has worked for years in quite public roles – all of them in the hospitality sector – and none of his colleagues, to his knowledge, have ever found out he has a visual impairment. Given that his is a vision impairment that requires the use of a long cane at night time makes it a matter of some pride to him that he has managed to do his job without his vision impairment either impeding him or impeding his colleagues sense of him:

'Why bring problems into your life? I'm seen for who I am in work and what I can do. Day one, after someone finds out I am a cane user, guarantee you suddenly I am not as good at my job'.

Work has become an area of particular interest to republican theorists.[36] The capacity for work places to be sites of domination is very clear given the asymmetries of power which inevitably exist in these settings. What seems apparent from the participants in this research is that, where possible, they prefer not to rely on their disability as something meriting special consideration, even though there is an acceptance there that such consideration might add both to their work satisfaction and their productivity. However, the fear of prejudice and the concern that they will find themselves judged as *less* mitigates against a more open relationship with colleagues and bosses. In a sense, republicans might see this as a form of inverse game playing or self-censorship, the purpose of which is to manipulate their work situation to their benefit even though this putative benefit may actually, over time, become a significant disadvantage, particularly if the nature of the impairment worsens. As one vision impaired participant elaborates:

'*I did myself no favours, I know that now, but as my sight deteriorated, I held off and held off on making the stupidest little change really. I use Zoom text which is a magnifier but with a built-in voice reader and, at home, when the sight got worse I was using the voice reader all the time, especially for long documents – plug in headphones and off you go. But, in work I was struggling away with the magnifier and it was getting harder and harder. I just couldn't bring myself to stand out any more than I already did from the others in the office. I made things really hard for myself but at the time felt I already was different enough*.'

Of a similar disposition, one blind participant talks of how, now in his forties, he has, only recently, commenced using a cane. Explaining that he has evolved strategies at work for representing himself as a person with much better vision than he actually has he feels he couldn't '*take the risk*' of a colleague seeing him carrying '*the blind man's stick*' even though he thinks of himself as '*the most blindest person in the world*.' Notwithstanding this, he continues:

---

[36] see, for instance, Keith Breen 'Non-domination, Workplace Republicanism and the Justification of Worker Voice and Control' (2017) 33 (3) Journal of Comparative Labour Law and Inclusive Relations 419

‘*not using the cane was kind of a badge of honour but a silly one. But one day I just had to cop myself on. The reason I started using it wasn’t for myself, it was for other people. I was walking to work one day without the cane and I bumped into a lady. Didn’t knock her over or anything but I startled her. I’m a big man. And I thought to myself, come’ere, if you’d knocked her over that could have been serious*.’

As to whether this introduction of the cane changed anything in work:

‘*a bit yeah, for sure. Some said, ‘wow never would have known,’ ‘fair play like’ and ‘you must have a kind of a superpower.’ But, with others I started to notice a kind of a negative shift. One guy straight up said to me ‘what else are you hiding?’ like it was an accusation or something. It was like you aren’t who we thought you were. Maybe they were thinking I’d been taking the proverbial out of them. I don’t know but definitely with some a shift. Not everyone but a few, for sure*.’

7.3 Discrimination

A number of the vision impaired participants describe instances where they feel that their impairment has been at the root of unfair treatment. Thus, one participant describes an internal advertisement seeking to recruit an office manager in the local authority where he already worked. Having applied for the job the participant received an email from recruitment saying he had been disqualified from the competition because he did not hold a clean driving license.

‘*The job spec stated a driving licence may be required from time to time for this post. So, I queried it with HR and asking what was the story, why was I disqualified on these grounds when I could not ascertain a driving licence? And they came back and said I should have read the job spec, I didn’t have a clean driving licence so the job wasn’t for me. So I asked about the Equality Act and was reasonable accommodation considered? But the recruitment officer missed the point again and did mention in the first line of the email that* [name of Council] *encouraged disabled people to apply for jobs there but totally disregarded the question about reasonable accommodation*.

The post was based in a city centre location and had excellent public transport links. The participant made this point in a follow up email, listing all of the transport options available, including utilising the Council’s contract with a taxi firm and reminding the recruitment officer that the job spec referred to only occasional driving being required. The participant requested a meeting but no reply was forthcoming: ‘*nada, not even a one liner*. *A real just go-away silence*.’ In a subsequent email the participant requested a copy of the Council’s disability policy. This ‘*has never been furnished*. *And this is a government agency.*’

This participant goes on to talk of the driving requirement a little more, suggesting how a '*very fixable, maybe even minor requirement of the job became the whole job*' and indicating his belief that what he experienced was discrimination. Asked, however, if he had considered some legal challenge the answer is phrased in the following terms:

'*I don't feel I had that option, well the freedom to do that. Not if I do want to advance someday*. *Plus, I don't want to be cast as the bitter blind guy*.'

The second story of employment discriminations refers to the university sector. This vision impaired participant also discusses going for promotion and, in gathering the necessary details together for submission, he realises that the format of the university forms required in this process are '*completely inaccessible*.' The participant asks her Head of School to indicate to the University management structure that she is withdrawing from the process due to this inaccessibility issue. There then ensues

'*a frantic scramble. They didn't want that. There were – by all accounts – there were off the record comments that I got from various people that 'they were terrified.' Now, what's really interesting is that I had an off the record comment from somebody who would certainly know, what's the current phrase, 'sources close to' – isn't that the current journalistic phrase? - and a very senior member of* [the University's] *management said, and I quote, 'well, can someone not do it for him?*'

The participant then recalls that the form was given to another blind person working on the staff to make it accessible '*which they did their very best and tried*' but there was too much work to undertake - inclusive of all the surrounding supporting documentation such as job spec, eligibility criteria, rules '*and everything else*.' In being '*rejected for promotion that year*' the participant becomes barred from applying for promotion the following year. However, two years on, when the participant applies again:

'*exactly the same materials, they had never updated, never fixed the materials so exactly the same process has to happen again. Except this time, they give the blind person designated to fix the form, the wrong form. So at this point, I send in an appeal claiming discrimination citing equity, diversity and inclusion and everything else. Interestingly, the very senior management don't engage with the complaint, they just say we are going to fix the form. No apology, nothing like that*.'

Eventually, an accessible format is available and '*a minimal extension is offered to get the application in*.' But by the participant's lights he had been delayed by about a month but only a week's extension is given:

'*I was again rejected. And, what was totally horrific is that the rejection letter is in a totally inaccessible format. My wife had to read it to me which upset her terribly. So I appealed it but the two people appointed to hear the appeal were the two people who had designed the process and who were most involved in putting the barriers in place. So, to be honest with you for the sake of my mental health I withdrew the appeal because I knew it wasn't going to go anywhere*.'

As to whether the participant considered challenging the legitimacy of having two people intimately involved in the original decision hearing his appeal the answer was '*I knew where this person was going in the hierarchy so that would have been career suicide*.'

Describing the whole experience as '*cynical and designed to use my disability against me*' the participant reports realising that the academic career he had given twenty years to – in the same university – was something he had '*to walk away from*.' Describing the letter as '*the last straw*' the participant volunteers

'*the subtext of the letter is, we know you, we know you are blind, we know you've reminded us you need accommodation but we are sending you this letter that we know someone else will have to read aloud to you to let you know that we actually don't care. Get the message*. *I got the message*.'

As a coda to this story the participant – now working outside academia – reports recently asking a friend from the University to share with him the promotions form and materials now in use:

'*guess what? Same form, same inaccessible form, same inaccessible job spec, rules, the lot. That's not accidental all these years later. It's a deliberate message to people like me, know your place, don't think the plumb jobs are for you*, *managing the rest of us*.'

Among the vision impaired participants in employment – and statistically this research cohort defy the national averages in this regard – there was a more or less even divide between those working in public sector and private sector employment. However, in itself this is interesting in that the *Comprehensive Employment Strategy for People with Disabilities 2015-2024*[37] seeks to increase the current statutory employment target of disabled persons in the public sector from

---

[37] Government of Ireland *Comprehensive Employment Strategy for People with Disabilities 2015-2024*

3% to 6%.[38] However, as one professional who has had experience working as a job coach puts it

'*since disabled people are around twice as likely to be unemployed as the non - disabled this represents a modest ambition and, in any event, across the public sector it's not looking great. There's very uneven spread across departments and councils and not much joined-up thinking with some parts of the system doing reasonably okay and others really badly*.'

Nonetheless, a number of vision impaired participants recognise that the public sector commitment has both symbolic and practical value, although as one vision impaired participant suggests '*the big test has to be visibility*' by which is intended

'*who do you see at counters and at public meetings and engaging with the public as traffic wardens and librarians and court clerks and when you go collect a passport? Great that disabled people have jobs in the public service but not great if they are in places no one gets to meet them. That's the bit that misses something important*.'

As for why public sector jobs may be attractive to disabled people the following is ventured:

'*if you do have a disability and you can work and want to work you tend to go for the safer options, what you term to be the safer job, protected, government departments, state entities, places that have to have disability recruitment quotas. Not so much private companies, maybe, but places you think you have a fairer shot*.'

Another participant makes a similar contribution, however describing a certain type of inertia:

'*the statistics on people with disabilities that get a job in a state set-up, say, they're frightening, the number who just stay in that job, who never move up, never think they can, even though they have the skills*.'

7.4 Reasonable accommodation

Linked clearly to promotion but, above all, central in many instances to getting and retaining a job in the first place, reasonable accommodation is mentioned by several cohort three participants as a concept which seems to frighten employers and so may have to be broached – if at all – tentatively. As one participant phrases it

---

[38] this 3% target is set out in S47 of the *Disability Act 2005*

‘if they think I am going to be a burden on them anyway and on top of it that I am going to cost them money, why would they give me a job?’

For another, when to broach reasonable accommodation is something of a strategic decision. She advises:

‘*I’d say, be wary, start small. If there are adaptations and equipment you absolutely have to have or adjustable working arrangements for God’s sake don’t go in shouting about your rights and the law and the Convention and what have you but think what’s the very least I can get by on for now. Get your feet under the table. Show your value. Prove yourself. Then, in my experience what you need is easier to get. I know not everyone would agree but I think you have to play the game, the long game even.*’

However, ‘playing the game’ may not necessarily work to everyone’s advantage. A male vision impaired participant describes being at a workplace meeting where the topic of discussion is gender equality and what needs to be done in the workplace to ensure gender equality. Following one

‘*long contribution from a very senior male colleague arguing passionately why the problem of gender inequality could not be tolerated I, as a disabled man, said I totally, completely agree, that’s brilliant, absolutely support everything you’re saying. But, I said, what about broadening it out so that instead of us addressing it just as gender equality we broaden it out to cover equality for people with disabilities too. And he said, honest to God, ‘well, there’s more women.*’

For this participant, the notion that there is a view within workplaces that reasonable accommodation is *unreasonable* is encapsulated in this quote. The participant subjected to this reply reports feeling ‘*dismissed, disrespected, mocked*.’ He continues:

‘*I wasn’t talking down women. I was just trying to open up the discussion. But at the end of the day if one of the big bosses is so strong about injustice against women and at the same time showing prejudiced towards disabled people – and, you know, maybe, worldwide the majority of disabled people are actually women – well there’s not a lot of hope for him, or bosses like him, that they are going to see me and people like me as worth accommodating*.’

Other participants describe avoiding asking for accommodations such as flexible working arrangements, or of bringing in their own personal equipment to work rather than asking their employer to fund what they need. One talks of a manager clearly telling him in front of other employees ‘*why would you think you need all this extra stuff when everyone else in this office doesn’t*’ referring to an electronic screen reader, while yet another described being told not to use his hand-held magnifier in meetings with clients because '*it makes us all look amateurish*.' The former academic describes his former University employer as technologically advanced in terms of the equipment available to seeing colleagues, yet

'*so many of the systems in there were actually inaccessible to me in there, whether it was the finance system, the research uploads, all these sorts of systems, So, what would take me an hour to do, my sighted colleague would do in ten minutes, which left them fifty minutes to prepare a lecture which in turn left them an additional fifty minutes to work on their grant or write their paper or everything else. So, the whole structure, this whole technological infrastructure was geared around ableism and there was no way – and I asked and asked – that I was going to get the smallest tweak to help me operate in those same sorts of timeframes*.'

All this said, a number of participants tell positive stories about accommodation, talking about a sympathy towards individual needs, as expressed in simply ways like ensuring clear pathways around the office environment or extra time to complete tasks or generous time off for medical appointments. As one participant says

'*I've been very lucky. The bosses I've had have been good to me. But they are good to everyone else too. They are just good bosses. But it also means it can never be a patronising thing*.'

Another offers:

'*I really feel valued in my job and appreciated as a colleague. Once or twice I encountered people who are maybe awkward or maybe conflicted about working with a person with disabilities but I think that is really about under-exposure to disability rather than prejudice. That's why we need more people with disability in the workforce*.'

A third says:

'*I had one eejit of a manager in [a telecommunications company] who saw me working with my face very close to the screen and he said I should get new glasses. So I went into his office, told him I have dodgy eyes and he nearly died. Couldn't do enough for me after that. Honestly, that's as bad As I've ever had it. The delivery side of the telecommunications industry is full –on, very intense, solutions focused. If you can't cut it that's obvious very quickly. So, once you show you can do the job that's all that matters to your team or the boss*.'

7.5 Unemployment

The final word in this section I leave to a blind man who has thought deeply about what lies at the root of why vision impaired people – and, by extension all people with disabilities - fare so badly in the employment market:

There are lots of ways of looking at this, the universal basic income for visually impaired people, as employed in Norway for example, where people get the average industrial wage just for the fact that they are human, this whole thing about being a productive member of society, we all know that the wage structure isn't necessarily based on that. In Norway for instance you get paid your average industrial wage, just for being blind, but extra costs on being blind. There's no pressure on you because it is realised that there is an institutionalised discrimination in terms of employment. I am not saying that that is good enough, its saying that if you want to do a certain job you have the right to be able to do that, just like anybody else. But its recognising that that institutionalised discrimination is there and that people don't end up beating themselves up. Because they internalise these failures, because we know that society puts so much store in employment and being in the workplace….. Unemployment doesn't go much below 75% in any country in the world for blind people. Its holding out this false expectation. The NCBI [National Council for the Blind] *can say we have these training programmes – they get money for it but it holds out this expectation and again the message is we can train and reshape the individual, but the individual is the problem, which again is the medical model. Society isn't the issue. And the message is if you're not part of that you're a failure.'*

8 Independent living/social inclusion

Particularly enfolded in so many of the stories parent participants and vision impaired participants share in this area of the data is a strong sense of being outsiders, even among some of those latter who are in employment and live independently in the community. This connects to the idea that inclusion – while admittedly an idea of some conceptual imprecision – relates fundamentally to a form of social life, specifically, embodied in the idea of living

> among respecting, loving and valuing others who, by having such attitudes, enable and support [disabled people] in leading their lives as fully as they can as persons among other persons. [39]

---

[39] Heikki Ikaheimo Personhood and the Social Inclusion of Persons with Disabilities: A Recognition-Theoretical Approach. In Kristjana Kristansen Simo Vehmas Tom Shakespeare (eds) *Arguing About Disability: Philosophical Perspectives* (Routledge, 2009) 88

In this context, it becomes clear that physically being in the community is not the same as being included in the community. Rather, inclusion is a function of *recognition*, what Taylor calls 'a vital human need.'[40] This understanding of inclusion is both broad and deep, referencing recreational, economic and political participation as well as concepts such as love and friendship, embracing different strata such as clubs and associations, workplace connections and sexual identities as well as communities – small and large – and, ultimately, society itself.

Hence, in a world suffused with crosscutting, multi-layered recognitions, its lack can inflict 'a grievous wound.'[41] Such wounds – and the resistance to (or inoculation against) their infliction – have already been evinced in much of the data encountered thus far. Here, in bringing this chapter to its end, I employ an ordering proposed by the critical theorist Axel Honneth. Honneth posits recognition as subsisting in three inter-connected, inter-dependent realms: the private sphere of family and friendships, the legal sphere of rights and liberties and the solidarity sphere, wherein the individual's participation in the community through, say, work or education or volunteering or political activity helps build up a sense of communal belonging and togetherness.[42] Hence, in this paradigm (suggesting resonances with republicanism)

> the social meaning of inclusion depends on a sense of belonging on the side of the individual and a form of acknowledgement on the other side, whether it be other individuals, communities, or institutions.[43]

Within his schema Honneth talks about love (or care) recognition, respect (or rights) recognition) and esteem (or merit) recognition, contending that, ideally, people gain and increase self-confidence in the affective sphere, self-respect in the legal sphere and self-esteem in the recognition provided through truly belonging in a community or communities. Scaling this to the instant research, I offer the following headings as entirely appropriate means of capturing a sense of the experiences of research participants as they relate to living independently and experiencing social inclusion.

9 Love, loneliness, grief and resentment

Deep intimations of love suffuse this data, particularly the love of parents for their children. However, it is love shot through with anxiety and fear and a sense of grieving for both the

---

[40] Charles Taylor The Politics of Recognition. In Amy Gutmann (ed) *Multiculuralism: Examining the Politics of Recognition* (Princeton University Press, 1994) 26

[41] *ibid*

[42] Alex Honneth *The Struggle for Recognition: The Moral Grammar of Social Conflicts* (Polity Press, 1996)

[43] Franziska Felder Inclusion and the Good Human Life. In Jerome E Bickenback Franziska Felder Barbara Schmitz (eds.) *Disability and the Good Human Life* (Cambridge University Press, 2014) 306

present and the future; an invocation of Taylor's grievous wound, sometimes expressed as loneliness and sometimes as guilt.

In particular, from parent participants this guilt comes across as a strong sense of *failing*, of not being good enough. Parents report their inability to rebuff intrusions into their private sphere that undermine their confidence and their sense of being respected as parents. They describe feeling disbelieved, mistrusted and report too feeling forced to either defend their accounts of need or to have to exaggerate and misrepresent their child's abilities or requirements in order to secure, for instance, as previously mentioned, a school place or even an adequate supply of specialist nappies:

'[other] *people wouldn't believe the hoops you have to jump through, the constant struggle just to be taken seriously, to be treated with a small bit of humanity.*'

With specific reference to the human rights enumerated in the CRPD:

'*They don't exist here. You're forgotten. If you have someone with a disability you know, you get certain amounts of it. You get a certain little amount, a certain little bit of it and, as I say, you really see so much box ticking exercises. You see so much, okay we'll tick that box and then you're forgotten. Ask for more and you are made feel like you are an annoyance*.'

As to precise expressions of the felt sorrow of grieving and guilt, these are captured in the following three quotes, all from mothers:

'*when he* [our son] *was born and we knew how complex his lifelong needs were going to be there was just blackness. Myself and my husband had this epiphany that his whole life was going to be black and we grieved for a long time that his life was going to be just harder, so much harder. He was going to have to work harder, learn very differently, not at all live the life he should have had. And it felt like that – should have had – that he was robbed of something and that we were robbed of something too and then you feel guilty for thinking of yourselves or thinking less of him*. There's enough people doing that, outside his family. But, absolutely no doubt *it effected our* [marital] *relationship. I had a really good job but I couldn't keep it on and then I became resentful of my husband getting to go out and do his job*. *We were a long time fixing this, if you can every fully fix something like this*.'

'when you have to fight for her rights all the time and you're not getting very far you can feel it's your fault, that you don't know how to get more from the system, that you don't have the right connections or the right words or you have somehow let her [my daughter] *down*.'

‘*I love him* [my son]*, I love him. But I’m a single parent and as he gets older I am afraid of him, not of him but his behaviours. They can be very extreme. He can’t help it. And I feel so depressed and guilty sometimes. I say this sometimes to my doctor, to the* [day service] *staff but they can’t help. Like they sympathise but that just makes it worse. Sympathy isn’t help*. *Then I feel guilty for telling the, like I’m making it all about me, and not* [my son].’

10 Respect, brave faces and family resources

The concept of respect, of feeling one belongs and is of social and personal importance or value sits intuitively at the heart of an array of moral relationships, including with sometimes intangible things. Hence, we talk of respecting human rights, of respecting the dead, the flag, the opinions of the courts. However, the recognition of another living human being as worthy of respect is, in a sense, to see some other as having authority over themselves as one sees oneself as having authority over oneself. An other in this position is someone who is socially included. By these same lights, someone not in this position must be someone who is socially excluded. Thus, the issue of respect figures prominently in the data, beginning with the idea that central to respect is that someone be *seen*.

Referencing ‘*the relative invisibility complex*’ impairment needs engenders in the wider public consciousness, a parent participant suggests:

‘*if you can’t put on the brave face, if either you couldn’t be bothered or just you aren’t able then people don’t know how to be with you. Like my daughter is grown now and she’s had experiences of sitting on packed public transport but nobody sits beside her. She brought this up with a counsellor once and the counsellor said she needs to smile more, put people at their ease and reassure them she’s okay. I think that’s just disgusting. It’s not her problem. It’s people just acting like she’s not there because I suppose really they’d like if she wasn’t there*.’

A member of the vision impaired cohort says

‘*if I introduce myself as a visually impaired person I usually get a comfortable response, people can relate to that a bit more. I get responses that are like ‘oh, I see’ and like ‘if you need a hand just let me know’ or ‘my eyes aren’t the best either’ kind of thing. But, if I introduce myself as a disabled person – which, of course, because of my vision, I am – that doesn’t get the same reaction. It’s almost like they’d prefer not to know*. *There’s no comfortable response easily to hand. But the daft thing is when I say visually impaired they seem to think I’m not disabled*.’

A participant from the staff cohort describes occasions when she has being out and about in the company of disabled people she has been working with and random people have stopped to say such things as ‘I couldn’t do your work’ or ‘aren’t you great to help them’ and, once, ‘you’d have to wonder is there really a God when you see people like them:’

‘*and this is always with the service-user there, listening, who are just ignored and disrespected and not spoken to as people*. *Being a social care worker is my job. It’s not a vocation or a special calling. I get paid to do it. So I said to this old man who rocked up once saying all this things that I get paid to work with people with disabilities and he said ‘not enough, not enough’ and tried to give me a tenner. I was really offended more for the service user than myself but afterwards, the service user said we should have split it*.’

Again and again, the disrespect and the indignity parents and persons with disabilities experience surfaces in the data, as has been apparent already. The impression is of a state apparatus that is often indifferent to the needs of disabled people – children and adults alike – and whose officials do not meet what McMahan calls ‘the threshold of respect.’[44] This indifference embraces parents too, subjecting at least some to feeling not dissimilar to what Goffman describes as experiencing curtesy or associative stigma.[45]

All of the parents interviewed see themselves as their children’s advocates, often, however, in circumstances where officials, representing one aspect of the state or another, appear to be ranged against them. Hence, parent participants describe getting little practical help of the type they need as opposed to the type of help the system seems geared up to offer. Hence, when parents report most needing help no help seems to be available. As one parent participant phrases it: ‘*our weekends are harder, the* [school] *holidays are harder*’ precisely because the limited help available is packaged around the *school* day, rather than the disabled child’s day.

There is expressed shame too in circumstances where parents have to ‘*impose on sisters, parents, neighbours, just to get the shopping in*.’ In terms of parents availing of wider family-based supports, parent participants report having to be very careful not to place too much reliance on this, especially where children’s presentations and/or behaviours can be quite disturbing, say, perhaps, for older grandparents. Yet parents report officials regularly advising that parents should look ‘*to your own family resources*’ before ‘*tapping the scarce resources*’ of the state. However, as one parent participant puts it such reliance – even if possible – jeopardizes relationships already often strained by the presence of a disabled child in the wider family:

---

[44] Jeff McMahan *The Ethics of Killing* (Oxford University Press, 2002) 246; McMahan is not a friend to the direction this dissertation seeks to chart

[45] Erving Goffman *Stigma* (Penguin, 1990)

‘*my mum loves seeing her other grandchildren visiting. Don’t get me wrong. She loves* [my son] *too. But he upsets her, I know that. He doesn’t play like the others, he can get very agitated, throw things. She’s so sad for him and that makes her sad for me*. *I can’t explain it and I know it’s stupid but sometimes it makes me feel I have let her down by having a disabled child*.’

Another parent participant describes the emotional distress of only seeing her geographically distant, elderly, ill mother perhaps three times a year and then only for very tightly scheduled hour long visits, such are the restrictions placed on her by the inability to find anyone reliable enough and experienced enough to care for her intellectually impaired and autistic child while she is away. Thus, this mother reports these visits full of emotionality and recrimination, her mother not understanding why her only daughter’s visits are so few and so fleeting, the participant full of sadness and distress to see her mother so upset but also agitated and anxious to be separated from her usually quite emotionally volatile child: ‘*I feel I’m not doing right by anyone, letting everyone down, feeling tearful and sick all the way down and worse all the way back*.’

Another mother describes the fear that if she and her husband cannot persuade the HSE to provide adequate home and respite supports, then they will have no viable choice other than to commence proceedings to place their ten year old child in the formal care of the state. The mother says ‘*we are broken, broken*’ and are ‘*literally begging the HSE to save us as a family*.’ Thus far, this mother reports that the HSE response is that ‘*you are getting more than anyone else*’ – this *more* being a recently provided respite package in a private care facility for their son consisting of one overnight a week every six to eight weeks. This mother continues

‘*can you imagine how that makes us feel? Begging for help and being treated like we are greedy bastards. One overnight – one, not a weekend, not two nights in a row – works out as maybe six, maximum eight respite nights a year. There’s just us, no other family. Me,* [partner] *and* [son]. *Two, maybe three consecutive hours sleep a night, every night. If that’s all [son] gets that’s all we get. We can’t cope much longer…. We’re on the very edge and the people who can help tells us how well they are doing by us and how grateful we should be*.’

Amid the love – and, again, parent participants (and, indeed, some of the staff cohort) reference love a lot – and amid the loneliness and guilt there is the sense of a cold reality of nothing gentle from the system, nothing *kind*, nothing *respectful*. Pace one parent: ‘*we are just always fighting, it wears you out*.’ There is the sense of not being listened to, of parents not feeling that they are held in high regard and respected, that their expertise in their own children’s needs is not given an appropriate weight when decisions affecting their children are being made.

An example here linking directly to national policy is found in relation to the decision to remove all therapists – speech and language, physiotherapists and occupational therapists - from special schools. Under this Progressing Disability Services (PDS) programme, the stated intention of the state is to ensure a more equitable and accessible therapy service to children with disabilities from birth to eighteen by ensuring a comprehensive spread of service provision across the country with access based on need and not just diagnosis.[46] In respect of children with less complex needs the programme envisions that these children's needs will be better served by local primary care teams, including by public health nurses and therapists based in primary care centres. However, for children with more complex needs, requiring the input of a team of professionals working together, nationally dispersed Children's Disability Network Teams (CDNTs) have been set up to provide this level of intervention.

On its face, PDS is a good plan. It's avowed intention is to address regional anomalies, to engage with need sooner and more fluently, to utilise resources more effectively and to ensure equity.[47] However, every parent of a young child that I interviewed disagreed with it, their reasons redolent with mistrust of any proposal to reassign therapists from special schools to PDS duties. In the main, this distrust is situated in terms of what a number of parent participants refer to as a lack of consultation. As one puts it:

> '*there was never any consultation with parents of children with additional needs to see what they felt was needed for their children. They don't consider parents' views because they don't value their views.*'

For one therapist participant:

'*PDS is a good idea, but there is no doubt the HSE saw it as an opportunity to ease their recruitment problems in a stroke*.'

Another parent, making a point that she regards the PDS as '*just window dressing*, *pretending to be doing something positive while actually doing the opposite*.' As this participant views it, the PDS model rests on a fallacy that there are enough therapists to properly staff it, such that she views the reallocation of therapists from special schools as significantly adding to their individual caseloads and actually making it less likely that complex needs will get the

---

[46] see HSE Progressing Disability Services for Children and Young People at https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/introduction/

[47] ibid

wraparound service the PDS literature envisages. This she views as '*another example'* of the state not seeing investing in disabled people as worth doing properly, saying:

'I think the government don't invest in children with additional needs because there is no return on them. What will they get back for their investment? Those with more complex or profound needs will need continuous lifelong care at a cost to the government. They will most likely never be in gainful employment where they [the government] *will get their money back through taxes and universal social charges. So why put the money into their care and education*?'

What is reflected here is that just as many of the parents interviewed present as disrespected by the state these parents are utterly cynical of the state's commitment to their children as equal citizens, seeing them instead as '*drains*' on scarce resources. On one level it is important to say that government has recently revoked the plan to remove therapists from special schools. However, since this redeployment has already happened in many cases there is concern that a simple reinstatement of therapy services will be problematic, for instance in circumstances where therapists may have moved to working arrangements which are more personally beneficial. That none of the parents I spoke to appear to be aware of the government u-turn, is in itself, perhaps, evocative of a distrust of the state such that remaining current with their various policy positions does not appear to matter, just, perhaps, as they feel the state has no particular regard for tracking their interests.

11 Someone must die

Within Honneth's schema, this idea of the solidarity sphere is the one, perhaps, which most challenges the stereotypical notion that simply decanting people with disabilities into the community will, *per force*, result in social inclusion. Rather, what is suggested, here again, is that physical presence can never be enough. Indeed, absent the social esteem and self-esteem that flows from having a valued role to play in the community, merely *being there* may, conceivably, do more harm than good.[48] Thus, evoking the solidarity sphere goes beyond simply seeing problems that are easily visible – thought no less intractable for that, it seems – such as the shortage of appropriate housing or the absence of adequate and accessible types of decent work for disabled people to do. Rather, even in societies where there are (whatever this means) acceptable levels of disabled people living in the community '[w]e may indeed find that there is far more misrecognition and far less inclusion, than previously assumed.'[49]

---

[48] see, for instance, Katharine Quarmby *Scapegoat: Why We Are Failing Disabled People* (Portobello, 2011)

[49] Jan MacArthur The Inclusive University: A Critical Theory Perspective Using a Recognition-Based Approach' (2021) 9 (3) Social Inclusion 6, 10

One disabled participant describes what he needs to live independently in his community in terms of it being '*all about choice and control, having the freedom in my life to do the things that I want to do and when I want to do it*.' For this participant, this means having a personal assistant (PA)[50] to enable '*me do the things I want to do when I want to do them and how I want to do them*.' He continues

'*when it came to being married and to be a family person and we decided we wanted to have children I wanted to look at things that were going to enhance my independence. Be it technology or be it people I was always interested in enhancing what I had and in enhancing the gift I was given, by that I mean the gift of independence. Not all of my peers were given this gift and they were often stifled and locked away and put off in a corner and not allowed to be themselves. So to enable me to have more choice and control in my life I decided that I would like to have a PA to enable me to do that, especially when it came to* [my wife] *and I having conversations around having children*.'

Describing '*wanting to push independence on another level*' this participant applied for a PA. However, he was told there was a long waiting list, that his wife '*was healthy*' and, therefore, it was implied, capable of also being his PA and that '*in any event, someone would probably have to die before I would get* [PA] *hours*.' This reference to 'hours' is instructive:

'*I discovered the PA service was a postcode lottery. So, if you lived in a certain area you may get a certain allocation of hours. If you're under a certain disability manager in the HSE you may get a certain allocation of hours. But somebody up in Donegal or down in Galway or in Mayo who have just as important a requirement as I have to be independent and to live an independent life might not get what I have right now. And that's a terrifying notion but that's fact, that's true*.'

As this participant continued '*to campaign*' for a PA he discovered '*you have to advocate for worse things than you actually have, really have to put it out there. Just shameful*.' However, as indicated by the HSE, '*eventually someone died and I did get a number of hours to start a PA service*.' Later, when the participants' twin children were born the participant advocated for additional hours '*to enable me to be a dad and to be independent*.'

'*So I went forward with well I want to be a dad, I want to be independent, to be a good father. Well, that wasn't good enough. The HSE wasn't going to give me hours based off that. They were*

---

[50] for background see Center for Independent Living, 'Center for Independent Living Leader Forum Consultation Report: Personal Assistance Services.' (2016) <https://ilmi.ie/wp-content/uploads/2018/07/Personal-Assistance-Report-2016-.pdf>

only going to give me hours based off risk. So I had to change tack and say I'm now at risk because [my wife] *can't look after me, she's too busy looking after our two infant children. That's the only way I could get more hours.'*

The participant explains that understanding the HSE's risk rationale – perhaps more properly understood as something that might expose the HSE to risk – has been very useful to him and he has used this recourse to risk repeatedly to improve his situation in terms of PA hours and the increased independence this provides. So, for example, when COVID struck and this participant was no longer going into his office each day but, rather, working from home, somewhat counterintuitively he crafted a risk-based argument around how being at home alone for long hours all day put him at risk of death if a fire or other accident was to occur. Again, this argument succeeded and PA hours were increased. However, these additional COVID hours came on condition '*that when I returned to work I had to return the hours I was given during COVID*.' This condition was enforced notwithstanding that, as the participant contended, its enforcement served as '*a COVID punishment that restricted my independence when lockdown ended at the very same time millions of people were celebrating their independence again*.'

Reflecting on this and the implicit absurdities replete in acquiring and holding and extending a PA service, what another participant calls '*a groveling fest*,' this participant describes how lucky he was as a child to be encouraged to be independent and to celebrate that and value it and to be actively part of every community he has ever lived in. Now he says

'*so, encouraged as a child to be independent and to take that into adulthood I had to then strip that away to get that freedom and choice and control in my life to have a personal assistant service that I could run effectively to give me that. So I had to strip away that independence to get my independence, if that makes sense: catch twenty-two*.'

Vision impaired participants from around the country describe either their own or others' experiences of the PA system as '*erratic*,' '*variable*' and '*pathetic, a complete undignified sham*.' One participant says: '*you hear about young disabled people ending up in nursing homes, non-existent PA services or* [PA] *services not fit for purpose, that's where that comes from*.'

As one vision impaired participant explains:

'*to have a personal assistant is not a right at the moment. It's a pilot scheme that was introduced in the 1990s and which could go at any time should the funding dry up. I remember going to the Dail in November 2019 when a motion was going to be debated that said a disabled person who* *desires a personal assistant has a right to that service. The motion passed but it's not a right yet. It hasn't been turned into law yet*.'

As to how well the Personal Assistance programme is understood in the Irish context a professional cohort participant suggests that '*there is very little awareness about the difference between a Personal Assistant and a Home Care worker, even, in my experience, among disabled people.'* She continues:

'*In line with the CRPD a PA is all about choice and control and the disabled person living her life as a full and active member of the community. So, while it may involve personal care needs, including intimate care, it is much more than that. It can be about facilitating success at college, it can be the difference between being able to meet the requirements of full-time employment, participating in democracy, whatever. Home Care work is pretty much that, daily living skills, supporting health care in the home, washing, dressing etcetera. A problem though is that both programmes are run by the HSE – through service providers - so even at that level there is confusion. Much better, I think, to fully follow what happens in other countries where the disabled person who needs a PA is given a budget that they spend on organising their own needs. So, the disabled person is the PA employer, not the state*. That *is available here too called a direct payments model but it's not rolled out everywhere and there are problems with the hourly rate* and it comes *with a huge admin* [administration] *burden on the disabled person to sort out public liability insurance, PRSI, taxes as the employer so that's not great*. *If you can't take that on you are in a different system and you probably won't get to pick who you want as a PA*. '

As several participants in the instant research affirm, the availability of a fully functioning, responsive PA system is emblematic of a state which esteems all its members. Drawing on Honneth's schema, esteem in this sense is best appreciated as an evaluative frame of reference that recognises that just saying disabled people are equal or just stating that disabled people have a right to live independently in the community – even in legal text - does not make it so. There is hard work required, plans to be made, money and consensus on resources to be found and all this happens proactively because disabled people are valued, they are esteemed. Yet, the experience of so many of the research participants flounder on two points. The first is the intractableness of what we may call the *system*, understood here as the intermeshed layers of privilege that through ideology and other symbolic codes prize and protect certain interests even unto, in Weber's phrase 'the domestication of the dominated.'[51] An unresponsive or barely

---

[51] cited in Pierre Bourdieu *Language and Symbolic Power* (Polity Press, 1992) 167

responsive system does not demonstrate esteem. Hence, as one vision impaired participant puts it

'ratifying the CRPD hasn't changed anything at all. Very few, including very few disabled people, I think, get that if I employ a PA or can get my rights in other areas of the CRPD then that benefits everybody in society. More disabled people in work means more tax revenue for everyone and a lot less welfare payments. More disabled children in mainstream education and universities transforms everybody's learning. More of us in the community means more ideas, more good ideas about building an inclusive society are out there. Accessible transport is there for me today and for you [a non disabled person] *tomorrow. Same for buildings. But instead, as soon as people hear money, what it will cost that's it, no more rights. It's back to the begging bowl and the same us versus them arguments. I really wish I could be more optimistic.'*

The second point of flounder is the expressed idea that disabled people are, routinely, forced to misrepresent themselves or to be misrepresented in order to angel towards some benefit, sometimes at no small cost to their self-esteem and their self-respect. In example after example, which map neatly onto the republican account of domination, participants in this research reference this. By way of summary here, I return to the vision impaired participant who already references using the language of risk to acquire and retain a PA service essential to his and his family's well-being.

'I'd be delighted to celebrate my life and how much better the PA makes it, talk up the positives. But that won't get me anywhere. I have to talk everything down. Get out the begging bowl. That's what they want to see so that's what I have to give them. That's fact. I know it's playing a game, not asserting a right. But if you want a service from this state you have to push the right buttons, leverage what's available to you. I'm a blind man in a wheelchair. I'm also capable, articulate, good at my job, a good dad, a good husband, active in the community, I have hobbies and a wide range of interests. I pay taxes. I make a difference. I love my life. I have friends, a great wife, two great kids, my own home. But if I want to be independent, if I want to actually, actively live the life the state says I am entitled to then I have to tell the HSE porkies, and make myself out to be pathetic and desperate and at risk. I don't like it but that's how it has to be.'

12 Voting with a Guard

By way of counterpoint to this second point of flounder, I draw this chapter to a close with one last vignette. The counterpoint is expressed thus: while the melody reprises people engaging functionaries of the state with whatever individual and personal story they feel is necessary to acquire some personal benefit, this final vignette involves a vision impaired man telling the state its *own* story. Enter here a blind man not seeking anything beyond a simple vindication of a constitutional right to vote in secret. Yet, what is encountered is an aggressive, even vengeful response, an anger on the part of functionaries of the state which goes far beyond the ordinary type of official indifference or incompetence or disinclination other participants report. Here, rather, is revealed, perhaps, a violent intention to dominate, notwithstanding the marked asymmetries of power involved. This too is a story of inclusion – inclusion on entirely equal terms in the political community – but hard fought for and vigorously resisted by the very state that ostensibly stands watch over our democracy and its protection.

Concerned that his basic right to vote in private was no longer available to him because his sight had now deteriorated to the point where he could not read the ballot paper, one of the research participants lobbied officials of the state and asked that they make a braille version of the balloting papers available to him. Explaining that referenda were *'easy enough because you just had to get a person to put your fingers on the yes and the no options'* this participant assumed that the state would be eager to vindicate his constitutional right to vote in secret, 2011 marking '*the first year I was not able to vote independently*.' Describing how he made several approaches to civil servants and elected officials '*always asking them nicely, always pointing out how many blind people would benefit*' the participant elaborates that the real crux of the matter is more than just voter secrecy:

'*it's non-verifiability. I had no way of knowing what way anyone was voting on my behalf. Not to speak of the fact that they could be talking about it down the pub afterwards*.'

Reporting that none of the officials spoken to seemed very interested, the participant continued nonetheless to raise his claim with as wide a circle of influential people as he could. Then, describing it as '*rudeness from the Department, pure ignorance'* the participant reports receiving an email which said *'if you feel that strongly about it, why don't you sue us?'* He continues

'*how snide is that, how dismissive? Just mockery and complete disrespect. The attitude is who is this upstart? This disabled nobody, this outsider telling us how to do our business, how to govern the state.'*

Eventually, in 2014 and without the benefit of a protected costs order – '*so I was completely exposed if I lost the case*' – the participant '*bit the bullet and commenced a High Court action seeking redress*.' As the participant describes it '*they* [the state] *threw the kitchen sink at me*:'

'they threatened me, they told me they'd have me in debt for the rest of my life. They used very strong language to my legal team but I wasn't budging. In all this time we didn't know, we were

doing it on the constitutional right to vote but we didn't know about the 1996 Electoral Amendment Act. If we hadn't got that it would have been very difficult.'

Having acquired the services of a former Attorney General as Senior Counsel and now armed with knowledge of a provision in the 1996 Act that said '*provisions would be made for visually impaired people to make their mark on the ballot in an election*' the state still did not concede, instead '*they were aggressive as hell*.' In the court case itself '*they actually put me on the stand for a week*.'

Describing how the state '*spent at least a million trying to defend the indefensible*,' the participant speaks of how while his motivation in bringing the case was '*aggressively*' dissected, they were '*just trying to tear me apart*.' When it was put to him that a Garda might assist him in voting the participant contended that anybody else being there was an infringement of his right. This, however, was re-phrased as a bias on the participant's part against the Gardai: '*so you don't like Guards, do you?*' Saying that his cross-examination '*took up most of the case*' the participant adds '*I know the* [state] *barrister's strategy was to rile me*,' reading repeatedly from emails the participant had sent over the years to the Department without the participant being able to access them himself so as to put the selected portions in context. The participant was described, without grounds, to be '*litigious by nature*' and as part of its evidence, the state produced a politics professor who, according to the participant, argued that it was *'good for the moral fibre of the state to have people helping blind people.'* The participant describes this argument as entirely reliant on the charities model reading of disability, identifying '*the word disabled as a verb, not as an adjective*.'

The centrality of republican freedom to inclusion and inclusive practice lies in its sharpening of the capacity to correctly identify what corrupts disabled people's abilities to make non-dominated choices about with whom they wish to be included and how. This is so because in the republican tradition freedom is, first, a property of the person.[52] It is the very antonym of domination. However, what is revealed in the immediately preceding vignette is an example of a state that misapplies its own democratic processes and rules, seeking to publically dominate a disabled man who simply requires that the state complies with its own constitutional duty. Rather than do so, this state seeks to isolate him from the political community by threatening to use the courts to reduce his social status and expose him to public opprobrium, seeking to

---

[52] Philip Pettit 'Free Persons and Free Choices' (2007) 28 (4) History of Political Thought 709

categorise him as a petty, ungrateful blind man with a chip on his shoulder and a greedy litigious streak.

As Pettit and other contemporary republican theorists phrase it, the challenge here is to discern how a state, with all its power to interfere in the lives of its citizens, can do so without dominating people. For republicans, the state is not necessarily the enemy, as libertarians or anarchists must insist. However, a state that bears no time for frank contestation and the rigorous upholding of people's rights under a mixed constitution, may well demonstrate antipathy. Indeed, it may already be as an enemy to those who feel disrespected and not esteemed by the state or who are threatened with an arbitrary and vengeful return if they dare challenge it. Such a state is a state bereft of dignified and dignifying standards. Such a state asks people to prostrate themselves before it, to play games to win its attentions, where the influence of the powerful few will always triumph arbitrarily over the vulnerable many. Such a state tells its people what it wants to hear from them, fails to track their legitimate interests and treats them more as supplicants than citizens. Such a state is not 'a democracy of standards.'[53] Such a state is one that excludes rather than includes.

13 Conclusion

Offering the authentic voices of this dissertation's research participants, this chapter positions these voices in dialogue with a range of republican insights. The intention in doing this is to draw out resonances between the experiences of participants and the account republicanism provides of life in the modern polity. Spanning across multiple domains, the participants represented in this chapter describe instances of arbitrary power that disrupts the quality of these lives and experiences, *inter alia*, damaging citizenship and discrediting the polity as a place of equal and dignified human encounter.

---

[53] Philip Pettit 'The General Will, the Common Good, and a Democracy of Standards' in Yiftak Elazer Genevieve Rousseliere (eds) *Republicanism and the Future of Democracy* (Cambridge University Press, 2019) 13 - 40

Chapter Six:

Conclusion

> 'the particular beauty of human excellence ….is its vulnerability'[1]

1 Introduction

Within the mainstream liberal Western compact the notion of freedom is perhaps best phrased in terms of basic liberties that the state commits to protect and extend, ideals of civic and political equality for all citizens, regardless of gender, race, religion, impairment or any other individual or collective characteristic. On this longstanding liberal consensus is built the entire modern edifice of human rights, the core concept being that the individual person can face down the power of the state, restraining its actions through the apparatus of a corpus of law that positions human dignity as its central, orientating principle.

At least such is the theory. However, what is described here is, perhaps, what Baxi identifies as a politics *of* human rights, suggesting a state-centric, discourse-heavy, normative (yet perhaps easily ignored) mechanism by which human rights are deployed – and sometimes ideologically weaponised - within the wider political and bureaucratic domain.[2] At its bleakest, what is conjured here is a rhetorical human rights, to which, often, only those too poor, too marginalised, too powerless and too brutalised seek recourse, less in hope than despair. This is an image of a human rights edifice which, while ceremonially extolled, fails to capture general allegiance, often referenced as aspirational but understood to be of weak general effect, and so little on the general populous' radar that many people profess little or no interest in or, indeed, need for, human rights law.[3]

However, Baxi also postulates a politics *for* human rights and it is in alignment with this idea that the present dissertation endeavours to position itself. A politics *for* human rights is a project of solidarity, one that places those who struggle for and demand freedom from oppression at the centre. It is a politics that disrupts, but, also, a politics that renews and rebuilds, one that affirms a shared humanity, which comprehends in the affirmation of one person's rights a benefit to all persons, a legitimate interest *for* all persons. This is something inherently republican in this; in the way the institution of the citizen bonds with the institution of the state to create something profoundly stronger, democratic and shareable, an implicit recognition that the freedoms

---

[1] Martha Nussbaum *The Fragility of Goodness: Luck and Ethics in Greek Tragedy and Philosophy* (Cambridge University Press, 1986) 86

[2] Upendra Baxi *The Future of Human Rights* (Oxford University Press, 2002)

[3] see, for instance, Eric A Posner *The Twilight of Human Rights Law* (Oxford University Press, 2014)

promised by the human rights discourse are either resiliently everyone's or resiliently no one's. It is in this context too that I contend that the CRPD - on its face, largely directed to disabled people - can be understood as of value, practical and symbolic, to all those whose lives come within the designation 'vulnerable.' Particularly, perhaps, in circumstances of globalisation, neoliberalism, ever encroaching war and environmental degradation I envision the CRPD as a heuristic for the multitude. In contending this, I cite Fitzpatrick who observes 'human rights have the incessant capacity to be something other than what they determinately are.'[4]

Resonant with these thoughts, in this chapter I seek to draw the substantive elements of this dissertation together.

2 The CRPD

The data which sits at the heart of this dissertation derives from three distinct cohorts of participants: people working with disabled people, parents of disabled people and disabled people, this latter cohort consisting of vision impaired participants.

The three cohorts represent people to whom the CRPD is reasonably presumed to be an important document, its innovative text focusing on the removal of barriers to disabled people's capacity to live lives as full, dignified participants in society. Embracing both the social model and the human rights model of disability, the CRPD's innovation is further exemplified in its fusing of civil and political rights with economic, social and cultural rights. More, in adopting a disability-specific perspective on pre-existing human rights and in its reframing of certain negative rights into positive duties, the Convention asserts itself as an inherently novel, inherently flexible legal text, one which, moreover, places a number of completely new concepts such as accessibility and reasonable accommodation before the international community of states and, indeed, the supra-national European Union, a signatory to the CRPD in its own right.

However, states and such aside, who precisely is the Convention's audience? For the CRPD to gain purchase in the imaginary a cascading awareness of it is vital. Indeed, this is provided for in the Convention itself. Hence article 8 (awareness raising) talks of raising awareness and fostering respect for the rights and dignity of persons with disabilities across society, including within families and at all levels of the education system, 'including in all children from an early age.' Nonetheless, of all of the people interviewed, across all three cohorts, knowledge of the CRPD is scant. Even people who identify themselves as disabled activists indicate that they have only

---

[4] Peter Fitzpatrick 'Is Humanity Enough? The Secular Theology of Human Rights' (2007) 6 (1) Law, Social Justice and Global Development 10

a familiarity with those parts of the text relevant to their particular cause or area of interest. Indeed, of all of the fifty plus participants only one disabled man expresses confidence that he has read the entire text. A number of parents say they intend to read it, with some suggesting that its relevance would most likely increase as their children grow older, abrogating entirely that the CRPD had anything of interest to say about younger children *per se* or indeed about their own situation as parents to young children in an ableist society. Not one of the professional cohort has read the full document, although some believed they have, as one person phrases it, '*a good sense of it*.'

This is not encouraging. The CRPD's central purpose, as expressed in its very first article, is 'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disability and to promote respect for their dignity.' Yet, it is suggested that even among what might be described as vested cohorts such as those willing to participate in the instant research, the CRPD has achieved such a slight purchase. In such a context, how might we move from Baxi's politics *of* human rights to a politics *for* human rights?

I believe the answer lies in a robust republicanism and in an explicit recognition of the Convention as, at root, a freedom charter. To present it in such explicit terms is to, intrinsically, draw attention to what deprives people of liberty. Hence, to talk of inclusive education is to talk of an education that draws people in from the margins, of education as a means of empowerment and as a gateway to other social and personal goods. But, to talk of special schools and segregated learning is to suggest a freedom truncated. It is to see instead diminished opportunities, not least the opportunity to contribute to a visceral awareness of disability as part of life's rich diversity and to 'the full development of the human personality' as contemplated by article 26(2) of the UDHR.

Again, to discern work and employment from an explicit freedom perspective is to explicitly confront prejudice and discrimination. The prejudice that keeps so many disabled people outside the labour market, the prejudice of a sliding scale of probabilities which delineates some disabled people as capable of work and many others as incapable, while at the same time sociocultural and political pressures continue to disparage welfare as a mark of moral failure. Difference continues to aggravate. The (so-called) normal continues to be fetishized. The capacity of disabled people to work and disabled people's entitlement to decent work remains weakly appreciated, the absence of disabled people in ordinary workplaces being represented as a proof that *they* don't want to or lack the ability to be in these spaces. In such contexts, reasonable accommodation can too easily be accorded a performative status rather than being accepted as a necessary aid to freedom and inclusion.

The ultimate oppression, perhaps, is the denial of disabled people's proper place as included members living independently in their local communities. From a republican perspective the idea of disabled people dependent upon service providers raises concern that, in effect, disabled people continue to be commodified – that they represent a value to the service provider in whose interest it may be to dis-incentivise independence. The domination that likely flows from this concern is corrosive across a range of other potential goods, including employment and education.

3 Returning to the republican proposal

There is no need here to rehearse at any length all that has already been offered on the character of republican freedom. This is largely addressed in Chapter Two where freedom is presented as a simple, yet richly pluralist ideal which posits the presence of a particular type of social design – overlapping social, medical, juridical, educational and like systems – which support the pre-eminent goal of restraining people's capacities to arbitrarily interfere in the lives of less powerful others. This is a vision of freedom as non-domination, understood both as something resiliently *held* and as a potentially powerful force against oppression, to borrow the language of promissory estoppel, a sword *and* a shield. To be in such a position is to be able to defend against any interference which might otherwise, in its absence, place a person in circumstances where they are compelled to placate or fawn over another who is in a position to do them harm, whether this latter capacity is active or merely possible.

As referenced in Chapter One, the public and private worlds of many persons with disabilities are well documented in terms of poor life outcomes, inclusive of social isolation, marginalisation, personal danger, indignity, institutionalisation, diminished citizenship and, even, contested personhood. In my reading of it – a reading affirmed by the data in the instant research – in circumstance such as these, correctly summarised, I believe, as *oppression* – it is no hyperbole to suggest that the CRPD can be, indeed, *must* be, interpreted, first and foremost, as a freedom charter, a call to liberation.

4 The CRPD as a freedom charter

To assert that the CRPD is a freedom charter is not merely to name it symbolically. However, absent a supporting theory of freedom what the Convention is cited to be may have little practical significance, especially if it is true that it occupies no particular place in the public imaginary. Of course, symbolism has a place, but absent some animating imperative, symbolism may be the place human rights quietly go to die. This notion is given credence, perhaps, by the reality that our era is simultaneously the era of expanding human rights and the era of exploding inequality, the era of incessant rights talk and massively increasing rights violation.

So what might this animating imperative be? In Chapters One and Two I discuss – and discount – liberalism's understanding of freedom as sufficient to the task. Instead, I identify freedom as non-domination – republican freedom – as offering a robust, unifying, trans-national means of energising the wider *civitas* to take the human rights of disabled persons seriously, and to *act* upon that. I propose this notwithstanding that in its more mainstream articulation, specifically, that deriving from Pettit, contemporary republicanism has an obvious ableist taint. However, following theorists such as O'Shea and others I contend that there is no necessary reason for this, other, perhaps, than that it is patterned on an all too familiar socio-political habit of failing to *see* persons with disabilities as full citizens. As the yet most thorough, international exegesis on human rights - even onto the point of positing what plausibly may be considered *new* rights – in its fusing of first and second generation rights and, above all, in its uniquely representative negotiation, drafting and review processes it is, to my mind, inevitable that the CRPD will be drawn into wider and wider interpretative use as a pragmatic standard across the whole human family. Nor, I believe, can there be doubt as to the CRPD's status as a freedom charter, a clarion call for total emancipation. What else could it be when its very existence is prefaced on a group's mass oppression? By way of proviso here, it must be remembered that although often referenced as the world's largest minority disabled people are not really in any heuristic way a group at all but rather an incalculably diverse intermix of peoples. Rather, this commonplace representation of homogeneity – a *they-ing* - may actually reflect a further oppression, representing people living with impairments being forced, to a greater or lesser extent, under the ableist gaze, to conform to this word *disabled*, to live lives often in the control of others, benign or not benign.

Freedom is long recognised as being caught up with subjective and intersubjective status. Machiavelli captures the ages old struggle here succinctly when he writes about the rich wishing to dominate the poor wishing *not* to be dominated. Domination, it is recalled, refers to the arbitrary capacity of a powerful other to make choices and decisions the dominated agent would otherwise be in a position to make (or discount making) herself. Further, as contemporary republicans perceive it, the curtailment of freedom encompasses not just actual interference or the overt threat of it but also circumstances where a person lives in dependence on the goodwill of another. This understanding enlarges the view of freedom considerably: not all interference constitutes domination and not every limitation of a person's liberty derives from interference. Add to this the strong requirement that a republican polity works towards laws that support and are consistent with everybody enjoying non-domination and it becomes clear that within the republican ethic there is a requirement for norms of civility, summarised here as a profound concern with respecting the needs and preferences of other citizens.

Thus, a tradition of freedom that finds its paradigmatic expression in the experience of slaves – including slaves who are exceptionally well treated – now presents as being instantiated across the whole range of human relationships when power either is, or can be, asymmetrical, assuming such instances are not permitted by properly constituted laws. Overlying this brief synopsis onto the Convention it is suggested that a republican reading serves to strengthen and clarify the rights claims found in the treaty. Sharing the view that 'coercion remains coercion even if it is morally impeccable'[5] republican freedom permits a means of thinking afresh about the experiences of disability in the Western imaginary even when these experiences may be thought of as - in the modern idiom – coming from a good place. This is returned to in the final sections of this Chapter, but before that it is necessary to offer a little more concerning contemporary republicanism's capacity to orientate itself fulsomely towards disability.

5 Rescuing republicanism from its lesser self

In the final part of Chapter Two, I employ a juxtaposing of contemporary republican theory with capabilities theory to indicate what I assert republicanism can derive from Sen's and, in particular, Nussbaum's work. I claim that engaging with the capabilities model helps remediate contemporary republicanism's implicit reputation as an ableist theory, or, at least, a theory with ableist aspects. A disability-conscious republicanism is one that incrementally expands on Pettit's own – if underdeveloped – assertion that people should be 'assured of access to what Amartya Sen (1985) and Martha Nussbaum (2006) describe as the basic capabilities for functioning in their society.'[6] It is one that recognises the inevitability of certain asymmetrical dependencies while looking to strategies that help ensure basic capabilities are understood as political entitlements applicable to people with disabilities at the *same* minimum threshold as everybody else. On this, Nussbaum argues that: 'if we say anything else, we fail to respect people

---

[5] Philip Pettit 'Freedom As Antipower' (1996) 106 (3) Ethics 576, 579

[6] Philip Pettit *Just Freedom* (W W Norton, 2014) 87

with disabilities as fully equal citizens.'[7] It is one that recognises, *ad idem* with Nussbaum, that to parse political entitlement differently for persons with disabilities violates human dignity.

In reprising this point I add now that O'Shea and an emerging coterie of disability-conscious republicans provide significant additional assurance that there is no structural reason for why contemporary republicanism cannot offer normative guidance in the context of disability, indeed across most – if not all – of impairments' considerable and diverse presentational range.

6 A disability friendly republicanism

Relying on Pettit's claims that republicanism's conception of freedom is a universally attractive ideal and seeking to extend this to the lived experiences of disabled persons I turn now to highlight two particularly salient features. The first is a high emphasis on social design. Non-domination does not just occur. It is a political endeavour which has a structural dimension, offering

> a clear vision of what law and government should be doing in matters of social justice – promoting people's equal enjoyment of freedom as non-domination – which makes a refreshing contrast to the jumbled, opportunistic shopping lists produced by social democratic and liberal democratic parties at the polls.[8]

Creating a polity founded on a resilient freedom is the republican programme's strongest, most sharable and most universally attractive feature, diversifiable across what happens in the home, the school, the workplace and throughout the wider democratic domain. More, it distils the sometimes airy and hard to grasp language of law – including human rights - into an immediately tangible asset, clearly indicating the necessity of transparency, sometimes expressed as a requirement for public reason. In grounding human rights in non-domination, inclusive of the procedural checks and balances associated with Pettit's conception of contestatory democracy, it is, in my view, entirely plausible, as Pettit maintains, to conceive of republican freedom as a personal good that virtually everyone has reason to want, to value and to share. Indeed, it is in the sharing that the concept has its potentially most profound expression in that the more non-domination there is around, axiomatically the less dominated one is likely to be. Pettit writes

---

[7] Martha Nussbaum Human Dignity and Political Entitlements. In *Human Dignity and Bioethics* (The President's Council on Bioethics, 2008) at 363 available at https://repository.library.georgetown.edu/bitstream/handle/10822/559351/human_dignity_and_bioethics.pdf?sequence=1&isAllowed=y

[8] Philip Pettit *Just Freedom* (W W Norton, 2014) 102

> I do not think anyone can be indifferent to the benefits that freedom as non-domination promises. To be able to live your life without uncertainty about the interference you will have to endure; to be able to live without having to stay on your toes in dealing with the powerful; and to be able to live without subordination to others; these are great and palpable goods and they make a powerful case for the instrumental attractions of freedom as non-domination.[9]

As a public philosophy rooted in political realism, contemporary republicanism seeks to orientate itself to solutions which are amenable to widespread accord, deriving its energy from the people and directing its efforts towards the people. It is not a closed political system or a set of pristine ethical principles. Rather, as Pettit and others have it, contemporary republicanism is a project, a programme, an exercise in public advancement, optimistic but not utopian. In this sense too, Pettit describes it as anti-deontologist and anti-transcendentalist[10] meaning, in the first, that, while a normative philosophy, it seeks to set targets that citizens can commit to and track rather than identifying constraints within which citizens must commit to operate and satisfy. There is a pliability in this but a certain rigor too, a coherence but not one that is ritualised: a less than complete compliance is, then, not fatal. This can be so because freedom as non-domination is a scalar value, multi-dimensional and amenable to local realities and conditions.

In describing the non-domination goal as anti-transcendentalist Pettit seems to contend that orientating towards a perfect political aim – say, the ideal Rawlsian society – gives us no help to get there, that its very remoteness militates against its achievement. In essence then, freedom as non-domination is an ideal but it is not *the* ideal. Rather, within Pettit's schema, freedom is not the only value in life or, even, the supreme one. It is, however, a gateway good, one which will inevitably bring more goods in its train. Thus, a state that consciously commits itself to providing for the freedom of its citizens is, axiomatically, committing to a range of other plausible goods as well, providing 'workable heuristics to measure progress on social, democratic, and international fronts' too.[11]

Freedom as non-domination is also described by Pettit as anti-moralist and non-utopian, the former inviting that we start not from notional ethical first principles but from the fact of

---

[9] Philip Pettit *Republicanism: A Theory of Freedom and Government* (Oxford University Press, 1997) 90

[10] Philip Pettit 'Political realism meets civic republicanism' (2017) 20 (3) Critical Review of International Social and Political Philosophy 331

[11] *ibid* at 338

domination in the world, from first-hand experience. This is important in the context of the instant research which draws on the insights of disabled people, the parents of disabled people and professionals working with disabled people to make vivid their experiences of domination as they manifest in relation to impairment. Republicans describe domination as ubiquitous in the world, as something experienced in the weave and weft of the everyday. Because contemporary republicanism is conceived of as a research programme – a mode of political engagement – its orientation is fundamentally not about justifying itself as theory but, rather, about achieving positive, valued, measurable outcomes in respect of empowering the disadvantaged and restraining the strong.[12] As Pettit summarises it

> The value of freedom as non-domination is not a philosopher's invention, then; it is an articulation of a concern that all of us have in our dealings with others. And it is a concern that naturally surfaces, not just in thinking about how we individually relate to other individuals or private organisations in social life, but also in thinking about how we relate individually and collectively to the government that rules over us.[13]

All this goes to the non-utopian aspect of contemporary republicanism too. The republican focus is on feasible and sustainable improvements, recognising that for a normative schema to take hold it has to speak to people's capacity to see the benefit of it taking hold, whether in the lives of individual citizens or corporate entities or, even, governments.

Taking all of these together – Pettit calling them desiderata – it is unclear why Pettit and other republican scholars pay scant attention to issues of disability. Each of these desideratum have clear applicability in a disability context. The goal of liberating disabled people globally from oppressive lives – the route-map for which is set out in the CRPD – is a necessary one that no contemporary republican would dispute as a worthwhile and imperative goal. The advancement of disabled people in educational experience and attainment, and their inclusion in work and in local communities are intuitively attractive benefits, good things which it is clear only an oppressive and perverse *polis* would seek to openly stymie. As capabilities theorists and republicans alike would have it, these are all objectively valuable goods, a strengthening of the *civitas* in its natural inclination towards solidarity. Representing a truly radical democratic turn, their attainment serves to increase the pool of freedom available within society as a whole.

---

[12] see Jose Luis Marti Philip Pettit *A Political Philosophy in Public Life* (Princeton University Press, 2010)

[13] Philip Pettit 'Political realism meets civic republicanism' (2017) 20 (3) Critical Review of International Social and Political Philosophy 331, 334

More, the true nature of this radicalism is found in its ordinariness, the notion that democracy means that, literally, the *demos* - the people – rule; *all* of the people.

7 Widening the republican appeal

Attaching the CRPD to republicanism as an animating principle is not proposed naively. The picture Pettit paints is intuitively attractive but it does not distract from the reality of bad actors and the inevitability that powerful others will perceive in the push for institutional safeguards against domination a visceral threat to their own sectional interests. The path to justice is almost always at a precipitous gradient. Yet walk it we must. In my reading of it, a properly refined contemporary republicanism offers a coherent means of aligning with the CRPD to advance the interests of disabled people and all those who may be called vulnerable, promoting a truly just – and an attainably just - society. I will seek to advance this point below, drawing on the instant data as it relates to article 24 (education). As to vulnerability I contend in this dissertation that any person, at any point, may succumb to life-changing misfortune, such that seeming certainties of place and position can alter rapidly. Indeed, this vulnerability and the prospect of adversity is writ large in contemporary modernity.

Ours is a world rife with seemingly intractable social, political and environmental problems, polluted by cynicism and factionalism, where 'rights talk' abounds yet rights are globally abused on a scale as likely never since the end of the Second World War. As a social and political stance characterised by trustworthiness, civility, deliberation, public participation and reciprocity, contemporary republicanism may appear utopian. Indeed, especially so, perhaps, in the context of an in-the-ascendant neoliberalism that presents as aggressively atomistic and an essentialist populist politics that disdains the ideal of impartiality and, instead, pontificates a grotesque victimhood while blaming, actual victims. In such a dystopian vision there seems scant hope for the peaceful advancement of weaker interests, such as disability mainstreaming, whereby in line with the CRPD a strategic social goal is to make disabled people's concerns and experiences 'an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes' so that equality is achieved.[14] This is an equality that comes about when political and policy outcomes consciously track the interests of the vulnerable, seeking out and then bringing into play the valuable social knowledge disabled people and others have about how a truly co-created, egalitarian society must look.

---

[14] Bill Albert, Mark Harrison 'Lessons from the Disability Knowledge and Research Programme' in Bill Albert (ed) *In or Out of the Mainstream? Lessons from Research on Disability and Development Co-operation* (Disability Press 2006) 6

8 The instant research: considering *imperium*

As exemplified in the instant research, despite Ireland's economic affluence and apparent political and administrative stability, disabled people and their families routinely experience conditions within which they must, if they can, placate or ameliorate an effective arbitrariness in their encounters with the state, as mediated in various ways. Lovett argues that political and legal authority is insulated from claims of arbitrariness if 'it is effectively constrained by common-knowledge rules, procedures or goals.'[15] This is not an entirely satisfactory position since such rules, procedures or goals may very well have an in-built element of discretion, such that the functionaries administering bureaucratic systems may well operate with considerable leeway. Perhaps mirroring this, in some of his latter texts, Pettit prefers to reference 'uncontrolled interference,' describing how 'interference that conforms to rules, and is non-arbitrary in that sense, may still be uncontrolled by you and can count as arbitrary.'[16]

For instance, a functionary whose role it is to account for the public distribution of certain materials is properly charged with establishing if those to whom materials are distributed really require them. However, having diligently made this inquiry – let's say of a mother whose child has a lifelong impairment requiring a certain type of nappy – to continue to make it each time an allocation is requested is an oppressive and uncontrolled interference. In a similar vein, for a school principal to require a disabled child enrolled in a mainstream school to adhere to a reduced school day or to be subject to other effective exclusions that mark her out from her peers and *officially* signify her as educationally different is to discriminate arbitrarily – and grievously so - against that child and her parents. To decide to use the financial and legal resources of the state to seek to damage the reputation and financial well-being of a blind man who has had the temerity to petition that the state afford him a basic constitutional right is to abuse power and deny freedom.

Goodley reminds that disability can operate as 'the space from which to think through a host of political, theoretical and practical issues that are relevant to all.'[17] Drawing on an analogy pressed into service by Pettit, the republican state's function as it applies to the CRPD is to guarantee the freedom of the city. As Pettit explains, this freedom contrasts with the Hobbesian freedom of the heath,[18] that kind of opportunistic freedom which can exist in the presence of others but also exists if a person is isolated from others. On the other hand, the freedom of the

---

[15] Frank Lovett *A General Theory of Domination & Justice* (Oxford University Press 2012) 99

[16] Philip Pettit *On the People's Terms* (Cambridge University Press 2012) 58

[17] Dan Goodley 'Dis/Entangling Critical Disability Studies' (2013) 28 (5) Disability & Society 631, 632

[18] Pettit (n 9) 67

city *requires* the presence of others. Whereas the freedom of the heath can be pre-social, the freedom of the city speaks to a high degree of social development and organisation, in the modern idiom essentially describing a self-governing democratic society. Thus, as this relates to persons with disabilities, the freedom of the city has both a practical and symbolic application. In the first instance, the republican state is concerned with maximising personal liberties precisely because personal freedom is the origin point for political liberty. Hence, the republican state is concerned with the quality of a disabled person's access not merely to the physical reality of the city – its streets, transport facilities and buildings – but also to the *life* of the city. This requires the state to make available to disabled people the city's multi-layered opportunities to affirm and be affirmed, to meaningfully show agency and to meld the unique individual story of the disabled person into the collective aesthetic – political and moral - of *making* the city together.

However, this is not an aesthetic much in evidence in the instant research. Let us look to the question of the distribution of educational resources. As Pettit has it, the state that is committed to promoting freedom as non-domination must, axiomatically, be 'systematically programmed to reduce material inequalities in resources and protections.'[19] As he explains, republicanism's natural antipathy to material inequality is, at base, about recognising that how a person can interact with another and what standing they can have in that other's view is conditioned by a not too great disparity in individually available resources. A state's commitment to determining those social conditions which best support the enjoyment of non-domination must include questioning the logic in supporting two different educational institutions: the mainstream school and the special school. In this dissertation, the state's persistence in providing for this twin system is taken now as a form of domination.

In my reading of it, the existence of the special school model – or, indeed, the special unit provision in mainstream schools where this does not conform to inclusion norms (including the length of the school day) – creates an inherent problem for republicans. On the one hand, the state's interest in promoting non-domination does not mean that there is a prescriptive list which would outlaw one form of educational institution in favour of another, assuming its existence meets appropriate legal and moral criteria.[20] Nonetheless, while acknowledging their 'special powers over children' Pettit reminds that this does not confer on parents and teachers any right of arbitrary interference. Rather:

---

[19] Pettit (n 16) 91

[20] see, for instance, Colin M Macleod 'Freedom as non-domination and educational justice' (2015) 18 (4) Critical Review of International Social and Political Philosophy 456

> [p]arents and teachers would be subject to such constraints, and exposed to such possibilities of sanction, that two things, ideally, are assured: first, they will seek to advance the relevant interests of the children; and second, that they will seek to promote these interests by non-idiosyncratic lights. Parents and teachers would be allowed to exercise considerable interference in the lives of children, in other words, but the interference would be designed to track the children's interests according to standard ideas, and it would not constitute a form of domination.[21]

There are a number of points here, all of which can be tied to the instant research. As affirmed in the CRPD, the fundamental nature of education as a right for persons with disabilities links its fulfilment to the principle of inclusion. However, as explored in Chapter Three, the precise contours of what inclusive education entails lacks precision. This has contributed to a well-entrenched phenomenon in Irish educational provision whereby a twin-track system exists, the mainstream school and the special school, both systems drawing down considerable state resources. On the data in the instant research, both systems generate distress and unhappiness and both systems are identified with what might reasonably be described as certain indignities and incivilities. Met in the data are parents who feel they must lie about their children, who must be obsequious, who must swallow insults, who must smile and play games and kotow and worry and, perhaps above all, who must fight frequently for their child. Met in the data too are disabled people who associate special schooling with life-long detriment, even as they may also acknowledge certain advantages conferred. Then there are the voices that describe an education delivery which is associated with school's prioritising self-protection and defensive practice and with arbitrary decision-making, summarised, perhaps, in the twin motif of teachers who do not seem to understand the pressures under which parents and their disabled children live and parents who have little time for teachers.

The data does not indicate an education system (and nor does it in respect of both employment policy and community living) that seeks to promote and track the interests of disabled children and their families. Indeed, despite Ireland's commitment to the CRPD and to previous human rights instruments and policies such as the 1994 *Salamanca Statement and Framework for Action on Special Needs Education* the fact that the special school system continues to grow suggests, in Pettit's phrase, the use of *idiosyncratic lights*. The availability of the special school

---

[21] Pettit (n 9) 120

option embeds a socially mediated discrimination that if disabled children *can* be segregated then perhaps best these children *should* be segregated, especially if not doing so is perceived as damaging the educational potential of *normal* children. Apart entirely from the duplication of resources involved, including human and pedagogical resources, the availability of the special school creates a particular form of domination in that children with disabilities are denied the mundane certainty of an ordinary school life – perhaps in the same physical school their parents attended or their siblings attend. Moreover, the availability of the special school system entrenches *ab initio* a pattern that connects viscerally to the dearth of disabled people in ordinary workplaces and living independently in ordinary homes in ordinary neighbourhoods. Segregated education – whether patterned around privilege, race, gender or disability - is inherently dominating and, therefore, repugnant to the republican ethic. In terms of disability, it denies children the opportunities to meet, learn together, socialise, understand each other and make the sorts of shared decisions contemporary republicanism – and democracy - presupposes the learned capacity for. It enshrines and repurposes all the old prejudices on which the great institutionalisations of Ireland's last two centuries rest, including eugenic notions around public safety and danger. It pathologises and ghettoises difference, denies ability, disrupting our common humanity and undermining the exercise of human rights, including the right to work and to live independently. It restricts the potential for wide friendships and entrenches the notion of disabled people as objects of sympathy or charity, takers rather than makers. In a culture of neoliberal atomisation it further restrains the social imagination as to who the productive citizen is, contributing to social scorn and the potential for hate crimes.

Perhaps by way of corrective to this, usefully Snir and Eylon posit the conception of school as a small-scale republic, inviting recognition that within the contemporary republican model children – including children with disabilities - are not nascent citizens but are *already* citizens.[22] Within such an emphasis, what is revealed is the need to ensure that schools' place within the republican order is respected and that education's crucial role in fostering a distinctly republican spirit is not neglected. Indeed, recognising schools as small-scale republics opens to consideration of how schools may be 'redesigned as places in which freedom is constituted rather than violated.'[23] This links to Peterson's concern that absent a clear focus on actively educating children from a young age in the ways of living civically – of being an active citizen - the entire republican project is 'seriously undermined.'[24] The critical pedagogical concern, as

---

[22] Itay Snir Yuval Eylon 'Pedagogy of non-domination: Neo-republican political theory and critical education' (2016) 14 (6) Policy Futures in Education 759

[23] *ibid* 762

[24] Andrew Peterson *Civic Republicanism and Civic Education* (Palgrave Macmillan, 2011) 119

theorised in Chapter Three, that schools can be sites that replicate privilege or reproduce oppression is also of relevance here, contrasting with the co-operative republican ethic that sees non-domination and its advancement as always a purposefully communal activity.

What Snir and Eylon, Peterson and, indeed, Pettit point to are dynamic school communities committed to making republican principles real in their separate locales but linking together in a wider civic project to lessen domination and support that ever-developing civic vigilance and those personal competencies necessary to protect one's own freedom and to promote the common good. The goal here then becomes ensuring an education system that is committed to every child having access to quality teaching, facilities and experiences, within environments attuned to nurturing ideas about responsibilities as well as rights, places where young people are involved in 'determining the values which shape and inform their own discursive deliberations.'[25]

Of course, not every child and young person will experience every school input in the same way: education's potency in promoting non-domination aligns with creating solidarity, not sameness. As to understanding what this solidarity practically requires, Maynor describes the value of civic virtue – that is, the ability to treat each other with civility – as crucial, enabling us to conceive our own ends in ways that do not interfere arbitrarily with others and to perceive how one's own actions impact the whole of society.[26] This is the serious work of learning how to respect and tolerate others, certainly, but its specifically republican educative content is found in the requirement that others are *engaged* with, not least because one's own non-domination is less secure if not anchored in the effort 'to secure all individuals from actual or threatened arbitrary interference.'[27] Arguably, the truly inclusive school provides for this, because it implicitly demonstrates the capacity to transgress restrictive educational borders, exemplifying an intention to work positively with complexity and diversity and to creatively promote engagement with multiple perspectives. It is suggested that the special school never can do this because in its very existence it is inherently an already unequal institution, prefaced on principles that are about separating children, not bringing them together, its pedagogy more likely to enforce stereotypes than challenge them. However, properly resourced, the inclusive school can provide practical opportunities for disabled young people to articulate their own narratives within the wider school community by being part of the discursive deliberation and

---

[25] Andrew Peterson 'Civic Republicanism and Contestatory Deliberation: Framing Pupil Discourse Within Citizenship Education' (2009) 57 (1) British Journal of Educational Studies 55, 66

[26] John W Maynor *Republicanism in the Modern World* (Polity, 2003)

[27] *ibid* 183

perhaps even exemplifying in their experiences how bad it is to be dominated. As sites of equality that challenge discrimination and oppression through curricula that are also inclusive – meaning they reflect locally relevant themes of marginalisation and are adapted to diverse learning styles – inclusive schools nurture positive expectations around other forms of participation, including in civic life, work and community living.

9 The instant research: considering *dominium*

There is a particular, attractive sinuousness in contemporary republicanism's capacity to address both domination as state mediated and as something present in relationships between private parties. Within the republican schema both *imperium* and *dominium* derive from their capacity to reduce a person to something akin to a slave, servant or subject, such that the person feels 'the bitter taste' of exposure to a power which can operate in that person's life at will and with relative impunity.[28] The data from the instant research depicts disabled people and the families of disabled people as almost casually subject to *dominium* and all the great and petty indignities such un-freedom brings. Examples are found in the formerly friendly man who reacts with violence and anger when he feels another person has manipulated his sentiments by pretending to be blind, the bus driver who insists that a person with a disability must sit in an assigned seat and the interviewer who enforces an employment requirement even when its effect is discriminatory. From the perspective of the research participants with lived experience of disability, the data captures instances in which powerful others are deferred to and offered respect and fawned over in the hope such tactics will assuage or persuade them to exercise a power in favour of a disabled person and/or their family.

The perceived need to play these kinds of games point to relationships that are inherently unsound, prefaced as they are not on the solidity of rights and a recognition of individual dignity but on the indignities of being reliant on grace and favour. In circumstances where the medical model of disability prevails – as discussed in Chapter Two – this is seen clearly. The lived experience of disability falls subservient to the expert who defines and diagnoses according to rules and norms which do not track the interests of the disabled person. Under this medical gaze whole swathes of institutions and institutional practices grow up separating *the disabled* from (supposedly) normal, productive people in processes which have enduring consequences for how questions of disability and inclusion are resolved. To counter this (still extant) institutionalised thinking, the contemporary republican must look to a different institutionalisation, this time, the institutionalisation of the disabled person's voice and the

---

[28] Jose Luis Marti Philip Pettit *A Political Philosophy in Public Life* (Princeton University Press, 2010) 34

regulation of public and private relationships in ways that are consistent with maximising freedom and diminishing disabled peoples' un-freedom. Such an approach is provided for within the republican schema and it is also *ad idem* with the general principles and general obligations of the CRPD.

Appearing at every point in the historical evolution of republicanism is the idea that freedom consists not in the presence of self-mastery (that is, positive freedom) nor in the absence of interference (negative freedom) but, rather, in the absence of arbitrary interference, whether actual or merely possible. This view, as has been referenced, is entirely consistent with the existence of coercive law, once that law is constitutionally sanctioned within a state that provides its citizens with adequate opportunities to contest and shape these laws. Traditionally, however, disabled people have been often subject to restrictions and coercions the determination of which have not met the required contestatory test. Rather, the not yet disabled have determined the conditions and circumstances and regimes under which disabled people have lived, with experts ordained to make judgements which but rarely put the disabled person at the centre, the status of the disabled person clearly inferior to that of the expert and the *normal* people they represent and, often, report to.

This is the very antithesis of the types of asymmetrical power with which republicans have always been concerned. Yet, as we have seen, disabled people have but lately - and partially - come onto contemporary republicanism's radar. There is in this, perhaps, a mark of how successful the great institutionalisation of disabled people has been, physically and intellectually. In the main, disabled people have been veiled from the general view, perhaps pitied when glimpsed but accorded little by way of relational status as fellow citizens. Moreover, people with disabilities are no less prone to the constrained choices, restricted options and stultifying uncertainties – including corrosive doubts as to the very self – that all dominated people throughout human history have endured. Given this ages-old defect in the way disability has been positioned as a socio-political concern, it may seem a tall order to consider republicanism capable of providing relief to the embedded asymmetries of power that afflict so many disabled people. Yet, if disability is viewed as relational – or, indeed, as situational or contextual – it becomes easier to discern how the broad problems of recognition and respect, the problems which arise from a denial of disabled peoples' essential dignity, can be usefully viewed through the prism of other marginalised groups' experiences of oppression. Thus, for example, feminist theory demonstrates how in challenging oppression the core goal is not incremental material improvements – valuable as these are – but, rather, an overturning of stultifying social structures that serve to elevate one group's preferences over those of another group's.

In phrasing this challenge, republicanism is very valuable. Where once traditional republicanism glorified the public sphere and showed antipathy to the private sphere, contemporary republicanism recognises that what goes on, *inter alia*, in relationships and marriages and workplaces and schools is crucial to understanding how people experience and interiorise un-freedom in their own bodies and lives. Hence, republicanism has evolved to recognise that, in essence, what goes on in private life feeds into public life and that, if this is not to turn the latter into a vehicle for accommodating powerful sectional interests, *everything* that shackles equality and independence – everything that excludes rather than unites people – has to become part of public debate and contestation. Hence, in the instant research are encountered disabled people who feel they must dissemble about their vision impairment and parents who must either exaggerate their child's presenting features or minimise them, lest the truth creates a palpable disadvantage for them. The necessity for this kind of game playing and strategizing is identified as exhausting, the affront to dignity and equality evident. Others offer accounts of how they must *play* at being the kind of disabled person their audience – even casual fellow bus passengers – require them to be, speaking to a widely entrenched stereotyping that implicitly communicates to disabled people that there is an assigned and subordinate place (literally and figuratively) from which they must not stray. Hence, we encounter a disabled person whose ambitions to be a good father and an independent provider must be debased and repackaged in the language of risk and fear, requiring that he, instead, literally present his children as being in *danger* from his disability. We meet a teacher who knows his entire career, even onto becoming an academic himself, is owed to a nun who over-rules a medical opinion that advises terminating his teacher training. We hear a parent who reports the desperately sad feeling that no-one ever sits beside her daughter on public transport. All these are examples of how disability exposes people to the power of others. These examples also prefigure a constrained access to the public realm, an access prefaced on ableist attitudes and policed by those who regard disabled people with distrust or requiring that they *prove* themselves, presumably in performative ways that validate a stereotype.

10 Republicanism rebukes stereotypes

Negative attitudes have palpable power, often giving off a visceral warning about how others are expected to disport themselves. Contemporary republicanism presents as well placed to counter stereotypes and – calibrated for disability – this dissertation contends that the theory can support those living with impairments to counter ableism and resiliently claim their rights in both the public and private spheres. It can do this both practically and at the level of symbolism, publically expressing the equal status of persons with disabilities.[29] Of course, freedom too is a status, and one all too vulnerable to the totalising effect of permitting stereotyping to go unchallenged. Hence, Rowell argues that museum and gallery tours permitting blind people touch the exhibits while prohibiting everyone else from doing so do not accord a freedom to vision impaired persons but, rather, serve to further emphasis blindness as a mark of exclusion and defect. Referring to 'the needless supremacy of the sense of sight in these spaces' Rowell writes: [t]hese tours aren't intended to unlock the riches of tactile engagement with art, or they would be open to everyone.'[30]

Rowell reveals a commonplace conceptualisation of disability that, while appearing to be sensitive to certain impairments, actually serves to implicitly discriminate against disabled people in drawing a needless attention to difference. This is pointed to in the research and perhaps especially in relation to the way all of the staff cohort participants refer to disabled people as 'they' or versions thereof. The *othering* indicated here is all the more striking in that it derives from a group of people who must be considered to be far more knowledgeable about and connected to disability issues than generally the case among the-not-yet-disabled population. Speaking to the extraordinary dominating nature of stereotype, here is encountered a way of referencing disabled people that suggests a homogeneity that simply cannot exist. More, it represents a denial of sorts, particularly in terms of reinforcing the most corrosive stereotype of all: that 'the disabled' not being *us* permits a narrative that marks this supposed us out as better, superior and, crucially, necessarily in charge. Hence, in this sense, good, well-meaning and doubtless caring staff talk of *giving* disabled people their rights.

As to countering the dominating effects of stereotyping, perhaps the most important thing is that disabled people are provided with the means of allowing their own narrative about the circumstances of their own lives talk precedence over the ideologies of the not-yet-disabled. At the heart of this, and central to a robust, disability-calibrated republicanism, must be identifying contestatory mechanisms suitable to the inclusion entitlement of disabled people. Doing this at local levels sufficient to address *dominium* and *imperium* calls for efforts of imagination to ensure that what ensues is not tokenistic but, rather, productive of meaningful opportunities for disabled people to articulate their narratives on issues that affect them and to contest and

---

[29] see Tom O'Shea 'Disability and Domination: Lessons from Republican Political Philosophy' (2018) 35 (1) Journal of Applied Philosophy 133

[30] Maud Rowell *Blind Spot* (Inklings, 2021) 72

review decisions and practices which disadvantage them. Only in the application of such systems, can the interests of disabled people be identified and tracked, recognising that people with impairments are accorded the dignity of being understood as being experts in their own experience.

Within the workplace this calibration may, for instance, require public commitment to significant costs associated with accommodations that place the amorphous concept of 'reasonable' in context with the idea that it is wholly *unreasonable* that so few disabled people are in paid employment and decent work. Positing the lack of such accommodation as inherently dominating, thought must also be given to how disabled people in employment can practically access the normal entitlement to change jobs without fearing the cost of exit, especially, but not exclusively, in circumstances where the person has low-level skills. This question of securing exit has implications too for the type of *dominium* found in respect of unchecked familial or service-provider relationships on which a disabled person may be dependent for support in terms of daily living, a point of particular significance in respect of resiliently holding rights under article 19 of the CRPD.

In terms of education and inclusion in the community, republicans must rebuke any system enshrining prejudice and which separates people according to impairment from other people deemed to be without impairment, the perfect from the imperfect. Seeing here a pushing to the fore of an organising system that makes certain implicit evaluative and procedural claims around what *good* education looks like and who can properly *live* in local communities, the republican must repudiate this as it removes a class of people from the deliberative ethos, marking this non-recognition as axiomatically oppressive.

As previously referenced, O'Shea theorises the extension of contemporary republicanism to the particular lived circumstances of disability and its interplay with *dominium*. However, importantly, O'Shea also reminds that rather than assuming that the presence of impairment axiomatically predisposes a person to domination it must be considered that '[t]he experience and skills developed in living with a disability can help some individuals become more resilient than they would otherwise have been.'[31] This is an important point. It reminds that for many people living with impairments nothing additional to the ordinary republican rubric is required to advance their interest in not being subject to domination. Indeed, several disabled people who it seems might come within this category are among the participants in the instant study.

---

[31] Tom O'Shea 'Civic Republican Disability Justice' in Adam Cureton David Wasserman (eds) *The Oxford Handbook of Philosophy and Disability* (Oxford University Press, 2020) 216

But these robust, resilient people can also be easily misrepresented by the dominating stereotype, including, of course, attributions of being in some ways *superhuman* and *inspirational*. All this further reminding that stereotypes about disability have real power to disrupt lives, just as racist, gendered and homophobic tropes can work to marginalise and deny people opportunities to live flourishing lives and, indeed, deny the *civitas* the benefit of communally sharing in that flourishing.

Stereotyping exemplifies a weakening of the capacity of individuals and systems and, ultimately, societies to encounter the unique individuality of every single person and to value what disabled people can bring to the deliberative community. More, because people with disabilities are not routinely *seen* in this vital way – as fellow individuals and citizens rather, say, than as *blind* people or *learning disabled* people – persons living with impairments (their own and others') often report, as evidenced in the instant research, a type of resignation, an acceptance of the inevitability of an ableist status que. In such circumstances, the ability to contest is, first and foremost, conditioned on being recognised as a person who is significant; who can attest '*I am here and I matter*.' Thus, shorn of its own ableist tendencies, the ability of republicanism to facilitate this becomes about not *not* seeing the disability but of always seeing the person *first*. Commencing from this vantage point of respect, of being dignified as a person, the disabled person is resourced in any necessary way, relative to the impairment, to live in a way that better secures her political and social freedom. Central here, then, must be an embracing of the concept of reasonable accommodation, as elaborated by the Convention and its processes, in recognising that dependence of itself is not fatal to individual freedom but, rather, an intrinsic component of human endeavour, including the republican research programme itself. Indeed, Pettit recognises that non-domination cannot occur in isolation since it literally entails the 'absence of domination in the presence of other people' rather than 'the absence of domination gained by isolation.'[32] Of course, dependence can be an intensely negative experience and, *if* such, must be judiciously policed and rigorously resisted if republican principles and republican concerns for the common good are to be made ever more real in the polity. However, dependence and interdependence are also norms of almost all human activity, including grand international activities such as agreeing treaties and conventions. For the person with impairments, however, this narrative often comes up hard against a deadening stereotype, this time that for people with disabilities dependency is some sort of lower order state, a mark of an inferior life.

---

[32] Pettit (n 9) 66

Again, visible here is the usurpation of image over form, reminding that the most insidious domination of all faced daily by disabled people and, indeed, their families and supporters, are those accretions of attitudes which permit that it is acceptable to think of disabled people as *less*, attitudes that are implicitly ableist. Challenging these attitudes calls for a radical republicanism of solidarity, positing a liberty that is either organised competently for everyone or is duplicitous, forever stagnant and inchoate. Moreover, I believe, drawing on the Convention as a lens through which to look anew at the contingencies and constraints imposed on people with impairments can serve to focus the polity on a new, dynamic, unifying way of thinking about equality and, indeed, on a new way of reimagining an ever-enlarging republicanism. In this – and thinking of the CRPD as a *living* document - the general principles, as found in article 3, speak powerfully to this reimagining in a way which offers clarity as to how a common, undifferentiated freedom is achievable within a human rights framework. Explicitly, this framework emphasises respect for inherent human dignity, autonomy and independence, respect for difference and acceptance of disability as simply part of human diversity, non-discrimination, equal opportunity, complete and meaningful participation, accessibility, sexual equality and respect for the evolving capacities of children. Implicitly, the framework invites a unity of purpose, a coming together of those living with impairment and those others – referred to in this dissertation as the not-yet-disabled – to reach beyond sectional interests and instead, seek to actively design a polity that eschews fear, pity, paternalism, charity and the like in favour of affirming a common and diversely rich humanity.

11 Cry freedom

That, perforce, this polity be republican is found, first, in the embracive, pluralist assertion that non-domination as a realistic and achievable good is one practically every individual has reason to value and to want. It is found too in the claim that enlightened governments and other institutions will seek to safeguard people from their susceptibilities and vulnerabilities to domination, equipping them to resiliently resist its corrosive content by expanding access to remediating options, ensuring resources are available and dispersed in ways which, situation to situation, increase and secure the individual's quotient of freedom. This is so because domination is a viral harm that blights relationships, working injustices in both the social and political spheres, undermining inclusivity and community and, left unchecked, making mockery of the idea that all people are equal in dignity and rights and deserving of recognition as citizens and human beings.

The great achievement of modern, democratic, responsive politics is that it permits whole strata of people, previously invisible, to be *seen*: people whose invisibility doubtless made easier – and harsher too - their suffering at the hands of powerful others. But being seen, while a necessary condition, is not, of itself, a *de facto* admission to the public realm. The instant research resonates a strong sense that disability confers an outsider status, that many disabled people and their families do not experience a full quotient of belonging in society; theirs is, at best, often only a partial visibility. To achieve a full measure of belonging, a focused and committed intentionality within the *polity* is required. The CRPD is a demand to states and to the wider citizenry that this intentionality be manifest, that the necessary measures be taken to ensure that disabled people's full inclusion and participation in society is enabled. This means recognising that all of the rights articulated in the Convention are understood as operating cohesively, as, in this dissertation, exemplified in the emphasis on the close connectivity between the goals of community inclusion, employment and education. Thus, the three rights come together in a socio-political act of informing, forming and transforming. However, notwithstanding the paradigm shift the CRPD undoubtedly is, as seen through the prism of the instant research there is concern that Ireland represents as two republics, one for *whole* people and a different, lesser dispensation for those who are deemed to come within the designation disabled or who are in other ways vulnerable. Concern that the rhetoric of rights is at quite a distance from the reality of how disabled people are *allowed* and effectively resourced to live their lives indicates that articulating the Convention, even to the point of legislative change, is not enough to bring about the widespread and multi-dimensional, cross-cutting change needed. Thus, it seems an ableist ideology still runs deep in the Irish psyche, permitting – and, even, excusing - a tyranny of the *normal* that echoes and re-echoes in the existential republican angst about the tyranny of the majority. In this reading, the CRPD serves to assert that disability is an important signifier of the contradictions in society yet to be resolved around all forms of difference.

As Arendt has it 'every one of us came into the world as a newcomer through birth. In other words we can begin something because we *are* beginnings and hence beginners.'[33] The cry freedom in this dissertation is that we, disabled and not-yet-disable persons, must truly begin something new, in this instance by renewing a fidelity to something old. That in harnessing the CRPD to a revitalised republicanism in the cause of disabled people's liberation from domination we must, in the phenomenological sense, see the world anew, as if for a first time. We must

---

[33] Hannah Arendt *Thinking Without A Bannister: Essays in Understanding 1953 – 1975* (Schocken Books 2018) 383 (emphasis in original)

begin, collaboratively, by committing to republicanism as a research project centred on impairment and disability as qualitatively different states of being. Implicit in this is that disabled people cannot but be recognised as moral agents in their own right, exercising capabilities in order to maximise agency in and control over their own lives, a final sundering of a world of abled insiders and disabled outsiders. Implicit in this too, at least as I perceive it, is that as a legal document produced uniquely with disabled people's complete involvement, the CRPD becomes a freedom charter, *and* a detailed map of where the many and multiple sources of un-freedom are found. In all of human socio-legal history no other such document exists of such a scale and magnitude, inchoate yet replete with astonishing transformative potential. In my view, the CRPD permits us as humans to connect to an enormously psychologically freeing awareness of our shared reality as each, at root, pockets of fleshy vulnerabilities, realising that, as Seibers has it, no understanding of human rights is plausible until disability is included as a defining characteristic of what it is to be human.[34] The Convention permits too that, as this human family, we encounter human rights not as artefacts of legal largess – doled out, as it were, to the needy, the poor or the downtrodden – but as shared resources resonant of the human insistence to hold ourselves, collectively, to a standard better than we often are reliably capable of and, in that act of supreme imagination, becoming better and better again in manifesting real, embracing, generous and resilient human solidarity. Within the republican lexicon, human freedom is, first, a property of a person. However, this is not the same as contending that freedom is entirely an individual prerogative. Rather, the truly fecund approach is to embrace individual freedom as a project that inherently benefits the community, such that acting in solidarity humans reclaim their individuality as people not disadvantaged by difference but the stronger for it, permitting the recognition that in liberating disabled people *all* people are less vulnerable to the degradations, indignities and injustices of domination. In this time of pressing precarity for humanity itself, this solidarity – an ambitious and robust republican solidarity – is never so needed as now.

---

[34] Tobin Seibers *Disability Theory* (The University of Michigan Press 2008)

Bibliography

Books

Adorno TW, *The Culture Industry* (Routledge 1991)

Agamben G, *Homo Sacer*: *Sovereign Power and Bare Life* (Stanford University Press 1998)

Agamben G, *The Open: Man and Animal* (Stanford University Press 2004)

Agamben G, *Use of Bodies* (Stanford University Press 2015)

Aho KA, *Heidegger's Neglect of the Body* (State University of New York Press 2009)

Ainscow M, Booth T, Dyson A, *Improving Schools, Developing Inclusion* (Routledge 2006)

Albrecht GL, *The Disability Business: Rehabilitation in America* (Sage 1992)

Alcock A, *History of the International Labour Organisation* (Macmillan 1971)

Alexander JM, *Capabilities and Social Justice: The Political Philosophy of Amartya Sen and Martha Nussbaum (*Ashgate 2008)

Anderson P, *'The Antinomies of Antonio Gramsci'* (Verso 2020)

Archard D, *Children, Rights and Childhood* (Routledge 2014)

Arena V, *Libertas and the Practice of Politics in the Late Roman Republic* (Cambridge University Press 2012)

Arendt H, *Thinking Without A Bannister: Essays in Understanding 1953 – 1975* (Schocken Books 2018)

Arendt H, *On Revolution* (Penguin Books 2006)

Arendt H, *The Human Condition* (University of Chicago Press 1998)

Arendt H, *The Origins of Totalitarianism* (Harvest 1968)

Aries P, *Centuries of Childhood: A Social History of Family Life* (Pimlico 1996)

Aristotle, *The Nicomachean Ethics* (Oxford University Press 1998)

Aristotle, *The Politics* (Penguin Classics 1981)

Armstrong AC, Armstrong A, Spandagou I, *Inclusive Education: International Policy and Practice* (Sage, 2010)

Arneil B, Nancy J. Hirschmann, (eds.) *Disability and political theory* (Cambridge University Press 2016)

Arnesen AL, Hadzhitheodoulou-Loizidou P, Bîrzéa C, Essomba MA, Allan J, *Policies and practices for teaching sociocultural diversity* (Council of Europe 2009)

Arnold B, *The Irish Gulag* (Gill & Macmillan, 2009)

Bailer B, Wetzel J, (eds.) *Mass Murder of People with Disabilities and the Holocaust* (Metropol Verlag 2019)

Balibar E, *Citizenship (*Polity 2015)

Balibar E, *The Philosophy of Marx* (Verso 2017)

Barasch M, *Blindness: the History of a Mental Image in Western Thought* (Routledge 2001)

Baraz Y, *A Written Republic: Cicero's Philosophical Politics* (Princeton University Press 2012)

Barclay L, *Disability With Dignity (*Routledge 2019)

Barnes C, Barton L, Oliver M, *Disability Studies Today* (Polity 2001)

Barnes C, Mercer G, *Exploring Disability* (Polity 2010)

Barrington R, *Health, Medicine and Politics in Ireland 1900 – 1970* (Dublin Institute of Public Administration 1987)

Bauman Z, *Intimations of Postmodernity* (Routledge 1992)

Bauman Z, *Liquid Modernity* (Polity 2012)

Baxi U, *The Future of Human Rights* (Oxford University Press 2002)

Beauvoir S de, *The Mandarins* (World Publishing Company 1956)

Beck CT, *Introduction to Phenomenology: Focus on Methodology* (Sage 2021)

Beck U, *The Brave New World of Work (*Polity Press 2000)

Beeman R, *Plain, Honest Men: The Making of the American Constitution* (Random House 2009)

Beitz CR, *The Idea of Human Rights* (Oxford University Press 2011)

Bellamy R, *Liberalism and Modern Society: A Historical Argument* (Pennsylvania State University Press 1992)

Bellamy R, *Citizenship: A Very Short Introduction* (Oxford University Press 2008)

Bentham J, *The Panopticaon Writings* (first published in 1789, Verso Books 2013)

Berlin I, *Liberty* (Oxford University Press 2016)

Black R, *Machiavelli: From Radical to Reactionary* (Reaktion Books 2022)

Bobbitt P, *The Garments of Court and Palace* (Grove Press 2015)

Bok DC, *The Politics of Happiness* (Princeton University Press 2010)

Bonner SE, *Of critical theory and its theorists* (Routledge 2013)

Booth T, Ainscrow M, *Index for Inclusion: Developing Learning and Participation in Schools* (CSIE 2002)

Bourdieu P, Passeron J C, *'Reproduction in Education, Society and Culture'* (Sage Publications 1977)

Bourdieu P, *Language and Symbolic Power* (Polity Press 1992).

Bourdieu P, *The Logic of Practice* (Polity Press 1990)

Bourdieu P, *Pascalian Meditations* (Polity Press 2000)

Brentano F, cited in Stephan Kaufer S, Chemero A, "*Phenomenology: An Introduction*" (Polity 2021)

Broberg G, Roll-Hansen N, *Eugenics and the Welfare State: Norway, Sweden, Denmark and Finland* (Michigan State University 2006)

Broderick A, 'The Right to Inclusive Education: Article 24 of the UN Convention on the Rights of Persons with Disabilities and the Irish Experience' in *The Irish Yearbook of International Law* (Bloomsbury Publishing, 2014)

Broderick A, *The Long and Winding Road to Equality and Inclusion for Persons with Disabilities* (Intersentia 2015)

Broderick A, Ferri D, *International and European Disability Law and Policy* (Cambridge University Press, 2019)

Bromfrenbrenner U, *The Ecology of Human Development* (Harvard University Press, 1979)

Brown CG, *Postmodernism for Historians (*Routledge 2005)

Brown RH, *Postmodern Representations* (University of Illinois Press 1995)

Brown W, *Undoing the Demos: Neoliberalism's Stealth Revolution* (Zone Books 2015)

Brune JA, Wilson DJ, *Disability and Passing* (Temple University 2013)

Buchanan I, *Oxford Dictionary of Critical Theory* (Oxford University Press 2018)

Buergenthal T, Shelton D, Stewart DP, *International Human Rights In a Nutshell* (West Academic 2009)

Burke JF, *Vision, the Gaze, and the Function of the Senses in Celestina* (Penn State University Press 2000)

Burns T, *Our Necessary Shadow: the Nature and Meaning of Psychiatry* (Allen Lane 2013)

Butler C, *Postmodernism: A Very Short Introduction* (Oxford University Press 2002)

Butler J*, Gender Trouble: Feminism and the Subversion of Identity (*Routledge 1990)

Butler J, *Precarious Life: The Powers of Mourning and Violence* (Verso 2006)

Butler-Kisber L, *"Qualitative Inquiry"* (Sage 2010)

Butterwick R, *The Polish-Lithuanian Commonwealth: Light and Flame* (Yale University Press 2020)

Campbell F, *Frontiers of Ableism (*Palgrave Macmillan 2009)

Cantor NL, *Making Medical Decisions for the Profoundly Mentally Disabled* (MIT Press 2005)

Carman T, *Merleau-Ponty* (Routledge 2020)

Cartledge P, *Democracy: A Life* (Oxford University Press 2018)

Cassese A, *International Law* (Oxford University Press 2005)

Charlton JI*, Nothing About Us Without Us: Disability Oppression and Empowerment* (University of California Press 1998)

Cicero MT, *The Republic and the Laws* (Oxford World Classics 2008)

Cicero MT *On the Commonwealth and On the Laws* (Cambridge University Press 1999)

Cisney VW, Morar N, (eds.) *Biopower: Foucault and Beyond* (The University of Chicago Press 2016)

Claeys G, *Marx and Marxism* (Nation Books 2018)

Clear C, *Nuns in Nineteenth Century Ireland* (Gill and MacMillan 1987)

Clement T, Bigby C, *Group Homes for People with Learning Disabilities: Encouraging Inclusion and Participation* (Jessica Kingsley Publishers 2010)

Cohen A, *Imbeciles: the Supreme Court, American Eugenics and the Sterilization of Carrie Buck* (Penguin Books 2017)

Collins PH, *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment* (Routledge 2000)

Conly S, *Against Autonomy: Justifying Coercive Paternalism* (Cambridge University Press 2008)

Coole D, Frost S (eds.) *New Materialisms: ontology, agency and politics* (Duke University Press 2010)

Cooper P Jacobs B, *From Inclusion to Engagement: Helping Students Engage with Schooling Through Policy and Practice* (Wiley 2011)

Corker M, Shakespeare, T, (eds.) *Disability/Postmodernity* (Continuum 2006)

Crocker DA, *Ethics of Global Development: Agency, Capability and Deliberative Democracy* (Cambridge University Press 2008)

Crotty M, *The Foundations of Social Research* (Sage 2015)

Cryle P, Stephens E, *Normality: A Critical Genealogy* (The University of Chicago Press 2017)

Cudd AE, *Analysing Oppression* (Oxford University Press 2005)

Dahlberg G, Moss P, Pence A, *Beyond Quality in Early Childhood Education and Care* (Routledge, 2013)

Dahlberg K, Drew N, Nystrom M, *Reflective Lifeworld Research* (Studentlitteratur, 2001)

Dahlberg K, Drew N, Nystrom M, *Reflective Lifeworld Research* (Studentlitteratur 2008)

Daly E, Hickey T, *The Political Theory of the Irish Constitution* (Manchester University Press 2015)

Darwall S, (ed) *Equal Freedom. Selected Tanner Lectures on Human Values* (University of Michigan Press 1995)

Davies N, *Heart of Europe: The Past in Europe's Present* (Oxford University Press 2001)

Davis A, *Women, Race, and Class* (Random House 1981)

Davis LJ, *Enforcing Normalcy: Disability, Deafness and the Body* (Verso 1993)

Davis LJ, (ed.) *The Disability Studies Reader* (Routledge 1997)

Davis LJ, *The End of Normal: Identity in a Biocultural Era* (The University of Michigan Press 2013)

Dawson H, *Hobbes (*Pegasus Books 2015)

de Beauvoir S, *The Mandarins (*World Publishing Company 1956)

de Beauvoir S, *The Ethics of Ambiguity (*Citidel Press 1976)

de Beauvoir S, *The Second Sex* (Vintage Books 2010)

De Dijn A, *Freedom* (Harvard University Press 2020)

De Santis D, Hopkins BC, Majolino C (eds.) *The Routledge Handbook of Phenomenology and Phenomenological Philosophy* (Routledge 2021)

Degener T, cited in Waddington L, Broderick A, *Promoting Equality and Non-Discrimination for Persons with Disabilities* (Council of Europe 2017)

Derrida J, *Given Time: I. Counterfeit Money* (University of Chicago Press 1992)

Descartes R, *Meditations and Other Metaphysical Writings* (Penguin Books 1998)

Devlin R, Pothier D, (eds.*) Critical Disability Theory: Essays in Philosophy, Politics and Law* (UBC Press 2006).

Dibley L, Dickerson S, Duffy M, Vandermause R, *Doing Hermeneutic Phenomenological Research* (Sage 2020)

Dicey AV, *Introduction to the Study of the Law of the Constitution* (Liberty Fund Inc 1982)

Dickman E, *Using Questions to Think* (Bloomsbury 2021)

Dolmage JT, *Disability Rhetoric* (Syracuse University Press 2014)

Donnelly J, *Universal Human Rights in Theory and Practice* (Cornell University Press 2013)

Donohoe J, *Husserl on Ethics and Intersubjectivity: From Static and Genetic Phenomenology* (University of Toronto Press 2016)

Douzinas C, *The End of Human Rights* (Hart Publishing 2000)

Dryzek JS, *Democracy in Capitalist Times: Ideals, Limits and Struggles* (Oxford University Press 1996)

Durkheim E, *The Division of Labour in Society* (first published 1893, The Free Press 1964)

Dworkin G, *The Theory and Practice of Autonomy* (Cambridge University Press 1988)

Dworkin R, *Taking Rights Seriously* (Bloomsbury 1997)

Dworkin R, *Justice for Hedgehogs* (Harvard University Press 2011)

Elden S, *Foucault: The Birth of Power* (Polity 2017)

Engelhardt HT Jr, *The Foundations of Bioethics (*Oxford University Press 1996)

Evans RJ, *The Third Reich in Power 1933 – 1939* (Penguin Books, 2005)

Everitt A, *Cicero* (Random House 2001)

Faulkner W, *Requiem for a Nun* (Chatto and Windus 1919)

Felluga F, *Critical Theory: The Key Concepts* (Routledge 2015)

Fineberg J, *Harm to Self: The Moral Limits of the Criminal Law* (Oxford University Press 1986)

Finnegan F, *Do Penance or Perish: Magdalene Asylums in Ireland* (Oxford University Press 2001)

Flynn E, *From Rhetoric to Action* (Cambridge University Press 2011)

Forst R, *Justification and Critique: Towards a Critical Theory of Politics* (Polity Press, 2014)

Foucault M, *Discipline and Punish: The Birth of the Prison* (Penguin Books 1979)

Foucault M, *Security, Territory, Population: Lectures at the College de France 1977-78* (Palgrave Macmillan 2007)

Foucault M*, The Foucault Reader* (Vintage Books 2010)

Frank J, *Constituent Moments: Enacting the People in Postrevolutionary America* (Duke University Press 2010)

Fredman S, *Discrimination Law* (Oxford University Press 2002)

Fredman S, *Human Rights Transformed: Positive Rights and Positive Duties* (Open University Press 2008)

Freire P, *Education for Critical Consciousness* (Seabury Press 1973)

Freire P*, The Politics of Education: Culture, Power and Liberation* (Bergin & Garvey 1985)

Freire P, *Pedagogy of the Oppressed* (Penguin 1993)

Freire P, *Pedagogy of Freedom: Ethics, Democracy and Civic Courage* (Rowman & Littlefield 1998)

Garnsey P, *Ideas of Slavery from Aristotle to Augustine* (Cambridge University Press 1996)

Giddens A, *Modernity and Self-Identity* (Stanford University Press 1991)

Godin ML, *There Plant Eyes* (Vintage, 2022)

Goffman E*, Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (Penguin Books 1991)

Goffman E, *Stigma: Notes on the Management of Spoiled Identity* (Penguin Books 1990)

Goodley D*, Disability: An Interdisciplinary Approach* (Sage 2010)

Goodley D, *Disability Studies* (Sage 2017).

Goodley D, Hughes B, Davis L, (eds) *Disability and Social Theory: New Developments and Directions* (Palgrave Macmillan 2012)

Gourevitch A, *From Slavery to the Cooperative Commonwealth* (Cambridge University Press 2015)

Gramsci A, in Hoare Q, Nowell Smith G, (eds) *Selections from the Prison Notebooks* (International Publishers 1971)

Griffin J, *On Human Rights* (Oxford University Press 2008)

Griffin S, Shevlin M, *Responding to Special Educational Needs: An Irish Perspective* (Gill Education 2011)

Gwynn DM, *The Roman Republic: A Very Short Introduction* (Oxford University Press 2012)

Habermas J, *Between Facts and Norms* (MIT Press 1993)

Habermas J, *The Theory of Communicative Action. Vol 1 Reason and the Rationalization of Society* (Polity Press 1981)

Hall N, *Hate Crime* (Routledge 2013)

Halldenius L, *Mary Wollstonecraft and Feminist Republicanism: Independence, Rights and the Experience of Unfreedom* (Routledge 2015)

Hamilton L, *Amartya Sen* (Polity 2019)

Hankins J, (ed.) *Renaissance Civic Humanism: Reappraisals and Reflections* (Cambridge University Press 2000)

Harding S, *The Science Question in Feminism* (Cornell University Press 1986)

Hardt M, Negri A, *Empire* (Harvard University Press 2000)

Harrington J, *The Commonwealth of Oceana* (Cambridge University Press 1992)

Harris J, *Value of Life* (Routledge 1985)

Hayek FA *The Constitution of Liberty* (University of Chicago Press, 1978)

Hayhoe S, *The Embarrassment of Riches* (Vintage Books 1987)

Hayhoe S, *God, Money and Politics* (Information Age Publishing 2008)

Hayhoe S, *Philosophy as Disability and Exclusion* (Information Age Publishing 2016)

Heidegger M, *Being and Time* (Blackwell 1962)

Heidegger M, *On the Way to Language* (Harper Collins 1982)

Heidegger M, *The Basic Problems of Phenomenology* (Indiana University Press 1982)

Held D, *Models of Democracy* (Polity Press 2006)

Helmers HJ, *The Royalist Republic: Literature, Politics and Religion in the Anglo-Dutch Public Sphere* (Cambridge University Press 2015)

Henkin L, (ed.) *The International Bill of Rights: The Covenant on Civil and Political Rights* (Columbia University Press 1981)

Hobbes T, *Leviathan* (first published 1651 Penguin Classics 1985)

Hobbes T, *The Elements of Law*, *Human Nature and De Corpore Politico* (Gaskin, JCA (ed.) (Oxford University Press 2008)

Hochschild AR, *The Managed Heart: Commercialisation of Human Feeling* (University of California Press 2012)

Holland T, *Rubicon: The Triumph and Tragedy of the Roman Republic* (Abacus 2003)

Holt J, *How Children Fail* (Pitman Publishing Company 1964)

Honneth A, *The Struggle for Recognition: The Moral Grammar of Social Conflicts* (Polity Press 1996)

Honohan I, *Civic Republicanism* (Routledge 2002)

Hooks B, *Feminist Theory: From Margin to Center* (South End Press 1984)

Horkheimer M, Adorno TW, *Dialectics of Enlightenment* (Stanford University Press 2002)

Horkheimer M*, Critical Theory Selected Essays* (Continuum 2002)

Hornby G, *Inclusive Special Education: Evidence-based Practices for Children with Special Needs and Disabilities* (Springer 2014)

Hull J, *Touching the Rock: An Experience of Blindness* (Pantheon 1991)

Hunt P, Nowak M, Osmani S, *Human Rights and Poverty Reduction* (OHCHR 2003)

Hunt P, *Stigma: the experience of disability* (Geoffrey Chapman 1966)

Husserl E, *Cartesian Meditations* (Martinus Nijhoff 1960)

Husserl E, *Ideas Pertaining to a Pure Phenomenology and to a Phenomenological Philosophy* (Kluwer Academic Publishers 1998)

Husserl E*, Logical Investigations* (Routledge 2001)

Ignatieff M, *Isaiah Berlin: A Life* (Vintage 2000)

Illich I, *Deschooling Society* (Penguin 1973)

Illich I, *Medical Nemisis: The Expropriation of Health* (Pantheon 1982)

Illich I, *Limits to Medicine* (Marion Boyars Publishers 1995)

Inglis T, *Moral Monopoly: the Catholic Church in Modern Irish Society* (Gill and Macmillan 1987)

Ingram D, *Critical Theory and Philosophy* (Paragon 1990)

Ingram D*,* (ed.) *The Political* (Blackwell 2002)

Isadore of Seville, cited in Horcher F, *The Political Philosophy of the European Cit*y (Lexington Books 2021)

Israel J, *The Dutch Republic: its Rise, Greatness and Fall 1477 – 1806* (Oxford University Press 1995)

James A, Jenks, C, Prout A, *Theorising Childhood* (Polity Press 1998)

Jeffries S, *Grand Hotel Abyss* (Verso 2016)

Johnston D, *An Introduction to Disability Studies* (Routledge 1998)

Jones K, Fowles AJ, *Ideas on Institutions* (Routledge and Kegan Paul 1984)

Jose RT, *Understanding Low Vision* (American Foundation for the Blind 1989)

Kaam VA, *Existential Foundations of Psychology* (Image Books 1969)

Kant I, *Groundwork of the Metaphysics of Morals in Practical Philosophy* (Cambridge University Press 1996)

Kanter AS, *The Development of Disability Rights under International Law: From Charity to Human Rights* (Routledge 2014)

Kass LR, *Life, Liberty and the Defence of Dignity: The Challenge for Bioethics* (Encounter Books, 2002)

Keane J, *Tom Paine: A Political Life* (Bloomsbury 1996)

King S, *Writing the Lives of the English Poor 1750s – 1830s* (McGill - Queen's University Press 2019)

Kong C, *Mental Capacity in Relationship: Decision-Making, Dialogue and Autonomy* (Cambridge University Press 2017)

Kuhse H, Singer P, *Should the Baby Live? The Problems of Handicapped Infants* (Oxford University Press 1985)

Kuklys W, *Amartya Sen's Capability Approach: Theoretical Insights and Empirical Applications* (Springer 2005)

Kymlicka W, *Contemporary Political Philosophy* (Oxford University Press 2002)

Laborde C, *Critical Republicanism* (Oxford University Press 2008)

Laborde C, Maynor J, (eds) *Republicanism and Political Theory* (Blackwell 2008)

Ladd P, *Understanding Deaf Culture: In Search of Deafhood* (Multilingual Matters Ltd 2003)

Laird S, *Mary Wollstonecraft* (Bloomsbury 2008)

Lake P, *Anglicanism and Puritans? Presbyterianism and English Conformist Thought from Whitgift to Hooker* (Harper Collins 1988)

Langille B, *The Capability Approach to Labour Law* (Oxford University Press 2019)

Larson EJ, (ed) *Sex, Race and Science: Eugenics in the Deep South* (John Hopkins University Press 1996)

LaSpina N, *Such Aa Pretty Girl: A Story of Struggle, Empowerment and Disability Pride* (New Village Press, 2019)

Latimier C, Šiška J, *Children's rights for all! Implementation of the United Nations Convention on the Rights of the Child for Children with Intellectual Disabilities* (Inclusion Europe, 2011)

Laurterpacht H, *An International Bill of Rights* (Columbia University Press 1945)

Lee J, *Ireland 1912 – 1985: Politics and Society* (Cambridge University Press 1989)

Lemke T, *Foucault's Analysis of Modern Governmentality* (Verso 2019)

Levine P, *Eugenics: a Very Short Introduction* (Oxford University Press 2017)

Lewis, D, Convention (Harvard University Press 1983)

Locke J, *An Essay Concerning Human Understanding* (Penguin Books 1997)

Lombardo P, *Three Generations, No Imbeciles: Eugenics, the Supreme Court and Buck v Bell* (John Hopkins University Press 2008)

Lorde A, *Sister Outsider: Essays and Speeches* (Crossing Press 1984)

Louden R, *Kant's Impure Ethics: from Rational Beings to Human Beings* (Oxford University Press 2000)

Lovett F, *A General Theory of Domination and Justice* (Oxford University Press 2012)

Lyons FSL, *Ireland Since the Famine* (Harper Collins 1985)

Lyotard JF, *The Postmodern Condition: A Report on Knowledge* (Manchester University Press 1984)

MacPherson CB, *The Political Theory of Possessive Individualism: Hobbes to Locke* (Oxford University Press, 2010)

McDonnell P, *Disability and Society: Ideological and Historical Dimensions* (Blackhall Publishing 2007)

McLellan D, *Marx's Grundrisse* (Paladin, 1973

McMahan J, *The Ethics of Killing* (Oxford University Press, 2002)

Lois McNay *The Gender of Critical Theory* (Oxford University Press 2022)

Machiavelli N, *Discourses on Livy* (first published 1531 Oxford University Press 2003)

Machiavelli N, *The Prince* (first published 1532 Dover 1991)

Machiavelli N, *The History of Florence and the Affairs of Italy* (first published 1532 Renaissance Classics 2012)

MacIntyre A, *Against the Self-Images of the Age* (University of Notre Dame Press 1979)

Mackenzie C, Stoljar N, (eds) *Relational autonomy: Feminist perspectives on autonomy, agency, and the social self* (Oxford University Press 2000)

MacPherson CB, *The Political Theory of Possessive Individualism: Hobbes to Locke* (Oxford University Press 2010)

Manent P, *The Tragedy of the Republic* (Wiseblood Books, 2017)

Mansfield HC, *Machiavelli's Virtue* (University of Chicago Press 1996)

Marion JL, *Being Given* (Stanford University Press 2002)

Marshall BK, *Teaching the Postmodern* (Routledge 1992)

Marti JL, Pettit P, *A Political Philosophy in Public Life* (Princeton University Press 2010)

Marx K, *Economic and Philosophical Manuscripts of 1884* (first published 1932 International Publishers 1975)

Marx K, *Capital Vol 1 (*first published 1867 Penguin, 2004)

Marx K, Engels F, *The Communist Manifesto* (first published 1848 Vintage 2010)

Matthews E, *The Philosophy of Merleau-Ponty (*Taylor & Francis Group 2002)

Maynor JW, *Republicanism in the Modern World* (Polity Press 2003)

McDonnell P, *Disability and Society: Ideological and Historical Dimensions* (Blackhall Publishing 2007)

McLellan D, *Marx's Grundrisse* (Paladin 1973)

McMahan J, *The Ethics of Killing* (Oxford University Press 2002)

McRuer R, *Crip Theory: Cultural Signs of Queerness and Disability* (New York University Press 2006)

Merleau-Ponty M, *Phenomenology of Perception* (Routledge 2014)

Merleau-Ponty M, *The Visible and the Invisible* (Northwestern University Press 1968)

Meyers SJ, *Civilizing Disability Society* (Cambridge University Press 2019)

Miller P, Parker S, Gillinson S, *Disablism: How To Tackle The Last Prejudice* (Demos 2004)

Mills C*, Biopolitics* (Routledge 2018)

Mitchell DT, *Neoliberalism, Ablenationalism and Peripheral Embodiment* (University of Michigan Press 2015)

Mladenov T, *Critical Theory and Disability* (Bloomsbury 2016)

Mooij A, *Intentionality, Desire, Responsibility. A Study in Phenomenology, Phychoanalysis and Law* (Brill 2010)

Moran D, Mooney T, (eds.) *The Phenomenology Reader* (Routledge 2002)

More T, *Utopia* (first published 1516 Penguin, 2010)

Morris J, *Pride Against Prejudice* (Women's Press 1991)

Morris KJ, *Starting with Merleau-Ponty* (Bloomsbury 2012)

Moyn S*, Human Rights and the Uses of History* (Verso 2017)

Murphy C*, Are We Rome? The Fall of an Empire and the Fate of Americ*a (Houghton Mifflin Company 2007)

Myers SJ, *Civilizing Disability Society* (Cambridge University Press 2019)

Nelson E, *The Greek Tradition in Republican Thought* (Cambridge University Press 2004)

Nelson E, *The Hebrew Republic* (First Harvard University Press 2010)

Nirje B, (ed.) *The Normalization principle papers* (Uppsala: Centre for Handicap Research, Uppsala University 1992)

Norbrook D, *Writing the English Republic: Poetry, Rhetoric and Politic*s (Cambridge University Press 1999)

Nozick R, *Anarchy, State and Utopia* (Blackwell Publishing 1974)

Nussbaum M, *The Fragility of Goodness: Luck and Ethics in Greek Tragedy and Philosophy* (Cambridge University Press 1986)

Nussbaum M, *Love's Knowledge: Essays in Philosophy and Literature* (Oxford University Press 1990)

Nussbaum, M, *Women and Human Development: the Capabilities Approach* (Cambridge University Press 2000)

Nussbaum M, *Frontiers of Justice: Disability, Nationality, Species Membership* (The Belknap Press 2006)

Nussbaum M, *Hiding from Humanity: Disgust, Shame and the Law* (Princeton University Press 2006)

Nussbaum M, *Creating Capabilities: the Human Development Approach* (The Belknap Press 2011)

Nussbaum M, *Political Emotions: Why Love Matters for Justice* (The Belknap Press 2013)

Nussbaum M, Glover J, (eds) *Women, Culture and Development: a study of human capabilities* (Clarendon Press 1995)

O'Mahony C*, Education Rights in Irish Law* (Thomson Roundhall 2006)

O'Sullivan G, Sharman E and Short SD, (eds.) *Goodbye Normal Gene: Confronting the Genetic Revolution* (Pluto Press 1999)

O'Brien GV, F*raming the moron: the social construction of feeble mindedness in the American eugenic era* (Manchester University Press 2015)

Oliver M, Barnes C, *The New Politics of Disablement* (Palgrave McMillan 2012)

Oliver M, *The Politics of Disablement* (MacMillan, 1990)

Oliver M, *Understanding Disability: From Theory to Practice* (Macmillan, 1996)

Oliver M, *Understanding Disability: From Theory to Practice* (Palgrave Macmillan, 2009)

Olsen R and Clarke H, *Parenting and Disability. Disabled Parents' Experiences of Raising Children* (Bristol University Press, 2022)

O'Mahony C, *Education Rights in Irish Law* (Thomson Roundhall 2006)

Paine T, *Rights of Ma*n (first published 1791 Dover Publications 1999)

Paine T, *Collected Writings* (Penguin Putnam, 1955)

Paine T, *Common Sense* (first published 1776 Dolphin Classics 2023)

Parsons T, *The Social System* (Free Press 1951)

Patocka J, *Heretical Essays in the Philosophy of History* (Open Court 1996)

Peltonen M, *Classical Humanism and Republicanism in English Political Thought 1570 – 1640* (Cambridge University Press 1995)

Peoples K, *How to Write a Phenomenological Dissertation* (Sage 2021)

Peragine V, Biagi F, *Equality of Opportunity: Theory, Measurement and Policy Implications* (Publications Office of the European Union 2019)

Perry B*, In the Name of Hate: Understanding Hate Crimes* (Routledge 2001)

Perry B, (ed.) *Hate Crime Volume One: Understanding and Defining Hate Crime* (Praeger, 2009)

Peterson A, *Civic Republicanism and Civic Education* (Palgrave Macmillan 2011)

Pettit P*, Republicanism. A Theory of Freedom and Government* (Oxford University Press 1997)

Pettit P, *A Theory of Freedom: From the Psychology to the Politics of Agency* (Oxford University Press 2001)

Pettit P, *Made with Words: Hobbes on Language, Mind and Politics* (Princeton University Press 2009)

Pettit P, *On the People's Terms: a Republican Theory and Model of Democracy* (Cambridge University Press 2012)

Pettit P, *Just Freedom. A Moral Compass for a Complex World* (WW Norton 2014)

Pettit P, *The State* (Princeton University Press 2023)

Plamenatz J, *Machiavelli, Hobbes and Rousseau* (Oxford University Press 2012)

Plato, *The Laws* (Harmondsworth 1975)

Plato*, The Republic* (Penguin 1987)

Pocock JGA, (ed) *The Political Works of James Harrington* (Cambridge University Press 1977)

Pocock JGA*, The Machiavellian Moment* (Princeton University Press 2016)

Polybius *The Histories* (Harvard University Press 1929)

Popper K, *Unending Quest* (Routledge 1992)

Posner EA, *The Twilight of Human Rights* (Oxford University Press 2014)

Powell F, *The Politics of Civil Society* (The Policy Press 2013)

Power A, Lord JE, deFranco AS, *Active Citizanship and Disability: Implementing the Personalisation of Support* (Cambridge University Press, 2013)

Prak M, *The Dutch Republic in the Seventeenth Century (*Cambridge University Press 2005)

Priestly M, *Disability: A Life Course Approach* (Policy Press, 2003)

Putnam R, *Bowling Alone: The Collapse and Revival of American Community* (Simon and Schuster 2000)

Quarmby K, *Scapegoat: Why We Are Failing Disabled People* (Portobello 2011)

Raaflaub K, *The Discovery of Freedom in Ancient Greece* (University of Chicago Press 2004)

Raftery M, O'Sullivan E, *Suffer the Little Children: The Inside Story of Ireland's Industrial Schools* (New Island Press 1999)

Rahe PA, *Against Throne and Alter* (Cambridge University Press 2008)

Ranciere J, *The Emancipated Spectator* (Verso 2009)

Rawls J, *A Theory of Justice* (Harvard University Press 1971)

Rawls J, *A Theory of Justice* (2nd edition Belknap Press 1999)

Rawls J, *Justice As Fairness: A Restatement* (The Belknap Press, 2001)

Rawls J, *The Law of Peoples* (Harvard University Press 2001)

Rawls J, *Political Liberalism* (Columbia University Press 2005)

Raz J, *The Morality of Freedom* (Oxford University Press 1986)

Raz J, *Ethics in the Public Domain: Essays in the Morality of Law and Politics* (Oxford University Press 1995)

Reidy C, *Ireland's 'Moral Hospital': The Irish Borstal System 1906 – 1956* (Irish Academic Press 2009)

Ricciardelli F, *The Myth of Republicanism in Renaissance Italy* (Brepols 2015)

Rich A, *Compulsory Heterosexuality and Lesbian Existence* (Onlywomen Press 1980)

Ricoeur P, *Oneself as Another* (University of Chicago Press 1992)

Riddle CA, *Disability and Justice: The Capabilities Approach in Practice* (Livingston Books 2014)

Rimmerman A, *Disability and Community Living Policies* (Cambridge University Press 2017)

Robins J, *The Lost Children: a study of charity children in Ireland 1700 – 1900* (Institute of Public Administration 1980)

Robins J, *Fools and Mad: History of the Insane in Ireland* (Institute of Public Administration 1986)

Rockmore T, *On Constructivist Epistemology* (Rowman & Littlefield 2005)

Rogers C, *The Carl Rogers Reader* (Constable 1990)

Rosen M, *Dignity: its History and Meaning* (Harvard University Press, 2012)

Rosenfeld M, Arato A, (eds) *Habermas on Law and Democracy: Critical Exchanges* (University of California Press 1998)

Rothman D, *Discovery of the Asylum: Social Order and Disorder in the New Republic* (Little Brown 1971)

Roulstone A, Mason-Bish H, (eds.) *Disability, Hate Crime and Violence* (Routledge 2014)

Rousseau JJ, *the Social Contract* (first published 1762 Wordsworth 1998)

Rowell M, *Blind Spot* (Inklings 2021)

Ryan A, *On Politics* (Penguin Books 2012)

Ryan A, The Making of Modern Liberalism (Princeton University Press 2012)

Ryan A, *On Hobbes* (Liveright Publications 2016)

Ryan A, *Walls of Silence: Ireland's Policy Towards People with a Mental Disability* (Red Lion Press 1999)

Ryan J, Thomas F, *The Politics of Mental Handicap* (Penguin 1980)

Sacks O, *The Mind's Eye* (Picador 2010)

Said E, *Orientalism* (Penguin Books 2003)

Sandel M, *Democracy's Discontent: America in search of a political philosophy* (Harvard University Press 1996)

Sandel M, *The Tyranny of Merit* (Allen Lane 2020)

Sapiro V, *A Vindication of Political Virtue: The Political Theory of Mary Wollstonecraft* (The University of Chicago Press 1992)

Sargent P, *Wild Arabs and Savages (*Manchester University Press 2014)

Scarborough C, *Viewing Disability in Medieval Spanish Texts* (Amsterdam University Press 2018)

Schilling C, *The Body and Social Theory* (Sage 1993)

Schillmeier M, *Rethinking Disabilit*y: Bodies, Senses and Things (Routledge 2010)

Schneewind JB, *The Invention of Autonomy* (Cambridge University Press 1998)

Schon DA, *The Reflective Practitioner: How Professionals Think in Action* (Basic Books 1983)

Schweik SM, *The Ugly Laws: Disability in Public* (New York University Press 2009)

Schweppe J, Haynes A, Carr J, *A Life Free from Fear: Legislating for Hate Crime in Ireland: An NGO Perspective* (University of Limerick 2014)

Scott J, *Commonwealth Principles: Republican Writing of the English Revolution* (Cambridge University Press 2004)

Scott RA, *The Making of Blind Men: a Study of Adult Socialisation* (Sage 1969)

Scull A, *The Most Solitary of Afflictions: Madness and Society in Britain 1700 – 1900* (Yale University Press 2005)

Sellers J, *Stoicism* (Routledge 2014)

Sellers J, (ed) *The Routledge Handbook of the Stoic Tradition* (Routledge 2016)

Sen A, *Poverty and Famines: An Essay on Entitlement and Deprivation* (Oxford University Press 1981)

Sen A, *Resources, Values and Development* (Basil Blackwell 1984)

Sen A, *Inequality Re-examined* (Oxford University Press 1992)

Sen A*, Development as Freedom* (Oxford University Press 1999)

Sen A, *Freedom, Rationality and Social Choice* (Oxford University Press 2001)

Sen A, *Rationality and Freedom* (Harvard University Press 2004)

Sen A, *Identity and Violence: The Illusion of Destiny* (Penguin Books 2007)

Sen A, *The Idea of Justice* (Penguin Books 2009)

Sennett R, *The Fall of Public Man* (W W Norton and Company 1992)

Shakespeare T*, Disability Rights and Wrongs Revisited* (Routledge 2014)

Shaw C, *Reason and Experience in Renaissance Italy* (Cambridge University Press 2021)

Sherry M, *Disability Hate Crimes: Does Anyone Really Hate Disabled People?* (Ashgate 2010)

Shilling C, *The Body and Social Theory* (Sage 1993).

Shue H, *Basic Rights: Subsistence, Affluence and U.S. Foreign Policy* (Princeton University Press 1996)

Siebers T, *Disability Theory* (The University of Michigan Press 2008)

Singer P, *Practical Ethics* (Cambridge University Press 1979)

Singer P, Kuhse H, *Should the Baby Live? The Problem of Handicapped Infants* (Oxford University Press 1985)

Skinner Q, *The Foundations of Modern Political Thought. Volume One: The Renaissance* (Cambridge University Press 1978)

Skinner Q, *Liberty Before Liberalism* (Cambridge University Press 1998)

Skinner Q, *Visions of Politics Vol 2 Renaissance Virtues* (Cambridge University Press 2002)

Skinner Q, *Visions of Politics Vol 3 Hobbes and Civil Science* (Cambridge University Press 2002)

Skinner Q, *Hobbes and Republican Liberty* (Cambridge University Press 2008)

Smart C, *Feminism and the Power of Law* (Routledge 1989)

Smith GB, *Political Philosophy and the Republican Future* (University of Notre Dame, 2018)

Smyth J, Hattam R, '*Dropping out', Drifting Off, Being Excluded: Becoming Somebody Without School* (Peter Lang 2004)

Soldatic K, *Disability and Neoliberal Formations* (Routledge 2019)

Stein E, *On the Problem of Empathy* (ICS Publications 1989)

Stiker HJ, *A History of Disability* (The University of Michigan Press 1999)

Stilz A, *Liberal Loyalty: Freedom, Obligation and the State* (Princeton University Press 2009)

Strunk TE, *On the Fall of the Roman Republic : Lessons for the American People* (Anthem Press 2022)

Strydom P, *Contemporary Critical Theory and Methodology* (Taylor and Francis 2011)

Sue DW (ed) *Microagreesions and Marginality* (Wiley 2010)

Sue DW, Spanierman LB, *Microaggressions in Everyday Life* (Wiley 2020)

Sullivan VB, *Machiavelli, Hobbes and the Formation of a Liberal Republicanism in England* (Cambridge University Press 2004)

Sunstein C, *Free Markets and Social Justice* (Oxford University Press 1997)

Tampio N, *Kantian Courage* (Fordham University Press 2012)

Taylor C*, Philosophy and the Human Sciences: Philosophical Papers 2* (Cambridge University Press 1985)

Taylor C, *Sources of the Self: The Making of the Modern Identity* (Harvard University Press 1989)

Taylor RS, *Exit Left: Markets and Mobility in Republican Thought* (Oxford University Press 2017)

Taylor S, *Responding to Racist Incidents and Crime: An Issues Paper for the Equality Authority* (Equality Authority 2011).

Taylor S, *Hate Crime Policy and Disability* (Bristol University Press 2022)

Thevenaz P, What Is Phenomenology? (Quadrangle Books 1962)

Thomas C, *Female Forms: Experiencing and Understanding Disability* (Open University Press 1999)

Titchkosky T, *Disability, Self and Soci*ety (University of Toronto Press 2003)

Tocqueville A de, *Democracy in Americ*a (first published 1835/1840 University of Chicago 2000)

Tomlin G, *Bound To Be Free* (Bloomsbury 2017)

Topliss E, *Provision for the Disabled* (Blackwell, 1979)

Townsend P, *The Last Refuge: a survey of residential institution sand homes for the aged in England and Wales* (Routledge and Kegan Paul 1962)

Toynbee A, *A Study of History* (Oxford University Press 1954)

Tremain S, *Foucault and the Government of Disability* (University of Michigan Press, 2015)

Twomey M, Carroll C, (eds) *Seen and Heard: Exploring Participation, Engagement and Voice for Children with Disabilities* (Peter Lang 2018)

Vagle MD*, Crafting Phenomenological Research* (Routledge 2018)

Vanhala L, *Making Rights a Reality? Disability Rights Activists and Legal Mobilization* (Cambridge University Press, 2011)

Van Manen M, *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy* (Routledge 2016)

Van Parijs P, *Real Freedom for All: what (if anything) can justify capitalism?* (Clarendon Press, 1995)

Ventegodt Liisberg M, *Disability and Employment: A Contemporary Disability Human Rights Approach Applied to Danish, Swedish and EU Law and Policy* (Intersentia 2011)

Waddington L, Broderick A, *Promoting Equality and Non-Discrimination for Persons with Disabilities* (Council of Europe 2017)

Waddington L, Broderick A, *Combatting disability discrimination and realising equality: A comparison of the UN CRPD and EU equality and non-discrimination law* (European Commission 2018)

Waldron J, *Dignity, Rank and Rights* (Oxford University Press 2012)

Walters MD, A*. V. Dicey and the Common Law Constitutional Position: A Legal Turn of Mind* (Cambridge University Press 2020)

Warnock M, Norwich B, *Special Education Needs: A New Look* (Continuum 2005)

Watts E, *Mortal Republic: How Rome Fell into Tyranny* (Basic Books 2018)

Weber M, *Economy and Society* (first published 1922 University of California Press 1978)

Weber M, *The Protestant Ethic and the 'Spirit' of Capitalism and Other Writings* (Penguin Books 2002)

Weiss G, Murphy AV, Salamon G, (eds.) *50 Concepts for a Critical Phenomenology* (Northwestern University Press 2020)

Wheatley E, *Stumbling Blocks Before the Blind: Medieval Constructions of a Disability* (University of Michigan Press 2010)

Williams-Findlay B, *Disability Praxis: The Body as a Site of Struggle* (Pluto Press, 2024

Whyte G, *Social Inclusion and the Legal System. Public Interest Law in Ireland* (IPA 2015)

Wilkinson R, *Minds and Bodies* (The Open University 2002)

Williams DL*, Rousseau's Social Contract: an introduction* (Cambridge University Press 2014)

Williams R, *Marxism and Literature (*Open University Press 1977)

Winship MP, *Godly Republicanism. Puritans, Pilgrims and a City on a Hill* (Harvard University Press 2012)

Wirszubski C, *Libertas as a Political Idea at Rome during the Late Republic and Early Principate* (Cambridge University Press 1950)

Wisnewski JJ*, Heidegger: An Introduction* (Rowman & Littlefield Publishers 2013)

Wolfe L, Copeland L, *Violence Against Women as Bias Motivated Hate Crime* (Centre for Women Policy Studies 1991)

Wolfensberger W, *The Principle of Normalization in Human Services* (National Institute on Mental Retardation 1972)

Wolfensberger W, *The SRV training package* (unpublished 1995)

Wolfensberger W, *A brief introduction to Social Role Valorization: A high-order concept for addressing the plight of societally devalued people, and for structuring human services* (Plantagenet 2014)

Wolfensberger W, *Thomas S, PASSING (Program Analysis of Service Systems' Implementation of Normalization Goals): Normalization criteria and ratings manual (*National Institute on Mental Retardation 1983)

Wolin R, *The Terms of Cultural Criticism: The Frankfurt School, Existentialism, Poststructuralism* (Columbia University Press 1992)

Wollstonecraft M, *A Vindication of the Rights of Women* (first published 1792 Penguin 2004)

Wood N, *Cicero's Social and Political Thought* (University of Berkley 1991)

Young IM, *Justice and the Politics of Difference* (Princeton University Press 1990)

Zahavi D, *Husserl's Legacy: Phenomenology, Metaphysics and Transcendental Philosophy* (Oxford University Press 2017)

Zahavi D, *Phenomenology: The Basics* (Routledge, 2019)

Zola IK, *Missing Pieces: a Chronicle of Living with a Disability* (Temple University Press, 1982)

Chapters in Books

Albert B, Harrison M, 'Lessons from the Disability Knowledge and Research Programme' in Albert B, (ed) *In or Out of the Mainstream? Lessons from Research on Disability and Development Co-operation* (Disability Press 2006)

Allen B, 'Foucault's Nominalism' in Tremain S, (ed) *Foucault and the Government of Disability* (University of Michigan Press, 2015)

Arduin S, 'Article 3 General Principles' in Bantekas I, Stein MA, Anastasiou D, (eds) *The UN Convention on the Rights of Persons with Disabilities. A Commentary* (Oxford University Press 2018)

Arnardottir OM, 'A Future of Multidimensional Disadvantage Equality' in Arnardottir OM, Quinn G, (eds) *The UN Convention on the Rights of Persons with Disabilities* (Matinus Nijhoff Publishers, 2009)

Bantekas I, Pennilas F, Tromel S, 'Article 27 Work and Employment' in Banktekas I, Stein MA, Anastasiou D, (eds) *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018)

Bauman DL, Murray JJ, 'Deaf Studies in the 21st Century: 'Deaf-Gain' and the Future of Human Diversity' in Davis LJ (ed) *The Disability Studies Reader* (Routledge, 2017)

Bayefsky AF, 'The Principle of Equality or Non-Discrimination in International Law' in Farrior S, (ed) *Equality and Non-Discrimination Under International Law Volume ii* (Routledge 2015)

Bellamy R, 'Republicanism, Democracy and Constitutionalism' in Laborde C, Maynor J, (eds) *Republicanism and Political Theory* (Blackwell, 2008)

Bell C, 'Is Disability Studies Actually White Disability Studies?' in J. Davis LJ, (ed) *The Disability Studies Reader* (Routledge, 2017)

Berger RJ, Lorenz LS, 'Disability and Qualitative Research' in Berger RJ, Lorenz LS, (eds) *Disability and Qualitative Inquiry* (Routledge, 2015)

Bohman J, 'Nondomination and Transnational Democracy' in Labordre C, John Mayno J, (eds) *Republicanism and Political Theory* (Blackwell, 2008)

Bourdieu P, 'Cultural reproduction and social reproduction' in Brown R, (ed) *Knowledge, Education and Cultural Change: papers in the sociology of education* (Tavistock, 1973)

Broderick A, 'The Right to Inclusive Education: Article 24 of the UN Convention on the Rights of Persons with Disabilities and the Irish Experience' in de Londras F, Mullally S, (eds) *The Irish Yearbook of International Law Vol. 9 2014* (Hart Publishing, 2017)

Broderick A, 'Article 7 UN CRPD: Children with Disabilities' in Della Fina V, Cere R, Palmisano G, (eds) *The United Nations Convention on the Rightts of Persons with Disabilities: A Commentary* (Springer, 2017)

Brune JA, Wilson DJ, ‘Introduction’ in Brune JA, Wilson DJ, (eds) *Disability and Passing* (Temple University, 2013)

Butler J, ‘Bodies That Matter’ in Price J, Shildrick M, (eds) *Feminist Theory and the Body: A Reader* (Routledge 1999)

Chappell AL, ‘From Normalisation to Where?’ in Barton L, Oliver M, (eds) *Disability Studies: Past, Present and Future* (The Disability Press, 1997)

Chataika T, ‘Disability, Development and Postcolonialism’ in Goodley D, Hughes B, Davis L, (eds) *Disablity and Social Theory* (Palgrave Macmillan, 2012)

Coats Junior WJ,’ Groundwork for a Theory of Republican Character in a Democratic Age’ in Kellow GC, Leddy N, (eds) *On Civic Republicanism: Ancient Lessons for Global Politics* (University of Toronto Press, 2016)

Colella AJ, Bruyère SM, ‘Disability and Employment’ in Zedeck S, (ed) *APA Handbook of Industrial and Organizational Psychology* Vol. 1 (American Psychological Association, 2011)

Corker M, Shakespeare T, ‘Mapping the Terrain’ in Corker M, Shakespeare T, (eds) *disability/postmodernity* (Continuum, 2006)

Crocker DA, ‘Functioning and Capability: The Foundations of Sen and Nussbaum’s Development Ethic, Part 2’ in Nussbaum M, Glover J, (eds) *Women, Culture and Development: A Study of Human Capabilities* (Oxford University Press, 1995)

Davis LJ, ‘Introduction: the need for disability studies’ in Davis LJ, (ed) *The Disability Studies Reader* (Routledge, 1997)

de Beco G, ‘Comprehensive Legal Analysis of Article 24 of the Convention on the Rights of Persons with Disabilities’ in de Beco G, Quinlivan S, Lord JE, (eds) *The Right to Inclusive Education in Human Rights Law* (Cambridge University Press, 2019

Degener T, ‘A New Human Rights Model of Disability’ in Della Fina V, Cera R, Palmisano G, (eds) *The United Nations Convention on the Rights of Persons with Disabilities. A Commentary* (Springer, 2017)

Degener T, Begg A, ‘From Invisible Citizens to Agents of Change: A Short History of the Struggle for the Recognition of the Rights of Persons with Disabilities at the United Nations’ in Della Fina V, Cera R,

Palmisano G, (eds) *The United Nations Convention on the Rights of Persons with Disabilities. A Commentary* (Springer, 2017)

Della Fina V, ‘Article 3 [General Principles’ in Della Fina V, Cera R, Palmisano G, (eds) *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer, 2017)

Della Fina V, ‘Article 24 [Education]’ in Della Fina V, Cera R, Palisano G, (eds) *The United Nations Convention on the Rights of Persons with Disabilities* (Springer, 2017)

Devlin R, Pothier D, ‘Introduction: Towards a Theory of Dis-Citizenship’ in Devlin R, Pothier D (eds) *Critical Disability Theory. Essays in Philosophy, Politics and Law* (UBC Press, 2006)

Diderot D, ‘Letter on the Blind for the Use of Those Who See’ (first published 1749) in Crocker LG, (ed) *Diderot’s Selected Writings* (Macmillan 1966)

Digby A, ‘Contexts and perspectives’ in Wright D, Digby A, (eds) *Historical Perspectives on People with Learning Disabilities* (Routledge, 1996)

Ellis E, ‘The Principle of Equality of Opportunity Irrespective of Sex: Some Reflections on the Present State of European Community Law and its Future’ in Dashwood A, O’Leary S, (eds) *The Principle of Equal Treatment in EC Law* (Sweet & Maxwell 1997)

Emmett T, ‘Disability and Poverty’ in Alant E, Lloyd L, (eds) *Augmentative and Alternative Communication and Severe Disabilities: Beyond Poverty* (Whurr Publishers 2005)

Fasciglione M, ‘Article 27 of the CRPD and the Right of Inclusive Employment of People with Autism’ in Della Fina V, Cera R, (eds) *Protecting the Rights of People with Autism in the Fields of Education and Employment* (Springer, 2015)

Felder F, ‘Inclusion and the Good Human Life’ in Jerome E Bickenback JE, Felder F, Schmitz B, (eds) *Disability and the Good Human Life* (Cambridge University Press, 2014)

Ferri D, ‘The Past, Present and Future of the Right to Inclusive Education in Italy’ in de Beco G, Quinlivan S, Lord JE, (eds) *The Right to Inclusive Education in Human Rights Law* (Cambridge University Press, 2019)

Fiala-Butora J, Rimmerman A, Gur A, ‘Living Independently and Being Included in the Community’ in Bantekas I, Stein MA, Anastasiou D, (eds) *The UN Convention on the Rights of Persons with Disabilities* (Oxford University Press 2018)

Fineman MA, ‘Equality, Autonomy and the Vulnerable Subject in Law and Politics’ in Fineman MA, Grear A, (eds) *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics* (Ashgate 2013)

Finklestein V, ‘Disability: An Administrative Challenge? (the Health and Welfare Heritage)’ in Oliver M, (ed) *Social Work: Disabled People and Disabling Environments* (Athenaeum Press 1991)

Fisher L, ‘The Illness Experience’ in Zeiler K, Folkmarson Kall L, (eds.) *Feminist Phenomenology and Medicine* (SUNY Press, 2014)

Foucault M, ‘Two Lectures’ in Gordon C, (ed) *Power/Knowledge: Selected Interviews and Other Writings 1972-1977* (Vintage Books 1980)

Foucault M, ‘The Subject and Power’ in Drayfus HL, Rabinow P, (eds) *Michel Foucault: Beyond Structuralism and Hermeneutics* (University of Chicago Press 1982)

Foucault M, ‘Technologies of the self’ in Martin LH, Gutman H, Hutton PH, (eds) *Technologies of the Self: a Seminar with Michel Foucault* (University of Massachusetts Press 1988)

Foucault M, ‘Governmentality’ in Faubian JD, (ed) Michel Foucault: Power: Essential Works of Foucault 1954 – 1984 Volume 3 (Penguin Books, 2000)

Foucault M,’ Right of Death and Power over Life’ in Campbell T, Sitze A, (eds) *Biopolitics: A Reader* (Duke University Press 2013)

Fredman S, ‘Disability Equality: A Challenge to the Existing Anti-Discrimination Paradigm’ in Lawson A, Gooding C, (eds) *Disability Rights in Europe: From Theory to Practice* (Hart, 2005)

Friedman M, ‘Pettit’s Civic Republicanism and Male Domination’ in Laborde C, Maynor J, (eds) *Republicanism and Political Theory* (Blackwell, 2008)

Frohmader C, Meekosha H, ‘Recognition, Respect and Rights: Women with Disabilities in a Globalised World’ in Goodley D, Hughes B, Davis L, (eds) *Disability and Social Theory* (Palgrave Macmillan, 2012)

Garrau M, Laborde C, ‘Relational Equality, Non-Domination and Vulnerability’ in Fourie C, Schuppert F, Wallimann- Helmer I, (eds) *Social Equality: On What it Means to be Equals* (Oxford University Press, 2015)

Grear A, 'Vulnerability, Advanced Global Capitalism and Co-symptomatic Injustice: Locating the Vulnerable Subject' in Fineman MA, Grear A, (eds) *Vulnerability* (Ashgate 2013)

Green SE, 'Staying True to Their Stories: Interviews with Parents of Children with Disabilities' in Berger RG, Lorenz LS, (eds) *Disability and Qualitative Inquiry* (Routledge, 2015)

Hahn H, 'Adjudication or empowerment: contrasting experiences with a social model of disability' in Barton L, (ed) *Disability, Politics and the Struggle for Change* (David Fulton Publishers 2001)

Halldenius L, 'Mary Wollstonecraft and Freedom as Independence' in Broad J, Detlefsen K, (eds) *Women and Liberty 1600 – 1800: Philosophical Essays* (Oxford University Press, 2017)

Hankins J, 'Introduction' in Hankins J, (ed) *Renaissance Civic Humanism: Reappraisals and Reflections* (Cambridge University Press 2000)

Hasler F, 'Developments in the disabled people's movement' in Swain J, Finklestein V, French S, Oliver M, (eds) *Disabling Barriers, Enabling Environments* (Sage Publications, 1993)

Hattersley J, 'The future of normalisation' in Baldwin S, Hattersley J, (eds) *Mental Handicap: Social Science Perspectives* (Tavistock Routledge 1991)

Hazareesingh S, 'The Utopian Imagination: Radical Republican Traditions in France, from the Enlightenment to the French Communists' in Leipold B, Nabulsi K, White S, (eds) *Radical Republicanism: Recovering the Tradition's Popular Heritage* (Oxford University Press 2020)

Higgins W, 'To him that hath . . . : the welfare state' in Kennedy R, (ed) *Australian Welfare History: Critical Essays* (Macmillan, 1982)

Hirschmann NJ, 'Rawls, Freedom and Disability. A Feminist Rereading' in Ruth Abbey R, (ed) *Feminist Interpretations of John Rawls* (The Pennsylvania State University Press 2013)

Honohan I, 'Educating citizens: nation-building and its republican limits' in Honohan I, Jennings J, (eds) *Republicanism in Theory and Practice* (Routledge, 2006)

Honohan I, 'Republicans, Rights, and Constitutions: Is Judicial Review Compatible with Republican Self-Government' in Besson S, Marti JL, (eds) *Legal Republicanism* (Oxford University Press 2009)

Hughes B, 'Civilising Modernity and the Ontological Invalidation of Disabled People' in Goodley D, Hughes B, Davis L, (eds) *Disability and Social Theory* (Palgrave Macmillan 2012)

Hughes B, 'Invalidating Emotions in the Non-Disabled Imaginary' in Watson, N, Vehmas S, (eds) *Routledge Handbook of Disability Studies* (Routledge 2020)

Hull R, 'Disability and Freedom' in Kristiansen K, Vehmas S, Shakespeare T, (eds) *Arguing About Disability* (Routledge, 2009)

Ikaheimo H, 'Personhood and the Social Inclusion of Persons with Disabilities: A Recognition-Theoretical Approach' in Kristansen K, Vehmas S, Shakespeare T, (eds) *Arguing About Disability: Philosophical Perspectives* (Routledge, 2009)

Kayess R, Green J, 'Today's Lesson is on diversity' in Blanck P, Flynn E, (eds) *Routledge Handbook of Disability Law and Human Rights* (Routledge, 2017)

Kellow, GC, 'Introduction' in In Kellow GC, Leddy N, (eds) *On Civic Republicanism* (University of Toronto Press 2016)

Keogh M, 'Disability, Gender and Development' in O'Mahony C, Quinn G, *Disability Law and Politics: An Analysis of the UN Convention* (Clarus Press, 2017)

Kymlicka W 'Liberal Egalitarianism and Civic Republicanism: Friends or Enemies?' in Allen AL, Regan MC, (eds) *Debating Democracy's Discontent: Essays on American Politics, Law and Public Philosophy* (Oxford University Press 1998)

Lawson A, 'Duties to Make Adjustments and Human Rights' in Lawson A, (ed) *Disability and Equality Law in Britain: The Role of Reasonable Adjustment* (Hart Publishing, 2008)

Lawson A, 'Reasonable Accommodation in the Convention on the Rights of Persons with Disabilities and Non-discrimination in Employment: Rising to the Challenges?' in O'Mahony C, Quinn G, (eds) *Disability Law and Policy: An Analysis of the UN Convention* (Clarus Press, 2017)

Lawson A, Priestley M, 'The Social Model of Disability: Questions for Law and Legal Scholarship?' in Blanck P, Flynn E, (eds) *Routledge Handbook of Disability Law and Human Rights* (Routledge 2017)

Lee TML, 'Multicultural Citizenship: the Case of the Disabled' in Pothier D, Devlin R, (eds) *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law* (UBC Press 2003)

Lord JE, Brown R, 'The Role of Reasonable Accommodation in Securing Substantive Equality for Persons with Disabilities: The UN Convention on the Rights of Persons with Disabilities' in Rioux MH, Basser LA, Jones M, (eds) *Critical Perspectives on Human Rights and Disability Law* (Martinus Nijhoff Publishers, 2011)

Luddy M, 'Gender and Irish Society' in Jackson A, (ed) *The Oxford Handbook of Modern Irish History* (Oxford University Press 2014)

Lueck AH, 'Comprehensive Low Vision Care' in Lueck AH, (ed) *Functional Vision: A Practitioner's Guide to Evaluation and Intervention* (AFB Press, 2004)

Meekosha H, Shuttleworth R, 'What's so "Critical" about Critical Disability Studies?' in Davis LJ (ed) *The Disabilities Studies Reader* (Routledge 2017)

Moran D, 'Editor's Introduction' in Moran D, Mooney T, (eds) *The Phenomenological Reader* (Routledge, 2002)

Moran D, 'Between Vision and Touch: From Husserl to Mearleau-Ponty' in Kearney R, Treanor B, (eds) *Carnal Hermeneutics* (Fordham University Press, 2015)

Mundlak G, 'Working Out the Right to Work in a Global Labour Market' in Mantouvalou V, (ed) *The Right to Work, Legal and Philosophical Perspectives* (Hart Publishing 2015)

Nirje B, 'The Normalization principle and its human management implications' in Kugel RB, Wolfensberger W, (eds) *Changing patterns in residential services for the mentally retarded* (President's Committee on Mental Retardation 1969)

Nirje B, 'Introduction' in Nirje B, (ed)*The Normalization principle papers* (Uppsala Centre for Handicap Research, Uppsala University 1992)

Nirje B, 'How I Came to Formulate the Normalization Principle' in Flynn RJ, Lemay RA, (eds) *A Quarter Century of Normalization and Social Role Valorization: Evolution and Impact* (University of Ottawa Press 1999)

Novis A, 'Disability hate crime; a campaign perspective' in Roulstone A, Mason-Bish H, (eds) *Disability, Hate Crime and Violence* (Routledge 2014)

Nussbaum M, 'Human capabilities, female human beings' in Nussbaum M, Glover J, (eds) *Women, Culture and Development: a study of human capabilities* (Clarendon Press 1995)

O'Cinneide C, 'Extracting Protection for the Rights of Persons with Disabilities' in Arnardottir OM, Quinn G, (eds) *The UN Convention on the Rights of Persons with Disabilities* (Matinus Nijhoff Publishers, 2009)

O'Cinneide C, 'The Right to Work in International Human Rights Law' in Mantouvalou V, (ed) *The Right to Work, Legal and Philosophical Perspectives* (Hart Publishing 2015)

O'Shea T, 'Civic Republican Disability Justice' in Cureton A, Wasserman D, (eds) *The Oxford Handbook of Philosophy and Disability* (Oxford University Press 2020)

Oliver M, 'Disability and Dependency: a Creation of Industrial Societies?' in Barton L, (ed) *Disability and Dependency* (The Falmer Press, 1989)

Oliver M, 'Capitalism, disability and ideology: a materialist critique of the normalization principle' in Flynn RJ, Lemay RA, (eds) *A Quarter Century of Normalization and Social Role Valorization: Evolution and Impact* (University of Ottawa Press 1999)

Palmisano G, 'Article 19 [Living Independently and Being Included in the Community]' in Della Fina V, Cera R, Palmisano G, (eds) *The United Nations Convention on the Rights of Persons with Disabilities. A Commentary* (Springer, 2017)

Perrin B,'The original "Scandinavian" Normalization principle and its continuing relevance for the 1990s' in Flynn RJ, Lemay RA, (eds) *A Quarter Century of Normalization and Social Role Valorization: Evolution and Impact* (University of Ottawa Press 1999)

Perry B, 'The sociology of hate: Theoretical approaches' in Perry B, (ed) *Hate Crime Volume One: Understanding and Defining Hate Crime* (Praeger 2009)

Pettit P, 'Republican Freedom and Contestatory Democratisation' in Shapiro I, Hacker-Cordon C, (eds) *Democracy's Value* (Cambridge University Press 1999)

Pettit P, 'Freedom in the Spirit of Sen' in Morris C, (ed) *Amartya Sen* (Cambridge University Press, 2010)

Pettit P, 'Two Republican Traditions' in Niederberger A, Schink P, (eds) *Republican Democracy: Liberty, Law and Politics* (Edinburgh University Press 2013)

Pettit P, 'The General Will, the Common Good, and a Democracy of Standards' in Elazer Y, Rousseliere G, (eds) *Republicanism and the Future of Democracy* (Cambridge University Press 2019)

Pinheiro LG, 'The Ableist Construct' in Arneil B, Hirschmann NJ, (eds) *Disability and Political Theory* (Cambridge University Press 2016)

Pradella L, 'Beyond Improvishment: Western Europe in the World Economy' In Pradella L, Marois T, (eds) *Polarising Development* (Pluto Press, 2015)

Proctor RN, 'Eugenics in Hitler's Germany' in Ryan DF, Schuchman JS (eds) *Deaf People in Hitler's Europe* (Gallaudet University Press 2002)

Procyshyn A, 'Phenomenology and Critical Theory' in De Santis D, Hopkins BC, Majolino C, (eds) *The Routledge Handbook of Phenomenological Philosophy* (Routledge, 2021)

Quarmby K, 'Media reporting and disability hate crimes' Roulstone A, Mason-Bish H, (eds) *Disability, Hate Crime and Violence* (Routledge 2014)

Ramcharan BC, 'Equality and Non-Discrimination' in Henkin L, (ed) *The International Bill of Rights: The Covenant on Civil and Political Rights* (Columbia University Press 1981)

Reeve D, 'Biopolitics and bare life: does the impaired body provide contemporary examples of *homo sacre?*' in Kristiansen K, Vehmas S, Shakespeare T, (eds) *Arguing About Disabilities* (Routledge, 2010)

Reuber M, 'Moral Management and the 'Unseen Eye': Public Lunatic Asylums in Ireland 1800 – 1845' in Jones G, Malcolm E, (eds) *Medicine, Disease and the State in Ireland 1650 – 1940* (Cork University Press 1999)

Rioux MH, Valentine F, ‘Does theory matter? Exploring the Nexus between Disability, Human Rights and Public Policy’ in Pothier D, Devlin R, (eds) *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law* (UBC Press 2003)

Rix J, Walsh C, Parry J, Kumrai R, ‘Introduction Another point of view’ In Rix J, Nind M, Sheehy K, Simmons K, Walsh C. (eds) *Equality, Participation and Inclusion 1: Diverse Perspectives* (Routledge, 2010)

Robeyns I, ‘Gender and the metric of justice’ In Brighouse H, Robeyns I, (eds) *Measuring Justice. Primary Goods and Capabilities* (Cambridge University Press, 2010)

Rogers C, ‘A Theory of Therapy, Personality, and Interpersonal Relationships as Developed in the Client-centered Framework’ in Koch S, (ed) *Psychology: A study of a Science, Vol. 3: Formulations of the Person and the Social context* (McGraw Hill, 1959)

Roulstone R, Sadique K, ‘Vulnerable to misinterpretation: disabled people, ‘vulnerability’, hate crime and the fight for legal recognition’ in Roulstone A, Hannah Mason-Bish H, (eds) *Disability, Hate Crime and Violence* (Routledge 2013)

Ruffer GB, ‘Legal Modes and Democratic Citizens in Republican Theory’ in Niedberger A, Schink P, (eds) *Republican Democracy: Liberty, Law and Politics* (Edinburgh University Press, 2015)

Said EW, ‘Orientalism Reconsidered’ in Robertson R, White KE, (eds) *Globalisation*. *Critical Concepts in Sociology* Vol v (Routledge 2003)

Schemmel C, ‘Social Equality – Or Just Justice’ in Fourie C, Schuppert F, Wallimann- Helmer I, (eds) *Social Equality: On What it Means to be Equals* (Oxford University Press 2015)

Seatzu F, ‘Article 9 [Accessibility]’ in Della Fina V Cera R, Palmisano G, (eds) *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer 2017)

Sen A, ‘Capabilities and Well-Being’ in Nussbaum M, Sen A, (eds) *The Quality of Life* (Oxford University Press 1993)

Sen A, ‘Equality of What?’ in Darwall S, (ed) *Equal Freedom. Selected Tanner Lectures on Human Values* (University of Michigan Press 1995)

Shakespeare T, ‘Cultural Representations of Disabled People: Dustbins of Disavowal? In Barton L, Oliver M, (eds) *Disability Studies: Past, Present and Future* (Disability Press, 1997)

Shakespeare T, ‘The Social Model of Disability’ in Davis LJ (ed) *The Disability Studies Reader* (Routledge 2017)

Sheehan T,’ Dasein’ in Dreyfus HL, Wrathall MA, (eds) *A Companion to Heidegger* (Blackwell Publishing, 2005)

Sherry M, ‘Reading me/me reading disability’ in Brueggemann BJ, Lupo ME, (eds) *Disability and/in Prose* (Routledge 2008)

Silvers S, ‘Formal Justice’ in Silvers A, Wasserman D, Mahowald MB, (eds) *Disability, Difference and Discrimination: Perspectives on Justice and Bioethics and Public Policy* (Rowman & Littlefield Publishers 1998)

Silvers A, ‘No Talent? Beyond the Worst Off! A Diverse Theory of Justice for Disability’ in Brownlee K, Cureton A, (eds) *Disability and Disadvantage* (Oxford University Press 2009)

Silvers A, ‘An Essay on Modelling: The Social Model of Disability’ in Ralston DC, Ho J, (eds) *Philosophical Reflections on Disability* (Springer 2010)

Silvers A, ‘A Diverse Theory of Justice for Disability’ in Kimberley Browniee K, Adam Cureton A, (eds) *Disability and Disadvantage* (Oxford University Press 2011)

Sin CH, 'Making disablist hate crime visible' in Roulstone A, Mason-Bish H, (eds) *Disability, Hate Crime and Violence* (Routledge 2014)

Skinner Q, 'The Paradoxes of Political Liberty' in David Miller D, (ed) *Liberty* (Oxford University Press 1991)

Slee R, 'Inclusive Education: A Framework Reform' in Hueng W, King V, Ainscow M, (eds) *Inclusive Education: A Framework for Reform. Proceedings of the International Conference on Inclusive Education* (Hong Kong Institute of Education, 2003)

Slee R, 'Inclusive Schooling as an Apprenticeship in Democracy?' in Florian L, (ed) *The Sage Handbook of Special Education. Volume 1* (Sage, 2014)

Snyder J, 'Empowering Rights Through Mass Movements' in Hopgood S, Snyder J, Vinjamuri L, (eds) *Human Rights Futures* (Cambridge University Press 2017)

Soldatic K, Meekosha H, 'Disability and Neoliberal State Formations' in Watson N, Roulstone A, Thomas C, (eds) *Routledge Handbook of Disabilities Studies* (Routledge, 2012)

Soorenian A, 'Media, Disability and Human Rights' in Gill M, Schlund-Vials CJ, (eds) *Disability, Human Rights and the Limits of Humanitarianism* (Routledge, 2016)

Spitz J-F, 'The 'defense repubicaine': Some Remarks about the Specificity of French Republicanism' in Besson S, Marti JL, (eds) *Legal Republicanism* (Oxford University Press 2009)

Sullivan M, 'Disabled People and the Politics of Partnership in Aotoaroa, New Zealand' in Len Barton (ed) *Disability, Politics & The Struggle For Change* (David Fulton Publishers 2001)

Taylor C, 'What's Wrong with Negative Liberty' in Ryan A, (ed) *The Idea of Freedom: Essays in Honour of Isaiah Berlin* (Oxford University Press 1979)

Taylor C, 'Cross-Purposes: The Liberal-Communitarian Debate' in Rosenblum NL, (ed) *Liberalism and the Moral Life* (Harvard University Press 1989)

Taylor C, 'The Politics of Recognition' in Gutmann A, (ed) *Multiculuralism: Examining the Politics of Recognition* (Princeton University Press, 1994)

Thomas P, 'Hate crime or mate crime?' in Roulstone A, Mason-Bish H, (eds) *Disability, Hate Crime and Violence* (Routledge 2014)

Thomas S,' Wolf Wolfensberger An Overview of Social Role Volorization' in Flynn RJ, Lemay RA, (eds) *A Quarter Century of Normalization and Social Role Valorization: Evolution and Impact* (University of Ottawa Press 1999)

Trausadottir R, 'Disability Studies, the Social Model and Legal Developments' in Arnardottir OM, Quinn G, (eds) *The UN Convention on the Rights of Persons with Disabilities* (Marinus Nijhoff Publishers 2009)

Tutu D, 'Forward' in Bell O, Gready P, *The No-Nonsense Guide to Human Rights* (New Internationalist 2006)

Viroli M, 'Machiavelli and the republican idea of politics' in Bock G, Skinner Q, Viroli M, (eds) *Machiavelli and Republicanism* (Cambridge University Press 1993)

Weiss G, Murphy AV, Salamon G, 'Introduction' in Weiss G, Murphy AV, Salamon G, (eds) *50 Concepts for a Critical Phenomenology* (Northwestern University Press 2020)

Whitburn B, Michalko R, 'Blindness/Sightedness. Disability studies and the defiance of de-vision' in Watson N, Vehmas S, (eds) *Routledge Handbook of Disability Studies* (Routledge 2020)

Whyte G, ‘Litigating the Right to Inclusive Education under Irish Law’ in de Beco G, Quinlivan S, Lord JE, (eds) *The Right to Inclusive Education in International Human Rights Law* (Cambridge University Press, 2019)

Wilson DJ ‘Passing in the Shadow of FDR: Polio Survivors, Passing, and the Negotiation of Disability’ in Brune JA, Wilson DJ, (eds) *Disability and Passing* (Temple University, 2013)

Wilkinson I, ‘Ulrich Beck’ in Ritzer G, Stepnisky J, (eds) *The Wiley-Blackwell Companion to Major Social Theorists*, vol 1 (2011)

Wolfensberger W, ‘Human Services Policies: the Rhetoric versus the Reality’ in Barton L, (ed) *Disability and Dependence* (Falmer 1989)

Yates J, ‘The North American formulation of the principle of Normalization’ in Flynn RJ, Lemay RA, (eds) *A Quarter Century of Normalization and Social Role Valorization: Evolution and Impact* (University of Ottawa Press 1999)

Journal Articles

Abberley P, 'The Concept of Oppression and the Development of a Social Theory of Disability' (2008) 2(1) Disability, Handicap & Society

Abrokwa A, ‘When They Enter, We All Enter’: Opening the Door to Intersectional Discrimination Claims Based on Race and Disability' (2018) 24(1) Michigan Journal of Race and Law

Abu Habib L, '‘Women and disability don’t mix!’: Double discrimination and disability women’s rights' (1995) 3(2) Gender and Development

Alexander JM, ‘Ending the liberal hegemony: Republican freedom and Amartya Sen’s theory of capabilities" (2010) 9(1), Contemporary Political Theory

Almog S, Bendor AL, 'The UN Convention on the Rights of the Child Meets the American Constitution: Towards a Supreme Law of the World' (2004) 11(3) International Journal of Children’s Rights

Alstott AL, 'Neoliberalism in U.S. Family Law: Negative Liberty and Laissez-Faire Markets in the Minimal State' (2014) 77(4) Law and Contemporary Problems

Alvesson M, Karreman D, 'Varieties of discourse: On the study of organizations through discourse analysis' (2000) 53(9) Human Relations

Anastasiou D, Kauffman JM, 'The Social Model of Disability: Dichotomy between Impairment and Disability' (2013) 38 Medicine and Philosophy

Anderson E, "What is the point of equality?" (1999) 109(2) Ethics

Arduin S, 'Implementing Disability Rights in Education in Ireland: An Impossible Task?' (2013) 36 Dublin University Law Journal

Arminian DK, 'Arminian Theology, Machiavellian Republicanism and Cooperative Virtue in Milton’s Paradise Lost' (2016) 50(4) Milton Quarterly

Arneson R, ‘Perfectionism and Politics’ (2000) 111(1) Ethics

Arstein-Kerslake A, Watson J, Browning M, Martinis J, Blanck P, ‘Future Directions in Supported Decision Making’ (2017) 37(1) Disabilities Studies Quarterly

Bagchi AK, ‘Freedom and Development as End of Alienation?’ (2000) 35(5) Economic and Political Weekly

Band-Winterstein T, Avieli H, 'The Experience of Parenting a Child With Disability in Old Age' (2017) 49(4) Journal of Nursing Scholarship

Barclay L, ‘Disability, Respect and Justice’ (2002) 27(2) Journal of Applied Philosophy

Barnes C, ‘Emancipatory disability research: project or process?' (2002) 15(3) Journal of Applied Research in Intellectual Disabilities

Bartlett S, 'Disabled or Deaf? Investigating mental health clinicians’ knowledge of and attitude towards Deafness as a culture' (2018) 11(4) International Journal of Culture & Mental Health

Bassiouni MC, ‘A Functional Approach to ‘General Principles of International Law’ (1990) 11(3) Michigan Journal of International Law

Batavia AI, ‘Disability Rights in the Third Stage of the Independent Living Movement: Disability Community Consensus, Dissention and the Future of Disability Policy’ (2003) 14 (2) Stanford Law & Policy Review

Bauberot J, 'Lacite and the Challenge of ‘Republicanism’' (2009) 17(2) Modern & Contemporary France

Baumberg Geiger B, 'Benefits conditionality for disabled people: Stylised facts from a review of international evidence and practice' (2017) 25 Journal of Poverty and Social Justice

Bell M, ‘The Implementation of European Anti-Discrimination Directives: Converging Towards a Common Model?’ (2008) 79 (1) The Political Quarterly

Bellace JR, 'Achieving Social Justice: the Nexus Between the ILO’s Fundamental Rights and Decent Work' (2011) 15(5) Employee Rights and Employment Policy Journal

Benbow S, Rudnick A, Forchuk C, Edwards B, 'Using a capabilities approach to understand poverty and social exclusion of psychiatric survivors' (2014) 29(7) Disability & Society

Berghs M, Atkin K, Hatton C, Thomas C, 'Do disabled people need a stronger social model: a social model of human rights?' (2019) 34(7-8) Disability & Society

Bertossi C, 'French republicanism and the problem of normative density' (2012) 10(3) Comparative European Politics

Best S, 'The social construction of pain: an evaluation' (2007) 22(2) Disability & Society

Black A, 'Christianity and Republicanism: from St. Cyprian to Rousseau' (1997) 91(3) The American Political Science Review

Bolt D, 'Disability and the Rhetoric of Inclusive Higher Education' (2004) 28(4) Journal of Further and Higher Education

Bolt D, 'From Blindness to Visual Impairment: Terminological Typology and the Social Model of Disability' (2005) 20(5) Disability & Society

Bolt D, 'Radio blindness: interdisciplinarity, ocularnormativity, and young people’s preparation for academia' (2020) 44(9) Journal of Further and Higher Education

Borsay A, 'Personal Trouble or Public Issue: Towards A model of Policy for People with Physical and Mental Disabilities' (1986) 1(2) Disability, Handicap & Society

Branco MC, 'Economics for the right to work' (2019) 159(1) International Labour Review

Breen K, 'Non-domination, Workplace Republicanism and the Justification of Worker Voice and Control' (2017) 33(3) Journal of Comparative Labour Law and Inclusive Relations

Brennan G, Lomasky L, 'Against reviving republicanism' (2006) 5(2) Politics, Philosophy & Economics

Brewer JD, 'Competing understandings of common sense understanding: a brief comment on ‘common sense racism’' (1984) 35(1) The British Journal of Sociology

Broderick A, 'Of rights and obligations: the birth of accessibility' (2020) 24(4) The International Journal of Human Rights

Brown H, Smith H, 'Whose "ordinary life" is it anyway?' (1989) 4(2) Disability, Handicap and Society

Buckley L-A, Quinlivan S, ‘Reasonable accommodation in Irish equality law: an incomplete transformation’ (2021) 41 (1) Legal Studies

Bueno N, 'From the right to work to freedom from work: introduction to the human economy' (2017) 33(4) International Journal of Comparative Labour Law and Industrial Relations

Burch L, '‘You are a parasite on the productive classes’: online disablist hate speech in austere times', (2018) 33(3) Disability & Society

Burchardt T, 'Capabilities and Disability: The Capabilities Framework and the Social Model of Disability' (2004) 19(7) Disability & Society

Burchardt T, Vizard P, 'Operationalizing’ the Capability Approach as a Basis for Equality and Human Rights Monitoring in Twenty-first-century Britain' (2011) 12(1) Journal of Human Development and Capabilities

Burns T, ‘‘Happy slaves?’ The adaptation problem and identity politics in the writings of Amartya Sen’ (2016) 43 (1) International Journal of Social Economic

Bussiere C, Sicsic J, Pelletier-Fleury N, 'Simultaneous effect of disabling conditions on primary health care use through a capability approach' (2016) 154 Social Science & Medicine

Byrne B, 'How inclusive is the right to inclusive education? An assessment of the UN convention on the rights of persons with disabilities’ concluding observations' (2022) 26(3) International Journal of Inclusive Education

Campbell FA, 'Exploring internalized ableism using critical race theory' (2008) 23(2) Disability & Society

Campbell FA, 'Inciting Legal Fictions: “Disability’s” Date with Ontology and the Ableist Body of Law' (2001) 10(1) Griffith Law Review

Carey G, Crammond B, Malbon E, ‘Personalisation schemes in social care and inequality: review of the evidence and early theorising’ (2019) 18 (1) International Journal for Equity in Health

Carr J, Hayes A, Schweppe J, 'Hate crime: an overview of relevance and significance to Irish sociology' (2017) 25(1) Irish Journal of Sociology

Casassas D, ‘Basic Income and the Republican Ideal? Rethinking Material Independence in Contemporary Societies’ (2007) 2 (2) Basic Income Studies

Casassas D. De Wispelaere J, 'Republicanism and the Political Economy of Democracy' (2016) 19(2) European Journal of Social Theory

Castaneda E, Chiapetta C, Guerrero L, Hernandez A, ‘Empowerment through work: the cases of disabled individuals and low-skilled women workers on the US-Mexico border’ (2019) 34 (3) Disability & Society

Chakraborti N, Garland J, 'Reconceptualising hate crime victimization through the lens of vulnerability and difference' (2012) 16(4) Theoretical Criminology

Chesterton L, Jack K, 'Using Heidegger's philosophy of dasein to support person-centred research' (2021) 29(4) Nurse Researcher

Claassen R, "An Agency-Based Capabilities Theory of Justice" (2016) 25(4) European Journal of Philosophy

Classen R, Gerbrandy A, 'Rethinking European Competition Law: From a Consumer Welfare to a Capabilities Approach' (2016) 12(1) Utrecht Law Review

Clayton J, Donovan C, MacDonald SJ, 'A critical portrait of hate crime/incident reporting in North East England: The value of statistical data and the politics of recording in an age of austerity' (2016) 75 Geoforum

Clement D, 'Human rights or social justice? The problem of rights inflation' (2018) 22(2) The International Journal of Human Rights

Cocks E, 'Normalization and Social Role Valorization: Guidance for Human Service Development' (2001) 11(1) Hong Kong Journal of Psychiatry

Colish MLC, 'The Idea of Liberty in Machiavelli' (1971) 33(3) Journal of the History of Ideas

Cornish P J, 'Augustine's Contribution to the Republican Tradition' (2010) 9 (2) European Journal of Political Theory

Corvino F, 'Republican Freedom in the Labour Market: Exploitation Without Interpersonal Domination' (2019) 66 (158) Theoria

Crowther N, 'Nothing without us or nothing about us?' (2007) 22(7) Disability & Society

Cudd AE, 'Commitment as Motivation: Amartya Sen's Theory of Agency and the Explanation of Behaviour' (2014) 30(1) Economics and Philosophy

Culham A, Nind M, 'Deconstructing normalization: Clearing the way for inclusion' (2003) 28(1) Journal of Intellectual & Developmental Disability

Curnock E, Leyland AH, Popham F, 'The impact of health on employment and welfare transitions for those receiving out-of-work disability benefits in the UK' (2016) 162 Social Science and Medicine

Dagger R. Neo-republicanism and the Civic Economy (2006) 5(2) Politics, Philosophy and Economics

Dahlberg H, 'Balancing at the Beginning of Words – Revisiting the Idea of Open Awareness in Qualitative Research' 2022 28(10) Qualitative Inquiry

Dahlberg H, Dahlberg K, 'Open and Reflective Lifeworld Research: A Third Way' (2020) 26(5) Qualitative Inquiry

Dahlberg H, Dahlberg K, 'The question of meaning—a momentous issue for qualitative research' (2019) 14(1) International Journal of Qualitative Studies on Health and Well-Being

Dahlberg H, Dahlberg K, 'To Not Make Definite What is Indefinite: A Phenomenological Analysis of Perception and its Epistemological Consequences in Human Science Research' (2003) 31(4) The Humanistic Psychologist

Dahlberg K, 'The essence of essences - the search for meaning structures in phenomenological analysis of lifeworld phenomena' (2006) 1(1) International Journal of Qualitative Studies on Health and Well-Being

Daly E, Hickey T, 'Religious freedom and the 'right to discriminate' in the school admissions context: a neo-republican critique' (2011) 31(4) Legal Studies

Daly E, ‘Freedom as Non-Domination in the Jurisprudence of Constitutional Rights’ (2015) 28 (2) Canadian Journal of Law & Jurisprudence

Daly E, 'Ostentation and republican civility: Notes from the French face-veiling debates' (2015) 14(3) European Journal of Political Theory

David-Menard M, ‘Kant’s 'An Essay on the Maladies of the Mind' and Observations on the Feeling of the Beautiful and the Sublime’ (2000) 15(4) Hypatia

Davy L, ‘Philosophical Inclusive Design: Intellectual Disability and the Limits of Individual Autonomy in Moral and Political Theory’ (2015) 30(1) Hypatia

de Beco G, 'The Right to Inclusive Education According to Article 24 of the UN Convention on the Rights of Persons with Disabilities: Background, Requirements and Remaining Questions' (2014) 32(3) Netherlands Quarterly of Human Rights

de Beco G, ‘Transitions to Inclusive Education Systems According to the Convention on the Rights of Persons with Disabilities’ (2016) 34 (1) Nordic Journal of Human Rights

de Beco G, ‘The Indivisibility of Human Rights and the Convention on the Rights of Persons with Disabilities’ (2019) 68 (1) International and Comparative Law Quarterly

de Burca G, ‘The EU in the Negotiation of the UN Disability Convention’ (2009) 35 (2) European Law Review

de Burca G, Keohane RO, Sabel C, ‘New Modes of Pluralist Global Governance’ (2012) 45(3) New York University Journal of International Law and Policy

De Wispelaere J, Casassas D, 'A life of one’s own: republican freedom and disability' (2014) 29(3) Disability & Society

Deneulin S, ‘Perfectionism, Paternalism and Liberalism in Sen and Nussbaum’s Capability Approach’ (2002) 14(4) Review of Political Economy

Denton K, Coneway B, Simmons M, Behl M, Shin M, 'Parents' voices matter: A mixed-method study on the dyslexia diagnosis process' (2022) 59(11) Psychology in the Schools

Dimova-Cookson M, 'Republicanism, philosophy of freedom and the history of ideas: An interview with Philip Pettit' (2010) 9(4) Contemporary Political Theory

Doherty MT, 'Inclusion and Deaf Education: The Perceptions and Experiences of Young Deaf People in Northern Ireland and Sweden' (2012) 16(8) International Journal of Inclusive Education

Douglas G, Hewett R, 'Views of Independence and Readiness for Employment amongst Young People with Visual Impairment in the UK'(2014) 20(2) The Australian Journal of Rehabilitation Counselling

Drake PA, ‘The Elephant Man (David Lynch, EMI Films, 1980): an Analysis from a Disabled Perspective (1994) 9 3 Disability & Society

Drydyk J, ‘Responsible Pluralism, Capabilities, and Human Rights’ (2011) 12(1) Journal of Human Development and Capabilities

Dubois JL, Trani J-F, 'Extending the capability paradigm to address the complexity of disability' (2009) 3(3) European Journal of Disability Research

Eggett C, ‘The Role of Principles and General Principles in the ‘Constitutional Processes’ of International Law’ (2019) 66 Netherlands International Law Review

Elsabbagh M, 'Global prevalence of autism and other pervasive developmental disorders' (2012) 5(3) Autism Research

Engsig TT, Johnstone CJ, ‘Is there something rotten in the state of Denmark? The paradoxical policies of inclusive education – lessons from Denmark’ (2015) 19 (5) International Journal of Inclusive Education

Etzioni A, 'Communitarianism Revisited' (2014) 19(3) Journal of Political Ideologies

Evensen KV, Standal ØF, '“I Guess that the Greatest Freedom ...”: A Phenomenology of Spaces and Severe Multiple Disabilities' (2017) 17(2) Indo-Pacific Journal of Phenomenology

Farrell L, ‘Towards a critique of neo-republican reason: the subject, discursive control, and power in Pettit’s political theory’ (2023) 24 (3) Distinktion: Journal of Social Theory

Feely M, 'Disability studies after the ontological turn: a return to the material world and material bodies without a return to essentialism' (2016) 31(7) Disability & Society

Fevre R, Robinson A, Lewis D, Jones T, 'The Ill –Treatment of Employees with Disabilities in British Workplaces' (2013) 27(2) Work, Employment and Society

Fitzpatrick P, 'Is humanity enough? The secular theology of human rights' (2006) 6(1) Human Rights & Human Welfare

Flynn S, ‘The Current Economic Recession: Social Work Perspectives on its Impact on People with Intellectual Disability’ (Spring 2015) The Irish Social Worker

Flynn S, ‘Perceptions on Austerity; the Impact of the Economic Recession on Children with Intellectual Disability’ (2017) 32 (5) Disability & Society

Formosa P, Mackenzie C, 'Nussbaum, Kant and the Capabilities Approach to Dignity' (2014) 17(5) Ethical Theory and Moral Practice

Forst R, 'Noumenal Power' (2015) 23(2) The Journal of Political Philosophy

Foucault M, 'About the Beginning of the Hermeneutics of the Self: Two Lectures at Dartmouth' (1993) 21(2) Political Theory

Fredman, S. ‘Emerging from the Shadows: Substantive Equality and Article 14 of the European Convention on Human Rights’ (2016) 16(2) Human Rights Law Review

Galton F, 'Eugenics: its Definition, Scope and Aims' American Journal of Sociology papers (1904) X (1)

Galton F, 'Hereditary Talent and Character. Parts I and II' (1865) 12(68) Macmillan's Magazine

Galton F, 'The Possible Improvement of the Human Breed Under Existing Conditions of Law and Sentiment' (1901) 64 Nature

Gartell A, Baesel K, Becker C, '‘We do not dare to love:’ women with disabilities’ sexual and reproductive health and rights in rural Cambodia' (2017) 25(50) Reproductive Health Matters

Garthwaite K., '‘The language of shirkers and scroungers?’ Talking about illness, disability and coalition welfare reform' (2011) 26(3) Disability & Society

Gaughin L, Paul Michael Garrett PM, ‘The most twisted and unaccountable force in

the state’? Newspaper accounts of social work in the republic of Ireland in troubled times (2012) 12 (3) Journal of Social Work

Garvin, T. Republicanism and Democracy in Ireland (2013) 102(406) Studies

Gasper D, ‘Is Sen’s Capability Approach an Adequate Basis for Considering Human Development?’ (2002) 14(4) Review of Political Economy

Genal K, 'The Question of Biopower: Foucault and Agamben' (2006) 18(1) Rethinking Marxism

Gheaus A. ‘Child-rearing With Minimal Domination: A Republican Account’ (2021) 69(3) Political Studies, 69(3)

Gilson SF, Depoy E, 'Multiculturism and Disability: a critical perspective' (2000) 15(2) Disability & Society

Giri AK, ‘Rethinking Human Well-being: a dialogue with Amartya Sen’ (2000) 12(7) Journal of International Development

Goldschmidt, J. E. New Perspectives on Equality: Towards Transformative Justice through the Disability Convention? (2017) 35(1) Nordic Journal of Human Rights

Goldsmith MM, 'Republican Liberty Considered' (2000) 21(3) History of Political Thought

Goodley, D. Runswick-Cole, K. Becoming dishuman: thinking about the human through dis/abilty (2016) 37(1) Discourse: Studies in the Cultural Politics of Education

Goodley D. ‘Dis/Entangling Critical Disability Studies’ (2013) 28(5) Disability & Society

Gourevitch A, ‘Labour Republicanism and the Transformation of Work’ (2013) 41 (4) Political Theory

Griffiths CA, Ainsworth E, ‘Personalisation: Direct Payments and Mental Illness’ (2013) 18 (1) ‘International Journal of Psychosocial Rehabilitation’

Grodin MA, Kelly EL, Kelly JI, 'The Nazi Physicians as Leaders in Eugenics and “Euthanasia”: Lesson for Today' (2018) 108(1) American Journal of Public Health

Grover C, Piggott L, 'Disability and Social (In)Security: Emotions, Contradictions of ‘Inclusion’ and Employment and Support Allowance' (2013) 12(3) Social Policy and Society

Guenther L, 'Six Senses of Critique for Critical Phenomenology' (2021) 4(2) Puncta. Journal of Critical Phenomenology

Gundersen T, ‘Human dignity at stake - how parents of disabled children experience the welfare system’ (2012) 14 (4) Scandinavian Journal of Disability Research

Haley M, Hammond H, Ingalls L, Romaro M, 'Parental reactions to the special education individual education program process: Looking through the lens of grief' (2013)16(3) Improving Schools

Hall E, ‘The entangled geographies of social exclusion/inclusion for people with learning disabilities’ (2005) 11 (2) Health & Place

Hall E, ‘Spaces of social inclusion and belonging for people with learning disabilities’ (2010) 54 (1) Journal of Intellectual Disability Research

Hall E, 'A critical geography of disability hate crime' (2019) 51(2) Area

Hall E, Bates E, 'Hatescape? A relational geography of disability hate crime, exclusion and belonging in the city' (2019) 101 Geoform

Hammersley R, 'Lessons from the Land of Liberty' (2011) 61(10) History Today

Hansen H, Bourgois P, Drucker E, 'Pathologizing poverty: New forms of diagnosis, disability and structural stigma under welfare reform' (2014) 103 Social Science & Medicine

Hart BW, Carr R, 'Sterilization and the British Conservative party: rethinking the failure of the Eugenics Society’s political strategy in the nineteen-thirties' (2015) 88(242) Historical Research

Hart CS, 'Education, inequality and social justice: A critical analysis applying the Sen-Bourdieu Analytical Framework' (2019) 17(5) Policy Futures in Education

Haugaard M, Pettit P, ‘A conversation on power and republicanism: an exchange between Mark Haugaard and Philip Pettit.’(2017) 10(1) Journal of Political Power

Hill MT, ‘Development as Empowerment’ (2003) 9(2-3) Feminist Economics

Hirschberg M, Papadopoulos C, ‘’Reasonable Accommodation’’ and ‘’Accessibility’’: Human Rights Instruments Relating to Inclusion and Exclusion in the Labour Market' (2016) 6(1) Societies

Hughes B, 'Being disabled: towards a critical social ontology for disabilities studies' (2007) 22(7) Disability & Society

Hughes B, Paterson K, 'The social model of disability and the disappearing body: towards a sociology of impairment' (1997) 12(3) Disability & Society

Hughes P, ‘Supreme Court of Canada Equality Jurisprudence and “Everyday Life”’ (2012) 58 The Supreme Court Law Review: Osgoode’s Annual Constitutional Cases Conference

Inglis T, 'Origins and Legacies of Irish Prudery: Sexuality and Social Control in Modern Ireland' (2005) 40(2) Eire/Ireland

Jacob D, Neuhauser C, ‘Workplace Democracy, Market Competition and Republican Self-Respect’ [2018] 21 Ethical Theory and Moral Practice

Jennings B, "Reconceptualizing Autonomy: a Relational Turn in Bioethics" (2016) 46(3) Hastings Centre Report

Johnson MM, Rhodes R, 'Institutionalization: A Theory of Human Behaviour and the Social Environment' (2007) 8(1) Advances in Social Work

Ruth Jeanes, Johnathan McGee ‘Social Exclusion and Access to Leisure in Northern Ireland Communities: Examining the Experiences of Parents with Disabled Children’ (2010) 33 (2) Loisir et Société / Society and Leisure

Junne J, Huber C, ‘The risk of users’ choice: exploring the case of direct payments in German social care’ (2014) 16 (7-8) Health, Risk & Society

Jurdjevic M, 'Machiavelli’s Hybrid Republicanism' (2007) 122(499) The English Historical Review

Kanter AS, 'Let’s Try Again: Why the United States Should Ratify the United Nation’s Convention on the Rights of Persons with Disabilities' (2019) 35(1) Touro Law Review

Kanter AS, ‘Do Human Rights Treaties Matter: The Case for the United Nations Convention on the Rights of People with Disabilities.’ (2021) 52(3) Vanderbilt Journal of Transnational Law

Kasa D, ‘Arminian Theology, Machievellian Republicanism and Cooperative Virtue in Milton’s Paradise Lost’ (2016) 50 (4) Milton Quarterly

Kayass R, French P, 'Out of Darkness into Light? Introducing the United Nations Convention on the Rights of Persons with Disabilities.’ (2008) 8(1) Human Rights Law Review

Keddie A, 'School Autonomy, Accountability and Collaboration: a Critical Review' (2015) 47(1) Journal of Educational Administration and History

Keleher L, ‘Sen and Nussbaum: Agency and Capability Expansion’ (2014) 11(2) Ethics and Economics

Kelleher JP, ‘Capabilities versus Resources’ (2015) 12(2) Journal of Moral Philosophy

Kenny M, Shevlin M, ‘Normality and Power: Desire and Reality for Students with Disabilities in Mainstream Schools’ (2007) 19 (2) Irish Journal of Sociology

Kinsella W, Senior J, 'Developing Inclusive Schools: a Systemic Approach' (2008) 12(5–6) International Journal of Inclusive Education

Koshan J, Watson Hamilton J, ‘The Continual Reinvention of Section 15 of the Charter’ (2013) 64 University of New Brunswick Law Journal

Kozou K, ‘Analysing the Definition of Disability in the UN Convention on the Rights of Persons with Disabilities: Is It Really Based on a ‘Social Model’ Approach?’ [2017] 23 International Journal of Mental Health and Capacity Law

Kraus PA, ‘Popular Republicanism versus Populism: Articulating the People’ (2021) 10 (10) Social Sciences 366, 372

Krischler M, Powell JJW, Pit-Ten Cate IM, 'What is meant by inclusion? On the effects of different definitions on attitudes toward inclusive education' (2019) 34(5) European Journal of Special Needs Education

Kvist AP, Nielsen HS, Simonsen M, ‘The importance of children’s ADHD for parents’ relationship stability and labour supply’ [2013] 88 Social Science & Medicine

Laborde C, ‘Republicanism and Global Justice. A Sketch’ (2010) 9(1) European Journal of Political Theory

Lang R, Kett M, Groce N, Trani J-F, 'Implementing the United Nations Convention on the Rights of Persons with Disabilities: Principles, Implications, Practice and Limitations' (2011) 5(3) Alter-European Journal of Disability Research

Leach Scully J, ‘Drawing Lines, Crossing Lines: Ethics and the Challenges of Disabled Embodiment’ (2003) 11 (3) Feminist Theology

Lofgren-Martenson L, '"Hip to be Crip?’’ About Crip Theory, Sexuality and Intellectual Disabilities' (2013) 31(4) Sexuality and Disability

Lourens H, Swartz L, '‘It’s Better if Someone Can See Me for Who I Am’: Stories of (in)Visibility for Students with a Visual Impairment within South African Universities' (2016) 31(2) Disability & Society

Lovett F, 'Harrington’s Empire of Laws' (2012) 60(1) Political Studies

Lovett, F and Whitfield, G, 'Republicanism, Perfectionism and Neutrality' (2016) 24(1) The Journal of Political Philosophy

Lovett F, and Pettit P, 'Neorepublicanism: A Normative and Institutional Research Program' (2009) 12 Annual Review of Political Science

Luckasson R, Schalock RL, ‘Defining an applying a functionality approach to intellectual disability’ (2013) 57 (7) Journal of Intellectual Disability Research

Lundeby H, Tossebro J ‘Exploring the Experiences of ‘‘Not Being Listened To’’ from the Perspective of Parents with Disabled Children’ (2008) 10 (4) Scandinavian Journal of Disability Research

MacArthur J, 'The Inclusive University: A Critical Theory Perspective Using a Recognition-Based Approach' (2021) 9(3) Social Inclusion

Macleod CM, ‘Freedom as non-domination and educational justice’ (2015) 18(4) Critical Review of International Social and Political Philosophy

MacMahon J A, 'The Catholic Clergy and the Social Question in Ireland 1891 – 1916' (1981) 70(280) An Irish Quarterly Review

Mahon C, ‘Progress at the Front: The Draft Optional Protocol to the International Covenant on Economic, Social and Cultural Rights’(2008) 8 (4) Human Rights Law Review

Marks D, 'Some Concluding Notes – Healing the Split Between Psyche and Social: Constructions and Experiences of Disability' (2002) 22(3) Disability Studies Quarterly

Marmamula, S, Keeffe, J, Challa, R, Mohd, J, Khanna, RC, 'Near-vision impairment and effective near-vision spectacle coverage in two districts in Telangana, India: a population-based cross-sectional study' (2021) 11 BMJ Open

Matz-Luck N, ‘Framework Conventions as a Regulatory Tool’ (2009) 1(3) Goettingen Journal of International Law

Mayerhoff DJ, 'Radical deinstitutionalization: Rousseau versus Freud' (2006) 15(2) Journal of Mental Health

McBride C, 'Freedom as non-domination: radicalisation or retreat?' (2015) 18(4) Critical Review of International Social and Political Philosophy

McCormick JP, 'Subdue the Senate: Machiavelli's "Way of Freedom" or Path to Tyranny?' (2012) 40(6) Political Theory

McCoy S, Shevlin M, Rose R, 'Secondary School Transition for Students with Special Educational Needs in Ireland' (2019) 35(2) European Journal of Special Needs Education

Mc Keon D, ‘Soft barriers’ – The impact of school ethos and culture on the inclusion of students with special educational needs in mainstream schools in Ireland’ (2020) 23 (2) Improving Schools

McKinstry C, Wilson E, Bagley K, Kenny A, 'Designing and Rating Options for Special School Expertise to Support Mainstream Educational Inclusion' (2020) 44(1) Australasian Journal of Special and Inclusive Education

McLoughlin H, 'What’s in a Name: ‘Client’, ‘Patient’, ‘Customer’, ‘Consumer’, ‘Expert by Experience’, ‘Service User’—What’s Next?' (2009) 39(6) British Journal of Social Work

McQueen A, 'Politics in Apocalyptic Times: Machiavelli’s Savonarolan Moment' (2016) 78(3) Journal of Politics

Meade T, Serlin D, ‘Editors’ Introduction’ [2006] 94 Radical History Review

Megret F, "The Disabilities Convention: Towards a Holistic Concept of Rights" (2008) 12(2) The International Journal of Human Rights

Michalko R, 'What’s Cool About Blindness' (2010) 30(3-4) Disability Studies Quarterly

Miele Rodas J, 'On Blindness' (2009) 3(2) Journal of Literary & Cultural Disability Studies

Mik-Meyer N, 'Othering, ableism and disability: A discursive analysis of co-workers’ construction of colleagues with visible impairments' (2016) 69(6) Human Relations

Mitchell DT, Snyder SL, 'The Matter of Disability' (2016) 13 Bioethical Inquiry

Mitlin D, 'Endowments, Entitlements and Capabilities – What Urban Social Movements Offer to Poverty Reduction' (2013) 25(1) The European Journal of Development Research

Mitra S,Disability and Poverty in Developing Countries: a Multidimensional Study [2013] 41 *World Development*

Mohamed K, Shefer T, 'Gendering disability and disabling gender: Critical reflections on intersections of gender and disability' (2015) 29(2) Agenda: Empowering Women for Gender Equality

Morgan J, 'Species Being in the Twenty-First Century' (2018) 30(3) Review of Political Economy

Morris J, ‘Including all children: finding out about the experiences of children with communication and/or cognitive impairments’ (2003) 17 (5) Children and Society

Mostert MP, 'Useless Eaters: Disability as Genocidal Marker in Nazi Germany' (2002) 36(3) The Journal of Special Education

Moyn S, ‘The Secret History of Constitutional Dignity’ (2014) 17(1) Yale Human Rights and Development Law Journal

Mudlark G, 'The right to work: linking human rights and employment policy' (2007) 146(3-4) International Labour Review

Muldoon J, ‘A Socialist Republican Theory of Freedom and Government’ (2022) 21 (1) European Journal of Political Theory

Mullaney S, ‘Sir William Wilde and provision for the blind in nineteenth century Ireland’ [2016]185 Irish Journal of Medical Science 281

Mulroy S, Robertson L, Aiberti K, Leonard H, Bower C, ‘The impact of having a sibling with an intellectual disability: parental perspectives in two disorders’ (2008) 52 (3) Journal of Intellectual Disability Research

Mun Y, Kim S, 'The spectra of concealment and disclosure of disability: the experiences of people with mild disability in South Korea', (2022) 39(2) Disability & Society

Murray JJ, De Meulder M, le Maire D, 'An Education in Sign Language as a Human Right? The Sensory Exception in the Legislative History and Ongoing Interpretation of Article 24 of the UN Convention on the Rights of Persons with Disabilities' (2018) 40(1) Human Rights Quarterly

Murray JJ, Snoddon K, De Meulder M, Underwood K, ‘Intersectional inclusion for deaf learners: moving beyond General Comment no. 4 on Article 24 of the United Nations Convention on the Rights of Persons with Disabilities’ (2020) 24 (7) International Journal of Inclusive Education

Natilier K, 'Micro-aggressions, single mothers and interactions with government workers: The case of Australia’s child support bureaucracy' (2017) 53(2) Journal of Sociology

Nelson E, ‘From Primary Goods to Capabilities: Distributive Justice and the Problem of Neutrality’ (2000) 36 Political Theory

Nilhorm C, Goransson K, 'What Is Meant by Inclusion? An Analysis of European and North American Journal Articles with High Impact' (2017) 32(3) European Journal of Special Needs Education

Norwich B, 'What future for special schools and inclusion?' (2008) 35(3) British Journal of Special Education

Nugent J, 'The Sword and the Prayerbook: Ideals of Authentic Irish Manliness' (2008) 50(4) Victorian Studies

Nussbaum M, 'Capabilities and Human Rights' (1997) 66 Fordham Law Review

Nussbaum M, ‘Political Animals: Luck, Love and Dignity’ (1998) 29(4) Metaphilosophy 274

Nussbaum M, 'Capabilities as Fundamental Entitlements: Sen and Social Justice' (2003) 9(2-3) Feminist Economics

Nussbaum M, ‘Inscribing the Face: Shame, Stigma and Punishment’ (2005) 46, Political Exclusion and Domination

Nussbaum M, 'The Capabilities of People with Cognitive Disabilities' (2009) 40(3-4) Metaphilosophy 335

O’Brien J, 'Down Stairs That Are Never Your Own: Supporting People with Developmental Disabilities in Their Own Homes' (1994) 32(1) Mental Retardation

O’Connell P, ‘The Death of Socio-Economic Rights’ (2011) 74 (4) The Modern Law Review

O'Keefe M, 'Students with Moderate General Learning Disabilities Speak of Their Experiences in Mainstream Schools' (2011) 25(1) REACH Journal of Special Needs Education in Ireland

Oksala J, 'The method of critical phenomenology: Simone de Beauvoir as a phenomenologist' (2023) 31(1) European Journal of Philosophy

Oliver M, 'Changing the Social Relations of Research Production?' (1992) 7(2) Disability, Handicap & Society

Oosterlaken I, ‘Is Pogge a Capability Theorist in Disguise?’ (2013) 16(1) Ethical Theory and Moral Practice

O'Shea T, 'Disability and Domination: Lessons from Republican Political Theory' (2018) 35(1) Journal of Applied Philosophy

O’Shea, T, 'Socialist Republicanism' (2020) 48(5) Political Theory

Parker Harris, S, Owen R, Gould R, 'Parity of participation in liberal welfare states: human rights, neoliberalism, disability and employment' (2012) 27(6) Disability & Society

Peterson A, ‘Civic Republicanism and Contestatory Deliberation: Framing Pupil Discourse Within Citizenship Education’ (2009) 57 (1) British Journal of Educational Studies

Paterson K, Hughes B, 'Disability Studies and Phenomenology: The Carnal Politics of Everyday Life' (1999) 14(5) Disability & Society

Percival J, Hanson J, Osipovic D, 'A Positive Outlook? The Housing Needs and Aspirations of Working Age People with Visual Impairment'(2006) 21(7) Disability & Society

Pettit P, 'Political realism meets civic republicanism' (2017) 20(3) Critical Review of International Social and Political Philosophy

Pettit P, 'Freedom as Antipower' (1996) 106(3) Ethics

Pettit P, 'Capabilities and Freedom: A defence of Sen' (2001) 17(1) Economics and Philosophy

Pettit P, ‘Deliberate Democracy and the Discursive Dilemma’ (2001) 11 (1) Philosophical Issues

Pettit P, ‘Liberty and Leviathan’ (2005) 4 (1) Politics, Philosophy and Economics

Pettit P, ‘The Domination Complaint’ (2005) 46 Nomos

Pettit P, 'Freedom in the Market' (2006) 5(2) Philosophy, Politics and Economics

Pettit P, ‘A Republican Right to Basic Income?’ (2007) 2(2) Basic Income Studies

Pettit P, 'Free Persons and Free Choices' (2007) 28(4) History of Political Thought

Pettit P, ‘The Instability of Freedom and Noninterference: The Case of Isaiah Berlin (2011) 121(4) Ethics

Pettit P, ‘Political realism meets civic republicanism’ (2017) 20(3) Critical Review of International Social and Political Philosophy

Pfafflin F, 'The Connections Between Eugenics, Sterilization and Mass Murder in Germany from 1933 to 1945' (1986) 5(1) Medicine and Law

Philips A, 'Feminism and Republicanism: Is This a Plausible Alliance' (2000) 8(2) Journal of Political Philosophy

Pinto C, Baines E, Bakopoulou J, 'The peer relations of pupils with special educational needs in mainstream primary schools: The importance of meaningful contact and interaction with peers' (2019) 89 (4) The British Journal of Educational Psychology

Poe A, 'Review Essay: Things-Beyond-Objects' (2011) 19(1) Journal of French and Francophone Philosophy

Pogge T, 'An Egalitarian Law of Peoples' (1994) 23(3) Philosophy and Public Affairs

Pogge T, 'Can the capabilities approach be justified' (2002) 30(2) Philosophical Topics

Pogge T, 'Responsibilities for Poverty-Related Ill Health' (2002) 16(2) Ethics & International Affairs

Pogge, T, 'World Poverty and Human Rights' (2005) 19(1) Ethics and International Affairs

Prendergast R, 'The concept of freedom and its relation to economic development – a critical appreciation of the work of Amartya Sen' (2005) 29(6) Cambridge Journal of Economics

Prunty A, Dupont M, McDaid R, 'Voices of students with special education needs (SEN): views on schooling' (2012) 27(1) Support for Learning

Qizilbash M, 'Dialogue: Sen on Freedom and Gender Justice' (2005) 11(3) Feminist Economics

Qizilbash M, 'Some Reflections on Capability and Republican Freedom' (2016) 17 (1) Journal of Human Development and Capabilities

Quinn G, 'The United Nations Convention on the Rights of Persons with Disabilities: Toward a New International Politics of Disability' (2009) 15(1) Texas Journal of Civil Liberties & Civil Rights

Rajapaska N, 'Bringing Ethics into the Capitalist Model: Amartya Sen's Approach to Economic Theory and Financial Capitalism' (2015) 13(2) La Revue Lisa

Rawls J, 'Kantian Constructivism in Moral Theory' (1980) 77(9) Journal of Philosophy

Renault E, 'Work and Domination in Marx' (2014) 15(2) Critical Horizons

Revillard A, 'Disabled People Working in the Disability Sector: Occupational Segregation or Personal Fulfilment?' (2022) 36(5) Work, Employment and Society

Rhodes R, 'Mental Retardation and Sexual Expression: An Historical Perspective' (1993) 8(2) Journal of Social Work & Human Sexuality

Roche JM, 'Monitoring Progress in Child Poverty Reduction: Methodological Insights and Illustration to the Case Study of Bangladesh' (2013) 112(2) Social Indicators Research

Rodas JM, 'On Blindness' (2009) 3(2) Journal of Literary & Cultural Disability Studies

Rogers ML, 'Republican confusion and liberal clarification' (2008) 34(7) Philosophy & Social Criticism

Rosano A, Mancini F, Solipaca A, 'Poverty in People with Disabilities: Indicators from the Capability Approach' (2009) 94(1) Social Indicators Research

Rose N, 'Community, Citizenship and the Third Way' (2000) 43(9) American Behavioural Scientist

Sandel MJ, 'The Procedural Republic and the Unencumbered Self' (1984) 12(1) Political Theory

Sarojini Hart C, ‘Education, inequality and social justice: A critical analysis applying the Sen-Bourdieu Analytical Framework’ (2019) 17 (5) Policy Futures in Education

Schillmeier M, 'Othering blindness – on modern epistemological politics' (2006) 21(5) Disability & Society

Schillmeier M, '(Visual) Disability – from exclusive perspectives to inclusive differences' (2008) 23(6) Disability & Society

Scott AW, Bressler NM, Ffolkes S. Wittenborn JS, Jorkasky J, ‘Public Attitudes about Eye and Vision Health’ (2016) 134(10) JAMA Ophthalmology

Seatzu F, ‘Empowering Persons with Disabilities: Socio-Economic Rights as a Pathway to Personal Autonomy and Independence’ (2020) 18(2) Northwestern Journal of Human Rights

Seldon S, ‘Eugenics and the social construction of merit, race and disability’ (2000) 32 (2) Curriculum Studies

Sen A, ‘Well-being, Agency and Freedom: The Dewey Lectures 1984’ (1985) 82(4) Journal of Philosophy

Sen A, ‘Behaviour and the Concept of Preference’ (1998) 40(159) Economia

Sen A, ‘Reply’ (2001) 17(1) Economics and Philosophy

Sen A, 'Human Rights and Capabilities' (2005) 6(2) Journal of Human Development

Sen A, ‘Mary, Mary Quite Contrary!’ (2005) 11(1) Feminist Economics

Sen A, ‘Reason, freedom and well-being’ (2006) 18(1) Utilitas

Sepulchre M, 'Disability, Justice and Freedom as Non-Domination' (2022) 2(1) The International Journal of Disability and Social Justice

Shakespere T, ‘Disabled Sexuality: towards rights and recognition’ (2000) 18 (3) Sexuality & Disability

Shine Thompson M, Svaerd A-KL, ‘Unintended consequences of special-needs law in Ireland and Sweden’ (2019) 48 (2) Kybernetes

Shumer SM, 'Machiavelli: Republican Politics and its Corruption' (1979) 7(1) Political Theory

Shyman E, 'The Reinforcement of Ableism: Normality, the Medical Model of Disability, and Humanism in Applied Behaviour Analysis and ASD' (2016) 54(5) Intellectual and Developmental Disabilities

Silva R, 'Non-domination and Political Institutions: The Contested Concept of Republican Democracy' (2015) 9(1) Brazilian Political Science Review

Skarstad K, ‘Human rights through the lens of disability’ (2018) 36 (1) Netherlands Quarterly of Human Rights

Slasberg C, Beresford P, ‘Independent living: the real and present danger’ (2020) 35 (2) Disability & Society

Snir I, Yuval E, ‘Pedagogy of non-domination: Neo-republican political theory and critical education’ (2016) 14(6) Policy Futures in Education

Sorkkila M, Aunola K, ‘Risk Factors for Parental Burnout among Finnish Parents: The Role of Socially Prescribed Perfectionism’ [2020] 3 Journal of Child and Family Studies

Srinivasan S, ‘No Democracy without Justice: Political Freedom in Amartya Sen’s Capability Approach’ (2007) 8(3) Journal of Human Development

Stefánsdóttir G, Björnsdóttir K, Stefánsdóttir Á, ‘Autonomy and People with Intellectual Disabilities Who Require More Intensive Support’ (2018) 20(1) Scandinavian Journal of Disability Research

Sunstein CR, ‘Beyond the Republican Revival’ (1988) 97 (8) Yale Law Journal

Swartz L, Bantjes J, Bissett F, ‘Fitting in and looking pretty: experiences of students with visual impairment participating in ‘inclusive’ ballroom dance classes’ (2018) 33 (7) Disability & Society

Sykes, H ‘The qBody Project: from Lesbians in Physical Education to Queer Bodies In/Out of School’ (2009) 13 (3) Journal of Lesbian Studies

Szelanyi I, ‘Weber’s theory of domination and post-communist capitalisms’ (2016) 45 (1) Theory and Society

Tak YR, McCubbin M, ‘Family stress, perceived social support and coping following the diagnosis of a child’s congenital heart disease’ (2002) 39 (2) Journal of Advanced Nursing

Tal-Alon N, Shapira-Lischinsky O, 'Ethical dilemmas among teachers with disabilities: A multifaceted approach' (2019) 86 Teaching and Teacher Education

Tanner R, 'Marx’s Theory of Commodity Fetishism as the Unstated Premise of What is to Be Done' (2001) 13(1) Rethinking Marxism

Taylor MJ, 'Autonomy and Common Good: Interpreting Rousseau’s General Will' (2017) 25(2) International Journal of Philosophical Studies

Taylor RS, 'Market Freedom as Antipower' (2013) 107(3) The American Political Science Review

Thompson MJ, 'Autonomy and Common Good: Interpreting Rousseau’s General Will' (2017) 25(2) International Journal of Philosophical Studies

Titchkosky T, ‘Disability in the news: a reconsideration of reading’ (2005) 20 (6) Disability & Society

Townsend P, '‘Absolute’ and ‘overall’ poverty: the 1995 Copenhagen approach to the fulfilment of human rights' (2006) 6(3) Global Social Policy

Tremain S, 'Feminist Philosophy of Disability: A Genealogical Intervention' (2019) 51(1) The Southern Journal of Philosophy

Tridimas T, ‘The general principles of EU law and the Europeanisation of national laws’ (2020) 13(2) Review of European Administrative Law

Turner GW, Crane B, 'Sexually Silenced No More, Adults with Learning Disabilities Speak Up: A Call to Action for Social Work to Frame Sexual Voice as a Social Justice Issue' (2016) 46(8) British Journal of Social Work

Van Der Rijt JW, ‘Republican Dignity: The Importance of Taking Offence’ (2009) 28(5) Law and Philosophy

Varda H, ‘Kant and Women’ (2017) 98(4) Pacific Philosophical Quarterly

Vogal G, Sharoni V, ‘‘My success as a teacher amazes me each and every day’ – perspectives of teachers with learning disabilities’ (2011) 15 (5) International Journal of Inclusive Education

Vorhaus J, ‘Dignity, Capability and Profound Disability’ (2015) 46(3) Metaphilosophy

Walker M, McLean M, Dison A, Peppin-Vaughan R, 'South Africa universities and human development: Towards a theorisation and operationalisation of professional capabilities for poverty’ (2009) 29(6) International Journal of Educational Development

Walker R, Hutchinson C, ‘Care-giving dynamics and futures planning among ageing parents of adult offspring with intellectual disability’ (2019) 39 (7) Ageing & Society

Walsh S, O'Shea E, Pierse T, Kennelly B, Keogh F, Doherty E, 'Public preferences for home care services for people with dementia: A discrete choice experiment on personhood' (2020) 245 Social Science & Medicine

Ward A, Moon N, Baker PMA, ‘Functioning, Capability and Freedom: A Framework for Understanding Workplace Disabilities’ (2012) 24(1) Employee Responsibilities & Rights Journal

Watson J, ‘The Role of Speech Language Pathology in Supporting Legal Capacity’ (2019) 21(1) Journal of Clinical Practice in Speech Language Pathology

Weddteijn A, 'The Power of 'Pliant Stuff': Fables and Frankness in Seventeenth Century Dutch Republicanism' (2011) 72(1) Journal of the History of Ideas

Weidel T, 'The ‘ugliness’ of economic efficiency: technology, species-being and global poverty' (2015) 8(1) Ethics & Global Politics

Wiggan J, ‘Telling Stories of 21st Century Welfare: The UK Coalition Government and the Neo-liberal Discourse of Worklessness and Dependency’ (2012) 32(2) Critical Social Policy

Williams C, Wilson S, ‘Pedagogies for social justice: did Bernstein get it wrong?’ (2010) 14 (4) International Journal of Inclusive Education

Williams L, Ettelt S, Perkins M, Wittenberg R, D Lombard D, Damant Nicholas J, Will M, ‘Direct Payments Make Adult Residential Care more Personalized? Views and Experiences of Social Care Staff in the Direct Payments in Residential Care Trailblazers’ (2017) 51 (7) Social Policy Administration

Williams SJ, 'Is anybody there? Critical realism, chronic illness and the disability debate' (1999) 21(6) Sociology of Health and Illness

Wong SI, ‘The Moral Personhood of Persons Labelled ‘Mentally Retarded’: A Rawlsian Response to Nussbaum’ (2007) 33 (4) Social Theory and Practice

Dissertations

Brennan DJ, ‘A Sociology of Institutionalisation of the ‘Mentally ill’ in Ireland’ (PhD dissertation, unpublished, Trinity College Dublin 2006)

Hickey T, ‘Liberty as Non-domination and Ethical Diversity in the Modern Polity’ (PhD dissertation, unpublished, National University of Ireland, Galway 2010)

Lawson MD, ‘Children of a One-Eyed God: Impairment in the Myth and Memory of Medieval Scandinavia’ (MA dissertation, unpublished East Tennessee State University 2019)

O’Keefe M, ‘The Rarely Heard Voice: Students with Moderate General Learning Disability Speak of Their Experiences in Mainstream Schools’ (Doctoral dissertation, unpublished Dublin City University, 2009)

Sheridan S, ‘A minority within a minority: deaf gay and lesbian people on their experiences within different communities’ (MA dissertation, unpublished Dublin City University 2008)

International Bodies (non-binding instruments)

Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities Working Group January 2004

Declaration on the Rights of Disabled Persons proclaimed by General Assembly resolution 3447 (XXX) of 9 December 1975

UNESCO, ‘The World Declaration on Education for All’ (the Jomtien Declaration) 1990

UNESCO, ‘The Salamanca Statement and Framework for Action on Special Needs Education’ (adopted by the World Conference on Special Needs Education: Access and Quality. Salamanca, Spain: 1994)

UN General Assembly, ‘World Programme of Action Concerning Disabled Persons’ (3December 1982)UNGA Res 37/5

UN General Assembly, 'Standard Rules on the Equalization of Opportunities for Persons with Disabilities' (20 December 1993) UNGA Res 48/96

Reports

Aras Attracta Swinford Review Group *What Matters Most* (HSE, 2016)

Brennan D, Browne H, *Education, Behaviour and Exclusion: the Experience and Impact of Short School Days on Children with Disabilities and Their Families in the Republic of Ireland* (Technological University of Dublin/Inclusion Ireland, 2019)

Chakraborti N, Garland J, Hardy SJ, *The Leicester hate crime project: Findings and conclusions* (University of Leicester 2014)

Collins D, Featherstone T, Moran P, *Spending Review 2021 Social Care for People with Disabilities: Trends in Expenditure and Delivery of Services* (Government of Ireland 2021)

Commission of Inquiry into the Reformatory and Industrial School System 1934 – 1936 [the Cussen Report] (The Stationery Office 1936)

Commission to Inquire into Child Abuse (The Ryan Report) (Government of Ireland 2009)

Cosgrove J, McKeown C, Travers J, Lysaght Z, Ni Bhroin, O, Archer P, *Educational Experiences and Outcomes of Children with Special Educational Needs. A Secondary Analysis of Data from the Growing Up in Ireland Study* (NCSE 2014)

Cosgrove J, McKeown C, Travers J, Lysaght Z, Ni Bhroin O, Archer P, *Educational Experiences and Outcomes of Children with Special Educational Needs: Phase 2 – from age 9 to 13. A Secondary Analysis of data from the Growing Up in Ireland Study* (NESC 2018)

Department of Education, *Report of the Special Education Review Committee* (The Stationery Office 1993)

Department of Education and Skills *Education Indicators for Ireland* (DES, 2019)

Department of Health and Social Welfare, *Towards a Full Life: Green Paper on Services for Disabled People* (Government of Ireland, 1984)

Department of Health, *Commission of Inquiry on Mental Handicap* (Government of Ireland 1965)

Department of Health, *Value for Money and Policy Review of Disability Services in Ireland* (Department of Health 2012)

Department of Health (UK), *Transforming Care. A National Response to Winterbourne View Hospital. Department of Health Review Final Report* (Department of Health 2012)

European Commission *European Disability Strategy 2010 – 2020: A Renewed Commitment to a Barrier-Free Europe* (EU Commission 2010)

Government of Ireland, *The Education and Training of Severely and Profoundly Mentally Handicapped Children in Ireland* (The Stationery Office, 1983)

Government of Ireland, *Comprehensive Employment Strategy for People with Disabilities 2015-2024* (Department of Health 2015)

Government of Ireland *Towards Personalised Budgets for People with a Disability in Ireland* (Department of Health, 2018)

Health Service Executive, *Report of the Working Group on Congregated Settings Time to Move on from Congregated Settings: a Strategy for Community Inclusion* (HSE 2011)

Inclusion Ireland *Deinstitutionalisation in Ireland: a failure to Act* (Inclusion Ireland, 2018)

International Labour Organization, *Decent Work. Report of the Director General of the ILO to the 87th Session of the International Labour Conference, Geneva* (ILO 1999)

Lansdown G, *The Evolving Capacities of the Child* (UNICEF Innocenti Research Centre 2005)

Minister for Education and Minister for Health and Social Welfare, *The Education and Training of Severely and Profoundly Mentally Handicapped Children in Ireland: Report of a Working Party to the Minister for Education and the Minister for Health and Social Welfare* (The Stationery Office 1983)

National Council for Curriculum and Assessment, *Report of the Special Education Review Committee (SERC)* (The Stationery Office 1999)

National Council for Special Education, *Implementation Report: Plan for the Phased Implementation of the EPSEN Act 2004* (NCSE 2006)

National Council for Special Education *Regulatory Framework on School Enrolment* (NESC 2011)

National Council for Special Education, *The Future Role of Special Schools and Classes in Ireland: Policy Advice* (NCSE 2011)

National Disability Authority *Engaging and consulting with disabled people in the development and implementation of legislation and policy* (NDA 2022)

Report of the Director General to the 81st Session of the International Labour Conference, *Defending Values, Promoting Change; Social Justice in a Global Economy –An Agenda for the ILO* (ILO 1994).

Sin CH, Hedges A, Cook C, Mguni N, Comber N, *Disabled people's experiences of targeted violence and hostility* (Equality and Human Rights Commission, 2009)

United Nations Department of Economic and Social Affairs, *Global Sustainable Development Report* (UN 2016)

United Nations High Commissioner for Human Rights, *Thematic study on the right of persons with disabilities to education. Report of the Office of the United Nations High Commissioner for Human Rights* (UNHCHR 2013)

Warnock M, *Report of the Committee of Enquiry into the Education of Handicapped Children and Young People* (Her Majesty's Stationery Office, 1978)

World Bank, *World Development Report 2000/2001 Attacking Poverty* (Oxford University Press, 2001)

World Health Organisation, *The International Classification of Functioning, Disability and Health* (WHO, 2001)

World Health Organization *World Report on Disability* (WHO 2011)

Dail Eireann proceedings

16 January 2018 written answer to Louise O’Reilly TD from Minister for Education and Skills

Department Circulars

Ireland, Department of Education and Skills, ‘Applications for the services of a full or part-time resource teacher to assist a school in providing education to meet the needs and abilities of children with disabilities’ Circular 8 of 1999

Ireland, Department of Education and Skills, ‘Applications for special classes for children with disabilities’ Circular 9 of 1999

Website Materials

Ad Hoc Committee UN Convention on the Human Rights of People with Disabilities – Daily Summaries Seventh Session 20 January 2006; available https://www.un.org/esa/socdev/enable/rights/ahc7sum20jan.htm

Bell D, *Communitarianism* (Stanford Encyclopaedia of Philosophy, 2020) at https://plato.stanford.edu/entries/communitarianism/

Bentham J, *Principles of the Civil Code* at chapter XVII, ‘The Power of Laws over Expectation’ at http://www.laits.utexas.edu/poltheory/bentham/pcc/index.html

Bohman J, *Critical Theory* (Stanford Encyclopaedia of Philosophy, 2005) at https://plato.stanford.edu/entries/critical-theory/

Buck v Bell at https://supreme.justia.com/cases/federal/us/274/200/

Centre for Independent Living, *Centre for Independent Living Leader Forum Consultation Report: Personal Assistance Services* at https://ilmi.ie/wp-content/uploads/2018/07/Personal-Assistance-Report-2016-.pdf

Central Statistics Office 2016 Census data at https://www.cso.ie/en/census/census2016reports/

Central Statistics Office, 2022 Survey on Income and Living Conditions (SILC) at https://www.cso.ie/en/releasesandpublications/ep/psilc/surveyonincomeandlivingconditionssilc2022/

Central Statistics Office, (2022) Survey on Income and Living Conditions (SILC) at silc/surveyonincomeandlivingconditionssilc2022/

Department of Children, Equality, Disability, Integration and Youth *AIM Rules* 2023/2024 at https://www.gov.ie/en/organisation/department-of-children-equality-disability-integration-and-youth/

Department of Children, Equality, Disability, Integration and Youth at https://www.gov.ie/en/publication/2459ee-early-childhood-care-and-education-programme-ecce/

Edwards C, Maxwell N, '*Disability and the Creation of SAFE(R)SPACE’* https://www.ucc.ie/en/iss21/researchprojects/researchprojects/earlieriss21projects/disabilityandthecreationofsaferspace/

Health Service Executive, Progressing Disability Services for Children and Young People at https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/introduction/

Inter-Agency Commission, World Declaration on Education for All adopted by the World Conference on Education for All – Meeting Basic Education Needs 9 March 1990 at https://unesdoc.unesco.org/ark:/48223/pf0000097551

Laser Eye Surgery Hub, 'Vision Impairment and Blindness Global Data and Statistics Q4 2020 Update' https://www.lasereyesurgeryhub.co.uk/data/visual-impairment-blindness-data-statistics/

Miserandino C, 'The Spoon Theory' https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/

National Council for the Blind Ireland, 'Facts About Sight Loss' https://ncbi.ie

NCSE Special Needs Assistants (SNA) Scheme: Information for Parents/Guardians of Children with Special Education Needs at https://ncse.ie

Nussbaum M, "Human Dignity and Political Entitlements" in Human Dignity and Bioethics (The President's Council on Bioethics, 2008) at https://repository.library.georgetown.edu/bitstream/handle/10822/559351/human_dignity_and_bioethics.pdf?sequence=1&isAllowed=y]

Quinn G, 'Key Note Address to German European Union Presidency Ministerial Conference: Empowering Persons with Disabilities, The UN Convention on the Human Rights of Persons with Disabilities: A Trigger for Worldwide Law Reform, Berlin, 11 June 2007, available at: http://www.eu2007.bmas.de/EU2007/Redaktion/Deutsch/PDF/2007-06-12-rede-quinn

Rose D, 'Do blind people really experience complete darkness?' at https://www.bbc.com/news/blogs-ouch-31487662

Union of the Physically Impaired Against Segregation (UPIAS) (1976) at https://disability-studies.leeds.ac.uk

World Health Organisation Disability fact sheet (2023) at https://www.who.int/news-room/fact-sheets/detail/disability-and-health

World Health Organization, 'Fact Sheet: Blindness and Vision Impairment' (2021) at https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment

Yeo R, 'Chronic Poverty and Disability' (Chronic Poverty Research Centre 2001) at http://dx.doi.org/10.2139/ssrn.1754542

Media Sources

Brown M, *'Disabled people are to be 'warehoused.' We should be livid.*' The Guardian (25 January 2017) at https://www.theguardian.com/commentisfree/2017/jan/25/disabled-people-disabilities-health-care-homes#:~:text=We%20should%20be%20livid,-This%20article%20is&text=The%20inescapable%20logic%20of,options%20and%20enjoyment%20of%20life

Inclusion Ireland, '*Deinstitutionalisation in Ireland: a failure to Act*' Inclusion Ireland Press Release 2018 at https://inclusionireland.ie/publication/deinstitutionalisation-in-ireland-a-failure-to-act/

Jones J, '*Second opinion: Interagency work doesn't have a hope without legislation'* Jan 19th Irish Times, 2016

Latifi F, '*Spoon theory: What it is and how I use it to manage chronic illness*' 14 January 2023 The Washington Post at: https://www.washingtonpost.com/wellness/2023/01/14/spoon-theory-chronic-illness-spoonie/

RTE, '*Inside Bungalow 3 Primetime Investigates*' at https://www.rte.ie/news/investigations-unit/2014/1209/805165-inside-bungalow-3-aras-atracta/

Scope Victoria, '*Listening to those rarely heard: Supported decision-making for people with severe to profound intellectual disability*' at https://vimeo.com/21176882

The Washington Post, '*Spoon Theory: Chronic Illness and Spoonie*' (2023) https://www.washingtonpost.com/wellness/2023/01/14/spoon-theory-chronic-illness-spoonie/

Young S, '*Inspiration Porn*' (2012) at https://www.abc.net.au/news/2012-07-03/young-inspiration-porn/4107006?utm_campaign=abc_news_web&utm_content=link&utm_medium=content_shared&utm_source=abc_news_web

Appendix 1 – REC Application Form – Professionals

Dublin City University

RESEARCH ETHICS COMMITTEE

APPLICATION FOR APPROVAL OF A PROJECT INVOLVING **HUMAN PARTICIPANTS**

Application No. *(office use only)* DCUREC/2021/____

Please read the following information carefully before completing your application. Failure to adhere to these guidelines will make your submission ineligible for review.

- **Applications must be submitted via the Research Ethics Application Portal here** – no hardcopy required**. All queries relating to submission should be e-mailed to the DCU Research Ethics Committee (REC) at rec@dcu.ie**

- **Section 4 of this form addresses the possible data protection issues of the proposed research and it must be completed prior to making a formal REC application.**

- **Student applicants must include their supervisor as an investigator on the Research Ethics Application Portal** – this applies to all masters by research and PhD students. The form should be checked, approved and signed by the supervisor in advance of submission to REC. ***NB – Taught Masters and Undergraduate students apply for ethical review via their local ethics review panel, not via REC.***

- **The application should consist of one electronic file only,** with an electronic signature from the PI (and supervisor if applicable). The completed application must incorporate all supplementary documentation, especially those being given to the proposed participants. The application will go through an initial triage process and will be returned to the applicant(s) if the form is incomplete or documentation is missing. If extensive changes are required, it will be reviewed at the next REC committee meeting. The application must be proofread and spellchecked before submission to the REC**.**

- **All sections of the application form must be answered as instructed and within the word limits given.**

Applications which do not adhere to all of these requirements will not be accepted for review and will be returned directly to the applicant.

Applications must be completed on the form; answers in the form of attachments will not be accepted, except where indicated. No hardcopy applications will be accepted. **Research must not commence until written approval has been received from the Research Ethics Committee.**

Note: If your research requires approval from the Biological Safety Committee (BSC) this must be in place prior to REC submission. Contact bio.safety@dcu.ie. Please attach the responses from these committees to this submission as directed below.

PROJECT TITLE	Domination and disability: a republican proposal in the light of the United Nations Convention on the Rights of Persons with Disabilities
PRINCIPAL INVESTIGATOR(S) *The named Principal Investigator is the person with primary responsibility for the research project. In the case of PhD/D.Ed./MSc Research projects the supervisor* ***must*** *be listed as Principal Investigator, in addition to the student.*	James Forbes Tom Hickey, Dr Aisling da Paor, Dr
START AND END DATE	1/4/2021 – 31/12/2021
LEVEL OF RISK *Please indicate whether this project requires (a) notification (b) expedited* ***or*** *(c) full committee review. Justification for your choice is required under section 3.1*	Full Committee Review

1. ADMINISTRATIVE DETAILS

PROJECT TYPE: **(mark Y to as many as apply)**	Research Project	…	Funded Consultancy	…
			Clinical Trial	…
	Student Research Project (please indicate level below, e.g. PhD/D.Ed./MSc Research)	…	Other - Please Describe:	…
	PhD / Other Doctorate	Y …		
	D.Ed.			
	MSc Research	…		

1.1 INVESTIGATOR CONTACT DETAILS

PRINCIPAL INVESTIGATOR(S): In the case of PhD/D.Ed./MSc Research projects the supervisor must be listed as Principal Investigator. *Doctoral researchers and Research Masters may be listed as Principal Investigators, depending on the conventions of the discipline and on the individual case. It should be made clear, in subsequent sections of this application, who is carrying out the research procedures.*

NAME	*SCHOOL/UNIT*	*EMAIL*
James Forbes	School of Law and Government	james.forbes3@mail.dcu.ie
Tom Hickey, Dr	School of Law and Government	tom.hickey@dcu.ie

OTHER INVESTIGATORS:

NAME	*SCHOOL/UNIT*	*EMAIL*
Aisling de Paor, Dr	School of Law and Government	aisling.depaor@dcu.ie

1.2 WILL THE RESEARCH BE UNDERTAKEN ON-SITE AT DUBLIN CITY UNIVERSITY?

YES or NO
… No

If NO, state details of the off-campus location – provide details of the approval to gain access to that location in section 2.7.

The proposed interviews to which this application refers – this application being the first of two – will be with professionals working with people with disabilities. For the duration of Covid-19 restrictions the strong likelihood is that interviews will happen via password protected Zoom and similar platforms, utilising a private office on the researcher's part. Where in-person interviews may occur these will be in the interview participants' workplaces utilising private, secure and safe spaces such as large offices and meeting rooms for which the interviewees have permission to access and where Covid-19 protocols can be adhered to. The researcher also has access to private meeting rooms which can be availed of if – Covid 19 restrictions allowing - the necessity arises.

1.3 WILL THIS RESEARCH INVOLVE ANIMALS?

YES or NO
… No

If YES, please provide details on the outcome from BRAG and attach copies of approval(s) received etc.

N/A

1.4 HAS THIS RESEARCH PROPOSAL BEEN SUBMITTED TO ANOTHER ETHICS COMMITTEE?

YES or NO
No

If YES, please provide details on the outcome and attach copies of approval(s) received etc.

N/A

1.4.1 HAS THIS RESEARCH PROPOSAL BEEN REFUSED ETHICAL APPROVAL FROM THIS OR ANOTHER RESEARCH ETHICS COMMITTEE PREVIOUSLY?

If YES, please provide details.

N/A

DECLARATION BY PRINCIPAL INVESTIGATOR(S)

The information contained herein is, to the best of my knowledge and belief, accurate. I have read the University's current research ethics guidelines, and accept responsibility for the conduct of the procedures set out in the attached application in accordance with the form guidelines, the REC guidelines, the University's Conflict of Interest Policy, its Code of Good Research Practice and any other condition laid down by the Dublin City University Research Ethics Committee. I have attempted to identify all risks related to the research that may arise in conducting this research and acknowledge my obligations and the rights of the participants.

If there exists any affiliation or financial interest for researcher(s) in this research or its outcomes or any other circumstances which might represent a perceived, potential or actual conflict of interest this should be declared in accordance with the University's Conflict of Interest Policy.

I and my co-investigators and/or supporting staff have the appropriate qualifications, experience and facilities to conduct the research set out in the attached application and to deal with any emergencies and contingencies related to the research that may arise. Supervisor(s) signature(s) is / are required as evidence that they have read and approve this submission.

Please note:

1. *Any amendments to the original approved proposal must receive prior REC approval.*

2. *As a condition of approval investigators are required to document and report immediately to the Secretary of the Research Ethics Committee any adverse events, any issues which might negatively impact on the conduct of the research and/or any complaint from a participant relating to their participation in the study.*

Electronic Signature(s):

Principal investigator(s): ____________________

____

Print Name(s) here: James Forbes

Date: 5th March 2021___________

I, the main supervisor of this research proposal, have read and approve this submission.

*Supervisor(s) signature (where relevant)_* Tom Hickey

Print Name(s) here:_ __Tom Hickey___

Date: _5/3/21____________

2. PROJECT OUTLINE

2.1 LAY DESCRIPTION, AIMS & JUSTIFICATION, METHODOLOGY *(Approx.900 words)*

Please outline, in terms that any non-expert would understand, what your research project is about, including what participants will be required to do. Please explain any technical terms or discipline-specific phrases. State the aims and significance of the project. Where relevant, state the specific hypothesis to be tested. Please provide a brief description of background research, a justification as to why this research project should proceed in that context and an explanation of any expected benefits to the community. ***NB*** *– all references cited should be listed in an attached bibliography. Provide an outline of the proposed method and state who is doing which task – include details of data collection techniques, the tasks participants will be asked to do, the estimated time commitment involved, and how data will be analysed. If the project includes any procedure which is beyond already established and accepted techniques, please include a description of it. There should be enough detail provided to facilitate ethical review, but applicants are encouraged to keep it as succinct as possible.*

This research project, for which REC agreement is being sought in two parts, derives from an intuition that republicanism has something of considerable value to bring to the lives and experiences of persons with disabilities, especially, perhaps, in the context of the United Nations Convention on the Rights of Persons with Disabilities 2007 (CRPD). In large part, this intuition draws on the work of Philip Pettit. Although republicanism is of ancient lineage –as represented, *inter alia*, in the works of Cicero and Machiavelli – Pettit's modern reworking of it coalesces around the idea that liberalism's conception of what it is to be a free citizen lacks robustness. Hence, whereas liberalism's sensitivities invite the equating of freedom with non-interference, contemporary republicanism articulates a much bolder turn, asserting that phrasing 'the demands of freedom as non-domination gives us a very full and persuasive picture of what it is reasonable to expect of a decent state and a decent civil society' (Pettit, 1997:4). Within such an arrangement, not to be dominated is to be resiliently free of another's actual or *potential* ability to arbitrarily interfere in one's life and legitimate choices. More, in this contemporary rendering, civic virtue and a distinctive emphasis on citizenship underwrite the conditions of non-domination, it becoming the primary object of the state to ever reduce the circumstances in which arbitrary power can manifest and function.

Presented as a theory for testing (Marti and Pettit, 2010), at the heart of Pettit's work is a concern with identifying and ameliorating opportunities for and instances of domination. As such, it is contended that there is much merit in testing whether republicanism can offer both a simple means of initiating an analysis of individual and collective freedom and - a further intuition - a remediating strategy. If this dual potential is true, this makes it particularly attractive in terms of applying the non- domination concept in the lives of disabled people, whose status as citizens – and, in some accounts, as persons – has traditionally been and, arguably, remains occluded (see, for instance, Quinn and Rekas -Rosalbo, 2016; Kittay, 2005). Indeed, the very existence of the CRPD speaks to the need to make explicit that persons with disabilities hold the same rights as those who might be described as non-disabled. Prefacing the CRPD as a call to freedom - as a powerful riposte to still-persisting notions that disabled people's entitlements are in the gift of others - this research project will also perforce seek to test the plausibility of a connection between conceptions of human rights for persons with disabilities and republicanism. Specifically, the proposed research will involve encountering the perceptions and experiences of two groups of people – people who come within the socially constructed category called *disabled* and people working as professionals in direct service provision to people with disabilities within Ireland. It is this latter group to whom this REC application applies.

Using semi-structured interviews to engage with the perspectives of professionals is expected to better inform an understanding and subsequent analysis of issues which the state, its institutions and others must address attention to if the promise of the CRPD is to take meaningful shape in the wider public consciousness. Such professionals occupy various roles in relation to the disabled people with whom they work, not just in terms of their diverse professional functions, but as advocates for, facilitators of and, possibly, inhibitors to disabled people's freedom. In a society where disability is often implicitly represented as a health issue – as exemplified in the simple reality that service provision responsibility resides primarily with the Health Service Executive – there must be plausible concern about the transition of persons with disabilities from dependent objects of protection and/or treatment to fully independent, autonomous subjects with inalienable rights. Hence, theorising professionals in this research as gate-keepers to the services disabled people receive unlocks the potential of using a republican lens to better understand not just how disabled people are perceived within services but also how disabled people are respected within the wider societal culture.

In summary, this research is being proposed to inform a view as to whether and, if so, how, a republican understanding – particularly in relation to notions of domination – might aid persons with disabilities in Irish society to better achieve and resiliently hold rights. Its value lies in the simplicity both with which domination, if present, can be discerned and in the way notions of domination might be harnessed across a variety of circumstances and life experiences to ground a unifying perspective about what is just and reasonable in the way we treat each other and in the expectations we can legitimately have of each other. Put simply, if, as seems intuitively likely, the lives of many people with disabilities in Irish society are wreathed in arbitrariness then, applying notions of non-domination, the whole of society is exposed to an imperfect freedom. If the rights outlined in the CRPD are imperfectly respected then, applying notions of non-domination, the rights of everyone in a society are under threat as imperfect. The republicanism posited here is egalitarian and fecund – a mechanism for entrenching and, even, expanding rights rather than simply enumerating them.

As to methodology, the overall project is framed in terms of a broadly interpretive approach – utilising thematic analysis - as appropriate to a piece of socio-legal research. Grounded in the empirical and seeking to better understand the world through engaging with individual perceptions and beliefs, the intention is to explore concepts, uncover assumptions and delineate points of convergence and points of divergence and, perhaps, disruption. The onus here is to do active reading, active thinking, active listening, active discussion and active writing using a qualitative approach underpinned by elements of critical discourse analysis to help discern how certain ideas come to dominate public consciousness. This is particularly apt in terms of disability where, it is suggested, images of the able body have been used as ideological totems to oppress and dominate those bodies deemed less able or un-able.

2.2 INVESTIGATORS' QUALIFICATIONS, EXPERIENCE AND SKILLS (Approx. 200 words)

List the academic qualifications and outline the experience and skills relevant to this project that the PI, other researchers and any supporting staff have in carrying out the research and in dealing with any emergencies, unexpected outcomes, or contingencies that may arise. ***State specifically who will be carrying out the research procedures.***

The principal investigator (PI) – that is, the person carrying out the research procedures - will be James Forbes.

In addition to having successfully undertaken DCU's research integrity training module and to holding an LLM from DCU, the PI also holds an MA(Ed) (University of Worcester) and an MSc (Trinity College, Dublin). Both of these latter degrees involved submitting dissertations which derived from direct research with persons with disabilities, the LLM involving direct research with people working in disability service providers. All of these degrees required extensive research methods and methodology training, via which the PI became conversant not just with a range of research techniques and their theoretical underpinnings but also, crucially, with the practicalities of applying some of them in direct face to face engagement with research participants. Because many of these participants came within the designation of 'vulnerable persons' the principle investigator became reasonably confident at adapting qualitative and mixed method research approaches to ensure that they were demonstrably ethically sound, pitched in ways which were accessible, nimble in terms of dealing appropriately with unanticipated issues and, above all, that the research process demonstrated empathy and respect.

In terms of the specific cohort of service provider staff who are the subject of this REC application - none of whom are expected to fall within the vulnerable designation - the PI also has the experience of working in such a service, suggesting that the issues to be discussed at interview are likely to be very familiar to the PI. It is expected that this familiarity should permit a nuanced engagement with the themes which arise and while, of course, it also has drawbacks of which the PI is aware of the need to mitigate, it should also, nonetheless, allow for rapport-building and an interview style which is sensitive and assured.

In terms of dealing with any emergencies, unexpected outcomes or other contingencies which might arise these can only be addressed here in general terms. At all times the research will proceed on the basis of informed and unambiguous consent and that, as far as reasonably foreseeable, no harm will occur as a result of it. The individual research participant will be informed that at every stage of the process, up to the point the data derived from their interview is submitted to DCU for final examination, they can withdraw from the research activity and that their data will be expunged. If an individual research participant experiences distress during interview the PI will terminate the interview if that is the person's wish. If distress occurs subsequent to the interview the PI will be available to the person, if they so wish, and will take whatever action the person deems appropriate in respect of the person's data. As to these and other contingencies and adverse scenarios which might arise, both of the PI's supervisors, Dr Hickey and Dr de Paor, are very experienced researchers and they will advise at every stage to help ensure that the research process is always ethically grounded and responsive to the need to consider and mitigate risk.

2.3 PARTICIPANT PROFILE

List and very briefly describe each participant group where applicable. For instance, participant group 1 will consist of…, participant group 2 will consist of… etc. Provide the number, age range and source of participants. Please provide a justification of your proposed sample size.

All of the proposed research participants under this REC application are professionals working in disability services:

Social care workers, meaning professionals who work directly with disabled adults in institutional settings such as residential units, day services and educational settings, some of whom will be involved in management and many of whom will have a statutory function under the *Health Act* 2005 in terms of complying with regulatory standards. It is intended to interview approx. 15 social care workers.

Social workers, meaning professionals who by virtue of their code of ethics have a social justice and human rights mandate to work creatively in expanding the life opportunities of vulnerable people, including disabled people. It is intended to interview approx. 5 social workers.

Therapists, meaning speech and language, occupational and physio therapists, working in rehabilitation roles with disabled people. I intend to interview approx. 5 therapists.

Teachers/tutors working in post-second level education provision. I intend to talk to approx. 6 teachers/tutors.

Senior managers or former senior managers of disability services. In this context I intend to talk to approx. 3 CEOs and 3 Heads of Service.

Members of state bodies responsible for ensuring safe provision for disabled persons, specifically current or former disability service managers in the HSE (approx. 3) and current or former HIQA inspectors (approx. 3).

Nursing staff working in service providers, specifically Clinical Nurse Managers (approx. 2) and senior nursing staff (approx. 3).

Social care and social work educators (approx. 4)

The proposed sample size and the proposed spread in terms of professions is expected to provide a comprehensive overview of how people working in the disability sector theorise the value of what they do and how they understand their jobs in relation to the needs and aspirations and entitlements of the adults with disabilities with whom they work. There will be a particular focus both on the CRPD and on the way the professionals understand and articulate the relationships they have with persons with disabilities. It is hoped the sample size might also allow for different emphasises to arise viz particular groups of professionals, thereby further contributing to a richer and more representative narrative.

As to age range, none of the proposed participants will be younger than 21 but it is not possible, at this point, to provide an upper age range.

2.4 PARTICIPANT RECRUITMENT

Please provide specific details as to how you will be recruiting participants. How will people be informed that you are doing this research? How will they be approached and asked if they are willing to participate? If you are mailing or phoning people, please explain how you have obtained their names and contact details. If a recruitment advertisement is to be used, please ensure you attach a copy to this application (Approx. 100 words).

The principal researcher has extensive professional contacts in each of the cohorts referenced and several of these contacts have indicated willingness to act on the researcher's behalf in contacting others in their respective professions and pass on the PI's invitation and plain language statement to participate in the research. In this way, it is envisaged that the PI will not be making first contact with potential research participants but, rather, that they will make first contact with the PI, thereby obviating any necessity for the PI to have to acquire email addresses or phone numbers in advance of a would-be participant expressing initial interest in taking part.

2.5 IS IT LIKELY THAT ANY PARTICIPANTS COULD BE CONSIDERED POTENTIALLY VULNERABLE?

Are some or all participants vulnerable in any way? (e.g. by virtue of the group they belong to, people who have undergone traumatic or adverse emotional events, people with diminished cognitive ability, power elations between researchers and participants etc.)?

YES or NO
… No

If Yes, please state and describe what this vulnerability (or vulnerabilities) is and justify why this research is being done with such participants

2.6 WILL THE IDENTITY OF THE PARTICIPANTS BE PROTECTED?

YES or NO
… Yes

If NO, please explain why

IF YOU ANSWERED YES TO 2.6, PLEASE ANSWER THE FOLLOWING QUESTION:

2.7 HOW WILL THE ANONYMITY OF THE PARTICIPANTS BE RESPECTED?

Please bear in mind that where the sample size is very small, it may be impossible to guarantee anonymity/confidentiality of participant identity. Participants involved in such projects need to be advised of this limitation in the Plain Language Statement/Information Sheet. If you intend to fully anonymize the data, please provide details.

Recognising the usefulness of pseudonymisation as a data protection security measure **(**Opinion 05/2014 on Anonymisation Techniques) each of the research participants will be assigned an identifier ensuring their actual identities are known only to the PI. This first measure will ensure that while transcripts will be available to the PI's supervisors and while a trusted third party will be engaged to type these transcripts the identity of each participant will be protected. Before each interview commences research participants will be asked to ensure that answers will be shorn of any specifics which might identify either themselves or others and the PI will be alert throughout each interview to further ensure this. Each of the professional cohorts identified from which participants will be drawn is large and this, coupled with the intention to invite participation from across Ireland, is further likely to ensure participants' identity is protected.

2.8 LEGAL LIMITATIONS TO DATA CONFIDENTIALITY

Participants need to be made aware that confidentiality of information provided cannot always be guaranteed by researchers and can only be protected within the limitations of the law - i.e., it is possible for data to be subject to subpoena, freedom of information claim or mandated reporting by some professions. This information should be included in your Plain Language Statement and Informed Consent Form. Depending on the research proposal and academic discipline, you may need to state additional specific limitations.

State how and where participants will be informed of these limitations.

This information will be contained in the plain language statement as well as in the consent form and reiterated at the start of each interview.

2.9 CHILD PARTICIPANTS (anyone under 18 years old)

If your participants include children, you ***must*** *confirm that you are in compliance with the research specific guidelines as detailed in [Keeping Children Safe - Policies and Procedures supporting Child Protection at DCU](#).*

Please indicate your compliance with the following guidelines:	**Mark here**
We confirm that we have read and agree to act in accordance with the DCU Child Protection policy and procedures	**N/A**
We confirm that we have put in place safeguards for the children participating in the research	**N/A**
We confirm that we have supports in place for children who may disclose current or historical abuse (whether or not this is the focus of the research)	**N/A**

2.10 PLEASE EXPLAIN WHEN, HOW, WHERE, AND TO WHOM RESULTS WILL BE DISSEMINATED, INCLUDING WHETHER PARTICIPANTS WILL BE PROVIDED WITH ANY INFORMATION AS TO THE FINDINGS OR OUTCOMES OF THE PROJECT?

The primary dissemination of the data obtained from research participants by way of interview will be in its analysed form within the PI's PhD. The PI also hopes that further dissemination might occur in the form of a book and via conference presentations and articles. Participants will be encouraged to request copies of the data once it becomes available in open source, this data not being the raw data but, rather, the analysed and anonymised data produced from the raw data. Further, should any of the professionals wish the PI to offer contextualised presentations to colleagues and relevant others the PI will endeavour to be available, where possible, to do this by way of both simple gratitude and a wish to help broaden the perspectives within disability service providers and analogous organisations.

2.11 ARE OTHER APPROVALS REQUIRED TO GAIN ACCESS TO ANOTHER LOCATION, ORGANISATION, SCHOOL ETC.?

YES or NO
… No

If YES, please specify from whom and attach a copy of the approval documentation. If this is not yet available, please explain when this will be obtained.

3. RISK AND RISK MANAGEMENT

3.1 EXPLAIN AND JUSTIFY THE STATED LEVEL OF RISK TO PARTICIPANTS

You must provide a justification for the stated level of risk and its corresponding level of review (Full Committee, Expedited, Notification), as indicated on the cover page of your application. Note that the level of risk may be influenced by the vulnerability of the research group, the methods employed and the nature of the research itself. For further information on risk levels, please refer to the Levels of Review information on the Research Support Services website.

The purposed research participants in this section of the proposed research are not considered to be a vulnerable group. Almost all of them belong to professions which are subject to state regulation – or in the case of social care workers are well on the way to this – and, as such, have highly developed professional codes of ethics which include guidance on research issues, including in respect of informed consent. The research proposed, while designed to garner clear opinions, is not likely, either in form or content, to be outside the usual experience of many (if not most) of the participants.

3.2 POTENTIAL RISKS TO PARTICIPANTS AND RISK MANAGEMENT PROCEDURES

Identify, as far as possible, all potential risks to participants (physical, psychological, social, legal, economic, etc.), associated with the proposed research. Will your research involve deception, investigation of participants involved in illegal activities, performance of any acts which might diminish the self-esteem of participants or cause them to experience embarrassment, regret or depression, administration of any substance or agent, collection of body tissues or fluid samples, use of non-treatment of placebo control conditions, collection and/or testing of DNA samples, administration of ionising radiation? Please explain what risk management procedures will be put in place to minimise these risks.

It is not anticipated that the proposed research will expose participants to risk and that any reasonable likelihood of harm flowing from participation in this research is remote.

3.3 ARE THERE LIKELY TO BE ANY BENEFITS (DIRECT OR INDIRECT) TO PARTICIPANTS FROM THIS RESEARCH?

YES or NO
… Yes

If YES, provide details

Possible indirect benefits to participants are in the realm of ideas. By inviting professionals to think deeply about their interactions with and relationships with persons with disabilities, particularly within a republican frame, there may be the same sorts of shifts in perspective that might ordinarily be expected to flow from attendance at, say, a novel seminar or a particularly interesting workshop.

3.4 ARE THERE ANY SPECIFIC RISKS TO RESEARCHERS?

Examples include use of dangerous materials, asking certain types of questions, research being undertaken in certain locations, researchers working alone in isolated areas, etc.

YES or NO
… No

If YES, please describe and explain what risk management procedures will be put in place to minimise these risks

N/A

3.5 DEALING WITH ADVERSE / UNEXPECTED OUTCOMES

Please describe what measures/protocols you have put in place in the event that there are any unexpected outcomes or adverse effects to participants arising from involvement in the project.

Unexpected outcomes or adverse events – if they occur – will be addressed in a sensitive and appropriate way, drawing on the advice of supervisors and on the PI's own professional training, it being useful, perhaps, to mention that the PI is also a mandated person within the meaning of the *Children First Act* 2015.

3.6 SUPPORT FOR PARTICIPANTS

Depending on risks to participants you may need to consider having additional support for participants during/after the study. Consider whether your project would require additional support, e.g., external counselling available to participants. Please advise what support will be available.

It is not expected that in respect of the cohorts referenced in this REC that support will be required but this will remain under review both during and after the study and participants are free to contact PI at any time.

3.7 HOW WILL THE CONDUCT OF THE PROJECT BE MONITORED?

Please explain how the principal investigator will monitor the conduct of the project (especially where several people are involved in recruiting or interviewing, administering procedures, etc.) to ensure that it conforms to the procedures set out in this application. In the case of student projects please give details of how the supervisor(s) will monitor the conduct of the project.

The PI will be the sole interviewer and as such will have primary responsibility for ensuring that agreed procedures and ethical requirements are fully adhered to. In addition, the PI's supervisors (Dr Tom Hickey and Dr Aisling de Paor) will have access to the data (but never the identity of the participants) in order to monitor ethical compliance and, if appropriate, risk minimisation.

3.8 DO YOU PROPOSE TO OFFER PAYMENTS OR INCENTIVES TO PARTICIPANTS?

YES or NO
… No

If YES, please provide further details

N/A

3.9 **DO ANY OF THE RESEARCHERS ON THIS PROJECT HAVE A PERSONAL, PHILOSOPHICAL, FINANCIAL, POLITICAL, IDEOLOGICAL, OR COMMERCIAL INTEREST IN ITS OUTCOME THAT MIGHT INFLUENCE THE INTEGRITY OF THE RESEARCH, OR BIAS THE CONDUCT OR REPORTING OF THE RESEARCH, OR UNDULY DELAY OR OTHERWISE AFFECT THEIR PUBLICATION?**

YES or NO
… No

If YES, please specify how this conflict of interest will be addressed

4. PERSONAL DATA

Definition of Personal Data

Personal data is any information about a living person, where that person is either identified or could be identified, from the data itself or when it is combined with other data. Typical examples of personal data in a research context are:

a) paper based records e.g. research participant files, patient records, consent declarations, interview notes etc.

b) electronic records e.g. database of participant details, online survey returns, photos, audio & visual recordings, IP addresses, diagnostic / clinical imaging etc.

c) other e.g. genetic data, biometric data, clinical or medical samples etc.

Note: Any data that is fully and completely anonymous is not considered to be personal data.

Further information on data protection is available from the University's Data Protection Unit. In addition, you should also consider consulting with your Unit's GDPR Advocate for help and advice on filling out this section of the form.

(A) Your knowledge of Data Protection		
Have you completed the online GDPR **'2020 Data Protection Staff'** module on Loop which is available to all staff of the University?	**YES or NO**	Yes

If you answered 'No' to the previous question then the DCU Data Protection Unit (DPU) strongly recommends that all applicants complete the training module on Loop before completing this section of the REC Application Form.

The Loop training module can be accessed at this **link** and searching for '2020 Data Protection Staff'. If you experience difficulties in doing so please contact the Teaching Enhancement Unit for assistance.

(B) Initial Assessment – Is the data to be used actually personal data? ***Rationale: Not all data used in a research project can be defined as 'Personal Data'***			
1	Will the proposed research include living human subjects? *Rationale – personal data applies only to living individuals.*	**YES or NO**	**Yes** **….**

2	Will the proposed research use any data that can be linked to an identified, or an identifiable, person? *Rationale – to be personal data it must be possible to associate it with a person.*	**YES or NO**	**No** **….**
3	Will the proposed research use any data identifiers that can be linked to a person? E.g. a participants name, code or ID number, their address, their IP address etc. *Rationale – fully anonymised data is not personal data.*	**YES or NO**	**No** **….**

If you answered ‘Yes’ to any of the questions 1 to 3 in sub-section (B), then continue to sub-section (C) and answer questions 1-9.

If you answered ‘No’ to all of the questions 1 to 3 in sub-section (B), then skip sub-section (C) and proceed section 5 of form.

(C) Assessing the degree of risk inherent in the personal data			
1	Will the proposed research involve the use of personal data on individuals which reveals any of the following attributes or characteristics about them? (State ‘Yes’ or ‘No’ as appropriate to all of the following)		
	Racial or ethnic origin	**YES or NO**	**No** **….**
	Political opinions	**YES or NO**	**No**
	Religious or philosophical beliefs	**YES or NO**	**No** **….**
	Trade union membership	**YES or NO**	**No** **….**
	Genetic data	**YES or NO**	**No**
	Biometric data	**YES or NO**	**No** **….**
	Data concerning health	**YES or NO**	**No** **….**

	Data concerning a person's sex life or sexual orientation	**YES or NO**	**No** **….**
2	Will the proposed research involve the use of personal data relating to children or vulnerable individuals? *A child, for data protection purposes, is defined as an individual below 18 years of age. Where the processing relates to 'electronic marketing' the age limit is reduced to 16 years. A vulnerable individual may be anyone who is unable to consent to, or to oppose, the processing of his or her data for any reason, including disability.*	**YES or NO**	**No** **….**
3	Will the proposed research involve the use of data relating to an individual's criminal convictions and / or offences?	**YES or NO**	**No** **….**
4	Will the proposed research involve the large-scale processing of personal data? *This may include: a wide range or large volume of personal data; processing which takes place over a large geographical area; processing where a large number of people are affected (e.g. over 100 individuals); or where the processing is extensive or has long-lasting effects.*	**YES or NO**	**No** **….**
5	Will the proposed research involve any form of automated processing of personal data? *In particular, to analyse or predict aspects concerning that person's performance at work, economic situation, health, personal preferences, interests, reliability, behaviour, location or movements.*	**YES or NO**	**No** **….**
6	Will the proposed research involve sharing or transferring any personal data to a 3rd party outside of DCU? *For example other research partners, providers of translation or transcription services, etc.*	**YES or NO**	**Yes** **….**
7	Will the proposed research require the sharing or processing of personal data outside the EU or the EEA? *The EEA is the European Economic Area (i.e. the EU plus Norway, Liechtenstein and Iceland)*	**YES or NO**	**No** **….**

8	Will the proposed research involve the matching or combining of separate datasets of information on individuals in a way that would exceed their reasonable expectations of privacy? *An example would be combining mobile phone location data along with any other dataset to identify individuals.*	**YES or NO**	**No**
9	Will it be possible to fully anonymise (as opposed to merely pseudo-anonymising) the personal data before it is obtained and used by you in the proposed research? *This might occur if the data is provided to you by an external organisation or another educational institution as part of a collaborative study.* *Anonymised data is not personal data. Anonymisation is the process of removing personal identifiers, both direct and indirect, that may lead to an individual being identified.* *Pseudonymisation is the processing of personal data in such a manner that the personal data can no longer be attributed to a specific living individual without the use of additional information, provided that such additional information is kept separately and is subject to technical and organisational measures to ensure its security.*	**YES or NO**	**Yes** **….**

Important Point: Next Step

If you answered 'Yes' to one or more of the questions 1 to 9 in sub-section (C) **you must contact the Data Protection Unit (DPU) prior to submitting this application form to the REC**. The DPU will assess whether there are any further data protection issues to be addressed or additional procedures to be followed.

5. DATA / SAMPLE STORAGE, SECURITY AND DISPOSAL

For the purpose of this section the term 'Data' includes personal data that is in a raw or a processed state (e.g. interview audiotape, transcript or analysis, etc.). The term 'Samples' include body fluids and/or tissue samples.

5.1 HOW AND WHERE WILL THE DATA / SAMPLES BE STORED?

DCU recommends that any data stored electronically offsite should utilise the DCU Google Drive. Alternative offsite storage will need to be justified and must meet data protection and GDPR compliance requirements.

The data will be stored on encrypted files on my personal computer and in an encrypted folder on DCU's Google Drive.

5.2 WHO WILL HAVE ACCESS TO DATA / SAMPLES?

If people other than the main researchers have access, please name who they are and explain for what purpose.

The PI will be the only person to have access to the data in its entirety. However, the PI's supervisors will have access to the analysed and pseudonymised data for the purposes of advising the PI. A transcriber will also have access to pseudonymised recordings for the purposes of typing them up, these transcripts then being stored on DCU's Google Drive. The transcriber will be paid and will be required to sign a GDPR compliant confidentiality undertaking. It is not possible to provide the transcriber's name at this point.

5.3 HOW LONG IS THE DATA TO BE HELD OR RETAINED?

Note that, with very few exceptions, ***Personal Data*** *may not be retained indefinitely. It is up to the research team to establish an upper retention limit for each category of Personal Data used within the project and to ensure it is applied at the expiry of that limit.*

The audio-recordings, as stored on encrypted files, will only be held until transcripts have been made and, thereupon, the recordings will be permanently erased. The pseudonymised transcripts will be held for some time longer, permitting a follow up project – most likely in article, conference presentation and/or book form. However, in any event, the PI has committed to not retaining the transcripts for more than 5 years.

5.4 WILL THE PERSONAL DATA BE USED AT A LATER DATE FOR THE PURPOSE OF PUBLICATION OF THE RESULTS OF THE RESEARCH?

YES or NO
Yes

Where it is intended that the personal data used in the project will be used at a later date for the purposes of publication please explain how consent to do so will be obtained.

As the earliest contact with would-be participants the plain language statement will indicate that, subject to individual consent, pseduonymised and securely stored transcripts of the interviews – but not the interview recordings – will be kept to enable the PI to complete a further project, most likely a book. If the individual participants give consent s/he will be asked to indicate this in writing, this consent being securely stored by the PI.

5.5 IF THE DATA/SAMPLES ARE TO BE DISPOSED OF AT THE END OF THE PROJECT PLEASE EXPLAIN HOW, WHEN AND BY WHOM THIS WILL BE DONE?

Note that simply deleting files is not sufficiently secure. The additional steps to be taken to maintain data security should be given. ***Personal data*** *must be disposed of in a safe and secure manner at the end of its retention period. If the data is stored in (a) a paper-based format, then shredding or disposal via a secure bin is recommended; or (b) in an electronic-based format, then deletion of the record or the full anonymization of the data is recommended. If data/samples are* ***not*** *being disposed of, please justify that intention.*

How will the data/samples be disposed? Please describe the means by which the personal data will be deleted or destroyed. This includes personal data held in hard copy and digital formats.	At the material time, consistent with answers above, all paper transcripts will be shredded and all electronically based data will be deleted in accordance with best practice advice to ensure it cannot be retrieved. For this latter purpose the PI will engage the advice of a computer expert.

When will the data/samples be disposed? Please indicate the intended retention period of the personal data, and reasons for this retention period. Please note that retention periods must be GDPR compliant and must be consistent with the DCU Retention Policy.	The audio recordings will be permanently deleted once transcribed. The anonymised transcripts – both in digital and paper form will be held for no longer than 5 years, post – dissertation submission. As stated above, this 5 year period allows for their use for the purposes of an article, conference presentation and/or a book. However, if a shorter period suffices the transcripts will be permanently deleted sooner. The master list held solely and securely by the PI – that is, the list by which the transcripts can be linked back to the individual research participants – must be retained in case the participants need to be notified of a data breach but it too will be permanently deleted at the same time as the transcripts.
By whom will the data/samples be disposed? Please indicate the designated team member(s) with responsibility for deletion and/or destruction of the research project's personal data.	The PI will be responsible for ensuring that all of the research data is destroyed in conformity with GDPR requirements and, consistent with answers above, as the material times for destruction fall due.

6. FUNDING OF THE RESEARCH

6.1 HOW IS THIS WORK BEING FUNDED?

DCU PhD scholarship

6.2 PROJECT GRANT NUMBER *(If relevant and/or known – otherwise mark as N/A)*

N/A

6.3 DOES THE PROJECT REQUIRE APPROVAL BEFORE CONSIDERATION FOR FUNDING BY A GRANTING BODY?

YES or NO
No

6.4 HOW WILL PARTICIPANTS BE INFORMED OF THE SOURCE OF THE FUNDING? *(E.g. included in the Plain Language Statement)*

This information will be included in the plain language statement.

6.5 DO THE FUNDERS OF THIS PROJECT HAVE A PERSONAL, FINANCIAL, POLITICAL, IDEOLOGICAL, OR COMMERCIAL INTEREST IN ITS OUTCOME THAT MIGHT COMPROMISE THE INDEPENDENCE AND INTEGRITY OF THE RESEARCH, OR BIAS THE CONDUCT OR REPORTING OF THE RESEARCH, OR UNDULY DELAY OR OTHERWISE AFFECT THEIR PUBLICATION?

YES or NO
No

If YES, please specify how this conflict of interest will be addressed

7. PLAIN LANGUAGE STATEMENT *(Attach to this document. Approx. 400 words)*

A Plain Language Statement (PLS) should be used in all cases. This is written information in plain language that you will be providing to participants, outlining the nature of their involvement in the project and inviting their participation. The PLS should specifically describe what will be expected of participants, the risks and inconveniences for them, and other information relevant to their involvement. Please note that the language used must reflect the participant age group and corresponding comprehension level– if your participants have different comprehension levels (e.g. both adults and children) then separate forms should be prepared for each group. The PLS can be embedded in an email to which an online survey is attached, or handed/sent to individuals in advance of their consent being sought. See the link to sample templates on the Ethics Approval section of the Research Support Services website.

PLEASE CONFIRM WHETHER THE FOLLOWING ISSUES HAVE BEEN ADDRESSED IN YOUR PLAIN LANGUAGE STATEMENT/ INFORMATION SHEET FOR PARTICIPANTS:

	YES or NO
Introductory Statement (PI and researcher names, school, title of the research)	**Yes**
What is this research about?	**Yes**
Why is this research being conducted?	**Yes**
What will the participant be expected to do/have to do if they decide to participate in the research study?	**Yes**
How will their privacy be protected?	**Yes**
How will the data be used and subsequently disposed of?	**Yes**
What are the legal limitations to data confidentiality?	**Yes**
Are there any benefits of taking part in the research study?	**Yes**
Are there any risks of taking part in the research study?	**Yes**
Confirmation that participants can change their mind at any stage and withdraw from the study	**Yes**
How will participants find out what happens with the project?	**Yes**
Contact details for further information (including REC contact details)	**Yes**
Details relating to GDPR Compliance where Personal Data is being sought	**Yes**

If any of these issues are marked NO, please justify their exclusion:

8. INFORMED CONSENT FORM *(Attach to this document. Approx. 300 words)*

In most cases where interviews or focus groups are taking place, an Informed Consent Form is required. This is an important document requiring participants to indicate their consent to participate in the study and give their signature. In cases where an anonymous questionnaire is being used, it is not enough to include a tick box in the questionnaire. Participants should indicate their consent to each aspect of the research in a staged manner by checking mandatory checkboxes.

See link to sample templates on the Ethics Approval section of the Research Support Services website.

NB – IF AN INFORMED CONSENT FORM IS NOT BEING USED, THE REASON FOR THIS MUST BE JUSTIFIED HERE.

9. ASSENT FORM & PLAIN LANGUAGE STATEMENT FOR CHILDREN *(Attach to this document.)*

A child specific Plain Language Statement (PLS) should be used in research where children will be involved. The PLS must be written in a way that is understandable for children within your targeted age group. It also must state, in plain language, the nature of their involvement in the project and inviting their participation. The PLS should specifically describe what will be expected of participants, the risks and inconveniences for them, and other information relevant to their involvement. In addition, child participants should also be provided with an Assent Form. Parents/guardians will be provided with the Informed Consent Form, but each child should provide assent before taking part in the research. The Assent Form needs to be understandable to the age-group you are targeting. See link to sample templates on the Ethics Approval Section of the Research Support Services website.

NB – IF AN ASSENT FORM IS NOT BEING USED, THE REASON FOR THIS MUST BE JUSTIFIED HERE.

10. SUBMISSION CHECKLIST *(Attach to this document)*

Please confirm that all supplementary information is included in your application (in electronic copy). If questionnaire or interview questions are submitted in draft form, please indicate this by putting (draft) after YES. A copy of the final documentation must be submitted for final approval when available.

My application has been collated as one electronic file which includes the following documentation:	**INCLUDED** **(mark as YES)**	**NOT APPLICABLE (mark as N/A)**
Bibliography	**Yes**	
Recruitment advertisement		N/A
Plain language statement/Information Statement	**Yes**	
Informed Consent form	**Yes**	
Informed Assent form		N/A
Evidence of external approvals related to the research		N/A
Questionnaire / Survey		N/A
Interview / Focus Group Questions	**Yes (draft)**	
Debriefing material		N/A
Other (e.g. BSC approval review letter, Data Protection Impact Assessment)		N/A

Appendix - references

Article 29 Data Protection Working Party *Opinion 05/2014 on Anonymisation Techniques* 0829/14/En WP2016, adopted 10 April 2014

Kittay, E.F. At the Margins of Moral Personhood *Ethics* 116:1, 2005, 100-131

Marti, J.L., Pettit, P. *A Political Philosophy in Public Life* (Princeton University Press, 2010)

Pettit, P. *Republicanism A Theory of Freedom and Government* (Oxford University Press, 1999)

Quinn, G., Rekas-Rosalbo, A Civil Death: Rethinking the Foundations of Legal Personhood for Persons with a Disability *Irish Jurist* 56, 2016 286-325

Appendix 2 – REC Application Form – Persons with visual impairment and parents of persons with disabilities

Research and Innovation Support

Dublin City University

RESEARCH ETHICS COMMITTEE

APPLICATION FOR APPROVAL OF A PROJECT INVOLVING HUMAN PARTICIPANTS

Application No. *(office use only)* DCUREC/2021/_____

Please read the following information carefully before completing your application. Failure to adhere to these guidelines will make your submission ineligible for review.

- **Applications must be submitted via the Research Ethics Application Portal here** – no hardcopy required**.** **All queries relating to submission should be e-mailed to the DCU Research Ethics Committee (REC) at rec@dcu.ie**
- **Section 4 of this form addresses the possible data protection issues of the proposed research and it must be completed prior to making a formal REC application.**
- **Student applicants must include their supervisor as an investigator on the Research Ethics Application Portal** – this applies to all masters by research and PhD students. The form should be checked, approved and signed by the supervisor in advance of submission to REC. ***NB – Taught Masters and Undergraduate students apply for ethical review via their local ethics***
- **The application should consist of one electronic file only,** with an electronic signature from the PI (and supervisor if applicable). The completed application must incorporate all supplementary documentation, especially those being given to the proposed participants. The application will go through an initial triage process and will be returned to the applicant(s) if the form is incomplete or documentation is missing. If extensive changes are required, it will be reviewed at the next REC
- **All sections of the application form must be answered as instructed and within the word limits given.**

Applications which do not adhere to all of these requirements will not be accepted for review and will be returned directly to the

Applications must be completed on the form; answers in the form of attachments will not be accepted, except where indicated. No hardcopy applications will be accepted. **Research must not commence until written approval has been received from the Research**

Note: If your research requires approval from the Biological Safety Committee (BSC) this must be in place prior to REC submission.

Contact bio.safety@dcu.ie. Please attach the responses from these committees to this submission as directed below.

PROJECT TITLE	Domination and disability: a republican proposal in the light of the United Nations Convention on the Rights of Persons with Disabilities
PRINCIPAL INVESTIGATOR(S) The named Principal Investigator is the person with primary responsibility for the research project. In the case of PhD/D.Ed./MSc Research projects the supervisor must be listed as Principal Investigator, in addition to the student.	James Forbes Tom Hickey, Dr Aisling da Paor, Dr
START AND END DATE	1/6/2021 – 31/12/2021
LEVEL OF RISK *Please indicate whether this project requires (a) notification (b) expedited* ***or*** *(c) full committee review. Justification for your choice is required under section 3.1*	Full Committee Review

1. ADMINISTRATIVE DETAILS

PROJECT TYPE: **(mark Y to as many as apply)**	Research Project	…	Funded Consultancy	…
			Clinical Trial	…
	Student Research Project(please indicate level below, e.g. PhD/D.Ed./MSc Research)	…	Other - Please Describe:	…
	PhD / Other Doctorate	Y…		
	D.Ed.	…		
	MSc Research	…		

1.1 INVESTIGATOR CONTACT DETAILS

PRINCIPAL INVESTIGATOR(S): In the case of PhD/D.Ed./MSc Research projects the supervisor must be listed as Principal Investigator. Doctoral researchers and Research Masters may be listed as Principal Investigators, depending on the conventions of the discipline and on the individual case. It should be made clear, in subsequent sections of this application, who is carrying out the research procedures.

NAME	*SCHOOL/UNIT*	*EMAIL*
James Forbes	**School of Law and Government**	
Tom Hickey, Dr	**School of Law and Government**	

OTHER INVESTIGATORS:

NAME	*SCHOOL/UNIT*	*EMAIL*
Aisling de Paor, Dr	**School of Law and Government**	

1.2 WILL THE RESEARCH BE UNDERTAKEN ON-SITE AT DUBLIN CITY UNIVERSITY?

YES or NO
… **No**

If NO, state details of the off-campus location – provide details of the approval to gain access to that location

The proposed interviews to which this application refers – this application being the second of two – will be with adult persons who are blind and visually impaired and parents of disabled people. A previously submitted REC application in respect of professionals working in disability services was granted permission to commence.

For the duration of Covid-19 restrictions the strong likelihood is that interviews will happen via password protected Zoom and similar platforms, utilising a private office on the researcher's part. Where in-person interviews may be requested by Dublin based participants, and assuming Covid 19 travel restrictions are not in place, these will take place in a private meeting room to which the PI has access in a North Dublin centre for the visually impaired. This room is spacious and permits Covid-19 protocols to be adhered to. Were similar requests to be made by non-Dublin based participants these will be considered on a case-by-case basis and factoring in all the relevant circumstances at the material time.

1.3 WILL THIS RESEARCH INVOLVE ANIMALS?

YES or NO
… **No**

If YES, please provide details on the outcome from BRAG and attach copies of approval(s)

N/A

1.4 HAS THIS RESEARCH PROPOSAL BEEN SUBMITTED TO ANOTHER ETHICS COMMITTEE?

YES or NO
No

If YES, please provide details on the outcome and attach copies of approval(s)

N/A

1.4.1 HAS THIS RESEARCH PROPOSAL BEEN REFUSED ETHICAL APPROVAL FROM THIS OR ANOTHER RESEARCH ETHICS COMMITTEE PREVIOUSLY?

If YES, please provide details.

N/A

DECLARATION BY PRINCIPAL INVESTIGATOR(S)

The information contained herein is, to the best of my knowledge and belief, accurate. I have read the University's current research ethics guidelines, and accept responsibility for the conduct of the procedures set out in the attached application in accordance with the form guidelines, the REC guidelines, the University's Conflict of Interest Policy, its Code of Good Research Practice and any other condition laid down by the Dublin City University Research Ethics Committee. I have

If there exists any affiliation or financial interest for researcher(s) in this research or its outcomes or any other circumstances which might represent a perceived, potential or actual conflict of interest this should be declared in

I and my co-investigators and/or supporting staff have the appropriate qualifications, experience and facilities to conduct the research set out in the attached application and to deal with any emergencies and contingencies related to the research that may arise. Supervisor(s) signature(s) is / are required as evidence that they have read and approve this

Please note:

1. *Any amendments to the original approved proposal must receive prior REC approval.*
2. *As a condition of approval investigators are required to document and report immediately to the Secretary of the Research Ethics Committee any adverse events, any issues which might negatively impact on the conduct of*

Electronic Signature(s):

Principal investigator(s): ____________________

Print Name(s) here: James Forbes

Date: **4th June 2021**

I, the main supervisor of this research proposal, have read and approve this submission.

Supervisor(s) signature (where relevant): Tom Hickey

Print Name(s) here: *Tom Hickey*

Date: *4.6.21*

2. PROJECT OUTLINE

2.1 LAY DESCRIPTION, AIMS & JUSTIFICATION, METHODOLOGY *(Approx.900 words)*

Please outline, in terms that any non-expert would understand, what your research project is about, including what participants will be required to do. Please explain any technical terms or discipline-specific phrases. State the aims and significance of the project. Where relevant, state the specific hypothesis to be tested. Please provide a brief description of background research, a justification as to why this research project should proceed in that context and an explanation of any expected benefits to the community. NB – all references cited should be listed in an attached bibliography. Provide an outline of the proposed method and state who is doing which task – include details of data collection techniques, the tasks participants will be asked to do, the estimated time commitment involved, and how data will be analysed. If the project includes any procedure which is beyond already established and accepted techniques, please include a description of *it. There should be enough detail provided to facilitate ethical review, but applicants are encouraged to keep it as succinct as possible.*

This research project, for which REC agreement is being sought in two parts, derives from an intuition that republicanism has something of considerable value to bring to the lives and experiences of persons with disabilities, especially, perhaps, in the context of the United Nations Convention on the Rights of Persons with Disabilities 2007 (CRPD). In large part, this intuition draws on the work of Philip Pettit. Although republicanism is of ancient lineage –as represented, *inter alia*, in the works of Cicero and Machiavelli – Pettit's modern reworking of it coalesces around the idea that liberalism's conception of what it is to be a free citizen lacks robustness. Hence, whereas liberalism's sensitivities invite the equating of freedom with non-interference, contemporary republicanism articulates a much bolder turn, asserting that phrasing 'the demands of freedom as non-domination gives us a very full and persuasive picture of what it is reasonable to expect of a decent state and a decent civil society' (Pettit, 1997:4). Within such an arrangement, not to be dominated is to be resiliently free of another's actual or *potential* ability to arbitrarily interfere in one's life and legitimate choices. More, in this contemporary rendering, civic virtue and a distinctive emphasis on citizenship underwrite the conditions of non-domination, it becoming the primary object of the state to ever reduce the circumstances in which arbitrary power can manifest and function.

Presented as a theory for testing (Marti and Pettit, 2010), at the heart of Pettit's work is a concern with identifying and ameliorating opportunities for and instances of domination. As such, it is contended that there is much merit in testing whether republicanism can offer both a simple means of initiating an analysis of individual and collective freedom and - a further intuition - a remediating strategy. If this dual potential is true, this makes it particularly attractive in terms of applying the non- domination concept in the lives of disabled people, whose status as citizens – and, in some accounts, as persons – has traditionally been and, arguably, remains occluded (see, for instance, Quinn and Rekas -Rosalbo, 2016; Kittay, 2005). Indeed, the very existence of the CRPD speaks to the need to make explicit that persons with disabilities hold the same rights as those who might be described as non-disabled. Prefacing the CRPD as a call to freedom - as a powerful rebuke to still-persisting notions that disabled people's entitlements are in the gift of others - this research project will also seek to test the plausibility of a connection between conceptions of human rights for persons with disabilities and republicanism.

The proposed research involves three groups of people:

- people with disabilities, specifically adults who share the characteristic of vision impairment, inclusive of blindness; some of these people may have additional impairments
- parents of persons with disabilities
- people working as professionals in direct service provision to people with disabilities.

This last group have already been the subject of a separate, successful REC application. The instant application concerns engaging by means of semi-structured individual interviews with both disabled persons and parents of disabled persons.

As to the decision to restrict one strand of the research to persons with vision impairment a word here as to the reasoning. Persons with disabilities do not constitute a homogenous group and, indeed, such is the vast range of impairment types and impairment circumstances that it is epistemologically dubious, at best, to seek to research disabled people as a supposed category. However, while no less prone to the dangers of generalisation, by focusing on one discrete facet of impairment – in this case, vision impairment – the intention is to produce data which, while always only a snapshot in time, may resonate in socially useful ways with other disabled peoples' experiences and which may offer something to the wider society in terms of better understanding the corrosive potential of domination in the lives of disabled persons.

Within this context, perhaps, the earliest, most comprehensive and most enduring example of the complex *othering* of disability is that represented by blindness. Even in the Enlightenment, philosophers argued about the efficacy of educating blind people, with Locke (1689), for instance, maintaining it to be a futile activity while others insisted that the ability to reason was not conditioned on seeing (Berkley, 1709; Diderot, 1749). Of course, weaving in and out of all this are other accounts: the blind person as seer, as exceptional, as possessed of superior senses though deprived of physical sight (Barasch, 2001). But, from another perspective, within this brief overview what becomes very clear, from earliest times, is the palpable *presence* of vision impaired people in society. Whether feared or lauded, ascribed powers or patronised, blind people have never been excised from the human narrative in the ways in which people with other types of experiences of disability have been and continue to be. Hence, the view that vision impairment – strange yet strangely ordinary - represents a useful lens through which to plausibly explore the wider reality of disability in relation to a trio of CRPD rights, education (article 24), work and employment (article 27) and living independently and being included in the community (article 19). Theorising these rights as gateways to successfully achieving other rights and – consistent with the CRPD – applying a social model reading of disability and utilising a republican interpretive frame, the chief focus of this research strand will be understanding what blockages and inhibitors the participants might identify as constraining their attainment and resilient enjoyment of these rights. Alongside hearing parents of disabled persons, it is anticipated that the voices attended to here have a message not just about the liberation of disabled people but about *all* people advancing together in a more dynamic understanding of rights, entitlements and responsibilities.

In summary, this research is premised on the view that a republican understanding of domination will aid persons with disabilities in Irish society to better achieve and resiliently hold rights. Its value lies in the simplicity both with which domination, if present, can be discerned and in the way notions of domination might be harnessed across a variety of circumstances and life experiences to suggest a unifying perspective about what is just and reasonable in the way we treat each other and in the expectations we can legitimately have of each other. Moreover, if the basic human rights outlined in the CRPD are imperfectly respected then, applying non-domination, the freedoms of everyone in a society are diminished and their rights less robust.

As to methodology, the overall project is framed in terms of a broadly interpretive approach – utilising thematic analysis - as appropriate to a piece of socio-legal research. Grounded in the empirical and seeking to better understand the world through engaging with individual perceptions and beliefs, the intention is to explore concepts, uncover assumptions and delineate points of convergence and points of divergence and, perhaps, disruption. The onus here is to do active reading, active thinking, active listening, active discussion and active writing using a qualitative approach underpinned by elements of critical discourse analysis to help discern how certain ideas come to dominate public consciousness. This is particularly apt in terms of disability where, it is suggested, images of the able body have been used as ideological totems to oppress and dominate those bodies deemed less able or un-able.

2.2 INVESTIGATORS' QUALIFICATIONS, EXPERIENCE AND SKILLS (Approx. 200 words)

List the academic qualifications and outline the experience and skills relevant to this project that the PI, other researchers and any supporting staff have in carrying out the research and in dealing with any emergencies, unexpected outcomes, or contingencies that may arise. **State specifically who will be carrying out the research procedures.**

The principal investigator (PI) – that is, the person carrying out the research procedures - will be James Forbes.

In addition to having successfully undertaken DCU's research integrity training module and to holding an LLM from DCU, the PI also holds an MA(Ed) (University of Worcester) and an MSc (Trinity College, Dublin). Both of these latter degrees involved submitting dissertations which derived from direct research with persons with disabilities, the LLM involving direct research with people working in disability service providers. All of these degrees required extensive research methods and methodology training, via which the PI became conversant not just with a range of research techniques and their theoretical underpinnings but also, crucially, with the practicalities of applying some of them in direct face to face engagement with research participants. Because many of these participants came within the designation of 'vulnerable persons' the principle investigator became reasonably confident at adapting qualitative and mixed method research approaches to ensure that they were demonstrably ethically sound, pitched in ways which were accessible, nimble in terms of dealing appropriately with unanticipated issues and, above all, that the research process demonstrated empathy, inclusivity, respect and was empowering. Indeed, a sense on the part of participants of being empowered is crucial, not least because many people with disabilities have reported the experience of research being *done* to them rather than with them (Oliver, 1992, 2009).

With specific reference to the PI's professional background working in the disability sector, this has encompassed direct work with disabled people and their families, teaching on disability issues and person centred practice at university level, sitting on HIQA advisory groups, being a ministerial social care and health service provision and training in both child protection and vulnerable adult safeguarding.

In terms of dealing with any emergencies, unexpected outcomes or other contingencies which might arise these can only be addressed here in general terms. At all times the research will proceed on the basis of informed and unambiguous consent and that, as far as reasonably foreseeable, no harm will occur as a result of it. The individual research participant will be informed that at every stage of the process, up to the point the data derived from their interview is submitted to DCU for final examination, they can withdraw from the research activity and that their data will be expunged. If an individual research participant experiences distress during interview the PI will terminate the interview if that is the person's wish. If distress occurs subsequent to the interview the PI will be available to the person, if they so wish, and will take whatever action the person wishes in respect of the person’s data and will seek to help guide the person to make personally appropriate decisions. The PI will also ensure that participants are supplied, via the use of a specifically designed distress protocol, with information concerning how to access counselling and other helping services, including a free national service specific to dealing with issues associated with sight loss.

As to these and other contingencies and adverse scenarios which might arise, both of the PI’s supervisors, Dr Hickey and Dr de Paor, are experienced academics and their advice will be sought at every stage to help ensure that the research process is always ethically grounded and responsive to the need to consider and mitigate any risk to participants.

Dr Tom Hickey BCL, LLM, PhD
Dr Tom Hickey holds a BCL (NUI Galway), an LLM (Queens’ College, Cambridge) and a PhD (NUI Galway). He joined the School of Law and Government at DCU in 2013, having previously worked at the School of Law, NUI Galway. He was a visiting professor at Université Montesquieu, Bordeaux IV from 2013-2018. He was a visiting scholar at the Bonavero Institute of Human Rights, University of Oxford in 2020, at the University of Glasgow School of Law (2012) and at the Center for Human Values, Princeton University (2009). He won the President’s Prize for Teaching Excellence in 2015, and was nominated again in 2020. He was programme chair of the LLM (Master of Laws) from 2015 through 2018.

Tom is a member of the Expert Advisory Panel to the Irish Citizens’ Assembly on Gender Equality (2020-21). He is the co-author of **Constitutional Law: Texts, Cases & Materials** (2nd ed., Clarus, 2019), co-editor of **Judges, Politics and the Irish Constitution** (MUP, 2017), and co-author of **The Political Theory of the Irish Constitution: Republicanism and the Basic Law** (MUP, 2015). He has published extensively in the areas of judicial power, republican theory and comparative constitutional law, in journals such as the *International Journal of Constitutional Law*, *Public Law, Legal Studies* and the *International Journal of Social Welfare and Family Law.* He is a regular contributor to public debates in broadcast and print media on matters relating to constitutional law, human rights and republicanism. He currently supervises three PhD students – all engaging questions relating to human and constitutional rights, institutional design, and political theory.

Dr Aisling de Paor BCL, LLM, PhD., Solicitor
Aisling is Associate Professor of Law at the School of Law and Government, Dublin City University, where she lectures modules including ‘Genetics Law and Society’, ‘Medical Law and Bioethics’ and Moot Court. She has been nominated for the President’s Award for Excellence in Teaching in 2017, 2018 and 2021, and won the Award in 2018.

Aisling graduated from National University of Ireland, Galway with a law degree (B.C.L.) in 2005 and graduated from University College Cork with a masters in law (LL.M.) in 2006. She is a qualified Solicitor (Law Society of Ireland) and trained in a commercial law firm in Dublin (2006 – 2009). In 2013 Aisling defended her PhD (funded by the Irish Research Council), entitled ‘Advancing Science and Controlling the Misuse of Genetic Information in Employment and Insurance – Towards an Effective European Union Regulatory Framework.’

From 2009 to 2014 Aisling was a part-time Lecturer in Law at the School of Law, NUI Galway, and also worked as a Research Assistant at the Centre for Disability Law and Policy, NUI Galway (2009 – 2010), and regularly collaborates with the staff and the network there. She is an honorary fellow and an affiliated researcher of the Burton Blatt Institute, Syracuse University, New York (which is a leading disability law and policy institute in the United States) and was a visiting scholar at this institute in October 2012, May 2014 and June 2018.

Aisling's research interests lie in the fields of genetics law and policy, medical law and disability law and policy. She has published in these intersecting fields in journals including the European Journal of Health Law, the European Yearbook of Disability Law, the Journal of Community Genetics and the Irish Journal of Medical Science. Aisling is author of a book entitled 'Genetics, Disability and the Law – Towards an EU Legal Framework' (Cambridge University Press 2017) and co- editor of a book entitled 'Genetic Discrimination – Transatlantic Perspectives on the Case for a European Level Legal Response' (Routledge 2014). She currently sits on the Ethics Advisory Board for an EU Horizon 2020 project, iReceptor Plus, a multidisciplinary initiative to develop personalised medicine and genetic advances. Aisling has supervised several research students in the area of disability law and medical, including one PhD candidate to completion (on the topic of the rights of persons with disabilities and the criminal justice system).

2.3 PARTICIPANT PROFILE

List and very briefly describe each participant group where applicable. For instance, participant group 1 will consist of…, participant group 2 will consist of… etc. Provide the number, age range and source of participants. Please provide a justification of your proposed sample size.

Participant group 1 will consist of approximately 20 adults who are vision impaired – some will be blind while others will have varying degrees of significant sight loss; there may also be other physical and/or sensory disabilities present. However, intellectual disability is not expected to feature. Drawn from around the country, it is not possible at this stage to give a precise age-range but a reasonable expectation would be that participants would be in the 23 to 70 age bracket. It is not envisaged that any of participant group 1 will be people who will have any issues in respect of giving – or withholding – informed consent.

Participant group 2 will consist of approximately 10 parents of persons with disabilities, the range of disabilities here likely to include vision impairment but not exclusively limited to vision impairment.

2.4 PARTICIPANT RECRUITMENT

Please provide specific details as to how you will be recruiting participants. How will people be informed that you are doing this research? How will they be approached and asked if they are willing to participate? If you are mailing or phoning people, please explain how you have obtained their names and contact details. If a recruitment advertisement is to be used, please ensure you attach a copy to this application (Approx. 100 words).

The PI has extensive professional contacts in the vision impaired community, making it important from an ethical perspective that recruitment to participant group 1 not be conducted directly by the PI. Would-be participants cannot feel in any way compelled or required to take part and, so, to this end, a trusted third party (hereafter, Gatekeeper 1) has already indicated their willingness to agree to distribute the plain language statement (also to be produced, as required, in large print, braille and audio versions) to would- be participants, entirely without the PI knowing who has been contacted or who might have refused to participate. The Gatekeeper – a social care professional well-known and respected in elements of the vision impaired community - will distribute the plain language statement to individuals who, if they agree to participate, will then be asked to introduce the Gatekeeper to other members of the vision impaired community who might be willing to consider involvement and to whom the appropriately formatted plain language statement will be furnished. This process will terminate when 20 participants have agreed to participate (or if less than 20 when it becomes apparent that a ceiling has been reached), at which point the PI will be provided with a list of names and contact details.

Participant group 2 will be recruited in a different manner. Here, two parents have indicated willingness to circulate the PLA to members of a number of support groups and to then subsequently, with consent, to provide the PI with the contact details of those persons who have expressed an interest in taking part in the study or who have further questions concerning possible participation. The parents will hand over to the PI much earlier in this process than the Gatekeeper as it is envisaged that this will ensure that their membership of the support groups themselves is not compromised in any way. This is important in that it recognises the value of such groups for parents and respects that the primary function of these types of groups is often intimate and private. If, however, insufficient numbers of parents can be recruited using this approach, while unlikely, the PI may need to ask parents already recruited to reach out directly to other possible parent participants in a snowballing approach.

2.5 IS IT LIKELY THAT ANY PARTICIPANTS COULD BE CONSIDERED POTENTIALLY VULNERABLE?

Are some or all participants vulnerable in any way? (e.g. by virtue of the group they belong to, people who have undergone traumatic or adverse emotional events, people with diminished cognitive ability, power relations between researchers and participants etc.)?

YES or NO
Yes

If Yes, please state and describe what this vulnerability (or vulnerabilities) is and justify why this research is being done with such participants

This application recognises that within mainstream research methods people with disabilities are often constructed as vulnerable notwithstanding that this is a designation many individuals with disabilities would recognise as reductive and inappropriate to themselves (see, for instance, Lawler *et al*., 2015). That it is accepted here in this application and, indeed, that the vulnerable descriptor is also extended to parents of disabled people, is prefaced on a conception of vulnerability as common to all living forms and, moreover, that across the life course the human condition is profoundly shaped by an inherent and constant state of precariousness such that all lives are vulnerable (Butler, 2004, Fineman and Grear, 2013; Fineman, 2019). However, what is rejected is any general conflation of notions of vulnerability with ideas about competence, legal or otherwise, or any other stigmatising and disempowering representation of disabled people.

2.6 WILL THE IDENTITY OF THE PARTICIPANTS BE PROTECTED?

YES or NO
...

If NO, please explain why

IF YOU ANSWERED YES TO 2.6, PLEASE ANSWER THE FOLLOWING QUESTION:

2.7 HOW WILL THE ANONYMITY OF THE PARTICIPANTS BE RESPECTED?

Please bear in mind that where the sample size is very small, it may be impossible to guarantee anonymity/confidentiality of participant identity. Participants involved in such projects need to be advised of this limitation in the Plain Language Statement/Information Sheet. If you intend to fully anonymize the data, please provide details.

Recognising the usefulness of pseudonymisation as a data protection security measure (Opinion 05/2014 on Anonymisation Techniques) each of the research participants will be assigned an identifier ensuring their actual identities are known only to the PI. This first measure will ensure that while transcripts will be available to the PI's supervisors the identity of each participant will be protected. The transcripts will be produced using licenced NVivo software, thereby obviating the use of a human transcriber. Further, before each interview commences research participants will be asked to take care that answers will be shorn of any specifics which might identify either themselves or others and the PI will be alert throughout each interview to further ensure this. While blindness or serious vision impairment is a relatively low incidence presence in the Irish population – 54,810 people (2016 Census) – this is still thought to be a sufficiently large cohort to ensure that quotes used in the final PhD and circumstances alluded to therein will not be traceable to an identifiable participant.

2.8 LEGAL LIMITATIONS TO DATA CONFIDENTIALITY

Participants need to be made aware that confidentiality of information provided cannot always be guaranteed by researchers and can only be protected within the limitations of the law - i.e., it is possible for data to be subject to subpoena, freedom of information claim or mandated reporting by some professions. This information should be included in your Plain Language Statement and Informed Consent Form. Depending on the research proposal and academic discipline, you may need to state additional specific limitations.

State how and where participants will be informed of these limitations.

This information will be contained in the plain language statement as well as in the consent form and reiterated at the start of each interview.

2.9 CHILD PARTICIPANTS (anyone under 18 years old)

If your participants include children, you must confirm that you are in compliance with the research specific guidelines as detailed in Keeping Children Safe - Policies and Procedures supporting Child Protection at DCU.

Please indicate your compliance with the following guidelines:	**Mark here**
We confirm that we have read and agree to act in accordance with the DCU Child Protection policy and procedures	**N/A**
We confirm that we have put in place safeguards for the children participating in the research	**N/A**
We confirm that we have supports in place for children who may disclose current or historical abuse (whether or not this is the focus of the research)	**N/A**

2.10 PLEASE EXPLAIN WHEN, HOW, WHERE, AND TO WHOM RESULTS WILL BE DISSEMINATED, INCLUDING WHETHER PARTICIPANTS WILL BE PROVIDED WITH ANY INFORMATION AS TO THE FINDINGS OR OUTCOMES OF THE PROJECT?

The primary dissemination of the data obtained from research participants by way of interview will be in its analysed form within the PI's PhD. The PI also hopes that further dissemination might occur in the form of a book and via conference presentations and articles. Participants will be encouraged to request copies of the data once it becomes available in open source, this data not being the raw data but, rather, the analysed and anonymised data produced from the raw data. Further, should any of the participants wish the PI to offer contextualised presentations to relevant others the PI will endeavour to be available, where possible, to do this by way of both simple gratitude and a wish to help broaden perspectives and initiate debate within the wider milieu.

2.11 ARE OTHER APPROVALS REQUIRED TO GAIN ACCESS TO ANOTHER LOCATION, ORGANISATION, SCHOOL ETC.?

YES or NO
…

If YES, please specify from whom and attach a copy of the approval documentation. If this is not yet available, please explain when this will be obtained.

3. RISK AND RISK MANAGEMENT

3.1 EXPLAIN AND JUSTIFY THE STATED LEVEL OF RISK TO PARTICIPANTS

You must provide a justification for the stated level of risk and its corresponding level of review (Full Committee, Expedited, Notification), as indicated on the cover page of your application. Note that the level of risk may be influenced by the vulnerability of the research group, the methods employed and the nature of the research itself. For further information on risk levels, please refer to the Levels of Review information on the Research Support Services website.

Proceeding on the basis laid out in 2.5 and, indeed, mindful that the CRPD asserts the presumption that *all* persons require support to realise personal freedom and autonomy, the perceived value of the proposed research rests first on the identification of disabled people and their families as experts in their own experience. Wanting to engage with participants in a research co-production, this proposed study is justified primarily because it seeks to give voice to this expertise and to uncover insights in an area not previously researched. Moreover, direct research with people who are disabled is important and, in itself, honours core CRPD concepts, including the principles of equality, full and effective participation and inclusion in society, respect for difference and accessibility.

But, naturally, inviting participants to talk about their life experiences involves probing sensitive areas and it is possible that something in this process might link to or trigger something painful, notwithstanding care that this not happen. Hence, convinced of the importance of the subject being researched a full committee review is sought, especially given that the research participants appear to come within the vulnerable descriptor.

3.2 POTENTIAL RISKS TO PARTICIPANTS AND RISK MANAGEMENT PROCEDURES

Identify, as far as possible, all potential risks to participants (physical, psychological, social, legal, economic, etc.), associated with the proposed research. Will your research involve deception, investigation of participants involved in illegal activities, performance of any acts which might diminish the self-esteem of participants or cause them to experience embarrassment, regret or depression, administration of any substance or agent, collection of body tissues or fluid samples, use of non-treatment of placebo control conditions, collection and/or testing of DNA samples, administration of ionising radiation? Please explain what risk management procedures will be put in place to minimise these risks.

While research indicates that only a small subset of research participants involved in emotionally charged research experience some degree of marked or unexpected upset (Newman and Kaloupek, 2004) it is plausible that some participants in the instant research may find reflecting on and talking about their life experiences painful or, even, that feelings of incredulity, anger or injustice may be invoked. Notwithstanding that the research is intended to be person-centred and empowering in the way it is designed and conducted it will not be possible, in advance, to anticipate how the interview process might impact on individuals. Hence, it will be important to assure each participant initially at interview commencement that the interview is theirs to terminate and withdraw from, at any point, if they find themselves distressed or in any way emotionally compromised or uncomfortable with continuing. Additional risk management strategies will include regularly checking with participants that they feel comfortable with the interview as it proceeds and that opportunities to pause and, if necessary, regroup are offered. Further, at interview's end the participants will be assured that they can access the PI at any time subsequent to the interview if they wish to discuss any matters relating to the interview. A distress protocol (Appendix 10) will also be in place to guide the PI in terms of where a participant might be directed for additional support if there is a wish to discuss specific emotional or personally sensitive matters (Draucker *et al* (2009)).

By way of a pre-stage, in addition, at the point of participant group 1's recruitment to the study the Gatekeeper will be required to ask would-be participants to consider the following question: 'are there any reasons you can think of which might make taking part in an interview about issues concerning your experience of impairment and disability too stressful for you?' By requiring the inclusion of this general question the intention is to demonstrate at the very earliest point that this research study - while respecting individual agency – takes seriously its ethical responsibility to take all reasonable steps to prevent harm to participants. In respect of participant group 2 this question will be put by the PI.

3.3 ARE THERE LIKELY TO BE ANY BENEFITS (DIRECT OR INDIRECT) TO PARTICIPANTS FROM THIS RESEARCH?

YES or NO
…

If YES, provide details

Because the study seeks to both uncover domination (disempowerment) and suggest strategies consistent with resisting domination (empowerment) it is suggested that participants may well derive benefits from this research in terms of enhanced self-knowledge, enhanced situational knowledge and, perhaps particularly, given the focus on the CRPD,

are in the range of those often identified in social research participation including the opportunity to tell their truth and to feel respected and validated in doing so.

3.4 ARE THERE ANY SPECIFIC RISKS TO RESEARCHERS?

Examples include use of dangerous materials, asking certain types of questions, research being undertaken in certain locations, researchers working alone in isolated areas, etc.

YES or NO
…

If YES, please describe and explain what risk management procedures will be put in place to minimise these risks

N/A

3.5 DEALING WITH ADVERSE / UNEXPECTED OUTCOMES

Please describe what measures/protocols you have put in place in the event that there are any unexpected outcomes or adverse effects to participants arising from involvement in the project.

Unexpected outcomes or adverse events – if they occur – will be addressed in a sensitive and appropriate way, drawing on the distress protocol and, if necessary, the advice of supervisors and on the PI's own professional training. In this context it may be useful, perhaps, to mention that the PI is both a mandated person within the meaning of the *Children First Act* 2015 and a trained designated officer within the meaning of the HSE's document, *Safeguarding Vulnerable Persons at Risk of Abuse; Policy and Procedures* (2014).

Any adverse event/unexpected outcome will be evaluated on its own terms and responded to in a proportionate, ethical and a deeply respectful, person-centred way. Again, the distress protocol is likely to be of use in this context.

3.6 SUPPORT FOR PARTICIPANTS

Depending on risks to participants you may need to consider having additional support for participants during/after the study. Consider whether your project would require additional support, e.g., external counselling available to participants. Please advise what support will be available.

The previously referenced distress protocol (Appendix 10) indicates a number of counselling and additional support mechanisms which can be availed of by participants to provide support should this be required during or after the study.

3.7 HOW WILL THE CONDUCT OF THE PROJECT BE MONITORED?

Please explain how the principal investigator will monitor the conduct of the project (especially where several people are involved in recruiting or interviewing, administering procedures, etc.) to ensure that it conforms to the procedures set out in this application. In the case of student projects please give details of how the supervisor(s) will monitor the conduct of the project.

The PI will be the sole interviewer and as such will have primary responsibility for ensuring that agreed procedures and ethical requirements are fully adhered to. In addition, the PI's supervisors (Dr Tom Hickey and Dr Aisling de Paor) will have access to the data (but never the identity of the participants) in order to monitor ethical compliance and, if appropriate, risk minimisation.

3.8 **DO YOU PROPOSE TO OFFER PAYMENTS OR INCENTIVES TO PARTICIPANTS?**

YES or NO
…

If YES, please provide further details

N/A

3.9 **DO ANY OF THE RESEARCHERS ON THIS PROJECT HAVE A PERSONAL, PHILOSOPHICAL, FINANCIAL, POLITICAL, IDEOLOGICAL, OR COMMERCIAL INTEREST IN ITS OUTCOME THAT MIGHT INFLUENCE THE INTEGRITY OF THE RESEARCH, OR BIAS THE CONDUCT OR REPORTING OF THE RESEARCH, OR UNDULY DELAY OR OTHERWISE AFFECT THEIR PUBLICATION?**

YES or NO
…

If YES, please specify how this conflict of interest will be addressed

4. PERSONAL DATA

Definition of Personal Data

Personal data is any information about a living person, where that person is either identified or could be identified, from the data itself or when it is combined with other data. Typical examples of personal data in a research context are:

a) **paper based records e.g. research participant files, patient records, consent declarations, interview notes etc.**

b) **electronic records e.g. database of participant details, online survey returns, photos, audio & visual recordings, IP addresses, diagnostic / clinical imaging etc.**

c) **other e.g. genetic data, biometric data, clinical or medical samples etc.**

Note: Any data that is <u>fully and completely anonymous</u> is not considered to be personal data.

(A) Your knowledge of Data Protection		
Have you completed the online GDPR **'2020 Data Protection Staff'** module on Loop which is available to all staff of the University?	**YES or NO**	**Yes**

If you answered 'No' to the previous question then the DCU Data Protection Unit (DPU) strongly recommends that all applicants complete the training module on Loop before completing this section of the REC Application Form.

The Loop training module can be accessed at this link and searching for '2020 Data Protection Staff'. If

(B) Initial Assessment – Is the data to be used actually <u>personal data</u>?			
1	**Will the proposed research include living human subjects?** *Rationale – personal data applies only to living individuals.*	**YES or NO**	**Yes**
2	**Will the proposed research use any data that can be linked to an identified, or an identifiable, person?** *Rationale – to be personal data it must be possible to associate it with a person.*	**YES or NO**	**No**
3	**Will the proposed research use any data identifiers that can be linked to a person? E.g. a participant's name, code or ID number, their address, their IP address etc.** *Rationale – fully anonymised data is not personal data.*	**YES or NO**	**No**

If you answered 'Yes' to any of the questions 1 to 3 in sub-section (B), then continue to sub-section (C) and answer questions 1-9.

If you answered 'No' <u>to all of the questions</u> 1 to 3 in sub-section (B), then skip sub-section (C) and proceed section 5 of form.

(C) Assessing the degree of risk inherent in the personal data			
1	**Will the proposed research involve the use of <u>personal data</u> on individuals which reveals any of the following attributes or characteristics about them?** **(State 'Yes' or 'No' as appropriate to all of the following)**		
	Racial or ethnic origin	**YES or NO**	**No**
	Political opinions	**YES or NO**	**No**

	Religious or philosophical beliefs	**YES or NO**	**No**
	Trade union membership	**YES or NO**	**No**
	Genetic data	**YES or NO**	**No**
		YES or NO	**No**
	Biometric data	**YES or NO**	**No**
	Data concerning health	**YES or NO**	**No**
2	**Will the proposed research involve the use of <u>personal data</u> relating to children or vulnerable individuals?** *A child, for data protection purposes, is defined as an individual below 18 years of age. Where the processing relates to 'electronic marketing' the age limit is reduced to 16 years. A vulnerable individual may be anyone who is unable to consent to, or to oppose, the processing of his or her data for any reason, including disability.*	**YES or NO**	**No**
3	**Will the proposed research involve the use of data relating to an individual's criminal convictions and / or offences?**	**YES or NO**	**No**
4	**Will the proposed research involve the large-scale processing of <u>personal data</u>?** *This may include: a wide range or large volume of personal data; processing which takes place over a large geographical area; processing where a large number of people are affected (e.g. over 100 individuals); or where the processing is extensive or has long*	**YES or NO**	**No**
5	**Will the proposed research involve any form of <u>automated processing</u> of personal data?** *In particular, to analyse or predict aspects concerning that person's performance at work, economic situation, health, personal preferences, interests, reliability, behaviour, location or movements.*	**YES or NO**	**No**
6	**Will the proposed research involve sharing or transferring any personal data to a 3rd party outside of DCU?** *For example other research partners, providers of translation or transcription services, etc.*	**YES or NO**	**No**
7	**Will the proposed research require the sharing or processing of personal data outside the EU or the EEA?** *The EEA is the European Economic Area (i.e. the EU plus Norway, Liechtenstein and Iceland)*	**YES or NO**	**No**
8	**Will the proposed research involve the matching or combining of separate datasets of information on individuals in a way that would exceed their reasonable expectations of privacy?** *An example would be combining mobile phone location data along with any other dataset to identify individuals.*	**YES or NO**	**No**
9	**Will it be possible to <u>fully anonymise</u> (as opposed to merely pseudo-anonymising) the personal data before it is obtained and used by you in the proposed research?**	**YES or NO**	**No**

	This might occur if the data is provided to you by an external organisation or another educational institution as part of a collaborative study. *Anonymised data is not personal data. Anonymisation is the process of removing personal identifiers, both direct and indirect, that may lead to an individual being identified.* *Pseudonymisation is the processing of personal data in such a manner that the personal*		

Important Point: Next Step

If you answered 'Yes' to one or more of the questions 1 to 9 in sub-section (C) **you must contact the Data Protection Unit (DPU) prior to submitting this application form to the REC**. The DPU will assess whether there are any further data

5. DATA / SAMPLE STORAGE, SECURITY AND DISPOSAL

For the purpose of this section the term 'Data' includes personal data that is in a raw or a processed state (e.g. interview audiotape, transcript or analysis, etc.). The term 'Samples' include body fluids and/or tissue samples.

5.1 HOW AND WHERE WILL THE DATA / SAMPLES BE STORED?

DCU recommends that any data stored electronically offsite should utilise the DCU Google Drive. Alternative offsite storage will need to be justified and must meet data protection and GDPR compliance requirements.

The data will be stored in an encrypted folder on DCU's Google Drive.

5.2 WHO WILL HAVE ACCESS TO DATA / SAMPLES?

If people other than the main researchers have access, please name who they are and explain for what purpose.

The PI will be the only person to have access to the data in its entirety. However, the PI's supervisors will have access to the analysed and pseudonymised data for the purposes of advising the PI. Transcription will be by means of DCU approved software, these transcriptions then being stored on DCU's Google Drive.

5.3 HOW LONG IS THE DATA TO BE HELD OR RETAINED?

Note that, with very few exceptions, Personal Data may not be retained indefinitely. It is up to the research team to establish an upper retention limit for each category of Personal Data used within the project and to ensure it is applied at the expiry of that limit.

The audio-recordings, as stored on encrypted files will only be held until transcripts have been made and, thereupon, the recordings will be permanently erased. The pseudonymised transcripts will be held for some time longer, permitting a follow up project – most likely in article, conference presentation and/or book form. However, in any event, the PI commits that no remaining data of any type relating to this research is retained beyond the 31 August 2027, the intention being that, if possible, all such data will be permanently and securely disposed of before this date.

5.4 WILL THE PERSONAL DATA BE USED AT A LATER DATE FOR THE PURPOSE OF PUBLICATION OF THE RESULTS OF THE RESEARCH?

YES or NO
Yes

Where it is intended that the personal data used in the project will be used at a later date for the purposes of publication please explain how consent to do so will be obtained.

At the earliest contact with would-be participants the plain language statement will indicate that, subject to individual consent, pseudonymised and securely stored transcripts of the interviews – but not the interview recordings – will be kept to enable the PI to complete a

participants give consent s/he will be asked to indicate this in writing, this consent being securely stored by the PI.

5.5 IF THE DATA/SAMPLES ARE TO BE DISPOSED OF AT THE END OF THE PROJECT PLEASE EXPLAIN HOW, WHEN AND BY WHOM THIS WILL BE DONE?

Note that simply deleting files is not sufficiently secure. The additional steps to be taken to maintain data security should be given. ***Personal*** *data must be disposed of in a safe and secure manner at the end of its retention period. If the data is stored in (a) a paper-based format, then shredding or disposal via a secure bin is recommended; or (b) in an electronic-based format, then deletion of the record or the full anonymization of the data is recommended. If data/samples are not being disposed of, please justify that intention.*

How will the data/samples be disposed? **Please describe the means by which the personal data will be deleted or destroyed. This includes personal data held in hard copy and digital formats.**	**At the material time, consistent with answers above, all paper transcripts will be shredded and all electronically based data will be deleted in accordance with best practice advice to ensure it cannot be retrieved. For this latter purpose the PI will engage the advice of a computer expert.**
When will the data/samples be disposed? **Please indicate the intended retention period of the personal data, and reasons for this retention period. Please note that retention periods must be GDPR compliant and must be consistent with the [DCU Retention Policy.](DCU Retention Policy)**	**The audio recordings will be permanently deleted once transcribed. The anonymised transcripts – both in digital and paper form will be held for no longer than 5 years, post – dissertation submission and, in any event, not later than 31st August 2027. As stated above, this 5- year period from the dissertation submission allows for their use for the purposes of an article, conference presentation and/or a book.** **However, if a shorter period suffices the transcripts will be permanently deleted. The master list held solely and securely by the PI – that is, the list by which the transcripts can be linked back to the individual research participants – must be retained in case the participants need to be notified of a data breach but it too will be permanently deleted at the same time as the transcripts and no later than 31st August 2027**
By whom will the data/samples be disposed? **Please indicate the designated team member(s) with responsibility for deletion and/or destruction of the research project's personal data.**	**The PI will be responsible for ensuring that all of the research data is destroyed in conformity with GDPR requirements and, consistent with answers above, as the material times for destruction arise, consistent with the absolute commitment in respect of the 31st August 2027.**

6. FUNDING OF THE RESEARCH

6.1 HOW IS THIS WORK BEING FUNDED?

DCU PhD scholarship

6.2 PROJECT GRANT NUMBER *(If relevant and/or known – otherwise mark as N/A)*

N/A

6.3 DOES THE PROJECT REQUIRE APPROVAL BEFORE CONSIDERATION FOR FUNDING BY A GRANTING BODY?

YES or NO
No

6.4 HOW WILL PARTICIPANTS BE INFORMED OF THE SOURCE OF THE FUNDING? *(E.g. included in the Plain Language Statement)*

This information will be included in the plain language statement.

6.5 DO THE FUNDERS OF THIS PROJECT HAVE A PERSONAL, FINANCIAL, POLITICAL, IDEOLOGICAL, OR COMMERCIAL INTEREST IN ITS OUTCOME THAT MIGHT COMPROMISE THE INDEPENDENCE AND INTEGRITY OF THE RESEARCH, OR BIAS THE

YES or NO
No

If YES, please specify how this conflict of interest will be addressed

7. PLAIN LANGUAGE STATEMENT *(Attach to this document. Approx. 400 words)*

A Plain Language Statement (PLS) should be used in all cases. This is written information in plain language that you will be providing to participants, outlining the nature of their involvement in the project and inviting their participation. The PLS should specifically describe what will be expected of participants, the risks and inconveniences for them, and other information relevant to their involvement. Please note that the language used must reflect the participant age group and corresponding comprehension level– if your participants have different comprehension levels (e.g. both adults and children) then separate forms should be prepared for each group. The PLS can be embedded in an email to which an online survey is attached, or handed/sent to individuals in advance of their consent being sought. See the link to sample templates on the Ethics Approval section of the Research Support Services website.

PLEASE CONFIRM WHETHER THE FOLLOWING ISSUES HAVE BEEN ADDRESSED IN YOUR PLAIN LANGUAGE STATEMENT/ INFORMATION SHEET FOR PARTICIPANTS:

	YES or NO
Introductory Statement (PI and researcher names, school, title of the research)	yes
What is this research about?	yes
Why is this research being conducted?	yes
What will the participant be expected to do/have to do if they decide to participate in the research study?	yes
How will their privacy be protected?	yes
How will the data be used and subsequently disposed of?	yes
What are the legal limitations to data confidentiality?	yes
Are there any benefits of taking part in the research study?	yes
Are there any risks of taking part in the research study?	yes
Confirmation that participants can change their mind at any stage and withdraw from the study	yes
How will participants find out what happens with the project?	yes
Contact details for further information (including REC contact details)	yes
Details relating to GDPR Compliance where Personal Data is being sought	yes

If any of these issues are marked NO, please justify their exclusion:

8. INFORMED CONSENT FORM *(Attach to this document. Approx. 300 words)*

In most cases where interviews or focus groups are taking place, an Informed Consent Form is required. This is an important document requiring participants to indicate their consent to participate in the study and give their signature. In cases where an anonymous questionnaire is being used, it is not enough to include a tick box in the questionnaire. Participants should indicate their consent to each aspect of the research in a staged manner by checking mandatory checkboxes.See link to sample templates on the Ethics Approval section of the Research Support Services website.

NB – IF AN INFORMED CONSENT FORM IS NOT BEING USED, THE REASON FOR THIS MUST BE JUSTIFIED HERE.

9. ASSENT FORM & PLAIN LANGUAGE STATEMENT FOR CHILDREN *(Attach to this document.)*

A child specific Plain Language Statement (PLS) should be used in research where children will be involved. The PLS must be written in a way that is understandable for children within your targeted age group. It also must state, in plain language, the nature of their involvement in the project and inviting their participation. The PLS should specifically describe what will be expected of participants, the risks and inconveniences for them, and other information relevant to their involvement. In addition, child participants should also be provided with an Assent Form. Parents/guardians will be provided with the Informed Consent Form, but each child should provide assent before taking part in the research. The Assent Form needs to be understandable to the age-group you are targeting. See link to sample templates on the Ethics Approval Section of the Research Support Services website.

NB – IF AN ASSENT FORM IS NOT BEING USED, THE REASON FOR THIS MUST BE JUSTIFIED HERE.

10. SUBMISSION CHECKLIST *(Attach to this document)*

Please confirm that all supplementary information is included in your application (in electronic copy). If questionnaire or interview questions are submitted in draft form, please indicate this by putting (draft) after YES. A copy of the final documentation must be submitted for final approval when available.

My application has been collated as one electronic file which includes the following documentation:	**INCLUDED**	**NOT APPLICABLE (mark**
Bibliography	**yes**	
Recruitment advertisement		N/A
Plain language statement/Information Statement	**yes**	
Informed Consent form	**yes**	
Informed Assent form		N/A
Evidence of external approvals related to the research		N/A
Questionnaire / Survey		N/A
Interview / Focus Group Questions	**yes (draft)**	
Debriefing material		N/A
Other (e.g. BSC approval review letter, Data Protection Impact Assessment)	**Guidance notes for Gatekeepers** **Guidance notes for parent recruiters**	

DUBLIN CITY UNIVERSITY

Sample Template – Plain Language Statement (approx. 400 words)

A Plain Language Statement (PLS) should use language that reflects the participant age group and corresponding comprehension level. It should contain the following information. The headings are there for guidance and do not need

Introduction to the Research Study

Identify the Research Study Title, the university department involved, the principal investigator (including his/her DCU

Privacy Notice

An appropriate Privacy Notice is the means by which data subjects are informed about the use of their data. If personal data is being collected and processed, please refer to the University's Data Protection Unit website for advice and include

- *The identity of the Data Controller (or in some cases the Joint Data Controllers) plus the details of any Data Processor (where applicable) should be clearly stated on the PLS. The Data Controller will nearly always be DCU (where the researcher is a DCU researcher). The PLS should also state the name of the research project and the identity of the particular School / Unit of DCU from which it originates. A Data Processor may hold or process personal data but does not exercise responsibility for or control over the personal data, for example, a transcription service, or a software or cloud hosting company.*
- *The identity of the DCU Data Protection Officer – Mr. Martin Ward (data.protection@dcu.ie Ph.: 7005118 / 7008257)*
- *The purpose of the data processing i.e. the reasons why the data is being requested and the purpose to which it will be applied.*
- *The reason(s) for which the data will be processed or held.*
- *The categories or types of personal data to be processed.*
- *The details of any third parties (i.e. data processors) with whom the data will be shared or transferred, and the reasons for sharing.*
- *The details of any external (i.e. non-DCU) parties with whom the data will be shared or transferred, and the reasons for sharing.*
- *Where relevant, details of any intention to transfer the data to other countries, especially if outside of the EEA*

Statement as to whether or not the research data is to be destroyed after a minimum period

Clearly state (if applicable) when data will be destroyed or fully anonymized after the end of the research project.

Details of what participant involvement in the Research Study will require

E.g., involvement in interviews; completion of questionnaire; audio/video-taping of events, and the estimated time

Potential risks to participants from involvement in the Research Study (if greater than that encountered in everyday life)

Any benefits (direct or indirect) to participants from involvement in the Research Study

Advice as to arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations

Participants need to be made aware that confidentiality of information provided cannot always be guaranteed by researchers – please include the following statement:

"Confidentiality of information can only be protected within the limitations of the law - i.e., it is possible for data to be

Statement that involvement in the Research Study is voluntary

State that participants may withdraw from the Research Study at any point. You should explain to the participant that their participation in the project will end, at the point they withdraw, and refer back to the data protection/privacy notice as to what will happen regarding their data. For example, withdrawing consent may mean that no future data collection

Any other relevant information – e.g.

- *if the sample size is small, advice to participants that this may have implications for privacy / anonymity.*

  if participants are in a dependent relationship with any of the researchers, a clear statement that their

A Plain Language Statement must end with the following statement:

If participants have concerns about this study and wish to contact an independent person, please contact:

The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel 01-7008000, e-mail rec@dcu.ie

DUBLIN CITY UNIVERSITY

Sample Template – Informed Consent Form (approx. 300 words)

An Informed Consent Form should generally contain the information detailed below. It should be written in the first person, e.g. "I will be asked to attend…I may withdraw from the research study at any point…..I am aware that the

Research Study Title

Also identify the school / centre involved, the principal investigator and any other investigators.

Clarification of the purpose of the research

If personal data is being collected and processed, please ensure that the participants acknowledge the identity of the data

Confirmation of particular requirements as highlighted in the Plain Language Statement

Requirements may include involvement in interviews, completion of questionnaire, audio / video-taping of events etc..

Participant – please complete the following (Circle Yes or No for each question)

Yes/No

I have read the Plain Language Statement (or had it read to me)

I understand the information provided *Yes/No*

Yes/No

I understand the information provided in relation to data protection *Yes/No*

Confirmation that involvement in the Research Study is voluntary

E.g. I may withdraw from the Research Study at any point.

Confirmation of arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations

Confirmation of arrangements regarding the retention / disposal of data

Confirmations relating to any other relevant information as indicated in the PLS

E.g. I consent to the use of my data for future studies within the following parameters (provide detail)

Signature:

I have read and understood the information in this form. My questions and concerns have been answered by the

Participants Signature: ____

Name in Block Capitals: ____

Witness:____

Date:____

Anonymous Online Consent Form Template

In cases where an anonymous questionnaire is being used, researchers are required to provide a separate tick box for each statement that the participant is being asked to consent to / acknowledge. Each statement must be included as an

An Informed Consent Form should generally contain the information detailed below. It should be written in the first person, e.g. "I will be asked to attend…I may withdraw from the research study at any point…..I am aware that the

Research Study Title

Also identify the school / centre involved, the principal investigator and any other investigators.

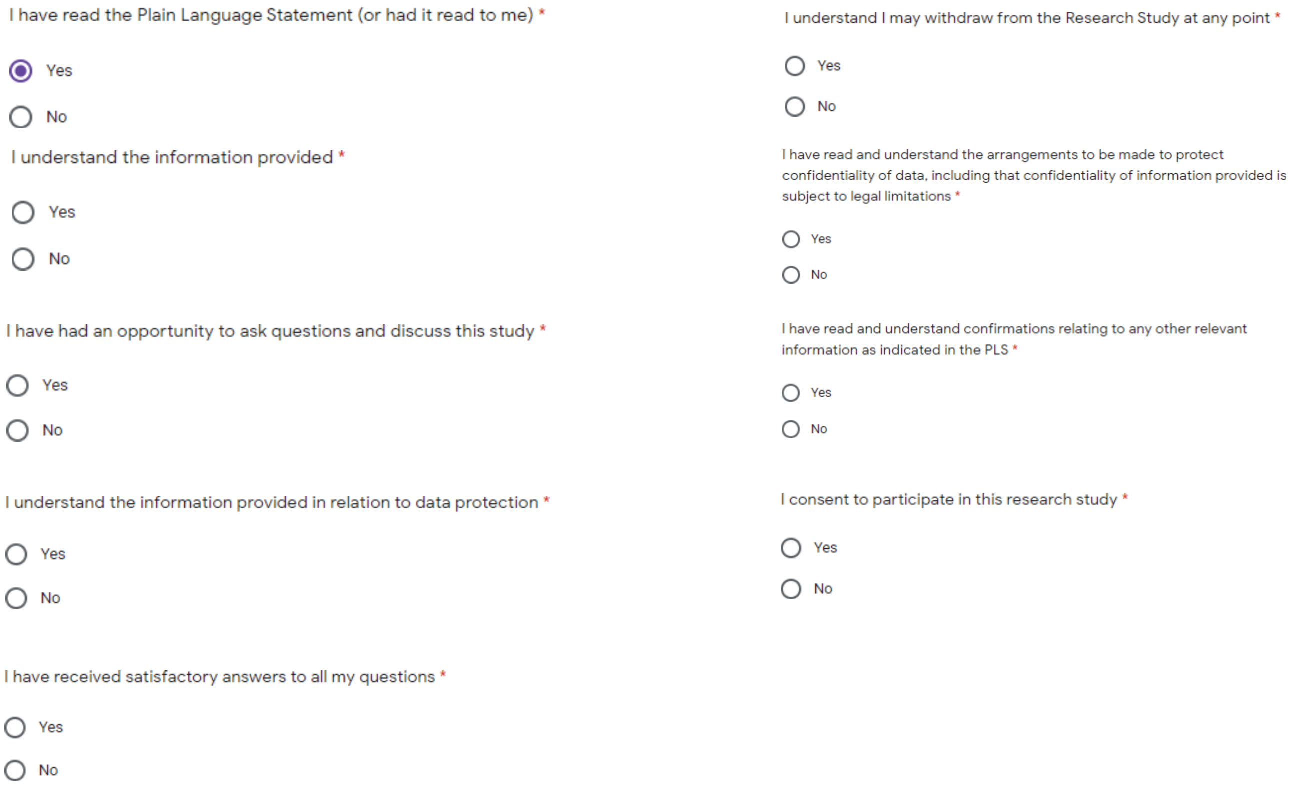
Clarification of the purpose(s) of the research

Confirmation of particular requirements as highlighted in the Plain Language Statement

Getting the participant to acknowledge the requirements is mandatory. Participants should not be able to access the

Example:

Participant – please complete the following (by clicking Yes/No for each question)



I have read the Plain Language Statement (or had it read to me) *

● Yes

○ No

I understand the information provided *

○ Yes

○ No

I have had an opportunity to ask questions and discuss this study *

○ Yes

○ No

I understand the information provided in relation to data protection *

○ Yes

○ No

I have received satisfactory answers to all my questions *

○ Yes

○ No

I understand I may withdraw from the Research Study at any point *

○ Yes

○ No

I have read and understand the arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations *

○ Yes

○ No

I have read and understand confirmations relating to any other relevant information as indicated in the PLS *

○ Yes

○ No

I consent to participate in this research study *

○ Yes

○ No

APPENDIX 1

References

Article 29 Data Protection Working Party *Opinion 05/2014 on Anonymisation Techniques* 0829/14/En WP2016, adopted 10 April 2014

Barasch, M. Blindness, *The History of a Mental Image* (Routledge, 2001)

Berkley, G. (1709) *An Essay Towards a New Theory of Vision* (Gale Ecco, 2010)

Butler, J. *Precarious Life: The Powers and Mourning of Violence* (Verso, 2004)

Diderot, D. (1749) *Letter on the Blind for Use of Those Who Can See* (Open Court Publishing – 1916)

Draucker, C.B., Martsolf, D.S. Poole, C. Developing Distress Protocols for Research on Sensitive Topics. *Archive of Psychiatric Nursing* 23 5 2009 345-350

Fineman, M.A. Vulnerability and Social Justice *Valparaiso University Law Review* 53 2 2019 341-369

Fineman, M.A. and Grear, A. (Eds) *Vulnerability. Reflections on a New Ethical Foundation for Law and Politics* (Ashgate 2013)

Kittay, E.F. *At the Margins of Moral Personhood Ethics 116:1, 2005, 100-131*

Lawler, D., Begley, C. and Lalor, J. (Re) constructing Myself: the process of transition to motherhood for women with a disability *Journal of Advanced Nursing* 71 7 2015 1672-1683

Locke, J. (1689) *An Essay Concerning Human Understanding* (Oxford University Press, 1979)

Marti, J.L., Pettit, P. *A Political Philosophy in Public Life* (Princeton University Press, 2010)

Newman, E., Kaloupek, D.G. The Risks and Benefits of Participating in Trauma-Focused Research Studies *Journal of Traumatic Stress* 17 5 2004 383-394

Oliver, M. *Understanding Disability from Theory to Practice* (Palgrave, 2009)

Oliver, M. Changing the Social Relations of Research Production? *Disability, Handicap & Society* 7 2 1992 101-114

Pettit, P. *Republicanism A Theory of Freedom and Government* (Oxford University Press, 1997)

Quinn, G., Rekas-Rosalbo, A Civil Death: Rethinking the Foundations of Legal Personhood for Persons with a Disability *Irish Jurist* 56, 2016 286-325

Appendix 2

PLAIN LANGUAGE STATEMENT – PERSONS WITH VISION IMPAIRMENT

Domination and Disability: a republican proposal in the light of the United Nations Convention on the Rights of Persons with Disabilities.

Plain Language Statement

My name is James Forbes and I am inviting you to participate in interviews relating to my PhD project, on which I am the Principal Investigator. My work is being supervised by Dr. Tom Hickey (tom.hickey@dcu.ie) and Dr. Aisling de Paor (aisling.depaor@dcu.ie), both of Dublin City University's School of Law and Government. The PhD, which is in law, is being funded by a DCU Scholarship.

My contact details:
james.forbes3@mail.dcu.i

What is involved in taking part?

I will want to talk to you about your thoughts and experiences of impairment and of disability, especially in relation to some rights contained in the Convention on the Rights of Persons with Disabilities (CRPD). In particular, I will want to talk to you about your thoughts and experiences around education, employment and being independent and

By taking part in this research, you will help me form a view about how persons with disabilities can better achieve and resiliently hold rights as citizens and about how wider society can support an understanding of difference which will bring benefits, potentially, to everyone.

Important information about how your data will be used and kept safe.

Your agreement to take part in this research can be withdrawn at any

Your privacy is very important to me as a researcher and to DCU. This means your identity will be known only

With your consent I will audio record our conversation. This will be stored securely and the recording will be completely erased as soon as a transcript has been made of it. This transcript will be produced using secure DCU

My supervisors will see the transcripts but they will never hear the audio or know whose transcripts they are seeing or any details which could identify you.

I will retain the transcripts only for as long as to facilitate additional academic work such as presentations, journal articles and, possibly, a book. All of your data, in whatever form, in relation to this project will be securely disposed of no later than August 2027.

Your interview with me will be turned into quotations in my PhD dissertation. However, I will make sure that these quotations are anonymised and that you cannot be identified either from them or from any subsequent work I produce in relation to this project.

I will store your name and contact details in case I need to get in touch with you in the event of a data breach. This information – to which no-one else will have access – will be held securely.

If you give me your consent to contact you when the PhD is finalised, or when any other work arising from your data is completed, I will contact you by email to advise you accordingly.

It is very important that you know that although confidentiality is at the heart of this research, information can only be protected within the limits of the law. If I am concerned about a risk of violence or other serious harm to yourself or others, dangerous practice or criminal activity I will have to breach confidentiality. It is also possible that data can be subject to freedom of information claims or mandated reporting.

This research project has been approved by DCU's Research and Ethics Committee. Below are the names and contact details which you will need to keep in case you have a concern, a complaint or a question concerning your data.

If you wish to contact an independent person, please contact:
The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel – 01 7008000 email rec@dcu.ie

DCU Data Protection Officer: **Mr. Martin Ward**
Tel: 01 7005118 / 01 7008257
Email:
DATA Protection Unit: Tel 01 7006466; 01 7007476; 01 700 8257; 01 7005118

data.protection@dcu.ie
Room A145, Albert College Extension,
DCU Glasnevin Campus,
Collins Avenue Extension, Dublin9

Thank you for taking the time to read this statement. I hope you will decide to participate in this research and that you will find it stimulating and of value to you.

APPENDIX 3

PLAIN LANGUAGE STATEMENT – PERSONS WITH VISION IMPAIRMENT – BRAILLE VERSION

Braille Version PLS - Persons with Vision Impairment 03.06.21.pdf

APPENDIX 4

PLAIN LANGUAUGE STATEMENT – PERSONS WITH VISUAL IMPAIRMENT – LARGE PRINT VERSION

Large Print Version PLS - Persons with Vision Impairment 03.06.21.pdf

APPENDIX 5

PLAIN LANGUAGE STATEMENT – PARENTS OF PERSONS WITH DISABILITIES

Domination and Disability: a republican proposal in the light of the United Nations Convention on the Rights of Persons with Disabilities.

Plain Language Statement

My name is James Forbes and I am inviting you to participate in interviews relating to my PhD project, on which I am the Principal Investigator. My work is being supervised by Dr. Tom Hickey (tom.hickey@dcu.ie) and Dr. Aisling de Paor (aisling.depaor@dcu.ie), both of Dublin City University's School of Law and Government. The PhD, which is in law, is being funded by a DCU Scholarship.

My contact details:
james.forbes3@mail.dcu.i

What is involved in taking part?

I will want to talk to you about your thoughts and experiences of being a parent of a person with disability, especially in relation to some rights contained in the Convention on the Rights of Persons with Disabilities (CRPD). In particular, I will want to talk to you about your thoughts and experiences around education, employment and about your child being independent and being included in the community.

By taking part in this research, you will help me form a view about how persons with disabilities can better achieve and resiliently hold rights as citizens and about how wider society can support an understanding of difference which will bring benefits, potentially, to everyone.

Important information about how your data will be used and kept safe

Your agreement to take part in this research can be withdrawn at any

Your privacy is very important to me as a researcher and to DCU. This means your identity will be known only to me. With your consent I will audio record our conversation. This will be stored securely and the recording will be completely erased as soon as a transcript has been made of it. This transcript will be produced using secure DCU

My supervisors will see the transcripts but they will never hear the audio or know whose transcripts they are seeing or any details which could identify you.

I will retain the transcripts only for as long as to facilitate additional academic work such as presentations, journal articles and, possibly, a book. All of your data, in whatever form, in relation to this project will be securely disposed of no later than August 2027.

Your interview with me will be turned into quotations in my PhD dissertation. However, I will make sure that these quotations are anonymised and that you cannot be identified either from them or from any subsequent work I produce in relation to this project.

I will store your name and contact details in case I need to get in touch with you in the event of a data breach. This information – to which no-one else will have access – will be held securely.

If you give me your consent to contact you when the PhD is finalised, or when any other work arising from your data is completed, I will contact you by email to advise you accordingly.

It is very important that you know that although confidentiality is at the heart of this research, information can only be protected within the limits of the law. If I am concerned about a risk of violence or other serious harm to

yourself or others or of dangerous practice or criminal activity I will have to breach confidentiality. It is also possible that data can be subject to freedom of information claims or mandated reporting.
This research project has been approved by DCU's Research and Ethics Committee. Below are the names and contact details which you will need to keep in case you have a concern, a complaint or a question concerning your data.

If you wish to contact an independent person, please contact:
The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel – 01 7008000 email rec@dcu.ie

DCU Data Protection Officer: **Mr. Martin Ward**
Tel: 01 7005118 / 01 7008257
Email:
DATA Protection Unit: Tel 01 7006466; 01 7007476; 01 700 8257; 01 7005118

data.protection@dcu.ie
Room A145, Albert College Extension,
DCU Glasnevin Campus,
Collins Avenue Extension, Dublin9

Thank you for taking the time to read this statement. I hope you will decide to participate in this research and that you will find it stimulating and of value to you.

APPENDIX 6

INFORMED CONSENT FORM: PERSONS WITH VISION IMPAIRMENT

INFORMED CONSENT FORM: PERSONS WITH VISION IMPAIRMENT

I give my consent to participate in an interview as part of research being conducted by James Forbes (Principal Investigator) in relation to a PhD dissertation entitled:

> Domination and Disability: a republican proposal in the light of the United Nations Convention on the Rights of Persons with Disabilities.

I understand that this research is being overseen by Dr. Tom Hickey and Dr. Aisling de Paor of Dublin City University's School of Law and Government. I also understand that the Data Controller in relation to my personal information is DCU and I acknowledge that I have the contact details for both Dr. Hickey and Dr. de Paor and for DCU's Data Protection Officer, Mr. I understand and further consent that in agreeing to be interviewed that my interview will be audio recorded. I understand and accept that my data will have my name, workplace or any other identifying feature removed from it. I consent to this and to the private storage of my data and its proper destruction at appropriate times. I also acknowledge and accept that while my audio recording will be destroyed once transcription to written form is complete that Mr. Forbes may retain the transcripts for some further period for the purposes such as completion of a

I further acknowledge by circling – or by permitting on my behalf the circling of - the appropriate answer that:

- I have read the Plain Language Statement (or have had it read to me)

  YES NO

- I understand the information provided

  YES NO

- I understand the information provided in relation to data protection

  YES NO

- I have had the opportunity to ask questions and discuss this study

YES NO

- I have received satisfactory answers to my questions

  YES NO

- I understand that the confidentiality of information I provide is subject to legal limitations

  YES NO

- I also assert and confirm that my participation in this research study is entirely voluntary and that I may revoke this consent and withdraw from the research project at any point.

  YES NO

SIGNATURE (if signing on behalf of the freely consenting person please indicate by adding pp before name**)**

I have read and understand the information in this form. My questions and concerns have been answered by the researcher, and I have retained a copy of this consent form. Therefore, I consent

Participants signature: _________________________

Name in block capitals: _________________________

Witness signature _________________________

Name in block capitals _________________________

Date _________________________

APPENDIX 7

INFORMED CONSENT FORM: PARENTS OF PERSONS WITH DISABILITIES

INFORMED CONSENT FORM: PARENTS OF PERSONS WITH DISABILITIES

I give my consent to participate in an interview as part of research being conducted by James Forbes (Principal Investigator) in relation to a PhD dissertation entitled:

> Domination and Disability: a republican proposal in the light of the United Nations Convention on the Rights of Persons with Disabilities.

I understand that this research is being overseen by Dr. Tom Hickey and Dr. Aisling de Paor of Dublin City University's School of Law and Government. I also understand that the Data Controller in relation to my personal information is DCU and I acknowledge that I have the contact details for both Dr. Hickey and Dr. de Paor and for DCU's Data Protection Officer, Mr. I understand and further consent that in agreeing to be interviewed that my interview will be audio recorded. I understand and accept that my data will have my name, workplace and any other identifying feature removed from it. I consent to this and to the private storage of my data and its proper destruction at appropriate times. I also acknowledge and accept that while my audio recording will be destroyed once transcription to written form is complete that Mr. Forbes may retain the transcripts for some further period for the purposes such as completion of a

I further acknowledge by circling the appropriate answer that:

- I have read the Plain Language Statement (or have had it read to me)

  YES NO

- I understand the information provided

  YES NO

- I understand the information provided in relation to data protection

  YES NO

- I have had the opportunity to ask questions and discuss this study

  YES NO

- I have received satisfactory answers to my questions

  YES NO

- I understand that the confidentiality of information I provide is subject to legal limitations

  YES NO

- I also assert and confirm that my participation in this research study is entirely voluntary and that I may revoke this consent and withdraw from the research project at any point.

  YES NO

SIGNATURE

I have read and understand the information in this form. My questions and concerns have been answered by the researcher, and I have retained a copy of this consent form. Therefore, I consent

Participants signature: ____________________________

Name in block capitals: ____________________________

Witness signature ____________________________

Name in block capitals ____________________________

Date ____________________________

APPENDIX 8

GATE-KEEPER GUIDANCE

GATE-KEEPER GUIDANCE

Thesis title: **Domination and Disability: a republican proposal in the light of the United Nations Convention on the Rights of Persons with Disabilities.**

Principal Investigator (PI): James Forbes

Thank you for agreeing to act as Gatekeeper in relation to recruiting blind and visually impaired participants for my PhD research.

This is a very important role and your willingness to undertake it is very much appreciated, not least because your independent involvement makes a significant contribution to showing that this research is being conducted to the highest ethical standards.

The terms under which you will undertake this role are as

- **the role is entirely voluntary and you will receive no payment or any other consideration, personal or professional, for undertaking it**
- **you will never disclose to me the names of anyone who declines to participate and you will ensure you explain this to those whom you approach**
- **you will provide the plain language statement (PLS) to each of the people you approach, ensuing it is provided in the appropriate audio, large print or braille format as required**
- **you will not offer any inducement, encouragement or in any way seek to persuade a would-be participant to take part**
- **if a person whom you contact voluntarily agrees either to take part in the research or wishes to speak to me directly concerning their possible participation you will pass their preferred contact details to me**
- **thereafter, all dealings between this person in relation to the research will devolve to me, as PI, and you are respectfully asked not to discuss the research, or the person's participation in it, with this person**
- **further**

  the decision as to whom you approach concerning participation is entirely yours but I would ask that you
  - **because of the nature of the subject matter, I, as PI, would like to discuss it is necessary that the people I speak to will be adults, ideally within the age range of 23 to 70 years of age**
  - **although the people you approach may have additional disabilities the presence of intellectual disabilities may present as potentially stressful for such would-be participants and so, you are asked, to be best of your abilities, to give due regard to this when you make your choice as to whom to**
  - **approach**

    the issues of stress arising from any form of research cannot, of course, be overlooked in relation to any would-be participant; therefore, in order to help minimize the possibility of it occurring in this research project you are asked please to ensure that the following formula of words is spoken to each

    > **'Are there any reasons you can thing of which might make taking part in an interview about issues concerning your experience of impairment and disability too stressful for you'.**

- **the target range for this element of the research project is 20 participants; if, however, you come to the view that this many participants will not be forthcoming I would be grateful if you would discuss this with me as soon as possible.**

Again, thank you for your willingness to take on the Gatekeeper role. If in the course of discharging this very valuable independent role there is anything of a practical nature you think I can do to help you, please do hesitate to contact me. You are reminded too that you may also contact either of my supervisors if you anything which you would wish to discuss with Their details are to be found in the Plain them. Statement.

Kind

James Forbes
Principal Investigator

APPENDIX 9

PARENT FACILITATOR GUIDANCE

PARENT FACILITATORS

Thesis title: **Domination and Disability: a republican proposal in the light of the United Nations Convention on the Rights of Persons with Disabilities.**

Principal Investigator (PI): James Forbes

Thank you for agreeing to facilitate my PhD research by circulating my plain language statement (PLS) to other parents of persons with disabilities.

Including the voice of parents in my research is very important to me and I want to assure you that any parents known to you who might be interested in participating will be treated with respect and sensitivity. Their identities will be protected and any direct quotes which might be contained in the PhD will be presented in such a way as to ensure that the quotes cannot identify the person from whom they came or any person whom they might be about.

Confidentiality is a core value of this research project and, as the PLS makes clear, it can only be breached in very specific circumstances.

Just to outline again for you what it is that I, as PI, am particularly interested in talking to parents about. I will want to talk to parents about their knowledge of the United Nation's Convention on the Rights of Persons with Disabilities (CRPD) and, in particular, their experiences or expected experiences around issues relating to education, work and employment and living independently and being part of the community. These experiences go to the heart of what it means to be a citizen and I will be interested in hearing people's stories about the supports and services they and their disabled children have received and any barriers or restrictions that can be identified as inhibiting full

Parents might also be interested to know that talking to them is just one strand of interviews for this research. I will also be interviewing people with disabilities – specifically persons with vision impairment – and people working in disability service providers and related roles.

Ideally, interviews will not last longer than one hour and I will want to audio record the interview. Only I, as PI, will ever hear the audio-recording and they will be securely and permanently deleted once I have made an anonymised transcript – which, in turn, will also be destroyed once the PhD and any related activities have been concluded. More information of my research can be found in the PLS.

Again, thank you for agreeing to help me secure parent participation for this research. If a parent agrees to take part – or wants to talk to me further – I will ask you to forward me their contact details and I will take it from there.

Please don't feel you have to try to persuade people to take part in this research. You are doing everything I ask just by circulating the PLS and seeing what happens next. Participation is entirely voluntary and shouldn't be influenced by anything other than a person's fully consensual wish to take part.

In the meantime, every good wish to you and your

James Forbes
Principal Investigator

APPENDIX 10

Distress Protocol

A protocol for managing distress in the context of a semi-structured interview process for use with vision impaired adults.
(designed by James Forbes, adapted from Draucker, C.B., Martsolf, D.S. Poole, C. (2009) Developing Distress Protocols for Research on Sensitive Topics. Archives of Psychiatric

Distress

- the participant indicates clearly that the interview is triggering an adverse emotional experience

  or

- the participant is displaying signs or behaviours which are consistent with heightened stress, distress, anger, confusion or

Response

- the participant is encouraged to take time to regain composure and offered the space to reflect on what they wish to do and

Review (Stage 1)

- if the participant feels able to carry on, the interview resumes
- if the participant is not able to carry on or if the researcher feels doing so is not in the participant's interests the researcher formally ends the interview and erases any recording made thus far; the participant is thanked for their participation and, if appropriate, the engagement may move to Stage 2

Review (Stage 2)

- in circumstances where the participant continues to be in distress or where the participant indicates that they would wish to avail of additional support the participant is reassured that help is available and if that is something which the participant is willing to discuss the researcher outlines a support or

INDICATIVE SUPPORT LIST

Counselling Supports

- Insight Counselling Service – free and confidential service providing face to face and telephone counselling to anyone directly or indirectly affected by sight loss. This service is offered by Fighting Blindness

Advocacy Supports

- National Council for the Blind of Ireland – NCBI provide advice and support to help give voice to individuals who are vision impaired in relation to claiming their rights and entitlements including campaigning on issues such as public awareness, resource allocation and public policy

- Enable Ireland – provides tailored, individualise supports in helping people identify and achieve those service changes which will improve their quality of life, including in terms of living independently

- National Advocacy Service – provides free and independent advocacy service to adults with disabilities

- Citizens Information Board – offers free and confidential on-line advice and advocacy, phone based and in-person information service

- Money Advice and Budgeting Service (MABS) – offers guidance and advice to people dealing with problem debt

- Inclusion Ireland – provides an inclusive advocacy and campaigning service to persons with intellectual disabilities, including the provision of self-advocacy resources and legal information

Other resources

- If necessary, participants may be directed to state agencies such as An Garda Siochana, the Health Service Executive or Tusla, the Child and Family Agency or to counselling services which specialise in specific issues.

Appendix 3 – Plain language statements

Sample Template – Plain Language Statement (approx. 400 words)

A Plain Language Statement (PLS) should use language that reflects the participant age group and corresponding comprehension level. It should contain the following information. The headings are there for guidance and do not need to be included in your form.

Introduction to the Research Study

Identify the Research Study Title, the university department involved, the principal investigator (including his/her DCU contact details) and any other investigators

Privacy Notice

An appropriate Privacy Notice is the means by which data subjects are informed about the use of their data. If personal data is being collected and processed, please refer to the University's Data Protection Unit website for advice and include the following information in the PLS:

- *The identity of the Data Controller (or in some cases the Joint Data Controllers) plus the details of any Data Processor (where applicable) should be clearly stated on the PLS. The Data Controller will nearly always be DCU (where the researcher is a DCU researcher). The PLS should also state the name of the research project and the identity of the particular School / Unit of DCU from which it originates. A Data Processor may hold or process personal data but does not exercise responsibility for or control over the personal data, for example, a transcription service, or a software or cloud hosting company.*
- *The identity of the DCU Data Protection Officer – Mr. Martin Ward (data.protection@dcu.ie Ph.: 7005118 / 7008257)*
- *The purpose of the data processing i.e. the reasons why the data is being requested and the purpose to which it will be applied.*
- *The reason(s) for which the data will be processed or held.*
- *The categories or types of personal data to be processed.*
- *The details of any third parties (i.e. data processors) with whom the data will be shared or transferred, and the reasons for sharing.*
- *The details of any external (i.e. non-DCU) parties with whom the data will be shared or transferred, and the reasons for sharing.*

- *Where relevant, details of any intention to transfer the data to other countries, especially if outside of the EEA (European Economic Area), and the legal basis invoked for such transfers.*
- *The data's retention period or the criteria used to determine retention periods.*
- *The right of the individual to lodge a complaint with the Irish Data Protection Commission.*
- *Information on the rights of the data subject - Individuals' have the right to access their own personal data and PLS should inform them how to do this and who to contact either within the research team, or alternatively by contacting the Data Protection Unit.*
- *Information on their rights to withdraw consent (if invoked) and who to contact to withdraw consent.*
- *If it is intended that the data be used for future studies, you must specify the general parameters of the future further research uses to which the participant's personal data may be used.*
- *In cases where personal data will later be anonymized (e.g. for statistical or aggregated data), it is best practice to describe this, so that the participant is fully informed.*

Statement as to whether or not the research data is to be destroyed after a minimum period

Clearly state (if applicable) when data will be destroyed or fully anonymized after the end of the research project.

Details of what participant involvement in the Research Study will require

E.g., involvement in interviews; completion of questionnaire; audio/video-taping of events, and the estimated time commitment for the activities

Potential risks to participants from involvement in the Research Study (if greater than that encountered in everyday life)

Any benefits (direct or indirect) to participants from involvement in the Research Study

Advice as to arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations

Participants need to be made aware that confidentiality of information provided cannot always be guaranteed by researchers – please include the following statement:

“Confidentiality of information can only be protected within the limitations of the law - i.e., it is possible for data to be subject to subpoena, freedom of information claim or mandated reporting by some professions”.

Depending on the research proposal and academic discipline, you may need to state additional specific limitations.

Statement that involvement in the Research Study is voluntary

State that participants may withdraw from the Research Study at any point. You should explain to the participant that their participation in the project will end, at the point they withdraw, and refer back to the data protection/privacy notice as to what will happen regarding their data. For example, withdrawing consent may mean that no future data collection will take place but previously collected data will still be processed etc.

Any other relevant information – e.g.

- *if the sample size is small, advice to participants that this may have implications for privacy / anonymity.*
- *if participants are in a dependent relationship with any of the researchers, a clear statement that their involvement / non-involvement in the project will not affect their ongoing assessment / grades / management.*

A Plain Language Statement must end with the following statement:

If participants have concerns about this study and wish to contact an independent person, please contact:

The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel 01-7008000, e-mail **rec@dcu.ie**

Domination and Disability: a republican proposal in the light of the United Nations Convention on the Rights of Persons with Disabilities.

Plain Language Statement

Parents of persons with disabilities

My name is James Forbes and I am inviting you to participate in interviews relating to my PhD project, on which I am the Principal Investigator. My work is being supervised by Dr. Tom Hickey (tom.hickey@dcu.ie) and Dr. Aisling de Paor (aisling.depaor@dcu.ie), both of Dublin City University's School of Law and Government. The PhD, which is in law, is being funded by a DCU Scholarship. The Data Controller for this project is DCU and the relevant contact details for the Data Protection Officer and the Data Protection unit can be found at the end of this Plain Language Statement. If anything about the way your Data is being used or held in this project concerns you, please remember you also have a right to complain to the Data Commissioner and their contact details can also be found at the end of this Plain Language Statement.

My contact details:
james.forbes3@mail.dcu.ie

What is involved in taking part?

I will want to talk to you about your thoughts and experiences of being a parent of a person with disability, especially in relation to some rights contained in the Convention on the Rights of Persons with Disabilities (CRPD). In particular, I will want to talk to you about your thoughts and experiences around education, employment and about your child being independent and being included in the community. Our conversation will be in the form of a person to person interview either face to face or via a password protected zoom or using a password protected DCU approved video platform. The conversation will not last longer than one hour. If we meet face to face this will be in an environment which allows us to be private but socially distanced and I will ensure that we will comply with all existing Covid guidelines.

By taking part in this research, you will help me form a view about how persons with disabilities can better achieve and resiliently hold rights as citizens and about how wider society can support an understanding of difference which will bring benefits, potentially, to everyone.

Important information about how your data will be used and kept safe

Your agreement to take part in this research can be withdrawn at any time. This can be done simply by contacting the Principal Investigator and indicating your wishes. If you withdraw, your Data will be securely erased and no element of it will be used in the PhD project.

Also, you always retain the right to access your own Data and you can do this up until the point it is erased by contacting either the Principal Investigator or Dr. Tom Hickey or Dr. Aisling de Paor or the DCU Data Protection Unit.

Your privacy is very important to me as a researcher and to DCU. This means your identity will be known only to me.

With your consent I will audio record our conversation. This will be stored securely and the recording will be completely erased as soon as a transcript has been made of it. This transcript will be produced using secure DCU approved software.

My supervisors will see the transcripts but they will never hear the audio or know whose transcripts they are seeing or any details which could identify you.

I will retain the transcripts only for as long as to facilitate additional academic work such as presentations, journal articles and, possibly, a book. All of your data, in whatever form, in relation to this project will be securely disposed of no later than August 2027.

Your interview with me will be turned into quotations in my PhD dissertation. However, I will make sure that these quotations are anonymised and that you cannot be identified either from them or from any subsequent work I produce in relation to this project.

I will store your name and contact details in case I need to get in touch with you in the event of a data breach. This information – to which no-one else will have access – will be held securely.

If you give me your consent to contact you when the PhD is finalised, or when any other work arising from your data is completed, I will contact you by email to advise you accordingly.

It is very important that you know that although confidentiality is at the heart of this research, information can only be protected within the limits of the law. If I am concerned about a risk of violence or other serious harm to yourself or others, dangerous practice or criminal activity I will have to breach confidentiality. It is also possible that data can be subject to freedom of information claims or mandated reporting.

This research project has been approved by DCU's Research and Ethics Committee. Below are the names and contact details which you will need to keep in case you have a concern, a complaint or a question concerning your data.

If you have any concerns about this project and wish to talk to an independent person, please contact:

The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel – 01 7008000 email rec@dcu.ie

DCU Data Protection Officer: Mr. Martin Ward

Tel: 01 7005118 / 01 7008257

Email: data.protection@dcu.ie

DATA Protection Unit: Tel 01 7006466; 01 7007476; 01 700 8257; 01 7005118

data.protection@dcu.ie

Room A145, Albert College Extension,

DCU Glasnevin Campus,

Collins Avenue Extension, Dublin9

Irish Data Commissioner can be contacted at: https://www.dataprotection.ie/

Thank you for taking the time to read this statement. I hope you will decide to participate in this research and that you will find it stimulating and of value to you.

Domination and Disability: a republican proposal in the light of the United Nations Convention on the Rights of Persons with Disabilities.

Plain Language Statement

Persons with vision impairment

My name is James Forbes and I am inviting you to participate in interviews relating to my PhD project, on which I am the Principal Investigator. My work is being supervised by Dr. Tom Hickey (tom.hickey@dcu.ie) and Dr. Aisling de Paor (aisling.depaor@dcu.ie), both of Dublin City University's School of Law and Government. The PhD, which is in law, is being funded by a DCU Scholarship. The Data Controller for this project is DCU and the relevant contact details for the Data Protection Officer and the Data Protection unit can be found at the end of this Plain Language Statement. If anything about the way your Data is being used or held in this project concerns you, please remember you also have a right to complain to the Data Commissioner and their contact details can also be found at the end of this Plain Language Statement.

My contact details:
james.forbes3@mail.dcu.ie

What is involved in taking part?

I will want to talk to you about your thoughts and experiences of impairment and of disability, especially in relation to some rights contained in the Convention on the Rights of Persons with Disabilities (CRPD). In particular, I will want to talk to you about your thoughts and experiences around education, employment and being independent and being included in the community. Our conversation will be in the form of a person to person interview either face to face or via a password protected zoom or using a password protected DCU approved video platform. The conversation will not last longer than one hour. If we meet face to face this will be in an environment which allows us to be private but socially distanced and I will ensure that we will comply with all existing Covid guidelines.

By taking part in this research, you will help me form a view about how persons with disabilities can better achieve and resiliently hold rights as citizens and about how wider society can support an understanding of difference which will bring benefits, potentially, to everyone.

Important information about how your data will be used and kept safe.

Your agreement to take part in this research can be withdrawn at any time. This can be done simply by contacting the Principal Investigator and indicating your wishes. If you withdraw, your Data will be securely erased and no element of it will be used in the PhD project.

Also, you always retain the right to access your own Data and you can do this up until the point it is erased by contacting either the Principal Investigator or Dr. Tom Hickey or Dr. Aisling de Paor or the DCU Data Protection Unit.

Your privacy is very important to me as a researcher and to DCU. This means your identity will be known only to me.

With your consent I will audio record our conversation. This will be stored securely and the recording will be completely erased as soon as a transcript has been made of it. This transcript will be produced using secure DCU approved software.

My supervisors will see the transcripts but they will never hear the audio or know whose transcripts they are seeing or any details which could identify you.

I will retain the transcripts only for as long as to facilitate additional academic work such as presentations, journal articles and, possibly, a book. All of your data, in whatever form, in relation to this project will be securely disposed of no later than August 2027.

Your interview with me will be turned into quotations in my PhD dissertation. However, I will make sure that these quotations are anonymised and that you cannot be identified either from them or from any subsequent work I produce in relation to this project.

I will store your name and contact details in case I need to get in touch with you in the event of a data breach. This information – to which no-one else will have access – will be held securely.

If you give me your consent to contact you when the PhD is finalised, or when any other work arising from your data is completed, I will contact you by email to advise you accordingly.

It is very important that you know that although confidentiality is at the heart of this research, information can only be protected within the limits of the law. If I am concerned about a risk of violence or other serious harm to yourself or others, dangerous practice or criminal activity I will have to breach confidentiality. It is also possible that data can be subject to freedom of information claims or mandated reporting.

This research project has been approved by DCU's Research and Ethics Committee. Below are the names and contact details which you will need to keep in case you have a concern, a complaint or a question concerning your data.

If you have any concerns about this project and wish to talk to an independent person, please contact:

The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel – 01 7008000 email rec@dcu.ie

DCU Data Protection Officer: Mr. Martin Ward

Tel: 01 7005118 / 01 7008257

Email: data.protection@dcu.ie

DATA Protection Unit: Tel 01 7006466; 01 7007476; 01 700 8257; 01 7005118

data.protection@dcu.ie

Room A145, Albert College Extension,

DCU Glasnevin Campus,

Collins Avenue Extension, Dublin9

Irish Data Commissioner can be contacted at: https://www.dataprotection.ie/

Thank you for taking the time to read this statement. I hope you will decide to participate in this research and that you will find it stimulating and of value to you.

Appendix 4 – Informed consent form

Sample Template – Informed Consent Form (approx. 300 words)

An Informed Consent Form should generally contain the information detailed below. It should be written in the first person, e.g. "I will be asked to attend…I may withdraw from the research study at any point…..I am aware that the data…etc." The headings are there for guidance and do not need to be included in your form.

Research Study Title

Also identify the school / centre involved, the principal investigator and any other investigators.

Clarification of the purpose of the research

If personal data is being collected and processed, please ensure that the participants acknowledge the identity of the data controller and the purpose(s) of the processing for which the personal data are intended.

Confirmation of particular requirements as highlighted in the Plain Language Statement

Requirements may include involvement in interviews, completion of questionnaire, audio / video-taping of events etc.. Getting the participant to acknowledge requirements is preferable, e.g.

Participant – please complete the following (Circle Yes or No for each question)

I have read the Plain Language Statement (or had it read to me)	*Yes/No*
I understand the information provided	*Yes/No*
I understand the information provided in relation to data protection	*Yes/No*
I have had an opportunity to ask questions and discuss this study	*Yes/No*
I have received satisfactory answers to all my questions	*Yes/No*
I am aware that my interview will be audiotaped	*Yes/No*

Confirmation that involvement in the Research Study is voluntary

E.g. I may withdraw from the Research Study at any point.

Confirmation of arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations

Confirmation of arrangements regarding the retention / disposal of data

Confirmations relating to any other relevant information as indicated in the PLS
E.g. I consent to the use of my data for future studies within the following parameters (provide detail)

Signature:

I have read and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. Therefore, I consent to take part in this research project

Participants Signature: ____

Name in Block Capitals: ____

Witness:____

Date:____

Anonymous Online Consent Form Template

In cases where an anonymous questionnaire is being used, researchers are required to provide a separate tick box for each statement that the participant is being asked to consent to / acknowledge. Each statement must be included as an essential field in order to ensure that full informed consent has been obtained (see example below).

An Informed Consent Form should generally contain the information detailed below. It should be written in the first person, e.g. “I will be asked to attend…I may withdraw from the research study at any point…..I am aware that the data…etc.” The headings are there for guidance and do not need to be included in your form.

Research Study Title

Also identify the school / centre involved, the principal investigator and any other investigators.

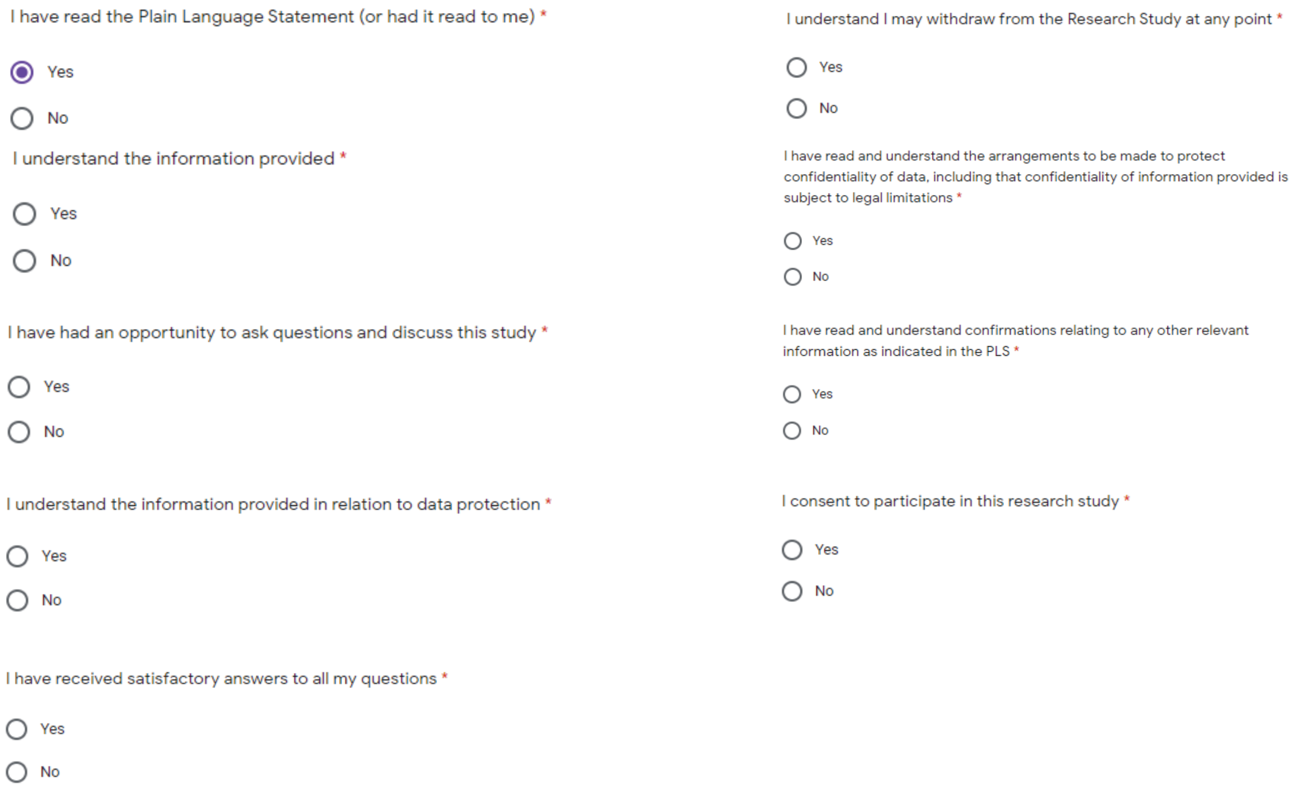
Clarification of the purpose(s) of the research

Confirmation of particular requirements as highlighted in the Plain Language Statement

Getting the participant to acknowledge the requirements is mandatory. Participants should not be able to access the survey until they have agreed to all items and indicated their consent. e.g.

Example:

<u>Participant – please complete the following (by clicking Yes/No for each question)</u>



I have read the Plain Language Statement (or had it read to me) *

● Yes

○ No

I understand the information provided *

○ Yes

○ No

I have had an opportunity to ask questions and discuss this study *

○ Yes

○ No

I understand the information provided in relation to data protection *

○ Yes

○ No

I have received satisfactory answers to all my questions *

○ Yes

○ No

I understand I may withdraw from the Research Study at any point *

○ Yes

○ No

I have read and understand the arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations *

○ Yes

○ No

I have read and understand confirmations relating to any other relevant information as indicated in the PLS *

○ Yes

○ No

I consent to participate in this research study *

○ Yes

○ No

Appendix 5 – Gatekeeper form

Ollscoil Chathair Bhaile Átha Cliath
Dublin City University

GATE-KEEPER GUIDANCE

Thesis title: Domination and Disability: a republican proposal in the light of the United Nations Convention on the Rights of Persons with Disabilities.

Principal Investigator (PI): James Forbes

Thank you for agreeing to act as Gatekeeper in relation to recruiting blind and visually impaired participants for my PhD research.

This is a very important role and your willingness to undertake it is very much appreciated, not least because your independent involvement makes a significant contribution to showing that this research is being conducted to the highest ethical standards.

The terms under which you will undertake this role are as follows:

- the role is entirely voluntary and you will receive no payment or any other consideration, personal or professional, for undertaking it
- you will never disclose to me the names of anyone who declines to participate and you will ensure you explain this to those whom you approach
- you will provide the plain language statement (PLS) to each of the people you approach, ensuring it is provided in the appropriate audio, large print or braille format as required
- you will not offer any inducement, encouragement or in any way seek to persuade a would-be participant to take part
- if a person whom you contact voluntarily agrees either to take part in the research or wishes to speak to me directly concerning their possible participation you will pass their preferred contact details to me
- thereafter, all dealings between this person in relation to the research will devolve to me, as PI, and you are respectfully asked not to discuss the research, or the person's participation in it, with this person further
- the decision as to whom you approach concerning participation is entirely yours but I would ask that you consider your choices within certain parameters, specifically

  - because of the nature of the subject matter, I, as PI, would like to discuss it is necessary that the people I speak to will be adults, ideally within the age range of 23 to 70 years of age
  - although the people you approach may have additional disabilities the presence of intellectual disabilities may present as potentially stressful for such would-be participants and so, you are asked, to be best of your abilities, to give due regard to this when you make your choice as to whom to approach
  - the issues of stress arising from any form of research cannot, of course, be overlooked in relation to any would-be participant; therefore, in order to help minimize the possibility of it occurring in this research project you are asked please to ensure that the following formula of words is spoken to each person who expresses a willingness to participate in this research project:

    > **'Are there any reasons you can thing of which might make taking part in an interview about issues concerning your experience of impairment and disability too stressful for you'.**

  - if in your reasonable opinion a person does not answer this question in a way which reassures you and if this person still seeks to participate in the research there is an onus on you to identify your concerns to the PI
- the target range for this element of the research project is 20 participants; if, however, you come to the view that this many participants will not be forthcoming I would be grateful if you would discuss this with me as soon as possible.
- Again, thank you for your willingness to take on the Gatekeeper role. If in the course of discharging this very valuable independent role there is anything of a practical nature you think I can do to help you, please do hesitate to contact me. You are reminded too that you may also contact either of my supervisors if you feel that there is anything which you would wish to discuss with them. Their details are to be found in the Plain Language Statement.

Kind regards,

James Forbes
Principal Investigator

Appendix 6 – Distress protocol

Distress Protocol

A protocol for managing distress in the context of a semi-structured interview process for use with vision impaired adults.

(designed by James Forbes, adapted from Draucker, C.B., Martsolf, D.S. Poole, C. (2009) Developing Distress Protocols for Research on Sensitive Topics. Archives of Psychiatric Nursing 23 5 343-350)

- the participant indicates clearly that the interview is triggering an adverse emotional experience

or

- the participant is displaying signs or behaviours which are consistent with heightened stress, distress, anger, confusion or emotional turmoil

Distress

- the participant is encouraged to take time to regain composure and offered the space to reflect on what they wish to do and feel able to do; there is no hurry here

Response

- if the participant feels able to carry on, the interview resumes
- if the participant is not able to carry on or if the researcher feels doing so is not in the participant's interests the researcher formally ends the interview and erases any recording made thus far; the participant is thanked for their participation and, if appropriate, the engagement may move to Stage 2

Review (Stage 1)

- in circumstances where the participant continues to be in distress or where the participant indicates that they would wish to avail of additional support the participant is reassured that help is available and if that is something which the participant is willing to discuss the researcher outlines a support or counselling option appropriate to the circumstances (see indicative list below).

Review (Stage 2)

INDICATIVE SUPPORT LIST

Counselling Supports:

- Insight Counselling Service Phone: (01) 891 0703– free and confidential service providing face to face and telephone counselling to anyone directly or indirectly affected by sight loss. This service is offered by Fighting Blindness

Advocacy Supports

- National Council for the Blind of Ireland Phone: (01) 830 7033 – NCBI provide advice and support to help give voice to individuals who are vision impaired in relation to claiming their rights and entitlements including campaigning on issues such as public awareness, resource allocation and public policy

- Enable Ireland Phone: (01) 872 7155 – provides tailored, individualise supports in helping people identify and achieve those service changes which will improve their quality of life, including in terms of living independently

- National Advocacy Service Phone: 0761 07 3000– provides free and independent advocacy service to adults with disabilities

- Citizens Information Board Phone: 076 107 9000 – offers free and confidential on-line advice and advocacy, phone based and in-person information service

- Money Advice and Budgeting Service (MABS) Phone: 076 107 2170 - offers guidance and advice to people dealing with problem debt

- Inclusion Ireland Phone: (01) 855 9891 – provides an inclusive advocacy and campaigning service to persons with intellectual disabilities, including the provision of self-advocacy resources and legal information

Other resources

  - If necessary, participants may be directed to state agencies such as An Garda Siochana, the Health Service Executive or Tusla, the Child and Family Agency or to counselling services which specialise in specific issues.