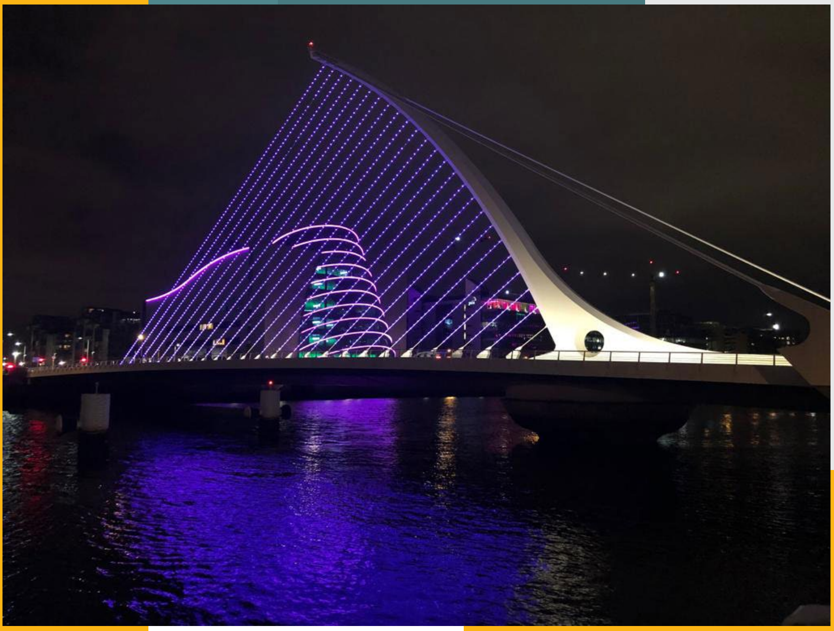

Mapping the Lived Experiences of Intersex/Variations of Sex Characteristics in Ireland:

Contextualising Lay and Professional Knowledge to Enable Development of Appropriate Law and Policy

Tanya Ní Mhuirthile, Maria Feeney,
Mel Duffy and Anthony Staines

Ollscoil Chathair
Bhaile Átha Cliath
Dublin City University

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Front cover image: Dublin's Samuel Beckett Bridge and the Convention Centre Dublin turned purple as part of the Intersex Mapping Study's #IrelandTurnsPurple public awareness campaign on Sunday, 8th November 2020 to mark International Intersex Solidarity Day. Photo by Maria Feeney.

Note: This report meets the Irish Research Council's requirements for COALESCE funded projects and represents one component of our overall Dissemination Strategy. Academic journal publications, a book proposal and educational material are currently in process. We are committed to continuing our contribution to intersex studies.

Abbreviations

ASC	Atypical Sex Characteristics
DSD	Disorders of Sex Development
DSH	Deliberate Self-Harm
ECtHR	European Court of Human Rights
FGM	Female Genital Mutilation
IGM	Intersex Genital Mutilation
PACE	Parliamentary Assembly of the Council of Europe
RSE	Relationships and Sexuality Education
SPHE	Social, Personal and Health Education
VSC	Variation(s) of Sex Characteristic

Table of Treaties

UDHR	Universal Declaration of Human rights, 1948
ECHR	European Convention on Human Rights, 1953
ESC	European Social Charter, 1961, revised 1996
ICERD	International Convention on the Elimination of All Forms of Racial Discrimination, 1965
ICCPR	International Covenant on Civil and Political Rights, 1966
ICESCR	International Covenant on Economic, Social and Cultural Rights, 1966
CEDAW	International Convention on the Elimination of All Forms of Discrimination Against Women, 1979
CAT	Convention Against Torture, Cruel, Inhuman or Degrading Treatment or Punishment, 1984
CRC	Convention on the Rights of the Child, 1989
CRPD	Convention on the Rights of Persons with Disabilities, 2006
CFREU	Charter of Fundamental Rights of the European Union, 2012

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Executive Summary

This study is the first of its kind in Ireland and sought to 'map' what it means to be intersex/have Variation(s) of Sex Characteristics (VSC). Having a body that's different according to its sex characteristics (i.e. sex organs, genitalia, hormones, and/or chromosomes) is a natural variation of the human body. Bodies with these types of differences do not align to typical male-female ones. There are more than thirty different ways that bodies can vary in this regard. Intersex/VSC are umbrella terms for this spectrum of human diversity. Some variations are extremely rare and require complex regimes of care. Others cause no threat to a person's wellbeing and in fact some people may never know they have such a variation. Public knowledge remains limited about intersex/VSC despite the United Nations noting that betwee .5 - 1.7% of people have this type of variation.

Data about being intersex/having VSC is limited especially in the socio-legal and socio-medical space in Ireland. Heretofore, little was known about how being intersex/having VSC could affect one's life in Ireland. Addressing this gap in knowledge was the primary aim of this research study. Using hermeneutical phenomenology, we conducted interviews with intersex people/those with VSC in Ireland to understand their lived experience. Additionally, we interviewed the partner of one of our intersex participants who shared their story with us. We also interviewed healthcare professionals working in this field in Ireland to learn about how they care for this hidden and vulnerable population. We developed a self-administered questionnaire for people who wished to share their story without participating in an interview. We expected to form some baseline information about Ireland's intersex population/those with VSC that would not only contribute to public knowledge about what being intersex means but also that it would help identify key areas where action is required to ensure this unique group are afforded the same benefits Irish society bestows on the broader, general public. Noteworthy also is the fact that we commenced our research just as the COVID-19 pandemic gripped Ireland in March 2020. Notwithstanding such unprecedented challenges, we continued with our efforts throughout 2020-2021 and report some profound and valuable findings in this report.

We have learned that intersex people/those with VSC are a very hidden population. They are a diverse group with equally diverse needs in terms of their health and welfare. Moreover, they are a vulnerable population. Irish law does not offer the same protection to intersex people/those with VSC as it does to the non-intersex population. Our interview sample were all over forty years and some describe profoundly negative life-experiences that they relate to being interex/having VSC. These types of experiences are discussed thematically in this report in terms of how they have come to learn about themselves, their trauma, their experiences of care in Ireland. These lived experiences are supported with the data that has been generated from our small survey sample based here in Ireland (n=23). Opportunities for meaningful, holistic healthcare were limited and systematic health services issues were implicated in this. Furthermore, our healthcare professionals acknowledged that more support was required to meet the needs of those with intersex/VSCs and thier families despite their best efforts as committed, collaborative and compassionate care, and particularly for those requiring fertility treatment. And while they point to a healthcare approach that is more patient-centred and inclusive, some intersex participants/those with VSCs point to the pathological male-female binary that structures the delivery of care in Ireland.

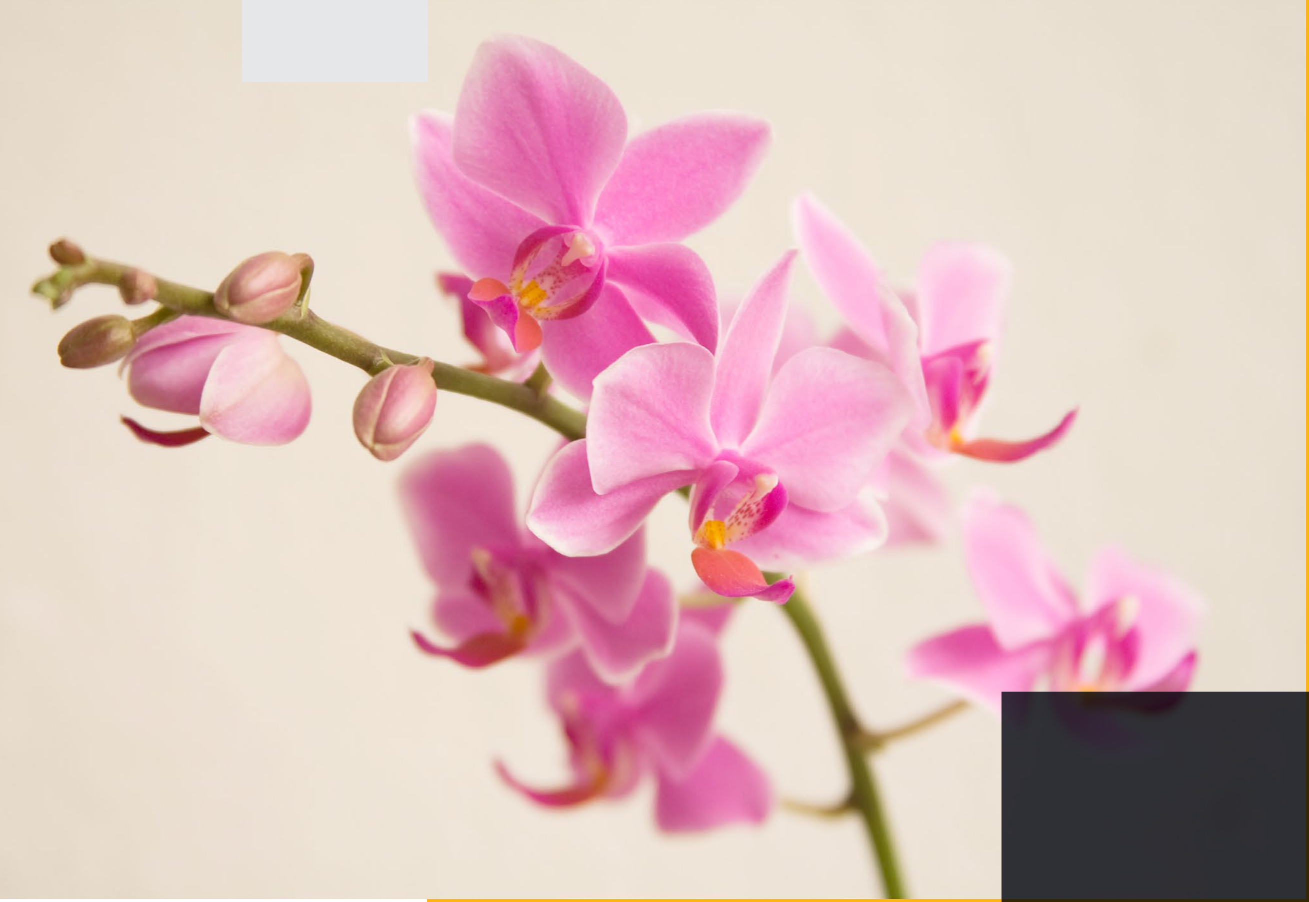
There are many ways that law is engaged by issues relating to intersex/variations of sex characteristics. Our research finds that it is essential that people can be correctly registered and that they have a facility to amend civil registration status where necessary. Of more concern for people with variations of their sex characteristics is the need for redress where they have had negative experiences of health care. We found that traditional legal approaches to such cases are unlikely to be successful. Therefore, human rights law becomes the shield by which the rights of people with intersex variations of their sex characteristics can be protected. We have identified a number of rights at international, regional and domestic level where people with intersex variations of their sex characteristics may be able to find protection, but have discovered that as these are currently implemented in Ireland, the protection they give is scant at best. Consequently we make a series of recommendations aimed at ensuring that intersex people can duly enjoy, without discrimination on the basis of their sex characteristics, the dignity and freedoms which are foundational to society.

Public knowledge about intersex/having VSCs is limited not least due to its absence from the post-primary school curriculum and the data demonstrates that this is another example of how intersex people/those with VSCs remain unrecognised in aspects of Irish life. Raising public awareness about intersex is important and we document our efforts in this regard by discussing our #IrelandTurnsPurple national public awareness campaign on 8th November 2020 in addition to our online international conference *Intersex 2021 - A Vision For The Future.* Our team has also presented our work at key national and international conferences in 2020 and 2021.

This study lays a solid foundation for much-needed future work in this area which we outline later in the report. We believe that stories about our participants' lives are an important contribution to knowledge about a unique and remarkably resilient group that Irish society fails to fully recognise and protect. We look forward to our future contributions to the field arising from this research and we welcome the many others that are required to ensure that intersex people in Ireland/those with VSC can enjoy the benefits that Irish society affords to the majority.

1

Introduction



Chapter 1: Introduction

Intersex/having a variation of sex characteristics (VSC), is a *naturally-occurring* human variation. Specifically, it relates to difference in the body's sex characteristics (i.e. chromosomes, hormones, genitalia, sex organs) that does not correspond to medical and social norms about male and female bodies.[1] In some instances, an intersex variation may be identified at birth (e.g. ambiguous genitalia) and in other instances the intersex variation may not be identified until adolescence or adulthood. Sometimes delayed puberty (e.g. late/no menstruation or slow growth) may prompt investigative tests which reveal an intersex variation. Indeed, many people will never know they are/were intersex.[2]

It is estimated that approximately 1.7% of the human population have a variation of sex characteristics,[3] but this is often disputed.[4] Gough et al. note that "calculating numbers" of those affected is difficult particularly when late, puberty-stage, diagnoses are also made.[5] For example, Herlin et al. report a prevalence estimate of MRKH (Mayer-Rokitansky-Küster-Hauser) of approximately 1 in 5,000 female births in Denmark;[6] Turner Syndrome occurs in approximately 1 in 2,000 - 2,500 live female births;[7] and Klinefelter Syndrome is more common than both MRKH and Turner Syndrome with an incidence of approximately 1 in every 500 – 1,000 newborn males. However, some variants of Klinefelter are much rarer *"... (such as 48, XXXY, 49, XXXXY) ... occurring in 1 in 50,000 to 1 in 85,000 or*

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[1] Morgan Carpenter, 'The Human Rights of Intersex People: Addressing Harmful Practices and Rhetoric of Change' (2016) 24 Reproductive Health Matters 74 <https://doi.org/10.1016/j.rhm.2016.06.003> accessed 26 February 2021.

[2] Tiffany Jones, 'Intersex Studies: A Systematic Review of International Health Literature' (2018) 8 SAGE Open 2158244017745577 <https://doi.org/10.1177/2158244017745577> accessed 26 February 2021.

[3] United Nations for LGBT Equality, 'Fact Sheet Intersex' <https://www.unfe.org/wp-content/uploads/2017/05/UNFE-Intersex.pdf> accessed 15 February 2022.

[4] P -L Chau and Jonathan Herring, 'Defining, Assigning and Designing Sex' (2002) 16 International Journal of Law, Policy and the Family 327 <https://doi.org/10.1093/lawfam/16.3.327> accessed 22 March 2022.

[5] Brendan Gough and others, '"They Did Not Have a Word": The Parental Quest to Locate a "True Sex" for Their Intersex Children' (2008) 23 Psychology & Health 493 <https://doi.org/10.1080/14768320601176170> accessed 14 March 2022.

[6] Morten Herlin and others, 'Prevalence and Patient Characteristics of Mayer–Rokitansky–Küster–Hauser Syndrome: A Nationwide Registry-Based Study' (2016) 31 Human Reproduction 2384 <https://academic.oup.com/humrep/article-lookup/doi/10.1093/humrep/dew220> accessed 14 March 2022.

[7] TCGI -Turner Contact Group Ireland, 'What Is Turner Syndrome ?' <http://tcgi.ie/what_is_turner_syndrome.html> accessed 14 March 2022. 'Turner Syndrome' (*NORD (National Organization for Rare Disorders)*) <https://rarediseases.org/rare-diseases/turner-syndrome/> accessed 14 March 2022.

fewer newborns.[8] Comparatively, the prevalence of intersex/VSC in Europe and the USA is more common than Down's Syndrome,[9] and on par with the estimated prevalence of Autism Spectrum Disorders (ASD) in Ireland.[10]

Intersex people/those with VSC are considered a sexual and gender minority by the US National Institutes of Health,[11] by the UK Government[12] and by the World Bank[13]. The World Bank survey confirms that intersex and transgender people are "often the most invisible part of the LGBTI acronym[14] - minority in a minority.

Terminology

The terms intersex is an umbrella terms that includes more than thirty ways the human body may differ according to its sex characteristics/traits[15]. Another term, *Variation of Sex Characteristics (VSC),* is often used. Debate abounds regarding terminology for people and their bodies that differ in this way.[16] Bodies that differ in this way are considered "non-standard" in some societies because they do not align to 'typical' male/female binaried bodies.[17] Debate also exists in the intersex community itself and also in the

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[8] 'Klinefelter Syndrome | Genetic and Rare Diseases Information Center (GARD) – an NCATS Program' <https://rarediseases.info.nih.gov/diseases/8705/klinefelter-syndrome> accessed 14 March 2022.

[9] K Zeiler and A Wickstrom, 'Why Do "we" Perform Surgery on Newborn Intersexed Children?: The Phenomenology of the Parental Experience of Having a Child with Intersex Anatomies' (2009) 10 Feminist Theory 359, 1464 <http://journals.sagepub.com/doi/10.1177/1464700109343258> accessed 11 January 2021.

[10] Department of Health, 'Estimating Prevalence of Autism Spectrum Disorders (ASD) in the Irish Population: A Review of Data Sources and Epidemiological Studies' (Department of Health 2018) <https://assets.gov.ie/10707/ce1ca48714424c0ba4bb4c0ae2e510b2.pdf>.

[11] Amy Rosenwohl-Mack and others, 'A National Study on the Physical and Mental Health of Intersex Adults in the U.S.' (2020) 15 PLOS ONE e0240088 <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0240088> accessed 14 March 2022.

[12] UK Government Equalities Office, 'National LGBT Survey: Research Report.' (Government Equalities Office 2018b) <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/721704/LGBT-survey-research-report.pdf>.

[13] World Bank, 'Life on the Margins: Survey Results of the Experiences of LGBTI People in Southeastern Europe' (World Bank 2018) <http://documents1.worldbank.org/curated/en/123651538514203449/pdf/130420-REPLACEMENT-PUBLIC-FINAL-WEB-Life-on-the-Margins-Survey-Results-of-the-Experiences-of-LGBTI-People-in-Southeastern-Europe.pdf> accessed 4 January 2021.

[14] ibid 54.

[15] interACT.org (Advocates for Intersex Youth), 'Intersex Definitions | InterACT: Advocates for Intersex Youth' (*What is intersex?*, 2016) <https://interactadvocates.org/intersex-definitions/> accessed 4 January 2022.

[16] Jones, 'Intersex Studies' (n 2).

[17] David A Rubin, 'Provincializing Intersex: US Intersex Activism, Human Rights, and Transnational Body Politics' (2015) 36 Frontiers: A Journal of Women Studies 51 <http://www.jstor.org/stable/10.5250/fronjwomestud.36.3.0051> accessed 5 July 2021.

medical community.[18] Historically, the word *hermaphrodite* was used to describe an intersex person but this is considered a harmful slur, "outdated and pejorative", demeaning and offensive .[19]

'Intersex' is widely used and accepted internationally.[20] In fact, two significant calendar days use this word: *Intersex Awareness Day* (October 26th) and *Intersex Solidarity Day* (November 8th). A recent review of intersex studies since 2015 (n= 61) found that over a third of the studies (n= 26) used the term 'intersex' including all 18 studies that used the Bioethical Narrative Inquiry theoretical lens within the Community Group-centered research category.[21] While the word intersex is not without criticism, the general consensus is that intersex is widely accepted globally and is more favourable to other more medical terms such as *Disorders of Sexual Development (DSD)*[22] despite this term being officially adopted into medicine in 2006,[23] and used across much research.[24] Jones noted that 24 studies of the 61 she examined used the DSD terminology - the majority of which featured the "Traditional Clinical/Medical theoretical lens".[25] Using the word *disorder* is problematic because it pathologizes bodily

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[18] Surya Monro, Daniela Crocetti and Tray Yeadon-Lee, 'Intersex/Variations of Sex Characteristics and DSD Citizenship in the UK, Italy and Switzerland' (2019) 23 Citizenship Studies 780 <https://doi.org/10.1080/13621025.2019.1645813> accessed 26 February 2021; Elizabeth Reis, 'Divergence or Disorder?: The Politics of Naming Intersex' (2007) 50 Perspectives in Biology and Medicine 535 <https://muse.jhu.edu/article/222245> accessed 3 October 2019.

[19] Jantine van Lisdonk, 'Living with Intersex/DSD: An Exploratory Study of the Social Situation of Persons with Intersex/DSD' (The Netherlands Institute for Social Research 2014); Elizabeth Reis, 'Divergence or Disorder?: The Politics of Naming Intersex' (2007) 50 Perspectives in Biology and Medicine 535 <https://muse.jhu.edu/article/222245> accessed 3 October 2019; Rubin (n 17).

[20] Markus Bauer, Daniela Truffer and Daniela Crocetti, 'Intersex Human Rights' (2020) 24 The International Journal of Human Rights 724 <https://doi.org/10.1080/13642987.2019.1671354> accessed 14 March 2022.

[21] Jones, 'Intersex Studies' (n 2)., at p8.

[22] Goergiann Davis, JODIE M DEWEY and ERIN L MURPHY, 'GIVING SEX: Deconstructing Intersex and Trans Medicalization Practices' (2016) 30 Gender and Society 490 <http://www.jstor.org/stable/24756183> accessed 24 May 2021.

[23] Tove Lundberg, Peter Hegarty and Katrina Roen, 'Making Sense of "Intersex" and "DSD": How Laypeople Understand and Use Terminology' (2018) 9 Psychology & Sexuality 161 <https://doi.org/10.1080/19419899.2018.1453862> accessed 26 February 2021.

[24] Anke Lux and others, 'Clinical Evaluation Study of the German Network of Disorders of Sex Development (DSD)/Intersexuality: Study Design, Description of the Study Population, and Data Quality' (2009) 9 BMC Public Health 110 <https://doi.org/10.1186/1471-2458-9-110> accessed 14 March 2022.

[25] Jones, 'Intersex Studies' (n 2).

differences,[26] is stigmatising,[27] and has the potential to infer that different/disordered bodies need to be fixed or repaired.[28] Yet, clinical evaluation research from the dsd-LIFE study undertaken between 2014-2015 among a sample of 1,040 patients, noted that

> a large majority of participants (69%) reported that the term *Disorders of Sex Development* applied to their condition or that they felt neutral about it.[29]

However, the following points should be noted: only 45% of participants agreed that the term DSD applied to their condition; 31% (296/941) of participants disagreed that the term DSD applied to their condition and 24% reported a neutral position. Interestingly, the authors - all with medical/clinical/healhcare backgrounds - found it "surprising" that 31% of participants did not believe the term DSD applies to their condition.[30] They also noted that intersex was the terms with the lowest rating and later in their paper they did acknowledge that

> Depending on the condition, up to one out of four participants strongly objected to the term Disorders of Sex Development.[31]

They also recommended that clinicians evaluate their "patients' preferences".[32] when using terminology.

To counter the pathologizing effects of the word 'disorder', Reis advocated for the use of *Divergence of Sex Development.*[33] Another variant is *Difference(s) of Sex Development* used by Rosenwohl-Mack and colleagues

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[26] Surya Monro and others, 'Intersex, Variations of Sex Characteristics, and DSD: The Need for Change' (2017) <http://eprints.hud.ac.uk/id/eprint/33535/1/Intersex%20Variations%20of%20Sex%20Characteristics%20and%20DSDreportfinal.pdf>.

[27] Matteo Cresti, Elena Nave and Roberto Lala, 'Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment' (2018) 15 Journal of Bioethical Inquiry 557 <https://doi.org/10.1007/s11673-018-9880-7> accessed 14 March 2022.

[28] Reis (n 18); Morgan Carpenter, 'Intersex Variations, Human Rights, and the International Classification of Diseases' (2018) 20 Health and Human Rights 205 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6293350/> accessed 3 October 2019.

[29] Elena Bennecke and others, 'Disorders or Differences of Sex Development? Views of Affected Individuals on DSD Terminology' (2021) 58 Journal of Sex Research 522.

[30] ibid. At p527.

[31] ibid. At p529.

[32] ibid.

[33] Reis (n 18).

in the first national study describing the physical and mental health of intersex adults in the US.[34] Still some medics find it best to use the term *Atypical Gonadal/Genital Development (AGD)* given the “confusion and discomfort” associated with previous terminology.[35]

Not all people, including those with variations of their sex characteristics, use the term intersex. Significant variation exists among those who are intersex/have VSC in terms of how they use terminology. Van Lisdonk’s research demonstrates that

> interviews with active members of patient organisations and persons with intersex/dsd revealed that they mostly do not use either term themselves. Instead, they generally tend to use the condition-specific term, such as ‘men with Klinefelter syndrome’ or ‘women with x y chromosomes’. Some of those interviewed were actually found to be entirely unfamiliar with the terms intersex and dsd.[36]

Greater general acceptance exists around the fact that a person’s choice of terminology ought to be respected. Some intersex people, such as Rose,[37] argue for intersex to be understood as a broad and inclusive spectrum that will permit acceptance of multiple and diverse experiences and such a belief aligns with our hermeneutical phenomenological approach where the person and their lived experience are front and centre. We are in full agreement with Rose, and also appreciate Lundberg et al.’s comment “that the debate on terminology is not yet settled.”[38] So, for the remainder of this report, we interpret the terms intersex/those born with VSC as umbrella terms and use them interchangeably throughout. While we are aware that some people find the word intersex to be offensive, we also know that it is a preferred term for others including some of our interview and survey participants and we report on on both of these realities in Chapter 7. Using the word intersex is in keeping with the use of the word by the EU Agency for Fundamental Rights (EU FRA) in their 2015 report on *The Fundamental*

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[34] Rosenwohl-Mack and others (n 11).

[35] Daniela B Gorduza and others, ‘Surgery of Anomalies of Gonadal and Genital Development in the “Post-Truth Era”’ (2018) 45 Urologic Clinics of North America 659 <https://www.sciencedirect.com/science/article/pii/S0094014318300570> accessed 14 March 2022.

[36] van Lisdonk (n 19).

[37] Maddie Rose, ‘Is MRKH Intersex? Ask a Different Question Instead’ (*interACT: Advocates for Intersex Youth*, 4 October 2020) <https://interactadvocates.org/is-mrkh-intersex/> accessed 17 December 2020.

[38] Lundberg, Hegarty and Roen (n 23).

Rights Situation of Intersex People.[39] Moreover, the word forms part of our project title and we became known as the Intersex Mapping Study.

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[39] EU Fundamental Rights Agency, 'FRA Focus Paper: The Fundamental Rights Situation of Intersex People' (2015) <https://fra.europa.eu/sites/default/files/fra_uploads/fra-2015-focus-04-intersex_en.pdf>.

2

Understanding Intersex

Chapter 2: Understanding Intersex

Learning about intersex/VSC involves a comprehensive, multi-disciplinary effort. Examining medical perspectives offers insight into the physiological/anatomical complexities associated with some variations. Examining legal perspectives helps us understand why the law fails to protect intersex people/those with VSC the way it protects the non-intersex population and at what points they become particularly vulnerable. Sociological perspectives help us cast a critical eye on how social structures and the way our societies are organised, affect different groups of people in different ways. Why do more men die by suicide compared to women? Why do children of wealthy people achieve better educational outcomes compared to children from poorer families? Why does medicine play such a prominent role in society? Sociology's robust ability to provide explanations for these types of questions is also invaluable for understanding what it means to be intersex. In this chapter, we provide a brief overview of one critical sociological concept - gender and it's relevance for understanding intersex/VSC. We then account for some of the reasons why intersex/VSC has become so medicalised before we examine some recent data that offers us an insight into the lives and experiences of some intersex people/those with VSC.

Why Gender Matters for Intersex/VSC

Sex is a biological category. It refers to two different types of bodies - male and female ones. This is the male-female binary. Babies are typically born male or female. Gender is different. Gender is a social category and we organise society according to gender. Gender is about what it means to be a man and a woman. Gender is learned. For example, we learn that men behave and dress differently to women and vice-versa. We are socialised according to this value system.

Traditionally, gender inequality, and women's subordination was easily justified through sex-role theory. Sex role theory depended on using biological sex to determine social organisation ("biological determinism").[40] In its most simplest form, sex-role theory determines that women were the inferior, weaker sex and needed to remain at home in the private, domestic sphere while men engaged in work outside the home, visibly participating in society and the economy. For some social theorists, this sex-role division worked. Mothers staying home and fathers 'out' working was "functional for the children, the parents and the society."[41] Dividing society along a sex-role line was functional, necessary and complimentary.[42] This way of thinking was referred to as *functionalism* and emerged from the work of Emile Durkheim and Talcott Parsons in the late nineteenth and early twentieth century. However, the functionalist way of thinking about sex-role divides was heavily criticised due to its limitations. One such limitation is that it did not necessarily consider that such sex-role divisions emerged as a result of power and domination.[43] Power relations ought to be to the fore when examining gender. Connell argued that it was essential to consider that gender be considered a "social structure of power" in order to fully understand men's widespread privilege in terms of their relations with and to women, but also their relations with and to other men.[44] For example, power relations explain why a gay, trans, or a disabled man (a minority) maintains a subordinate position compared to the more powerful and esteemed position of the straight and able man.

In a seminal work on masculinities theory, Connell explains that a key component of gender is that it is relational - for example, women learn how to be women from the relationships they have with other women and men.[45] Similarly, boys learn how to be men from their relationships with the men and women in their young lives. Unbeknownst to many of us, gender

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[40] RW Connell, *Masculinities* (University of California Press 1995); Demetrakis Demetriou, 'Connell's Concept of Hegemonic Masculinity' (2001) 30 Theory and Society 337 <http://www.jstor.org/stable/657965 .> accessed 19 October 2021.

[41] Arlie Russell Hochschild, 'A Review of Sex Role Research' (1973) 78 American Journal of Sociology 1011 <http://www.jstor.org/stable/2776619> accessed 24 March 2022. At 1017.

[42] Tim Carrigan, Bob Connell and John Lee, 'Toward a New Sociology of Masculinity' (1985) 14 Theory and Society 551 <http://www.jstor.org/stable/657315> accessed 5 October 2021.

[43] Douglas Schrock and Michael Schwalbe, 'Men, Masculinity, and Manhood Acts' (2009) 35 Annual Review of Sociology 277 <http://www.jstor.org/stable/27800079> accessed 5 October 2021; RW Connell, *Gender and Power: Society, the Person and Sexual Politics* (Stanford University Press 1987); Carrigan, Connell and Lee (n 42); Demetriou (n 40).

[44] RW Connell, 'A Very Straight Gay: Masculinity, Homosexual Experience, and the Dynamics of Gender' (1992) 57 American Sociological Review 735 <http://www.jstor.org/stable/2096120> accessed 7 October 2021. A p736.

[45] Connell, *Masculinities* (n 40).

relations have an enormous impact on our lives as it operates in obvious and not-so-obvious ways in society. For example, using a gender relations approach to study health inequality posits that "gender interactions facilitate and constrain health and illness".[46] When devising an initial systematic framework for examining gender and sexuality, Connell sought to 'map' how gender relations were structured in society.[47] Connell argued they are structured through (1) labour (sexual division of labour), (2) power (powerful men, subordinated women) and (3) cathexis, "practices that shape emotional attachment and desire".[48] We also learn about gender relations through three key social institutions that correspond to these structures: (i) the labour market, (ii) the state and (iii) the family, what Connel refers to as "gender regimes".[49] Through our day-to-day interactions, relations and practices - in places like the family, school and work - gender, gender relations, hierarchies and inequality are reproduced.

Connell's work in this regard, in addition to many others, that sought to reject biological determinism and sex-role theory, marked the development of socio-cultural explanations to understand people and society in more meaningful and realistic ways. It prompted the further development of feminist, masculinities, queer theories and new research methodologies all of which are relevant to understanding intersex.

Oakley brought this concept of socialisation from functionalism into feminist theory and argued that children are socialised such that they are taught the appropriate behaviour for their gender.[50] Millett argues that feminists should aim to diminish the effects of gender socialisation.[51] She contends that feminine and masculine socially produced gender norms are problematic in that gendered behaviour conveniently fits with and reinforces women's subordination so that women are socialised into subordinate social roles and learn to be passive, ignorant, docile, emotional

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[46] John Scott, 'Raewyn Connell: Hegemonic Masculinities, Gender and Male Health' in Fran Collyer (ed), *The Palgrave Handbook of Social Theory in Health, Illness and Medicine* (Palgrave Macmillan UK 2015) 535 <https://doi.org/10.1057/9781137355621_34> accessed 25 November 2021.

[47] Connell, *Gender and Power* (n 43).

[48] Scott (n 46) 540.

[49] Demetriou (n 40). At p341.

[50] Ann Oakley, *Subject: Women* (Penguin 1981).

[51] Kate Millett, *Sexual Politics* (Granada Publishing 1971).

helpmates for men.[52] Kimmel argues that although the precise manner in which gender socialisation occurs has changed, nonetheless social distinctions between socially acceptable feminine and masculine behaviour persist at the end of the twentieth century.[53] Therefore, while not denying the differences in male and female anatomy, feminists contended that since gender was a cultural phenomenon, then gender, like any other cultural aspect of the self, was learned and could accordingly be unlearned.

The importance of power in the male/female dyad features in the work of MacKinnon who argues that gender is something which is always oppressive. She defines masculinity as sexual dominance and femininity as sexual submissiveness therefore genders are 'created through the eroticization of dominance and submission. The man/woman difference and the dominance/submission dynamic define each other. This is the social meaning of sex.'[54] Therefore there can be no such thing as non- oppressive gender differences. MacKinnon asserts that a built in tension exists between the concept of equality which presupposes sameness, and the concept of sex, which presupposes difference.[55] Gender neutrality is, she argues, the male standard which benefits only men.[56] Thus genders are by definition hierarchical and this hierarchy is fundamentally tied to sexualised power relations.

This notion of sex/gender concealing power and social control is also evident in Foucault's work.[57] He suggests that the binary sex/gender paradigm is a system of understanding human sexuality such that it can be best harnessed to achieve the aims of society and government.[58] In other words, Government and society can control sexuality and deploy it in a manner which ensures that life is both healthy and prolonged. He contends that the

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[52] ibid. At p26.
[53] Michael S Kimmel, *The Gendered Society* (Oxford University Press 2000).
[54] Catherine A MacKinnon, *Towards a Feminist Theory of State* (Harvard University Press 1989). At p113.
[55] ibid.
[56] Catherine A MacKinnon, 'Feminism, Marxism, Method and the State: Toward Feminist Jurisprudence' (1983) 8 Signs 635. At p658.
[57] The contributions of this author to scholarship in the field of gender studies are indisputable, however we do acknowledge that recent controversy has surrounded this author.
[58] Michel Foucault, *The History of Sexuality : Volume 1 The Will to Knowledge* (Robert Hurley tr, Penguin Books 1998).

seventeenth century saw a shift in the way power was wielded. From the seventeenth century, Foucault suggests that society moved towards a notion of 'bio-power'.[59] The primary interest of power became life, and how to secure, extend, and improve it.[60] Thus bio- power is concerned with the 'task of administering life',[61] a process that works on two levels. From an individual point of view there is an 'anatomo-politics of the human body'.[62] This centres on the body as a machine and its integration into systems of efficient and economic control. From a social perspective there is a 'bio-politics of populations'.[63] This focuses on the population as a resource that must be protected, supervised and improved. Therefore, capitalism requires universal medical care and education to ensure an adequate workforce.[64] Sex has become such a preoccupation in the modern world because it deals with both these forms of bio-power. In support of this thesis he argues that modern power created new forms of sexuality by inventing discourses about it.[65]

Judith Butler's work about gender is also of critical relevance for thinking about sex, gender and intersex. Butler has been critical of feminists writings. Firstly, they critique the deployment of the sex/gender dyad by feminists. Secondly, they contend that feminist writing has produced a hegemonic understanding of 'woman' which fails to acknowledge that the lived reality of women may incorporate such different experiences that the very existence of a shared identity 'woman' becomes tenuous.[66]

Another important component of Butler's work is that gender is performative. For example, dressing differently is an example of a gender performance (Butler). In this way, we use our bodies to 'do' gender by dressing and behaving in certain ways thus demonstrating that society is organised by "normative heterosexual principles" (Butler). Such outward performances of gender are socially constructed and socially expected. Moreover, it was expected that this performance would reflect aspects of

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[59] ibid. At p140.

[60] ibid. At p139-140.

[61] ibid. At p139.

[62] ibid. At p139.

[63] ibid. At p139.

[64] Foucault, Michel, *The History of Sexuality Volume 1: The Will to Knowledge* (Robert Hurley tr, Penguin Books 1998). At p138-146.

[65] Foucault (n 58). At p97-98.

[66] Judith Butler, *Gender Trouble (10th Anniversary Ed)* (Routledge 1999). At p7-8.

our identities such as our bodies (whether the body was male or female) and our beings. 'Doing drag' is another example of a gender performance involving the body which Butler frames as a practice that

> exposes the illusory nature of an inner gendered self that is expressed on the outside or surface of the body.[67]

Through gender, and gender performances, bodies become sites or markers of who we are and our place in the world. However, Butler takes thinking about gender a step forward by noting that it is not just "assigned at birth", rather it is "imposed at birth". Butler clarified this at interview when asked if gender is in fact "assigned at birth"

> Gender is an assignment that does not just happen once: it is ongoing. We are assigned a sex at birth and then a slew of expectations follow which continue to "assign" gender to us. The powers that do that are part of an apparatus of gender that assigns and reassigns norms to bodies, organises them socially, but also animates them in directions contrary to those norms.
> Perhaps we should think of gender as something that is imposed at birth, through sex assignment and all the cultural assumptions that usually go along with that. Yet gender is also what is made along the way – we can take over the power of assignment, make it into self-assignment, which can include sex reassignment at a legal and medical level.[68]

In this way, we can understand that bodies remain heavily regulated - not just by our own personal selves, but by the state and medicine because societies and cultures modify bodies as per their cultural (and beauty) scripts over time.

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[67] Judith Butler, 'Bodily Inscriptions, Performative Subversions', *Routledge International Handbook of Heterosexualities Studies* (Routledge 2020) <https://www.taylorfrancis.com/books/edit/10.4324/9780429440731/routledge-international-handbook-heterosexualities-studies-james-joseph-dean-nancy-fischer>.

[68] Jules Gleeson, 'Judith Butler: "We Need to Rethink the Category of Woman"' *The Guardian* (7 September 2021) <https://www.theguardian.com/lifeandstyle/2021/sep/07/judith-butler-interview-gender> accessed 24 March 2022.

Medicine, Social Control and Intersex

Increased intersex activism and advocacy in recent decades has followed the increased medicalisation of intersex bodies/those with VSC from the 1950s. Greenberg explains that prior to this intersex babies were not subjected to medical intervention.[69] The development of surgical techniques and ideas about gender identity (nurture not nature) resulted in increased medical intervention on intersex infants.[70]

In a review of the concept of medicalisation, Busfield noted that the concept of medicalisation as a means of social control was first noted by the sociologist Jesse Pitts in 1968.[71] Moreover, he argued that "illness is socially constructed and a product of social factors".[72] Similarly, Zola argued that

> …medicine is becoming a major institution of social control, nudging aside, if not incorporating, the more traditional institutions of religion and law. It is becoming the new repository of truth, the place where the absolute and often final judgements are made by supposedly morally neutral and objective experts. And these judgements are made, not in the name of virtue or legitimacy, but in the name of health. Moreover, this is not occurring through the political power physicians hold or can influence, but it is largely an insidious and often undramatic phenomenon accomplished by 'medicalising' much of everyday living, by making medicine and the labels 'healthy' and 'ill' *relevant* to an ever increasing part of human existence. … If we search for the 'why' of this phenomenon, we will see instead that it is rooted in our increasingly complex technological and bureaucratic system – a system which has led us down the path of the reluctant reliance on the expert.[73]

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[69] Julie A Greenberg, *Intersexuality and the Law: Why Sex Matters* (NYU Press 2012). At p856.

[70] ibid; Carpenter, 'Intersex Variations, Human Rights, and the International Classification of Diseases' (n 28).

[71] Joan Busfield, 'The Concept of Medicalisation Reassessed' (2017) 39 Sociology of Health & Illness 759 <https://onlinelibrary.wiley.com/doi/abs/10.1111/1467-9566.12538> accessed 16 July 2021.

[72] Quoting Pitts, ibid. At p760.

[73] Irving Kenneth Zola, 'Medicine as an Institution of Social Control' (1972) 20 The Sociological Review 487 <https://doi.org/10.1111/j.1467-954X.1972.tb00220.x> accessed 16 July 2021. At p487.

This is a good example of one aspect of the multiple ways that a child and their body can be socially controlled via "armies' ' of interventionalist professionals.[74] Mayall explains

> "Children and childhood have become the object of massive interventions. Whole armies of health and social workers work to modify childhood. The concept of children's needs – derived from professionals' concepts, assumptions, priorities and goals – justifies interventions, including the education of mothers, health promotion and social work practice (Woodhead 1997)".[75]

In a recent sociology of childhood perspective, Brady et al. also acknowledges that

> Children are diagnosed with an increasing range of conditions and are subject to more and more elaborate child health and welfare interventions, reflecting a medical perspective on the changing panorama of illness and health risks in the 21st century.[76]

The shift towards what we refer to as a hyper-medicalisation as it relates to intersex people has meant that intersex people and their bodies, especially children's ones, "have been objects of intense medical scrutiny."[77] In this way, intersex bodies become "normalised or eliminated by medicine, while society and the law "others" intersex identities.[78]

Consequently, negative experiences abound in some intersex people's stories – dealing with childhood medical intervention, accepting a later diagnosis, chronic health issues and infertility are some that were noted in van Lisdonk's work from the Netherlands.[79] We draw attention to similar negative experiences from our own data later in the analysis chapters.

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[74] Berry Mayall, 'Towards a Sociology of Child Health' (1998) 20 Sociology of Health & Illness 269 <https://onlinelibrary.wiley.com/doi/abs/10.1111/1467-9566.00102> accessed 15 July 2021.

[75] ibid. At p243.

[76] Geraldine Brady, Pam Lowe and Sonja Olin Lauritzen, 'Connecting a Sociology of Childhood Perspective with the Study of Child Health, Illness and Wellbeing: Introduction' (2015) 37 Sociology of Health & Illness 173 <https://onlinelibrary.wiley.com/doi/abs/10.1111/1467-9566.12260> accessed 5 July 2021. At p175.

[77] ELLEN K FEDER, 'Tilting the Ethical Lens: Shame, Disgust, and the Body in Question' (2011) 26 Hypatia 632 <http://www.jstor.org/stable/23016572> accessed 15 March 2022.

[78] Carpenter, 'Intersex Variations, Human Rights, and the International Classification of Diseases' (n 28). At p487.

[79] van Lisdonk (n 19).

Intersex People and Intersex Experiences - What We Know So Far

A dearth of data exists pertaining to certain minority and hidden groups. Data pertaining to intersex people/those with VSC is scarce,[80] and was "limited and conflicting".[81] Moreover, intersex studies and intersex-only data, is a fractional proportion of what is publicly available compared to the more general LGBT minority. Notwithstanding this paucity of data, robust research has been undertaken about intersex/VSC, much of it is clinical in nature.[82] Varied approaches, with innovative perspectives, "from autobiographical analyses through to large-scale online surveys" have shed new light on the intersex/VSC subject since 2015.[83] However, certain aspects of the intersex/VSC experience remain under-researched, for example, educational experiences and issues abound relating to researching such a hidden and diverse population.[84] More subjective realities of being intersex/having VSC (e.g. quality of life QoL) were "rarely measured"[85] yet, even when such realities were examined the research generalisability is limited and large data sets are rarely generated for research about rare conditions.[86] However two non-clinical studies, namely surveys about intersex people's health and wellbeing, from Australia,[87] and the USA,[88] are welcome contributions to the field as is the recent global survey of 86 intersex people's experiences of education.[89] Another two surveys have also

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[80] Henrik Falhammar and others, 'Health Status in 1040 Adults with Disorders of Sex Development (DSD): A European Multicenter Study' (2018) 7 Endocrine Connections 466.

[81] Garry Warne and others, 'A Long-Term Outcome Study of Intersex Conditions' (2005) 18 Journal of pediatric endocrinology & metabolism: JPEM 555.

[82] Falhammar and others (n 80); Warne and others (n 81); Valeria Messina and others, 'Cognitive Function of Children and Adolescents With Congenital Adrenal Hyperplasia: Importance of Early Diagnosis' (2020) 105 The Journal of Clinical Endocrinology and Metabolism dgaa016; Lux and others (n 24).

[83] Jones, 'Intersex Studies' (n 2).

[84] Mandy Henningham and Tiffany Jones, 'Intersex Students, Sex-Based Relational Learning & Isolation' (2021) 21 Sex Education 600 <https://doi.org/10.1080/14681811.2021.1873123> accessed 27 March 2022.

[85] Anne Wæhre and others, 'Longitudinal Study of Individuals with Differences in Sex Development: A 15-20-Year Follow-Up of Mental Health, Psychosocial Functioning and Quality of Life in a Cohort of Norwegian Patients.' 28 <https://www.researchgate.net/publication/356368904_Longitudinal_Study_of_Individuals_with_Differences_in_Sex_Development_A_15-20-year_Follow-Up_of_Mental_Health_Psychosocial_Functioning_and_Quality_of_Life_in_a_Cohort_of_Norwegian_Patients>.

[86] Lux and others (n 24).

[87] Tiffany Jones and others, *Intersex: Stories and Statistics from Australia* (Open Book Publishers 2016) <https://researchers.mq.edu.au/en/publications/intersex-stories-and-statistics-from-australia> accessed 3 October 2019.

[88] Rosenwohl-Mack and others (n 11).

[89] Henningham and Jones (n 84).

made valuable contributions; the EU Agency for Fundamental Rights study and the UK Government Equalities Office LGBT Survey.[90] These latter studies were not specifically focused on the intersex community, rather they focused on the LGBT/LGBTI minority. Nonetheless, they provide valuable national and supra-national level data pertaining to a hidden population, with the UK LGBTI survey accounting for 1,980 intersex participants – an incredibly valuable data set.[91] Survey research is beneficial because it can capture larger numbers of participants but it remains a less common method in recent works in the field of intersex studies with only three studies from a total of 61 employing this method.[92] Despite our best intentions as researchers, we must tread carefully when employing such methods/instruments and analysing the data they generate given the complexities associated with survey research among this population,[93] not least due to the rarity of some intersex conditions and the consequent low sample populations that can inhibit robust statistical analysis.[94] This is in addition to other methodological issues pertaining to rare conditions such as generalisability of findings, clinical bias, and lack of standardised instruments.[95] Moreover, cultural variance limits the effectiveness of some tools designed to assess long-term psychosocial outcomes among those with DSDs further demonstrating why there is no such thing as a "one size fits all" approach and research findings and outputs will not have global applicability or scalability.[96]

Much of what we do not from the literature is that academics, activists, advocates and intersex people themselves, have long documented the ways

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[90] European Union Agency for Fundamental Rights (EU FRA), *A Long Way to Go for LGBTI Equality.* (Publications Office 2020) <https://data.europa.eu/doi/10.2811/582502> accessed 11 January 2021. UK Government Equalities Office (n 12).

[91] UK Government Equalities Office (n 12).

[92] Jones, 'Intersex Studies' (n 2).

[93] M Carpenter, 'Intersex Human Rights, Sexual Orientation, Gender Identity and the Yogyakarta Principles' (2021) 31 European Journal of Public Health ckab164.164 <https://doi.org/10.1093/eurpub/ckab164.164> accessed 14 March 2022; Morgan Carpenter, 'Researching Intersex Populations – Intersex Human Rights Australia' (*Researching Intersex Populations*, 25 May 2012) <https://ihra.org.au/research/> accessed 14 January 2022.

[94] Wæhre and others (n 85). Lux and others (n 24).

[95] Eva Kleinemeier and others, 'Psychological Adjustment and Sexual Development of Adolescents With Disorders of Sex Development' (2010) 47 Journal of Adolescent Health 463 <https://linkinghub.elsevier.com/retrieve/pii/S1054139X10001473> accessed 24 January 2022; Lux and others (n 24).

[96] S Julka and others, 'Quality of Life and Gender Role Behavior in Disorders of Sexual Differentiation in India' (2006) 19 Journal of Pediatric Endocrinology and Metabolism 879 <https://www.degruyter.com/document/doi/10.1515/JPEM.2006.19.7.879/html> accessed 25 January 2022.

in which intersex people have experienced various, and mass, forms of discrimination (Intersexphobia) and violence across multiple social and seemingly ethical platforms such as medicine and the law,[97] – for example having their bodies subjected to medical/surgical intervention as non-consenting children, experiencing discrimination in employment, health and sport, limited access to appropriate healthcare given their bodies and lives are so often interpreted through lenses of pathology and abnormality, lack of information, not to mention difficulty engaging with 'officialdom' for proper recognition [e.g. on official documents (birth certificates, passport)].[98] When the intersex community's basic human rights are "threatened by society's key institutions" in this way, it becomes impossible for one to develop a sense of "empowered selfhood".[99]

Furthermore, "minority stress" is evident from the research that has been conducted with the global intersex population and it has the potential to have enormous effects on a person's health and well-being.[100] Minority stress refers to negative feelings a minority group may experience in a society that is built for the majority such as persistent discrimination and

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[97] Tanya Ní Mhuirthile, 'Intersex Individuals, Gender and the Limits of Law' (University College Cork 2010); Tanya Ní Mhuirthile, 'Realising Gender Recognition: Rendering the Vulnerable Visible or Further Vulnerabilisng the Invisible?' Research Paper No. 41/2010 UCD Working Papers in Law, Criminology & Socio-Legal Studies; Tanya Ní Mhuirthile, 'Building Bodies: A Legal History of Intersex in Ireland' in Jennifer Redmond and others (eds), *Sexual Politics in Modern Ireland.* (Irish Academic Press 2015) <https://doras.dcu.ie/23128/> accessed 27 March 2022; Tanya Ní Mhuirthile, 'Recent Reforms in LGBTI Rights in Ireland: Tightening the Tourniquet in the Rights of Vulnerable Intersex People' in James Gallen and Tanya Ní Mhuirthile (eds), *Law, Responsibility and Vulnerability: State Accountability and Responsiveness* (Routledge 2021). Tanya Ni Mhuirthile, 'Gender Identity, Intersex and Law in Ireland' in Lynsey Black and Peter Dunne (eds), *Law and Gender in Modern Ireland : Critique and Reform.* (Bloomsbury Publishing Plc 2019) <https://doras.dcu.ie/26711/> accessed 27 March 2022; Tanya Ni Mhuirthile, 'The Legal Status of Intersex Persons: Malta' in Jens M Scherpe, Anatol Dutta and Tobias Helms (eds), *The Legal Status of Intersex Persons.* (Intersentia 2019) <https://doi.org/10.1017/9781780687704> accessed 27 March 2022. Zieselman, *XOXY: A Memoir* (Jessica Kingsley Publishers 2020); Georgiann Davis, *Contesting Intersex: The Dubious Diagnosis* (NYU Press 2015); Sharon E Preves, *Intersex and Identity: The Contested Self* (Rutgers University Press 2003); Surya Monro and others, 'Intersex: Cultural and Social Perspectives' (2021) 23 Culture, Health & Sexuality 431 <https://digitalscholarship.unlv.edu/sociology_pubs/244>; Monro, Crocetti and Yeadon-Lee (n 18); Sean Saifa Wall, 'Intersex Activism' (*Sean Saifa Wall*, 2021) <https://www.seansaifa.com/activism> accessed 24 January 2022; Morgan Carpenter, 'Morgan Carpenter's Webpage' (21 August 2015) <https://morgancarpenter.com/> accessed 24 January 2022.

[98] Alexander Berezkin, 'Silent Violence' (*Silent Violence*, 18 May 2018) <https://ilga.org/interphobia-turnitoff-campaign-silent-violence> accessed 14 January 2022; Ní Mhuirthile, 'Intersex Individuals, Gender and the Limits of Law' (n 97).

[99] Tiffany Jones, 'The Needs of Students with Intersex Variations' (2016) 16 Sex Education 602. At p604.

[100] Jennifer J Muehlenkamp and others, 'Nonsuicidal Self-Injury in Sexual Minority College Students: A Test of Theoretical Integration' (2015) 9 Child and Adolescent Psychiatry and Mental Health 16 <https://doi.org/10.1186/s13034-015-0050-y> accessed 13 January 2022.

hostility which is linked to an increased prevalence of mental ill-health among minorities.[101] Recent EU research found that 14% of intersex youth (15-17 years) experienced violence and physical or sexual attacks in the twelve months prior to the LGBTI Survey in 2019. Following the attack, 59% of intersex victims were “afraid to go out and visit places” and another 56% noted they had psychological problems (e.g. depression or anxiety).[102] Moreover the EU LGBTI survey (2020) reveals that 22% of intersex respondents experienced physical or sexual attacks in the five years prior to the survey – this is twice the average rate for all LGBTI respondents in the survey (11%).[103] This survey data lends itself to intersex people’s personal stories and experiences.

As a minority within the minority, intersex people live daily with the “silent violence of intersexphobia”[104] and along with trans people “face an even more uphill struggle”.[105] Berezkin, an intersex activist, explains how this reality manifests and becomes internalised due to the fact that intersex people have

> lived experience of the socio-cultural consequences of being born with a body that does not fit with normative social constructions of male and female. … Fear ignorance, lack of information, unwillingness to hear intersex voices; all this leads to intolerable pain, suffering, hatred. Intersex people live in a situation of estrangement and non-acceptance. We continuously face fear and hate, we start hiding our bodies, our uniqueness. We begin to be ashamed of ourselves. We start denying ourselves we cannot be like all people, with their unique characteristics. We are afraid to believe that we are human beings too.[106]

Internalised intersexphobia is not unlike internalised homophobia with the latter having damaging consequences for one’s self-concept since it is characterised by “anxiety, shame and devaluation of LGB people and one’s

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[101] Ilan H Meyer, ‘Prejudice, Social Stress, and Mental Health in Lesbian, Gay, and Bisexual Populations: Conceptual Issues and Research Evidence’ (2003) 129 Psychological bulletin 674 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2072932/> accessed 23 March 2022.

[102] European Union Agency for Fundamental Rights (EU FRA) (n 90).

[103] ibid. At p18.

[104] Berezkin (n 98).

[105] European Union Agency for Fundamental Rights (EU FRA) (n 90). At p3.

[106] Berezkin (n 98).

self".[107] Interestingly, Frost and Meyer argue that internalised homophobia should *not* be considered a personal/individual trait, rather they conceptualise it as a social stressor since it is related to the social stigma LGB people experience.[108] The data from the Australia intersex study attest to Frost and Meyer's findings. Jones collected eighty open-ended responses about participants' experiences of self-harm and suicide.[109] Thirty-one comments linked negative well-being to other people's responses to the intersex person's variation. The intersex survey participants described

> feelings of disconnection from people with the same or similar variations, isolation due to stigma or discrimination, family rejection and school bullying from peers and teachers for example.[110]

Elsewhere, increased psychopathology was also noted in a longitudinal, quality of life study among Norwegian intersex people compared to the control group

> ...more psychiatric problems in the DSD group than in the control group. Also, the DSD group...scored significantly higher than the control group...on the anxious/depressed subscale... . Furthermore, the DSD group as a whole, including small children to adolescents, had significantly lower overall psychosocial function...than the control group.[111]

Research points to a varied and complex diversity of variation and experience among the global intersex population. In the following analysis chapters we map how our participants' diversities and experiences can be mapped onto global ones.

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[107] David M Frost and Ilan H Meyer, 'Internalized Homophobia and Relationship Quality among Lesbians, Gay Men, and Bisexuals' (2009) 56 Journal of counseling psychology 97 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2678796/> accessed 14 January 2022. At p2.

[108] ibid. At p14.

[109] Jones, 'The Needs of Students with Intersex Variations' (n 99). At p609.

[110] ibid.

[111] Wæhre and others (n 85). At p10.

3

Intersex in Law

Chapter 3: Intersex in Law

The first mention of intersex within a legal context can be seen in the writings of Henry de Bracton in the 1100s.[112] In his writings he discussed that mankind could be classified as male, female or hermaphrodite, the word then used to describe people with intersex variations. In discussing how law recognised people with intersex variations, de Bracton notes that it was the predominance of the sexual organs which determine whether such a person would be considered male or female by the law.[113] In other words, genitals were determinative. A half a century later, law still recognised that sex exists on a spectrum. Writing in the early 1600s about inheritance laws, the then Chief Justice of England, Lord Coke discussed the legal position of hermaphrodites. This was important, as men could inherit land and other assets, but women could not own property. Thus, when determining how a person with an intersex variation, would inherit it is important that law knows whether to treat them as male or female. Law was not concerned with detailing how this would be determined. Coke uses the loose phrase 'according to that kind of the sexe which doth prevaile'[114]. In essence Coke was saying that only men could inherit land at that time. Therefore, it was important for law to know whether a potential heir is a man. Where a person has an intersex variation, they simply tell law whether they wish to be considered and man or a woman and the law will proceed accordingly.

Things changed with the introduction of the *Registration of Births and Deaths (Ireland) Act, 1863*. This legislation required for the first time that the State be officially notified about the birth of every child within the jurisdiction. This notification had to take place within 21 days of birth. It was Schedule A to the 1863 Act which contained the list of 'required particulars', the information which must be inputted on the register. This information includes a declaration as to the sex of the child. Interestingly, neither the Act nor the Schedule provides instruction as to how the sex of a child should be determined other than that it must be recorded as either male or female. In the absence of such instruction, the practice developed of using biological criteria, or to be more precise, genital appearance to

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[112] Henry de Bracton, *On the Laws and Customs of England* (Harvard University Press 1968).
[113] ibid.
[114] Sir E. Coke, *The First Part of the Institutes of the Law in England* (Robert H, Smith 1853).

determine the sex of a child.[115] Thus the legislative innovation mirrors the old common law practice identified by de Bracton where the genitalia determine the gender by which a person will be legally recognised. It is from the moment of the introduction of the 1863 Act that official silence on the existence of intersex can be explicitly traced.

Legal Gender Recognition

Prior to the introduction of laws requiring that all people born within the state be officially declared as either male or female it is clear that law understood that there were people in the world with intersex variations, and had a mechanism for ensuring that they would participate fully within society. This changes with the introduction of the 1863 Act. By requiring that a legal sex for all be declared so shortly after birth, this particular law seemed to lose the previous flexibility that had been inherent in the old common law understanding on this issue.[116] In addition to lacking an express legal test to determine a person's gender, the 1863 Act also failed to clarify whether the legal sex declared was determinative for all time, or until such as time a different legal sex might be declared. Both of these questions were considered by the English High Court in *Corbett v Corbett* in 1970.[117]

The *Corbett* case concerned nullity of a marriage. Mr Corbett alleged that the marriage could not be legal as Mrs Corbett was a trans woman who had been registered as male at birth. Therefore, the Court was required to make a legal determination of the sex of Mrs Corbett in order to decide whether she was a woman for the purposes of marriage. Mr Justice Ormrod developed a biological and temporal test. Legal gender is to be determined by the congruence of the chromosomes, gonads and genitals at the moment of birth. He clarified that once this congruity exists at the moment of birth then legal sex and gender is set for life. The evidence strongly suggested that Mrs Corbett had been born with a congruence along the lines traditionally expected of males, and thus being a legal man, could not enter a valid marriage. Ormrod did consider briefly what should happen if a

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[115] Tanya Ní Mhuirthile, 'Foy v An TArd Chlaraitheoir & Ors [2002] IEHC 116.', *Judges' Troubles: Northern/Irish Courts and the Gendered Politics of Identity* (Hart Publishing).

[116] Common law is a term used to describe the law that exists prior to legislation on particular issues. It is most easily ascertained by reading the judgments handed down in cases.

[117] *Corbett v Corbett (Otherwise Ashley)* [1970] 2 All ER 33 (EWHC).

person was born without the congruence required, in other words, what is a person with an intersex variation is born. In these cases, Ormrod stated that the genitals should be decisive. The decision in this case punches far above its weight. Although when handing down the decision, Ormrod worked hard to limit the ambit of the case just to cases involving marriage, in *R v Tan* the test set out in *Corbett* was adopted as the de facto test for legal gender in all circumstances.[118]

A different approach to this legal test was taken a few years later by the Superior Court of New Jersey in the 1976 case of *MT v JT*.[119] This case also concerned the nullity of a marriage. Justice Handler, the judge in *MT,* looked to the decision in *Corbett* and held that it had been incorrectly reached.[120] Ultimately, Handler decided that sex was only one fact to be considered when deciding if a marriage contract had been correctly concluded. For marriage contracts, it is necessary that both parties can consummate the contract. Handler said:

> 'Sexual capacity or sexuality in this frame of reference requires the coalescence of both the physical ability and the psychological and emotional orientation to engage in sexual intercourse as either a male or a female.'[121]

Once a trans person has 'harmonized' their physical and psychological sex and can engage in intercourse, then the marriage is valid.[122] In essence, sex here is just one of a number of facts to be considered by the court. Thus a decision about a person's legal gender is made in the context within which it is required. In other words, at the moment of marriage was this person able to function as a husband or wife for the purposes of consummation? Considered from the perspective of a person with an intersex variation, this test kind of approach seems to be more open to maintaining the older flexibility towards sex that was apparent in de Bracton and Coke.[123]

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[118] *R v Tan* [1983] QB 105.

[119] *MT v JT* [1976] 140 NJ Super 77.

[120] ibid. At p86.

[121] ibid. At p87.

[122] ibid.

[123] For a critique of both of these approaches see Alex Sharpe, *Transgender Jurisprudence Dysphoric Bodies of Law* (Routledge-Cavendish 2002).

A third way of thinking about framing a test for legal gender is to use human rights, and the concept of our inherent dignity as human beings which underpins all human rights laws. This is the approach that was taken by the European Court of Human Rights (ECtHR) in the case *Goodwin v UK* in 2002.[124] Here the 26 judge panel of the Grand Chamber concluded unanimously that the continued failure of the UK Government to recognise trans people in their preferred legal gender was a violation of Ms Goodwin's right to respect for her private and family life under Article 8 of the European Convention on Human Rights. Contained within this right, is the right to be legally recognised in your preferred gender.

The first time an Irish court had to consider what the legal test for gender would be in Ireland was in *Foy v An tArd Chlaraitheoir* in 2002.[125] The Court adopted the *Corbett* test. There is nothing in the judgment to suggest that the Court was made aware of the possibility of a different approach such as that in *MT* and thus there is not detailed judicial reasoning underpinning the decision to prefer the *Corbett* approach. It is important to note that this judgment was handed down two days before that in *Goodwin* and therefore the possibility of a human rights based approach was not available to the Court when making its decision. In light of the *Goodwin* decision and some other factors, Dr Foy came before the court again in *Foy v An tArd Chlaraitheoir (No 2)* in 2007.[126] Here the Court found that the absence in Irish law of a mechanism to alter the gender of legal recognition was a violation of Dr Foy's rights under Article 8 of the ECHR. The Court called upon the Government to review this matter urgently and officially declared Irish law on this matter incompatible with Ireland's obligations under the regional human rights law of the Council of Europe.

Eventually, in 2015, the *Gender Recognition Act, 2015* was introduced. This established a self-declaration model of gender recognition. Under the Act, a person could swear a statutory declaration stating their preferred gender and intention to live henceforth in that gender permanently and this will be legally recognised. What is revolutionary about the act is that it does not require adults to produce any certificate or supporting material from medical practitioners in order to justify this change. Therefore, it is not

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[124] *Goodwin v UK* [2002] EHRR 588 (ECHR).

[125] *Foy v An t-Ard Chlaraitheoir & Ors [2002] IEHC 116*.

[126] *Foy -v- An t-Ard Chláraitheoir & Ors (No 2) [2007] IEHC 470*.

confined to trans people but can also be used by people with intersex variations who may wish to change their gender of legal recognition.

The Importance of Legal Recognition

Why is it important to be recognisable by law? Law offers many opportunities and protections but only to those who come within its range of influence. To come *sui juris,* which means to be able to access all legal rights and protections, law must be able to recognise you. This means that a person must be an adult, of sound mind, in order to benefit from law. If one is not recognisable, one is *alieni juris,* literally an outlaw. The consequences of this are evident in one of the very few cases to come before a court involving an applicant with an intersex variation.

In *Re the Marriage of C v D (falsely called C)* was a case that came before the Brisbane Family Court in 1979.[127] These were nullity proceedings where it was claimed that because the putative husband had an intersex variation that he was not sufficiently male to be considered a man.[128] Under the old case of *Hyde v Hyde* (1866) civil marriage was defined as the union of one man and one woman.[129] As we discussed above, although the law required that a person's sex be legally declared shortly after birth with the introduction of the *Registration of Births and Deaths (Ireland) Act, 1863*, until Corbett in 1970, there had been no legal test to help determine a person's legal gender. In the *C v D* case, the Court looked to the recent *Corbett* decision, and applying the test found that Mr C, the putative husband:

> was neither man nor woman but was a combination of both, and a marriage in the true sense of the word ... could not have taken place and does not exist.'[130]

In acknowledging that Mr C had an intersex variation, the Court here states that he is neither man nor woman. Consequently, he is unrecognisable to

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[127] *Re the Marriage of C v D (Falsely C)* [1979] 35 FLR 340.

[128] A putative marriage is an apparently valid marriage, entered into in good faith on the part of at least one of the partners, but that is legally invalid due to a technical impediment, such as a preexistent marriage on the part of one of the partners.

[129] *Hyde v Hyde* [1866] LR 1 P & D 130.

[130] *Re the Marriage of C v D (Falsely C)* (n 127).

the law. The innate human right to marry, which Mr C might have expected to enjoy simply because he is a human person is denied to him as the law cannot 'see' him and thus cannot extend its protections and rights to him. This is the essence of the issue. Where law cannot recognise a person, it can neither shield them from harm, nor defend them from unjust attack. Remember, everything is governed by laws. The simple act of purchasing a chocolate bar in a shop is contract law in action. Law governs everything from the small mundane thing to large things like mortgages, employment contracts, marriages, parental rights and wills. To be unrecognisable to law is to be excluded from full participation in society. The rights and protections that a person might otherwise expect are denied to them.

Modern Legal Response to Intersex Variations

Despite the previous discussion about the importance of gender recognition, this is not the key concern evident in the literature on intersex issues, particularly that coming from intersex advocacy organisations. Their main concerns centre around problems with medical management of intersex variations.[131] A particular focus of criticism is conducting medical and/or surgical interventions on the bodies of those with intersex variations before the age of consent to medical treatment, particularly where these are exclusively cosmetic.[132] In light of this, we now turn to a consideration of how law might respond to such criticisms.

The majority of disputes involving medical practitioners proceed on the basis of the tort of negligence.[133] The case which first established the concept of the 'duty of care' which underpins negligence law is *Donoghue v Stephenson* in 1932.[134] That this concept extends to cover the doctor patient relationship is well established. The test for negligence is set out in

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[131] Dan Christian Ghattas, 'Protecting Intersex People in Europe: A Toolkit for Law and Policy Makers' <https://oiieurope.org/wp-content/uploads/2019/05/Protecting_intersex_in_Europe_toolkit.pdf>; Bauer, Truffer and Crocetti (n 20).

[132] Carpenter, 'The Human Rights of Intersex People' (n 1); Davis (n 97).

[133] Eloise Powers, 'Why Doctors Get Sued' in Swati Jha and Emma Ferriman (eds), *Medicolegal Issues in Obstetrics and Gynaecology* (Springer International Publishing 2018) <https://doi.org/10.1007/978-3-319-78683-4_2> accessed 26 July 2021.

[134] *Donoghue v Stevenson* [1932] AC 562 (House of Lords).

the *Bolam* case in England and Wales,[135] and the *Dunne* case in Ireland.[136] According to this test, a practitioner is negligent in diagnosis and/or treatment where it is established that no other medical practitioner of equal specialist or general status or skill will be guilty of such failure if acting with ordinary care. In other words, courts, not being experts in the practice of medicine, defer to the professional standards when determining whether a particular course of action was negligent. In the context of complaints by a person with an intersex variation about their treatment, where another doctor will testify that they would have treated in a similar manner, the medical practitioner will not be found negligent. This makes it virtually impossible for a person with an intersex variation to successfully sue using the law of negligence.

An alternative legal argument that one could try is to sue on the basis of trespass to the person. A medical professional who intentionally or recklessly touches a patient without their consent commits both the crime of battery and the tort of trespass to the person.[137] As stated by Cordozo J in *Schloendorff v Society of New York Hospital:*

> 'Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages.'[138]

Thus to legally touch a patient a medical professional must possess what the Court of Appeal in England and Wales has termed a 'flak jacket'.[139] Consent is pivotal to defending against suit. The consent 'flak jacket' can take three forms: the consent of the patient, consent of an authorised proxy such as for example a parent consenting to the treatment of a child, and the defence of necessity.[140] Rarely are interventions on the sex characteristics of a person with an intersex variation necessary to preserve life,[141] thus, the defence of

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[135] *Bolam v Friern Hospital Management Committee* [1957] WLR 582.

[136] *Dunne v National Maternity Hospital* [1989] IR 91.

[137] *Sidaway v Bethlem Royal Hospital Governors* (1985) 1 All ER 643.

[138] *Schloendorff v Society of New York Hospital* (1914) 211 NY 125.

[139] *Re W* (1993) 4 All ER 627 (Court of Appeal).

[140] Mason, J.K and Laurie, G.T., *Mason and McCall Smith's Law and Medical Ethics* (7th edn, Oxford University Press 2006).

[141] L Rangecroft, 'Surgical Management of Ambiguous Genitalia' (2003) 88 Archives of Disease in Childhood 799 <https://adc.bmj.com/content/88/9/799> accessed 22 March 2022.

necessity is not available to practitioners. Children are inherently incompetent to consent and thus the legitimacy of the interventions rests on the validity of the parental proxy consent. Once the capable adult, even one giving proxy consent to a cosmetic procedure, is fully informed, and aware of all potential benefits and risks and consents in the absence of coercion, then the practitioner possesses the 'flak jacket' and is protected from suit under the *Bolam* and *Dunne* tests. If a person with an intersex variation wished to sue the practitioner who performed the interventions, how can they when their parents gave a valid consent? Hence such a suit is highly unlikely to be successful.

Considering this reality, how might a person with an intersex variation bring a case to court? As we have seen, a case based on negligence is unlikely to be successful due to the deference the courts give to standard medical practices. Similarly, where a valid proxy consent has been given, it would be entirely unexpected for an action in trespass to be successful before the courts.

Human Rights Law

Given the inadequacies of the above-mentioned torts of negligence and tresspass to the person to protect people with intersex variations, intersex activists and advocates have turned to human rights for protection and to effect change. Everyone has human rights by virtue of our inalienable human dignity. The core concept of international human rights law is that everybody is valuable and worthy of respect. Indeed it is the very first statement in the Universal Declaration of Human Rights (UDHR).

> Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,[142]

In the first two substantive Articles of the UDHR it affirms that we are all free and equal,[143] and that we are entitled to freedom from discrimination based on any particular characteristic without distinction of any kind, such

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[142] Universal Declaration of Human Rights 1948.

[143] ibid. Article 1.

as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.[144] In so doing, the Declaration grounds the promise of the preamble in actionable human rights norms. In a similar fashion, Article 1 of the *Charter of Fundamental Rights of the European Union (CFREU), 2000* states that human dignity is an inviolable right.

Human rights law articulates how that respect and anti-discriminatory promise is to be actioned in daily life. In so doing, it recognises that these universal rights play out in vastly different cultural contexts across the globe. Flexibility to respond to cultural specificity and national contexts can be ascertained through reservations and derogations. When a state enters a reservation to a part of an international treaty, such as the International Covenant for Civil and Political rights (ICCPR), it purports to exclude or to modify the legal effect of certain provisions of the treaty as they apply to that state.[145] Derogations enable states to depart for a time from strict adherence to their obligations under a treaty.[146] They are distinct from reservations as they are intended to be short-term strictly in times of public emergency. Article 4 of the *International Covenant on Civil and Political Rights, 1966* includes a list of rights which are non-derogable, meaning they can never be suspended even in times of acute crisis.[147] Technically, it is not possible for a State to enter a reservation to a non-derogable human right. Nonetheless such reservations have been made by states.

Ireland has ratified seven of the nine core international human rights treaties. This means that Ireland is bound by the obligations contained within these treaties. Both of the general rights treaties the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) have been ratified by the Irish State.[148] Ireland has also ratified subject specific treaties

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[144] ibid. Article 2.

[145] Vienna Convention on the Law of Treaties 1969. Article 2.1(d).

[146] International Covenant on Civil and Political Rights 1966. Article 4.

[147] ibid. Article 4.2.

[148] ibid; International Covenant on Economic, Social and Cultural Rights 1966.

on race,[149] women,[150] torture,[151] children,[152] and disability.[153] At a regional level, Ireland ratified the European Convention on Human Rights (ECHR) in 1953, the Revised European Social Charter (ESC) in 1996, and the Charter of Fundamental Rights of the European Union (CFREU) in 2000. Finally, there is an extensive scheme of human rights protection contained within the Constitution of Ireland and other domestic legal provisions. So we now turn to consider the system of human rights protections which may be engaged where medical and/or surgical interventions are undertaken on the body of a person with an intersex variation without their personal informed consent.

Freedom from Torture, Cruel, Inhuman and Degrading Treatment and Punishment

Table 3.1 Freedom from Torture, Cruel, Inhuman and Degrading Treatment and Punishment

International Human Rights Law	**Regional European Human Rights Law**	**Domestic Irish Law**
Article 5 UDHR; Article 5.6 ICERD; Article 7 ICCPR; CAT; Article 37 CRC	Article 3 ECHR; Article 4 CFREU	Article 40.3 of the Constitution – unenumerated right.[154] *Criminal Justice (United Nations Convention Against Torture) Act, 2000*; *European Convention on Human Rights Act, 2003*.

Since the 1990s intersex activists have sought to draw analogies between non-consensual medical and surgical management of intersex variations and female genital mutilation (FGM) in light of the equivalent potential

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[149] International Convention on the Elimination of All Forms of Racial Discrimination 1965.

[150] Convention on the Elimination of All Forms of Discrimination against Women 1979.

[151] Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment 1984.

[152] Convention on the Rights of the Child 1989.

[153] Convention on the Rights of Persons with Disabilities 2006.

[154] *Ryan v AG* [1965] IR 345.

physical and psychological harm which can be experienced by those cut.[155] The International Convention Against Torture, Cruel, Inhuman and Degrading Treatment (CAT), 1984 defines torture as:

> any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as obtaining from him or a third person information or a confession, punishing him for an act he or a third person has committed or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.[156]

There are some key elements in this definition which apply to neither nor interventions on intersex characteristics. First, such interventions are not carried out with the intention to inflict pain and suffering or to coerce information nor to punish. Neither are they carried out by an agent of the state acting in an official capacity. Nonetheless the UN Special Rapporteur on Violence against Women has clearly stated that FGM is 'torture-like' in its manifestation, and thus contrary to customary international law.[157] Additionally, in his 2008 Report, the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, stated that he considered FGC a violation falling within his mandate,[158] and further remarked that it 'can amount to torture if States fail to act with due diligence.'[159] More recently, UN Special Rapporteur on Torture, Mendez stated that

> medical treatments of an intrusive and irreversible nature, when lacking a therapeutic purpose, may constitute torture or ill-treatment

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[155] Cheryl Chase, 'Intersex Society of North America's Amicus Brief on Intersex Genital Surgery to the Constitutional Court of Colombia' (7 February 1998) <https://isna.org/node/97/>.

[156] Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. Article 1.

[157] Radhika Coomaraswamy, 'Cultural Practices in the Family That Are Violent towards Women: Report of the Special Rapporteur on Violence Against Women, Its Causes and Consequences UN Doc E/CN.4/2002/83' (2002).

[158] Manfred Novak, 'Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment UN Doc. A/HRC/7/3' (2008).

[159] ibid.

> when enforced or administered without the free and informed consent of the person concerned.[160]

Consequently, where people with intersex variations do not personally give a full, free and informed consent to undergo cosmetic medical and/or surgical interventions this right may be engaged.

It is important to note the sliding scale of behaviours encapsulated in this right, from torture at the most extreme end to degrading treatment at the other end. In *Ireland v UK* (1978) the European Court of Human Rights (ECtHR) found that the difference between 'torture' and 'inhuman or degrading treatment' was said to derive 'principally from a difference in the intensity of the suffering inflicted'.[161] According to the ECtHR in *Yankov v Bulgaria* (2003) there is a two part test to determine whether a treatment is degrading.[162] First, was the object of the treatment to humiliate and debase the person? Second, did adversely affect his personality in a manner incompatible with the rights in Article 3 ECHR? For treatment to be considered within the meaning of the article it must meet a minimum level of severity which is a relative concept established by the circumstances of the case, such as the duration of the treatment, its physical and mental effects and, in some cases, the sex, age and state of health of the victim.[163] The key question is whether the medical management of intersex variations meets the test to be considered degrading treatment contrary to human rights norms. The reports of some adults with intersex variations who have experienced it suggest that it does.[164]

Therefore, recently the Office of the UN High Commissioner for Human Rights (OHCHR) reminded states of their obligations to eliminate forced, coercive, and unnecessary medical interventions to modify variations of sex characteristics, and violence against intersex persons includes investigating,

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[160] Juan Mendez, 'Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment A/HRC/22/53' (2013).

[161] *Ireland v UK* (1978) 2 EHRR 25.

[162] *Yankov v Bulgaria App No 39084/97* (ECHR).

[163] ibid. At para 106.

[164] Morgan Carpenter, 'What Do Intersex People Need from Doctors' (2018) 20 *O&G Magazine* 32 <https://www.ogmagazine.org.au/20/4-20/what-do-intersex-people-need-from-doctors/ viewed 29 November 2018.>.

prosecuting alleged perpetrators, providing victims with remedy, addressing patterns of violence, and tackling root causes.[165]

Right to Bodily Integrity

Table 3.2 Right to Bodily Integrity

International Human Rights Law	**Regional European Human Rights Law**	**Domestic Irish Law**
Article 3 UDHR; Article 5 ICERD; Article 7 ICCPR;[166] Article CRC, Article 17 CRPD	Article 8 ECHR;[167] Article 3 CFREU	Article 40.3 of the Constitution – unenumerated right.[168] *European Convention on Human Rights Act, 2003*

The international protection for the right to bodily integrity is reflected in both regional and national human rights laws. In General Comment No 20, the Human Rights Committee confirmed that the right was included under the prohibition in Article 7 of the ICCPR on Torture.[169] It also exists as part of the right to a private life under Article 8 of the ECHR. In *X v Austria* (1979) which concerned a compulsory blood test, the ECtHR held that a compulsory medical intervention, even if it is of minor importance, must be considered an interference with the right.[170] In *X & Y v The Netherlands* (1985) the Court stated that respect for private life is 'a concept which covers the physical and moral integrity of the person, including his or her sexual life.'[171]

There is a paucity of long-term studies establishing the effectiveness of the medical management of intersex variations. Consequently, medical

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[165] Office of the United Nations High Commissioner, 'Office of the United Nations High Commissioner, 'Background Note Human Rights Violations against Intersex People' (2019) <https://www.ohchr.org/sites/default/files/Documents/Issues/Discrimination/LGBT/BackgroundNoteHumanRightsViolationsagainstIntersexPeople.pdf>.

[166] Human Rights Committee, 'General Comment No 20 Concerning the Prohibition on Torture and Cruel Treatment or Punishment (Article 7)' (1992) 20.

[167] *Denisov v Ukraine (App no 76639/11)* (ECHR).

[168] *Ryan v AG* (n 154).

[169] Human Rights Committee (n 166).

[170] *X v Austria Application (No 8278/78)* (ECHR).

[171] *X & Y v The Netherlands (Application no 8978/80)* (ECHR).

practitioners report that there is an absence of agreement between professionals about surgical timing, indications, necessity, procedure or outcome evaluation, and the quality of supporting clinical evidence is low.[172] Many of the adults with intersex variations who have voiced their displeasure at the results of the procedures undergone by them in childhood have been dismissed by some in the medical community as a vocal, but tiny, minority of malcontents.[173]

There is evidence from adults who have undergone genital surgery in infancy that their sexual lives are impaired as a result. At the more minor end of the scale one survey of men who have undergone surgery to correct hypospadias noted that the hypospadiac men were more sexually timid than the men in the control group, and that there was a direct correlation between the number of corrective surgeries undergone and the degree of sexual inhibition experienced by the men.[174] More seriously, some adults report that early surgery has left their genitals insensitive and thus they are unable to achieve orgasm, or they report that they experience pain during arousal.[175] Some women who have undergone vaginoplasty report they are unable to engage in sexual intercourse as the tissues of their vaginas are either so scarred as to prevent penetration, or they shrink back to their pre-operative size.[176] Hester quotes one woman's experience:

> 'After my last surgery I now have pain when aroused or while having sex. I have what can only be described as many red-hot needles sticking me where my clitoris was and where my stitches were. I also get this feeling anytime day or night, sitting, standing, walking, or just anytime it decides to come. The pain comes and goes and lasts anywhere between 10 – 30 seconds at any given time. This pain can be enough for me to want to double over but not be able to because I might be in a public place or at work. I have learned through the years to just act like nothing is happening and keep on going. That is to say,

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[172] Peter A Lee and others, 'Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care' (2016) 85 Hormone Research in Paediatrics 158 <https://www.karger.com/Article/FullText/442975> accessed 25 March 2022.

[173] Preves (n 97). At p59.

[174] Anne Fausto-Sterling, *Sexing the Body: Gender Politics and the Construction of Sexuality* (Basic Books 2000). At p87.

[175] Suzanne J Kessler, *Lessons from the Intersexed* (Rutgers University Press 1998). At p55.

[176] ibid. At 61-63.

> I still feel all the pain, but [have learned] not to draw attention to myself. I act like I am fine.'[177]

To cause these long term impacts without the consent of the person undergoing the interventions is to infringe the right to bodily integrity. The similarities between the lived experience of those who have had interventions performed on them and those who have undergone FGC, in terms of the impact each procedure has on both the short and long term physical health of the person is clear. If the latter is an extreme practice endured in the name of culture,[178] then there is some merit in the argument of intersex activists that the former is likewise socially mandated. Many international human rights institutions including the Office of the United Nations High Commissioner for Human Rights, and UN and regional human rights mechanisms, have advised that States should, as a matter of urgency, protect the autonomy of intersex adults and children and their right to physical and mental integrity.[179] In the context of Ireland, in 2016, the Committee on the Rights of the Child (CRC) recommended that the State:

> (a) Ensure that no one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to children concerned, and provide families with intersex children with adequate counselling and support;
> (b) Undertake investigation of incidents of surgical and other medical treatment of intersex children without informed consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation;
> (c) Educate and train medical and psychological professionals on the range of sexual, and related biological and physical, diversity and on the consequences of unnecessary surgical and other medical interventions for intersex children.[180]

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[177] David J Hester, 'Intersex and the Rhetorics of Healing' in Sharon E Sytsma (ed), *Ethics and Intersex* (Springer Netherlands 2006) <https://doi.org/10.1007/1-4220-4314-7_3> accessed 25 March 2022. At p58.

[178] Efua Dorkenoo, *Cutting the Rose: Female Genital Mutilation - The Practice and Its Prevention* (New edition, Minority Rights Group 1995).

[179] Office of the United Nations High Commissioner (n 165). At p37.

[180] UN Committee on the Rights of the Child, 'Concluding Observations on the Combined Third and Fourth Periodic Reports of Ireland CRC/C/IRL/CO/3-4' (2016). At 40.

The following year, in 2017, similar recommendations were made to Ireland by the Committee on the Elimination of All Forms of Discrimination Against Women.[181]

Right to the Highest Attainable Standard of Health

Table 3.3 Right to the Highest Attainable Standard of Health

International Human Rights Law	**Regional European Human Rights Law**	**Domestic Irish Law**
Article 25 UDHR; Article 5 ICERD; Article 12 ICESCR; Article 11.1(f) and Article 12 CEDAW; Article 24 CRC, Article 25 CRPD.	Article 35 CFREU; Article 11 ESC.	Article 45 of the Constitution

Lau et al note that the right to health is a nebulous phrase.[182] In 2000, the UN Committee on Economic, Social and Cultural Rights issued a General Comment No 14 on the right to health to elaborate exactly what the right involves: both the freedoms it guarantees to individuals and the obligations it imposes on States to ensure that the right is respected.[183] According to Hunt, General Comment No 14 is 'ground-breaking and marks the moment when the right to health ceased to be a slogan and became an important instrument for all health policymakers and practitioners.'[184] Firstly, the Comment confirms that the existence of the right to the enjoyment of the highest attainable standard of health is a fundamental human right and is conducive to living a life in dignity.[185] The Comment notes that the right is not a right to be healthy but rather it includes the right to control one's

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[181] UN Committee on the Elimination of Discrimination Against Women, 'Concluding Observations on the Sixth and Seventh Periodic Report of Ireland CEDAW/C/IRL/CO/6-7' (2017).

[182] Manfred Lau and others, 'Creating Universal Health Care in Ireland: A Legal Context | Elsevier Enhanced Reader' (2021) 125 Health Policy 777.

[183] UN Committee on Economic, Social and Cultural Rights, 'General Comment No 14: Right to the Highest Attainable Standard of Health E/C 12/2000/4' (2000) 14.

[184] Paul Hunt, 'The Human Right to the Highest Attainable Standard of Health: New Opportunities and Challenges' (2006) 100 Transactions of The Royal Society of Tropical Medicine and Hygiene 603 <https://doi.org/10.1016/j.trstmh.2006.03.001> accessed 25 March 2022.

[185] UN Committee on Economic, Social and Cultural Rights (n 183) 14. At para 1.

health and body and the right to be free from interference, such as torture or non-consensual medical treatment.[186]

A series of Special Rapporteurs on this right in their reports further clarified what is meant by this right in the context of children accessing treatment. In 2009, the Special Rapporteur stated that 'health-care providers should strive to postpone non-emergency invasive and irreversible interventions until the child is sufficiently mature to provide informed consent'.[187] He further noted that this was 'particularly problematic in the case of intersex genital surgery, which is a painful and high-risk procedure with no proven medical benefits.'[188] The next holder of the office went further by including a specific recommendation about intersex in his report.[189] He urged Governments:

> To prohibit discrimination against intersex people, including by banning unnecessary medical or surgical treatment, and adopt measures to overcome discriminatory attitudes and practices through awareness-raising, training for public officials and medical professionals and the elaboration of ethical and professional standards that respect the rights of intersex persons, in consultation with intersex people and their organizations[190]

At a regional level, the Parliamentary Assembly of the Council of Europe issued a resolution *Promoting the human rights of and eliminating discrimination against intersex people* in 2017.[191] In relation to the right to the highest attainable standard of health, they call on states to:

- provide all intersex people with health care offered by a specialised, multidisciplinary team taking a holistic and patient-centred approach and comprising not only medical professionals but also other relevant professionals such as psychologists, social workers and ethicists, and

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[186] ibid. At para 8.
[187] Anand Grover, 'Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Anand Grover A/64/272' (2009). At para 49.
[188] ibid. At footnote 76.
[189] Dainius Pūras, 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health Dainius Pūras A/HRC/29/33' (2015) 33.
[190] ibid. Recommendation m at p24-25.
[191] Parliamentary Assembly of the Council of Europe, 'Promoting the Human Rights of and Eliminating Discrimination against Intersex People. Resolution 2191' (2017).

based on guidelines developed together by intersex organisations and the professionals concerned;[192]

- ensure that intersex people have effective access to health care throughout their lives;[193]
- ensure that intersex people have full access to their medical records;[194]
- provide comprehensive and up-to-date training on these matters to all medical, psychological and other professionals concerned, including conveying a clear message that intersex bodies are the result of natural variations in sex development and do not as such need to be modified;[195]

The right to the highest attainable standard of health is not expressly protected within Irish law. In 2019, Michael Harty, TD introduced a private members' bill proposing an amendment to the Constitution to enshrine the right at the highest level with Ireland's domestic laws.[196] He argued that doing so would ensure that the Government made proper provision and planning for the long term delivery of healthcare. He stated a constitutional right to health makes certain that initiatives like *Sláintecar*e[197] are backed by a constitutional mandate, with no excuse for delay or negligence.[198] With the dissolution of the Dáil prior to the 2020 General Election, the Bill lapsed. Introducing the right on a Constitutional or legislative basis would be a huge shift in approach by Ireland. Generally speaking, socio-economic rights are governed by Article 45 of the Constitution, the Directive Principles of Social Policy. As stated specifically in that Article, these are non-justiciable. In other words, you cannot bring a case to court based on the rights contained in Article 45. In *O'Reilly v Limerick Corporation* (1989), Justice Costello explained that if the Court found in favour of the applicant's claim on the

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[192] ibid. At 7.1.3.

[193] ibid. At 7.1.4.

[194] ibid. At 7.1.5.

[195] ibid. At 7.1.6.

[196] Michael Harty, Thirty-Ninth Amendment of the Constitution (Right to Health), Bill 2019.

[197] *Sláintecare* is a reform of Ireland's health service. It is "transforming how we deliver healthcare in Ireland, building towards equal access to services for every citizen based on patient need and not their ability to pay. … The aim is to deliver the Sláintecare vision of one universal health service for all, providing the right care, in the right place, at the right time." (Department of Health, 2018/2022) Department of Health, 'Sláintecare' (8 August 2018) <https://www.gov.ie/en/campaigns/slaintecare-implementation-strategy/> accessed 27 March 2022.

[198] Michael Harty, Thirty-Ninth Amendment of the Constitution (Right to Health) Bill 2019: First Stage 2019 [Vol. 989 No. 5].

basis of a right to housing, this would amount to the courts getting involved in matters of distributive justice.[199] In other words, the courts would be telling the Government how to spend public money and this is a breach of the separation of powers doctrine which underpins the foundation of the state.[200] Lau et al argue that the introduction of imaginative legislation such as that proposed by Harty in 2019, would not risk judicial policy-making but rather would bring 'consistent accountability to the political system' so that healthcare initiatives such as Sláintecare could become a reality.[201] Systemic reimagining of healthcare in Ireland may also prompt possibilities for ensuring that Ireland is compliant with its international and regional obligations as regards healthcare.

Prohibition on Discrimination

Table 3.4 Prohibition on Discrimination

International Human Rights Law	Regional European Human Rights Law	Domestic Irish Law
Article 2 & 7 UDHR; ICERD; Article 2(1) & 26 ICCPR; Article 2 ICESCR; CEDAW; Article 2 CRC, Article 5 CRPD.	Article 14 ECHR; Article 21 CFREU; Article 20 & 27 ESC.	Article 40.1 Employment Equality Acts 1998-2015; Equal Status Acts 2000-2018

Discrimination occurs where one person is treated less favourably than another, in a similar situation, because they are different. Under Irish law there are nine protected grounds of difference. These are gender, marital status, family status, sexual orientation, religion, age, disability, ethnicity or race, and membership of the travelling community. Taking a closer look at some of these grounds, the gender ground is described in equality legislation as 'that one is male and the other is female.'[202] Where the legal definitions of male and female continue to be interpreted using the congruence test established in the *Corbett* case we discussed earlier this may create a

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[199] *O'Reilly v Limerick Corporation* [1989] ILRM 181.

[200] *O'Reilly v Limerick Corporation* [1989] ILRM 181. At 194.

[201] Lau and others (n 182).

[202] Equal Status Act 2000. Section 2(a).

problem for people with intersex variations who may lack congruity. Introducing specific protection against discrimination for people with intersex variations will ensure that there are no gaps in legal protection which might seem to justify less favourable treatment.

Much of the literature focuses on discriminations that people with intersex variations experience in healthcare contexts.[203] However, the literature reveals that intersex people experience discriminations in other parts of their lives also.

Express protection against discrimination for people with intersex variations in not typically included in equality or anti-discrimination laws. Consequently, people with intersex variations can experience discrimination across their lives such as relating to education and employment. The literature is full of stories shared by people with intersex variations and surveys which demonstrate that they may experience higher rates of poverty as a result of higher than average rates of early school leaving, stigmatisation and discrimination.[204]

Jones reported in her study on Australian experiences of intersex in schools that only 18% of people with intersex variations completed primary school.[205] She reports that the majority of those who left school early did so between the ages of 12-15, during the years most associated with puberty and hormone therapy interventions.[206] Discrimination experienced by students was direct e.g. bullying from students and staff, usually focused on atypical characteristics and developmental delays, and indirect e.g. curricula were non-inclusive and school counsellors were unaware of intersex variations, schools were not accommodating in relation to the need for periods of medical leave or making reasonable adjustments.[207]

In this light, it is not surprising that the literature reports high levels of unemployment or underemployment among people with intersex variations. Furthermore, there are multiple reports of discriminatory treatment in workplaces and in social services. An additional factor which impacts

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[203] See Chapter 4 Intersex in Medicine.

[204] Office of the United Nations High Commissioner (n 165). At p30.

[205] Jones, 'The Needs of Students with Intersex Variations' (n 99). At p610.

[206] ibid.

[207] ibid.

employment opportunities and career development is the impact of medical and surgical interventions.[208]

Perhaps the most well-known discrimination that people with intersex variations experience is in relation to participation in sport. The regulations of elite sport, women's sport in particular, has become a contested space where concerns about athletes with intersex variations have been very widely reported in the media. In his report on sport, healthy lifestyles and the right to health, Special Rapporteur Puras, noted that many women with intersex variations competing in sport have been disqualified, humiliated or subjected to medical and/or surgical interventions due to their variations.[209] Perhaps the most famous sportsperson to experience these discriminations is Caster Semenya who took her case to the Court of Arbitration in Sport.[210] Having lost that case, and the appeal to the Swiss Supreme Court,[211] Semenya filed a case before the ECtHR claiming that the restriction imposed on her by World Athletics amounted to a violation of her rights under Articles 3 (prohibition of inhuman or degrading treatment) and 8 (right to respect for private life), taken alone and in conjunction with Article 14 (prohibition of discrimination), and also a breach of Articles 6 (right to a fair hearing) and 13 (right to an effective remedy) of the ECHR.[212]

In responding to the issue of discrimination against people with intersex variations the Parliamentary Assembly of the Council of Europe (PACE) recommends that [member] states:

> ensure that anti-discrimination legislation effectively applies to and protects intersex people, either by inserting sex characteristics as a specific prohibited ground in all anti-discrimination legislation, and/or by raising awareness among lawyers, police, prosecutors, judges and all other relevant professionals, as well as intersex people, of the possibility of dealing with discrimination against them under the prohibited ground of sex, or as an "other" (unspecified) ground where

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[208] Office of the United Nations High Commissioner (n 165). At p31.

[209] Dainius Puras, 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health A/HRC/32/33' (2016) 33. At paras 55-57.

[210] *CAS 2018/O/5794 Mokgadi Caster Semenya v International Association of Athletics Federations & CAS 2018/O/5798 Athletics South Africa v International Association of Athletics Federations* [2019].

[211] Jeré Longman, 'Track's Caster Semenya Loses Appeal to Defend 800-Meter Title' *The New York Times* (28 June 2021).

[212] *Semenya v Switzerland App no 10934/21* (European Court of Human Rights).

> the list of prohibited grounds in relevant national anti-discrimination provisions is non-exhaustive;[213]

The phrase ‘sex characteristics’ was first used in a legal context in the Maltese *Gender Identity, Gender Expression and Sex Characteristics Act, 2015*. Section 2 stated:

> ‘sex characteristics’ refers to the chromosomal, gonadal and anatomical features of a person, which include primary characteristics such as reproductive organs and genitalia and, or in chromosomal structures and hormones; and secondary characteristics such as muscle mass, hair distribution, breasts and, or stature.

In their Legal Toolkit, Organisation International Intersex (OII) Europe, the regional European NGO for intersex rights, set out the case for the use of the phrase ‘sex characteristics’ in equality or anti-discrimination laws. Using this phrase is universal everyone has sex characteristics (whether they have an intersex variation or not); the phrase ensures equality and equity; use of the phrase enables recognition of bodily diversity; the phrase increases the visibility of intersex and finally, it brings clarity to the cause of the discrimination a person may experience.[214] Use of this phrase is further supported by the resolution of the European Parliament on the rights of intersex people, where the Parliament:

> Deplores the lack of recognition of sex characteristics as a ground of discrimination across the EU, and therefore highlights the importance of this criterion in order to ensure access to justice for intersex people.[215]

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[213] Parliamentary Assembly of the Council of Europe (n 191). At para 7.4.

[214] Ghattas (n 131). At p21.

[215] European Parliament, ‘The Rights of Intersex People. European Parliament Resolution of 14 February 2019 on the Rights of Intersex People’ (2019).

Right to Privacy

Table 3.5 Right to Privacy

International Human Rights Law	**Regional European Human Rights Law**	**Domestic Irish Law**
Article 12 UDHR; Article 17 ICCPR; Article 16 CRC, Article 22 CRPD.	Article 8 ECHR; Article 7 CFREU.	Article 40.3

Although the right to privacy is not expressly stated in the Irish Constitution, it has long been acknowledged as one of the unenumerated, or implied, rights forming part of the personal rights in Article 40.3. This was first established in *McGee v AG (1974).*[216] In a later case, the Supreme Court confirmed that the 'nature of the right to privacy is such that it must ensure the dignity and freedom of the individual in a democratic society.'[217]

Defining what precisely is meant by privacy has been described as 'notoriously difficult'.[218] This is partly explained by the diversity of entitlements it covers. The right includes everything from respect for confidentiality of correspondence, medical history, financial affairs to non-publication of photographs, or video or audio recordings without permission. Essentially the concept of privacy implies an expectation of a zone of personal space together with freedom from unwanted attention. The Law Reform Commission identified four aspects of the concept: territorial privacy, privacy of the person, informational privacy, and freedom from surveillance and the interception of communications.[219] The Working Group on Privacy adopted the following working definition of privacy:

> The right of the individual to be protected against intrusion into his personal life or affairs, or those of his family, by direct physical means or by publication of information.[220]

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[216] *McGee v Ireland* [1974] IR 284.

[217] *Kennedy and Arnold v Ireland* [1987] IR 587.

[218] Working Group on Privacy, 'Report on the Working Group on Privacy' (2006).

[219] Law Reform Commission, 'Privacy: Surveillance and the Interception of Communications' LRC 57-1998.

[220] Working Group on Privacy (n 218). At p11.

The literature on intersex is replete with instances where the privacy of a person with intersex variations has not been respected. This lack of privacy may be experienced when travelling, in institutions or in medical spaces.[221] Given the relative rarity of intersex variations and the medical interest in the success of interventions, people with intersex variations, including children, have regularly been participants in medical photographic sessions and been subjected to repeated genital exams as teaching opportunities for trainee medical staff. Many report these experiences as humiliating, deeply shaming and traumatic.[222]

The Special Rapporteur on Privacy discussed the issue of privacy and intersex variation in his 2021 report. He noted that the negative experiences of children with intersex variations may include pathologisation of their gender identity or body; unnecessary medical treatment; publication of details concerning genitalia; and denial of access to medical records.[223] He further noted that birth certificates and a limited ability to correct information initially registered at birth may 'pose challenges to attaining dignity, identity, privacy and development' for children with intersex variations.[224] While the *Gender Recognition Act, 2015* does enable young people aged 16 and 17 to apply for an exemption on the age ground, thus enabling them to apply to be legally recognised in their preferred gender, for those under 16 years of age the 2015 Act contains no mechanism to change their gender of legal recognition. Section 63 of the *Civil Registration Act, 2004* enables correction of an entry on the birth register where there is an 'error on the face of the document' where there is sufficient medical evidence to support such a request. In the context of a person with intersex variations it was recently confirmed that this power is

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[221] Alice Domurat Dreger, *Hermaphrodites and the Medical Invention of Sex* (Harvard University Press 2000) <http://ebookcentral.proquest.com/lib/dcu/detail.action?docID=3300278> accessed 26 February 2021.

[222] Alice Domurat Dreger, 'Jarring Bodies: Thoughts on the Display of Unusual Anatomies' (2000) 43 Perspectives in Biology and Medicine 161 <https://muse.jhu.edu/article/46497> accessed 26 February 2021; Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority, and Lived Experience* (Illustrated edition, Duke University Press 2008); S Creighton and others, 'Medical Photography: Ethics, Consent and the Intersex Patient' (2002) 89 BJU international 67; Surya Monro and others, 'Intersex, Variations of Sex Characteristics, and DSD: The Need for Change' (2017) <http://eprints.hud.ac.uk/id/eprint/33535/1/Intersex%20Variations%20of%20Sex%20Characteristics%20and%20DSDreportfinal.pdf>.

[223] Joseph A Cannataci, 'Annual Thematic Report: Artificial Intelligence and Privacy, and Children's Privacy. A/HRC/49/55' (2021). At para 98(c).

[224] ibid. At para 103.

only exercised where the person's sex on the birth notification form is entered as indeterminate.[225] Not all intersex variations are evident as a result of ambiguous genitalia. Thus, there may be people with intersex variations which do not emerge until a later stage in life but as there was no question or doubt about their sex at the moment of registration they were not noted as indeterminate. Consequently, such children would not be able to exercise the power in s63 of the 2004 Act to achieve an amendment in their registration and would have to wait until they age into the rights contained in the 2015 Act.

Summary

This chapter has demonstrated that there are many instances where law can have a direct impact on the lives of people with intersex variations. Where a person's legal gender of recognition is incorrect this may result in that person being excluded from access to legal rights and protections. Yet the main concerns for intersex activists revolve around medical management of intersex. Where a person with an intersex variation is unhappy with the interventions they have experienced and to which they have not personally consented traditional legal solutions for redress in negligence and trespass may not yield results which vindicate their position. While human rights law does hold the potential to ensure that such vindication for people with intersex variations, and indeed to protect them from needing to seek redress in the first place, as these rights currently stand in Ireland, they do not expressly and adequately support people with intersex variations. This it is hard to conclude other than that law is tacitly complicit in the violation of the rights of people with intersex variations.[226]

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[225] Minister for Employment Affairs and Social Protection, 'Gender Recognition Act 2015: Report to the Oireachtas under Section 7 Ofthe Act' (Department of Social Protection 2009) <https://www.gov.ie/pdf/?file=https://assets.gov.ie/69547/dd757168e2e44d3faa7196b4b17fc4d8.pdf#page=1> accessed 27 March 2022. At p11.

[226] Ní Mhuirthile, 'Recent Reforms in LGBTI Rights in Ireland: Tightening the Tourniquet in the Rights of Vulnerable Intersex People' (n 97).

4

Intersex in Medicine

Chapter 4: Intersex in Medicine

There have always been intersex people in the world. From ancient times to today we see mention of them in literature, art and cultural life. Hippocrates and Aristotle both discuss them in their work.[227] However, as Dreger notes, it was in the 1800s that medicine became very focused on intersex bodies as objects of difference and it was in the 20th century that medical professionals began to actively intervene to reshape intersex bodies along more apparently typical male or female lines.[228]

There are no formal treatment protocols for the medical management of intersex. In part this is due to the complexity of some bodies, every body being different, and the fact that the needs of each person differ depending on what interventions they may have undergone previously. Nonetheless, Ní Mhuirthile has identified from the literature four different approaches to the medicalisation of intersex bodies. These are the optimum gender of rearing approach (OGR), the modified approach, the consensus approach, and the moratorium approach.[229]

The Optimum Gender of Rearing Approach (OGR)

This first approach is predominantly associated with the processes stemming from John Money and the John's Hopkins Hospital,[230] although it is important to note that some intersex people were being medically managed in this way before Money published his work.[231] The approach was formally endorsed by the American Academy of Pediatric Surgeons (APPS) in 2000.[232]

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[227] Geoffrey Ernest Richard Lloyd, *Science, Folklore and Ideology: Studies in the Life Sciences in Ancient Greece* (Hackett Publishing 1999).

[228] Dreger (n 221).

[229] Ní Mhuirthile, 'Intersex Individuals, Gender and the Limits of Law' (n 97).

[230] John Money, 'Hermaphroditism, Gender and Precocity in Hyperadrenocorticism: Psychologic Findings' (1955) 96 Bulletin of the Johns Hopkins Hospital 253; John Money, 'Gender Role, Gender Identity, Core Gender Identity: Usage and Definition of Terms' (1973) 1 Journal of the American Academy of Psychoanalysis 397 <https://guilfordjournals.com/doi/abs/10.1521/jaap.1.1973.1.4.397> accessed 15 March 2022.

[231] David Andrew Griffiths, 'Diagnosing Sex: Intersex Surgery and "Sex Change" in Britain 1930–1955' (2018) 21 Sexualities 476 <https://doi.org/10.1177/1363460717740339> accessed 3 October 2019.

[232] American Academy of Pediatric Surgeons, 'Evaluation of the Newborn With Developmental Anomalies of the External Genitalia' (2000) 106 Pediatrics 138.

This approach considered the birth of a child with an intersex variation a 'social emergency'.[233] Low and Hutson stated that '[n]ext to perinatal death, genital ambiguity is likely the most devastating condition to face any parent of a newborn.'[234] Therefore, the approach recommended early surgical intervention to 'recreate' the intersex body as either male or female. In choosing which sex to assign the child, the treatment team decided based on the outcome of tests and following the guidelines such as those contained in the APPS Statement. This approach recommends the following. All potentially fertile females should be assigned to the female gender regardless of the degree of virilisation, although the presence of a low-lying vagina was considered advantageous if assigning female it was 'not of critical importance'.[235] Alternatively, when considering a male gender of rearing the size of the phallus and its potential to develop at puberty into a sexually functional penis was 'of paramount importance'.[236] Any males with a penis considered too small to function 'normally' in later life were assigned female.[237] Thus it is apparent that what was important is that females are potentially fertile and males can engage in penetrative intercourse.

According to this OGR approach, it is the medical team who decides which gender an intersexed child should be assigned.[238] Although the APPS Statement did note that '[a]s much as possible, the parents need to be included in the discussions regarding sex of rearing',[239] It was important that parents received the clear message that the child really did have a gendered identity but that the physical development was incomplete and thus the 'true sex' of the child must be detected prior to naming, birth registration etc. Creighton and Minto emphasise that the key to the protocol's success was an active policy of withholding any details of their condition from children with intersex variations and ensuring that early genital surgery was

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[233] ibid.

[234] Y Low, Jm Hutson and Murdoch Childrens Research Institute Sex Study Group, 'Rules for Clinical Diagnosis in Babies with Ambiguous Genitalia' (2003) 39 Journal of Paediatrics and Child Health 406 <http://onlinelibrary.wiley.com/doi/abs/10.1046/j.1440-1754.2003.00179.x> accessed 15 March 2022.

[235] American Academy of Pediatric Surgeons (n 232).

[236] ibid.

[237] John Money, *Sex Errors of the Body and Related Syndromes: A Guide to Counseling Children, Adolescents, and Their Families, 2nd Ed* (Paul H Brookes Publishing 1994).

[238] Dreger (n 221).

[239] American Academy of Pediatric Surgeons (n 232).

performed before 18 months of age.[240] Indeed some proponents of this approach argue that withholding information about diagnosis is essential to fulfilling a physician's duty to the patient.[241] This was considered necessary due to the 'psychological distress' that families experience at the birth of an intersexed child, the AAP guidelines concluded that:

> '[a]lthough newborns with ambiguous genitalia are encountered rarely in a primary care pediatrician's practice, their diagnosis and prompt treatment require urgent medical attention.'[242]

This is an extreme statement, and indicative of the mind-set underpinning the OGR approach. When viewed from this perspective, the birth of an intersex child is a tragedy, and traumatising for parents.

In insisting on early surgical intervention, the OGR approach denied to people with an intersex variation the opportunity to develop an independent gender identity and furthermore irrevocably surgically inscribed that gender which had been chosen for them on their bodies. Yet it also denied parents any meaningful involvement in the treatment of their child. In this regard the OGR approach is doubly paternalistic, the approach attempts to manage not only the intersex variation but also the response of the parents to the treatment options selected by the medical team by denying parents the right to be fully informed of their child's condition and to fully participate in important decision affecting their child such as the choice of gender of rearing.

In February 2007, the APPS published a statement of retirement for their policy statement from 2000 and adopted and endorsed the Consensus Statement as their new approved approach.[243] Nonetheless, the approach has been outlined here in detail for two reasons: first, many intersex adults have been treated according to this approach and second, in outlining the approach and investigating the normative assumptions on which it was

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[240] Sarah Creighton and Catherine Minto, 'Managing Intersex: Most Vaginal Surgery in Childhood Should Be Deferred' (2001) 323 BMJ 1264 <https://www.bmj.com/content/323/7324/1264> accessed 15 March 2022.

[241] Anita Natarajan, 'Medical Ethics and Truth Telling in the Case of Androgen Insensitivity Syndrome' (1996) 154 Canadian Medical Association Journal 568.

[242] American Academy of Pediatric Surgeons (n 232).

[243] American Academy of Pediatrics, 'AAP Publications Retired or Reaffirmed, October 2006' (2007) 119 Pediatrics 405 <https://doi.org/10.1542/peds.2006-3222> accessed 22 March 2022.

based, it is possible to identify whether any of these continue to permeate the more modern approaches to the medical management of intersex.

The Modified Approach

The appropriateness of the OGR approach began to be questioned in the 1990s with the establishment of the Intersex Society of North America (ISNA) among other groups. The emergence of accounts from adults with intersex variations where they claimed that medical management of their intersex variations had resulted in harm, both physical and mental, were initially dismissed as political and non-representative of the vast majority of patients who had been successfully treated and that the continued silence of these patients was of itself an indication of the success of the gender assignment performed.[244] Yet, some commentators and medical professionals suggested that the OGR approach be modified.[245] This modified approach is supported by the statement from the British Association of Paediatric Surgeons.[246]

The modified approach notes the importance of meaningful consultation with parents and in particular the need to ensure an awareness of the parents on the possibility of non-operative management of the condition with psychological support for both the child and parents.[247] This modified approach notes the statements from adult intersex people which have indicated that the treatment according to the OGR approach was 'damaging or mutilating and, as it is essentially cosmetic, should not be performed until the fully informed consent of the patient could be obtained'.[248] However, the modified approach does not support a radical amendment to the OGR approach to treatment, such as for example a

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[244] Dreger (n 221); Fausto-Sterling (n 174); Kessler (n 175).

[245] Jorge Daaboul and Joel Frader, 'Ethics and the Management of the Patient with Intersex: A Middle Way' (2001) 14 Journal of Paediatric Endocrinology and Metabolism 1575; SF Ahmed, S Morrison and IA Hughes, 'Intersex and Gender Assignment; the Third Way?' (2004) 89 Archives of Disease in Childhood 847 <https://adc-bmj-com.dcu.idm.oclc.org/content/89/9/847> accessed 15 March 2022; NR Maharaj and others, 'Intersex Conditions in Children and Adolescents: Surgical, Ethical, and Legal Considerations' (2005) 18 Journal of Pediatric and Adolescent Gynecology 399 <https://www.sciencedirect.com/science/article/pii/S1083318805001609> accessed 15 March 2022.

[246] Rangecroft (n 141).

[247] Julie A Greenberg, 'International Legal Developments Protecting the Autonomy Rights of Sexual Minorities: Who Should Determine the Appropriate Treatment for an Intersex Infant?' in Sharon E Sytsma (ed), *Ethics and Intersex* (Springer Netherlands 2006) <https://doi.org/10.1007/1-4220-4314-7_5> accessed 26 February 2021.

[248] Rangecroft (n 141).

moratorium on gender assignment surgery on intersex infants, but rather argues that '[t]here are, however, so many specific issues related to the different diagnostic groups that such a policy would seem to be too prescriptive.'[249] According to this approach, when making potentially life altering decisions for intersex children which might affect both their ability to reproduce and to achieve sexual satisfaction, it is parents who are fully educated on all the treatment options who are best placed to determine what is in the best interest of their children.[250]

In essence, the modified approach mirrors the OGR approach and continues to permit early surgical intervention, provided that the decision to operate and the decision as to the gender of assignment, is made primarily by parents who have given a valid and fully informed consent. The main difference between these two approaches is that, according to the OGR approach, the physicians decide which gender would be most appropriate for the intersex child whereas according to the modified approach this decision is made by the parents in conjunction with the treatment team. Thus both approaches deny to the child with an intersex variation the possibility of participation in the decision regarding preferred gender identity and surgical inscription of same. In permitting parents to participate in the decision regarding gender assignment, the modified approach is less open to accusation of paternalism on the part of medical professionals.

The Consensus Approach

In October 2005 a meeting was held in Chicago of fifty international experts on intersexuality in various fields such as paediatric endocrinology, paediatric urology, genetics, gynaecology , and gender-identity development, including Cheryl Chase of the Intersex Society of North America, to revise the treatment guidelines for intersex infants.[251] The purpose of the meeting was threefold: to review the management of intersex disorders from a broad perspective; to review data on longer-term

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[249] ibid.

[250] Ahmed, Morrison and Hughes (n 245).

[251] A full list of all participants at the conference is contained in the acknowledgements at the end of the Consensus Statement. See Lee, P.A. et al, 'Consensus Statement on the Management of Intersex Conditions' (2006) 118 Pediatrics e488.

outcome; and to formulate proposals for future studies.[252] The outcome of the meeting was the Consensus Statement on the Management of Intersex Disorders.

The major contribution of the Consensus Statement is a change in nomenclature. It notes that terms such as 'hermaphrodite', 'intersex' and 'sex reversal' are 'perceived as potentially pejorative by patients.'[253] Consequently, the Consensus Statement recommends a new system of terminology. The authors stress the importance of ensuring that the new terminology can be sufficiently flexible to incorporate new information while simultaneously remaining robust enough to maintain a consistent framework.[254] The Consensus Statement recommends that intersex conditions should be renamed Disorder of Sexual Development (DSDs). This choice of words has caused considerable controversy as we detail in the terminology section at the beginning of this report.

The Consensus Statement also outlines guidelines for the optimal management of patients with DSDs. These consist of the following:

1. gender assignment must be avoided before expert evaluation in newborns;
2. evaluation and long-term management must be performed at a centre with an experienced multidisciplinary team, which should include paediatric subspecialists in endocrinology, surgery or urology or both, psychology/psychiatry, gynaecology, genetics, neonatology, and, if available, social work, nursing, and medical ethics;
3. all individuals should receive a gender assignment;
4. open communication with patients and families is essential and participation in decision-making is encouraged; and
5. patient and family concerns should be respected.[255]

Like the OGR Approach, the Consensus Statement stresses that the initial contact with the parents of a child with DSD is important due to the lasting impact of first impressions, thus it notes the importance of stressing the

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[252] ibid.

[253] ibid. See also Houk Christopher P. & Lee, Peter A, 'A Commentary on the Intersex Consensus Statement' (2007) 15 The American Academy of Pediatrics Section on Endocrinology Newsletter 3.

[254] Lee, P.A. et al (n 251).

[255] ibid.

potential such a child has 'to become a well-adjusted, functional member of society.'[256] Unlike the OGR approach, the Consensus Statement notes that DSD is not shameful, and notes that homosexual orientation in a person with DSD is not an indication of incorrect gender assignment.[257] Like the modified approach, the Consensus Statement emphasises the importance of educating both the patient-child and family about the particular DSD with which the child is diagnosed.[258]

The Consensus Statement recommends treatment for DSD by either surgical intervention, administration of sex-steroid replacement, psychosocial management or any combination of these treatment options.[259] Interestingly, although the Consensus Statement acknowledges that information regarding the outcome of the surgical and medical management of DSDs is insufficient to conclusively comment on either its success or suitability it nonetheless permits treatment in this manner.[260] Therefore, it calls for future studies which will evaluate the effects of early versus later surgical interventions in a holistic manner. It also recognises the need for studies on the psychological management of DSDs, particularly in relation to information management with regard to timing and content, and studies on the long-term outcomes of treatment of those with DSDs.

The Moratorium Approach

The call for a moratorium on medical and/or surgical interventions until the child concerned can actively participate in the decision regarding treatment is not exclusive to intersex advocacy groups. Diamond and Sigmundson were among the first medical practitioners to advocate that a moratorium be placed on non-therapeutic early surgical intervention until the child was old enough to participate in the decision to treat.[261] They recognised that it is the lasting impact which such procedures can cause on a person's physical and mental health which is the main source of controversy regarding the medical management of intersex variations.

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[256] ibid.
[257] ibid.
[258] ibid.
[259] ibid.
[260] ibid.
[261] Milton Diamond and H Keith Sigmundson, 'Management of Intersexuality: Guidelines for Dealing With Persons With Ambiguous Genitalia' (1997) 151 Archives of Pediatrics & Adolescent Medicine 1046 <https://jamanetwork.com/journals/jamapediatrics/fullarticle/518550> accessed 3 October 2019.

The management approach proposed by Diamond & Sigmundson resembles to a certain extent the Consensus Approach but also differs from it significantly. Like the Consensus Approach, the Diamond/Sigmundson approach places the patient at its centre. At all times this fourth approach emphasises that the patient is the child and that the child must be considered and consulted.[262] The most significant divergence between these approaches is the statement contained in point seven of the Diamond/Sigmundson approach to perform no major surgery for exclusively cosmetic reasons but rather only for conditions related to physical/medical health. Their suggested treatment approach goes even further by requiring full informed consent (again preferably of the intersexual) prior to the administration of prolonged hormones.[263] Underpinning their approach is the acknowledgment that surgery can potentially impair sexual/erotic function and that '[m]any intersex or sex reassigned individuals have felt they were not consulted about their use and effects and regretted the results.'[264]

Which Approach Operates in Practice?

Each of these approaches is a suggested method for the management of intersex by medical professionals. Although various medical professional bodies have supported one or other approach, no approach is mandatory in any jurisdiction, and any combination of approaches is also acceptable. In the USA, for example, for a period following the publication of the Consensus Statement in 2006 and prior to the publication of the retirement of the 2000 APPS Statement, both were concurrently recommended by that body. In the UK, both the BAPS Statement and the Consensus Statement are followed, although there is a preference among some of the leading practitioners in the field to follow the more recent statement. In Ireland, there is very little engagement with the question of the various approaches to the medical management of intersexuality to be gleaned from literature. There is no formally prescribed or endorsed approach to the treatment of intersex variations for Irish medical professionals. Two years after the publication of the Consensus statement 60 centres of excellence DSD clinics

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[262] ibid.

[263] ibid.

[264] ibid.

across 23 countries in Europe were surveyed and the study reported that 35.6% (n=21) had ideal multidisciplinary teams where all the specialities identified in the Consensus approach, including the allied healthcare professionals were present; 57.6% (n=35) had intermediate multidisciplinary teams, i.e. did not have specialist nursing, social work or medical ethicists on the team, and 6.8% (n=4) teams were missing key specialities such as paediatric endocrinologist, psychological services or urologist/surgeon.[265] Thus it is evident that the Consensus approach has been implemented in the majority of the European DSD Centres surveyed.

Fifteen years after the publication of the Consensus Statement, Gramc et al noted that there was a lack of clarity in the literature about how multidisciplinary teams work in practice, an absence of information about the composition of teams, collaboration processes and ethical frameworks.[266] They report that as described in the literature, teams tend to work in a medically oriented fashion which leads to poor collaboration.[267] The teams are focused on paediatric care with no mention of care for adults with intersex variations in the iterature.[268] Finally, they note that despite references to shared decision making processes, informed consent, and the importance of including people with itersex variations in the work of the team, they found that in practice people with intersex variations are generally excluded from team meetings, their presence not considered beneficial.[269]

Critiquing Early Interventions

When problems are identified in relation to a child's educational development and their health and wellbeing more generally,[270] early intervention is a favoured approach not least due to its ability to deliver

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[265] V Pasterski, P Prentice and IA Hughes, 'Consequences of the Chicago Consensus on Disorders of Sex Development (DSD): Current Practices in Europe' (2010) 95 Archives of Disease in Childhood 618 <https://adc-bmj-com.dcu.idm.oclc.org/content/95/8/618> accessed 15 March 2022.

[266] Martin Gramc, Jürg Streuli and Eva de Clercq, 'Multidisciplinary Teams Caring for People with Variations of Sex Characteristics: A Scoping Review' (2021) 5 BMJ Paediatrics Open e001257 <https://bmjpaedsopen.bmj.com/content/5/1/e001257> accessed 18 February 2022.

[267] ibid. At p8.

[268] ibid. At p9.

[269] ibid. At p9.

[270] Alcohol and Drug Education and Prevention Information Service (ADEPIS), 'Early Intervention and Prevention Briefing Paper.' <https://www.drugsandalcohol.ie/24069/1/Early-Intervention-and-Prevention-briefing-paper.pdf>.

better and long-term outcomes. Early intervention aims to enhance the child's development to ensure they reach their full potential and is also beneficial for families and communities.[271] Some interventions address the child's specific needs (e.g. provision of extra resources such as a Special Education Needs Assistant)[272] while others target broader social circumstances such as educational/social disadvantage.[273] Early intervention seeks to prevent further development of the problem. Yet, this fundamental aim is upended when it comes to some early intervention on intersex babies and children since it is widely documented that early intervention has been, and continues to be, profoundly harmful due to many of its unknown and future implications on a person's physical and psychological development and we document such realities later in our report.

With the exceptions of the moratorium approach, all other approaches enable early medical and surgical interventions on the bodies of children with intersex variations before the child is competent to participate in the consent process. Such interventions are the main source of critique by adults with intersex variations and others when it comes to medical management of intersex.[274] The critique lies in the perceived absence of respect for the dignity and privacy of people with intersex variations. The criticisms centre on two main themes. First, that interventions harm otherwise healthy people both physically and psychologically. The second criticism concerns the manner in which gender is assigned, and often medically and/or surgically inscribed by medical professionals and/or parents, based on gender guidelines which encapsulate preconceived notions of the appearance and performance of gendered genitalia and statistically most likely gender identity without reference to the gender preference of the individual with the intersex variation.

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[271] CDC, 'Why Act Early If You're Concerned about Development?' (*Centers for Disease Control and Prevention*, 19 April 2021) <https://www.cdc.gov/ncbddd/actearly/whyActEarly.html> accessed 22 March 2022.

[272] National Council for Special Education (NCSE), 'Special Needs Assistants – National Council for Special Education' (2022) <https://ncse.ie/special-needs-assistants> accessed 16 March 2022.

[273] Government of Ireland, 'Early Start Pre-School Programme' (*Early Start Programme*, 1 July 2021) <https://www.gov.ie/en/service/78ff8-early-start-programme/#> accessed 16 March 2022.

[274] Chase, Cheryl, 'Hermaphrodites with Attitude: Mapping the Emergence of Intersex Political Activism' in Stryker S and Whittle S (eds), *The Transgender Studies Reader* (Routledge 2006); Dreger (n 221); Fausto-Sterling (n 174); Kessler (n 175); Sharon E Sytsma, *Ethics and Intersex* (Springer Science & Business Media 2006); Preves (n 97); Davis (n 97).

Physical and Psychological Harm

Gender assignment surgery is an umbrella term for a variety of surgical interventions which are routinely performed on intersex children to create gendered genitals. Such procedures include: cliteroplasty,[275] phalloplasty,[276] vaginoplasty,[277] labioplasty,[278] and gonadectomy.[279] The side effects of such interventions can include: pain, scarred tissue, pain during erection,[280] loss of sexual sensation,[281] blood clots,[282] colitis,[283] the elimination of the natural contour and pigmentation of the labia minora,[284] and infertility.[285] As a result of complications such as these it is not uncommon for people with intersex variations to require more than one surgical intervention to correct the after effects of previous surgeries.

It is not simply the physical impact which gender assignment surgery has that is a source of commentary, but the impact which undergoing such procedures has on the lives of people with intersex variations is also much discussed. Criticisms centre on the sense of shame and stigma which people with intersex variations report experiencing as a result of the ongoing and alienating medical focus on genital difference and inadequacy. In her study on this point Preves reports that people with intersex variations state that repeated 'corrective' medical and surgical interventions decreased their sense of autonomy and undermined the development of a solid sense of self, that they felt treated as objects of medical research and as a result they felt

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[275] Procedures performed on the phallus to create a cosmetically acceptable clitoris.

[276] Procedures performed on the phallus to create a cosmetically acceptable penis capable or urination while standing and penetrative intercourse.

[277] Procedures performed on the vagina or to create a vagina capable of engaging in intercourse.

[278] Also known as labial reduction and refers to those procedures which are designed to reduce the size of the labia, particularly the labia minora.

[279] The removal of the gonads.

[280] Ian A Oyama and others, 'Reduction Clitoroplasty: A Technique for Debulking the Enlarged Clitoris' (2004) 17 Journal of Pediatric and Adolescent Gynecology 393 <https://www.sciencedirect.com/science/article/pii/S1083318804001925> accessed 15 March 2022.

[281] Ida Ismail and Sarah Creighton, 'Surgery for Intersex' (2005) 5 Reviews in Gynaecological Practice 57 <https://www.sciencedirect.com/science/article/pii/S1471769704000905> accessed 23 July 2021.

[282] ibid.

[283] ibid.

[284] Maas, Sylvester M. and Hage, J. Joris, 'Functional and Aesthetic Labia Minora Reduction' (2000) 105 Plastic and Reconstructive Surgery 1453.

[285] Removal of the gonads necessarily involves rendering a person infertile.

freakish. Finally, she notes that medical interventions impaired their ability to engage in healthy sexual relationships due to both physical and psychological trauma.[286]

Guidelines for Understanding Gender

The manner in which medical professionals determine to which gender a child with intersex variations ought to be assigned is the second main source of criticism. These guidelines have emerged organically as journal articles were published in the area. The guidelines are very prescriptive. Meyers-Steifer and Charest identify the three criteria which underpin these gender guidelines '[g]ender assignment requires consideration of the potential for (1) an umbiguous appearance of the genitalia before and after puberty, (2) adequate sexual functioning, and (3) fertility.'[287] Of these three criteria, it is genital appearance which features most prominently in the discussion in the literature. In a widely cited article from the *Johns Hopkins Magazine* Hendricks states '[i]n truth, the choice of gender still often comes down to what the external genitals look like.'[288] Genital appearance is considered an important factor for gender determination in all four of the approaches discussed above. The weight and significance given to genital appearance differs across the approaches, but it is never absent as a factor for consideration.

The majority of intersex conditions identified in infancy are indicated by the appearance of the ambiguous genitalia. Although there are several underlying conditions which might cause intersexuality, in general, the tests to ascertain which precise condition is responsible for the intersexuality of an individual are only performed subsequent to a suspected diagnosis of intersexuality. Therefore, initial diagnosis is very heavily dependent on the appearance of the genitalia, in particular on the size of the phallus. In order to determine whether something is ambiguous, there must be an agreement as to what is unambiguously male or female. However, there are no universally accepted rules as to what constitutes unambiguous phallic length indicating maleness or femaleness. Whether the phallus is a clitoris or

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[286] Preves (n 97).

[287] CH Meyers-Seifer and NJ Charest, 'Diagnosis and Management of Patients with Ambiguous Genitalia' (1992) 16 Seminars in perinatology 332. At p336-337.

[288] Melissa Hendricks, 'Is It a Boy or a Girl' (1993) 45 Johns Hopkins Magazine 10.

a penis depends on the subjective individual interpretation of the treating physician.

According to Feldman and Smith, neo-natal penile length can vary between 2.8 and 4.5 centimetres.[289] When measuring a phallus to determine its size, it is important to decide whether the length is determined by the flaccid, stretched or erect measurement. The consensus seems to be that flaccid lengths are too varied to be a reliable indicator and that there is a correlation between stretched and erect lengths. However, it seems that length alone does not determine whether a phallus should be considered a penis or a clitoris. Some commentators, such as Money, consider the presence of an urethra and a meatus essential to a penis.[290] Therefore, if the phallus under examination lacks an urethra or a meatus, it is by this definition, a clitoris. The location of the meatus is also important. Hypospadias is a condition where the meatus is located other than at the tip of the penis: the urethral opening can be located anywhere along the shaft and in some cases is located at the base of the penis where it has been described as 'in the female position'.[291] In these severely hypospadic phalluses, both the urethra and meatus are absent: should these be considered large clitorises? Yet hypospadias is technically only correctly diagnosed when the scrotum is fused and contains testes, thus a determination as male has already been made. Furthermore, although the estimated occurrence of hypospadias is one in 200 male births, according to Tong, Donaldson & Hutson, it is only an indicator of intersexuality in one of 10,000 births.[292]

Determining that a phallus is a clitoris, is no less problematic. Unlike with penises where the concern is that the phallus would be too small to qualify, regarding clitorises, the concern is that the phallus is too large. Despite the publication of standard tables of normative clitoral size ranging from .2 to

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[289] Kenneth W Feldman and David W Smith, 'Fetal Phallic Growth and Penile Standards for Newborn Male Infants' (1975) 86 The Journal of Pediatrics 395 <https://www.sciencedirect.com/science/article/pii/S0022347675809693> accessed 16 March 2022.

[290] Money, *Sex Errors of the Body and Related Syndromes* (n 237). The Meatus is the opening of the urethra, generally situated on the glans penis in males, and in the vulva in females.

[291] Money, John and Ehrhardt, Anke A., *Man and Woman, Boy and Girl: Differentiation and Dimorphism of Gender* (Johns Hopkins University Press 1973).

[292] Steven YC Tong, Karen Donaldson and John M Hutson, 'When Is Hypospadias Not Hypospadias?' (1996) 164 Medical Journal of Australia 153 <https://onlinelibrary.wiley.com/doi/abs/10.5694/j.1326-5377.1996.tb122014.x> accessed 16 March 2022.

.85 centimetres,[293] according to Kessler, many physicians refer to clitoral size by references to food e.g. the size of a pea or small bean.[294] Furthermore, not all physicians treating intersex infants are familiar with the published tables. Kessler quotes one physician who had performed many intersex surgeries as stating that 'overall appearance is most important.'[295]

In the absence of a defined and universally accepted medical standard of genital appearance, any decision on ambiguity is inevitably entangled with cultural and aesthetic preconceptions of how the genitalia should look and function. As Kessler puts it, ambiguity depends not only on how the genitals look, but on who is doing the looking. Not all parts of the genitalia are given equal weight. For males, the penis is especially significant. The penis is full of cultural meaning, and is oftentimes referred to as a person's 'manhood'. Thus possession of a large penis can override all other genital indicators of sex.[296] If the phallus is too small to be a penis, then the child will be assigned to the female sex, and if it is too large to be a clitoris, the child will be assigned to the male sex. Thus, it can be argued that the gender of assignment is determined based on preconceived notions of male and female genital anatomy. Girls have clitorises and boys have penises. Therefore, the perceived gender as deduced from the appearance of the genitals will in no small way determine how the child's ambiguity is viewed and will play a significant role in deciding the necessary surgical interventions.

Intersex variations are therefore not a medical issue, but rather a cultural one which medicine has attempted to control endeavouring to bring the intersexed body into conformity with the norms expected of male and female bodies. In attempting this medicine seeks not only to inscribe a more socially acceptable sex on bodies with intersex variations, but also to etch a gender identity which will correspond with that sexual inscription.

The OGR approach is most explicit of the approaches in stating that what is important is that once fertility has been preserved if possible, female genitalia can function as a site for heterosexual intercourse and that male

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[293] Sharon E Oberfield and others, 'Clitoral Size in Full-Term Infants' (1989) 6 American Journal of Perinatology 453 <http://www.thieme-connect.de/DOI/DOI?10.1055/s-2007-999638> accessed 16 March 2022.

[294] Kessler (n 175).

[295] ibid.

[296] ibid.

penises can function properly, i.e. permit urination while standing and engage in penetrative intercourse. Yet the Consensus approach also notes that the factors which influence gender assignment include diagnosis, genital appearance, surgical options, need for lifelong replacement therapy, fertility potential, views of the family and sometimes cultural concerns.[297] Thus while genital appearance remains a significant factor, the Consensus statement is more concerned with functionality.

A Note with Medical Care for Adults with Intersex Variations

All of the discussion in this chapter so far has focused on paediatric service provision for children with identified intersex variations. There is no discernible approach offering wrap around, holistic care to adults with intersex variations evident in the literature. Therefore, it seems as if adults are required to navigate accessing healthcare themselves, without the support of a multidisciplinary team or co-ordinating service that can direct them towards expert provision of care.

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[297] Lee, P.A. et al (n 251).

5

Methodology

Chapter 5: Methodology

This was an exploratory study and the first of its kind in Ireland. As noted in the title, we intended to 'map' what it means to be intersex in Ireland. Using hermeneutical phenomenology as our methodological approach, this study sought to understand the lived experience of what it means to be intersex from the perspectives of three distinct groups: (1) intersex people, (2) their families and partners and (3) healthcare professionals who work in this field. Data from these three groups would generate the lay and professional knowledge we expected to use to inform the development of appropriate law and policy in Ireland to ensure the rights of the intersex community are protected and upheld in Irish society.

Phenomenology

The research sought to articulate the experiences of intersex people through the use of hermeneutic phenomenology. Through interviews the voices of intersex people, their family member and health care providers, can be heard, offering us an insight into their 'ideas, thoughts, and memories in their own words rather than in the words of the researcher'.[298] In doing this we seek the meaning(s) and understandings(s) that participants gave to their experiences. Hermeneutic phenomenology's aim is to bring forth that which needs to be thought about. It is an invitation to think. To articulate thinking, one needs to listen in the corners and the shadows of the lived experience(s) of the phenomenon being investigated. The method "embraces multi-perspectival, embodied and experiential ways of knowing".[299] Smythe et al. articulate there are no set of steps or a step-by-step guide, rather each hermeneutic phenomenological researcher enacts a process that centres on reflection, writing, re-writing and thinking.[300]

Hermeneutic phenomenology is underpinned by the philosophy of Heidegger as he was concerned with being *in* the world.[301] The essence of

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[298] Shulamit Reinharz, *Feminist Methods in Social Research* (Oxford University Press 1992). At p9.

[299] Lesley Dibley and others, *Doing Hermeneutic Phenomenological Research: A Practical Guide* (SAGE 2020). At p7.

[300] Elizabeth A Smythe and others, 'Doing Heideggerian Hermeneutic Research: A Discussion Paper' (2008) 45 International Journal of Nursing Studies 1389 <https://www.sciencedirect.com/science/article/pii/S0020748907002350> accessed 14 March 2022.

[301] Martin Heidegger, *Being and Time* (John Macquarrie and Edward S Robinson trs, Harper 1963).

Heidegger's hermeneutic phenomenology is 'Dasein' which he explains as the human being in the world. 'The 'essence' of Dasein lies in its existence'.[302] The human being is always involved in the world as they experience it. Johnson suggests that Heidegger views the human being as 'always involved in the practical world of experience'.[303] Heidegger indicates that 'Being-in-the-world is a basic state of Dasein'.[304] Relating this to the participants in this study, being-in-the-world (Dasein) as intersex people can be seen as active participants in that world, creating meaning and understanding to being themselves in a world that may not recognise or speak to them. Hermeneutic phenomenology seeks to understand the meaning that participants give to this experience.

Interviews

All participants were invited to participate in a one-to-one, in-person interview. A total of twelve participants were interviewed for the study. Seven intersex people, one of whom was accompanied by their spouse/partner who also participated in the interview and was our only participating family member/partner. Four healthcare professionals also participated in the study.

At interview, participants were simply asked to talk about their experience of (being) intersex/working in the intersex field. Further questions arose from the interviewees' responses, giving rise to the prompt or probe questions, which sought clarity where necessary. Interviews ranged in duration from 60 minutes to 150 minutes. Being human in the world of intersex is complex and the telling of their story was never a short conversation. Rather, it was a profoundly reflective practice whereby the participant unravelled their story in their own time. Indeed, some participants re-engaged with us for a second and third interview to clarify aspects of their original telling of their story or to share more about themselves given that the first interview established trust between the participant and our team and they knew they could trust us to hold their

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[302] ibid. At p67.

[303] Emilie K Johnson, 'Heidegger and Meaning: Implications for Phenomenological Research' [2000] Nursing Philosophy <https://onlinelibrary-wiley-com.dcu.idm.oclc.org/doi/full/10.1046/j.1466-769x.2000.00027.x> accessed 14 March 2022.

[304] Heidegger (n 301). At p86.

stories and honour their lives. Three members of the research team conducted interviews. Interviews were recorded and then transcribed.

The first interview was conducted with an intersex person in March 2020 just as the COVID pandemic caused a global shutdown. Following an expedited 'Ethics Amendment Application, our university research ethics committee approved telephone/zoom as a means to engage with participants given the constraints associated with the pandemic and the fact that we were unable to offer the University as a suitable site for a private interview because it was closed. The next in-person interview with an intersex person did not occur until September 2020. Between March 2020 – September 2021, we conducted interviews using Zoom and/or telephone. All healthcare professionals (N=4) participated via Zoom/telephone.

Online, self-administered questionnaire

At a later stage in the study design process, we included the (supplemental) use of an anonymous online questionnaire. This was not a feature of the study's original design since it is widely known that survey research with hidden and vulnerable populations, particularly the intersex population, are not entirely effective.[305] The self-administered questionnaire is an adapted version of a similar instrument used in by in Australia in 2015 by Intersex Human Rights Australia to produce their report 'Intersex: Stories and Statistics from Australia'.[306] It was adapted to ensure it was an appropriate cultural fit for use in Ireland and we also added items, including ones that are considered very sensitive such as (1) questions to establish if a person had previous deliberate self-harm (DSH) ideation and behaviour and (2) we also asked about the nature of people's sexual activities. Both sets of questions were offered with explicit explanations that they were not obligatory. These were 'unforced' items on Qualtrics, meaning participants could choose to skip these items to reduce the burden of response and avoid potentially upsetting/triggering inquiry.

The final version of the instrument emerged from an iterative process whereby it was reviewed on a number of occasions by members of Ireland's

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[305] Carpenter, 'Intersex Human Rights, Sexual Orientation, Gender Identity and the Yogyakarta Principles' (n 93).

[306] Jones and others (n 87).

intersex community and subsequently adapted by the team to ensure its cultural fit and appropriateness. This process is an almost identical fit described in the USA intersex study.[307] Ours was a lengthy, 79 question instrument with some questions having multiple items therein (e.g. Q5 may have parts A, B, C and D) and some of these sub-items may be open text formats that require a written personalised response. In total, it is a 178-item instrument. Not all items apply to all participants and responses are not forced. Nonetheless, our questionnaire 'translates' as a sixty-page, MS Word document and is divided into ten parts, outlined in the table below, with the intention of capturing as much of the intersex experience as possible.

Table 5.1 Research Instrument sections

Part		Questions
1	About You	1 – 14
2	Your Identity	15 – 22
3	Your Identity Today	23 – 25
4	Other People	26 – 34
5	Your experience of Health, Education, Other Services and Opportunities	35 – 51
6	Your Health	52 – 57
7	Sexuality, Relationships and Sex	58 – 64
8	Parenting (if applicable to you)	65 – 67
9	Community, Activism and Research	68 – 77

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[307] Amy Rosenwohl-Mack and others, 'A National Study on the Physical and Mental Health of Intersex Adults in the U.S.' (2020) 15 PLOS ONE e0240088 <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0240088> accessed 14 March 2022.

10	Over to you…	78 - 79

We are acutely aware that this represents a significant burden of response which is no doubt a deterring factor and may be implicated in a low response rate. Qualtrics, our online survey platform estimated at least one hour for completion but that did not factor into account lengthy and considered replies that some individuals may have chosen to offer. Participants were alerted to this fact when it was explained at the beginning of the questionnaire, that the time it would take to complete would depend on how much of their experience the participant was willing to share. No incentive was offered for participation.

Interestingly, some participants did comment on this burden of response with one noting

> Sorry, I am trying to complete this, it takes hours (25)

We were also aware that our questionnaire had the potential to have a triggering effect on participants who could become distressed when engaging with any of the items contained in the questionnaire in terms of the negative experiences they may have in relation to accessing/availing of healthcare services and the items that relate to their health and wellbeing. Two parts of our survey instrument are highly sensitive: (1) Part 6 which asks about a person's health. This part includes optional questions asking if a person has ever had thoughts of deliberate self-harm ideation and behaviour and if they ever engaged in any such behaviours with an intention to die. (2) Part 7 asks about relationships, sexuality and sex. In this part we asked about a person's sexual activity/behaviour. Other questions throughout, which have the potential to be triggering for others relate to their experiences of support, or lack thereof, from family/friends and their experiences of healthcare. Our intention was to capture as broad as possible experiences of what it means to be intersex.

One of our participants specifically documented that completing the questionnaire was a triggering experience that required them to gradually complete it over time. However, they also note that it has prompted them to reflect on their own circumstances. This person used the survey to structure the telling of their story during their second interview because they had never told their own story before. Moreover, they explained that they didn't know their story because information was withheld from them about their childhood medical experiences. Participating in our research was the first time that this person was able to tell their story. Despite the triggering nature of some items in the questionnaire, they were grateful for this opportunity to participate. They explained

> It has taken at least 20+ hours to complete this survey, to avoid getting overly triggered & overwhelmed! (24)
>
> In working on this last few days one question has surfaced above the other distractions. How does 50-54 year old semi-virilized male (figuratively speaking not medical jargon)
> (i) Learn better emotional literacy
> (ii) Learn better intimacy literacy
> (iii) Learn better literacy on my variation in all its shadow parts!
> Thanks for the interviews. & thanks for allowing me to participate in this survey. (24)

We report three interesting points of comparison pertaining to surveys capturing the intersex community. The USA intersex survey was an 84-question instrument but offer no detail with regard to time required to respond.[308] In 2017, an online survey was administered to the LGBT community in the UK. 108,100 valid responses were recorded. Its methodology reports that there was also an "optional free text question at the end of the survey"[309]. Less than one-third of the valid respondents (n = 32,720 of total 108,100 = 30.3%) chose to write a text response to this "free text question"[310] . Where the UK instrument provided only one "free text" (text box) optional response, our instrument has in excess of sixty. It was estimated that the UK instrument would take fifteen minutes to complete given its mostly multiple-choice response format despite being a 154-item instrument.[311] Similarly, in December 2020, Pride Sports UK (LGBTIQ+

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[308] ibid.

[309] UK Government Equalities Office, 'National LGBT Survey: Summary Report' (UK Government Equalities Office 2018a) 7 <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/722314/GEO-LGBT-Survey-Report.pdf>.

[310] UK Government Equalities Office (n 12) 6.

[311] ibid 301.

Sports Inclusion), partnered with NGO Intersex UK, to launch an online survey to learn about intersex people's experiences of sport and physical activity. This was a 78-item instrument and potential participants were advised that it may take 15-20 minutes to complete "… and slightly longer if you wish to leave a testimony". In a previous clinical evaluation study in Germany,[312] the adult questionnaire was a 112-item instrument, the adolescent version was a 53-item instrument.

We initially launched our survey on Google Forms in February, 2020. In June 2020, we moved over to the *Qualtrics* platform. A secure link to our online survey was available on our study's official university website. We finished collecting data (36 valid responses, detailed below) in June 2021. Interestingly, when we moved our instrument onto the Qualtrics platform we had meetings with their representatives. It was hoped that Qualtrics may be able to assist us with reaching our targeted population. Our team member presented details about the intersex population and a representative in Qualtrics engaged in a scoping exercise to determine how they may be able to use their systems/resources to assist. We very much welcomed this potential assistance, however, having investigated all possibilities, Qualtrics determined that our targeted population was indeed a 'hard-to-reach' one and they would not be able to assist with recruitment compared to other populations they can reach for more standard-type research exercises (e.g. marketing research). This in itself was another interesting finding.

Sampling

Our sampling method was non-probability sampling. Three distinct groups of participants were identified: (1) intersex people, (2) their family member(s)/partner(s) and (3) medical/allied health professionals. We intended to conduct in-person, face-to-face, interviews with all three groups.

Given the vulnerable status of our primary group - the intersex community themselves - we also offered an anonymous way for people to participate through our online survey.

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[312] Lux and others (n 24).

Our samples

Interview participants

Table 5.2 Interview participants

Group	Number
Interviews	
Intersex Individuals	7
Family member/partner	1
Medical Professionals	4
Intersex individuals (survey)	36 valid responses

We had a sample size of seven intersex participants for interviews, three of whom were not from Ireland. Two international candidates did have an Irish connection, a third had no connection affiliation to Ireland. We could find no justifiable reason to exclude this person from interview. Our survey returned thirty-six (n= 36) valid responses from a total of 57 engagements.

37 individuals responded 'Yes' to the following item

Were you born with congenital differences in your sex characteristics?

However, this was the only item in the entire survey that two individuals responded to. These two cases were removed thus leaving 35 responses for analysis.

Another person replied 'Unsure'. We determined that their identification with the intersex variation "gonadal dysgenesis (partial & complete)" warranted inclusion. This individual further supported their variation by writing "streak ovaries" in the optional text box response. This person's inclusion as intersex the number of valid response to 36. Twelve responses selected ‘No’ to the above question. They were not included in our valid responses. A further seven engagements with the survey were left blank. These were not included in our analysis.

Participant Recruitment Strategies

Recruiting our sample was an ongoing effort between 2020-2021. In a later section we report the enormous impact COVID-19 had on our research and also the sampling challenges we encountered in our attempts at reaching our sample populations. We engaged in multiple strategies to raise public awareness about our work which we outline below.

Community Partnership

Our research design is similar to those implemented for the non-clinical intersex studies in Australia and in the USA.[313] Central to these, and ours, is the notion of “community partnership” – working with support and community groups to engage with, and gain access to, the intersex population.

In our case, we sought the support of *Intersex Ireland* - Ireland’s only intersex support group, established in 2016. There are less than twenty members in the group, one of whom is a member of our Steering Committee. Intersex Ireland is the second-largest intersex support group in Europe after *OII Europe – Organisation Intersex International Europe,* established in 2012. Their assistance with recruitment is an example of “derived rapport” which is a well-established strategy for reaching hidden participants[314] and is not uncommon practice in non-probability methods such as (1) snowball sampling, whereby one participant (the initial seed) connects the researcher to another participant(s) in their network who then subsequently connect the researcher to others and (2) in convenience sampling in follow-up studies.[315] However, snowball sampling like this is not without its own bias

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[313] Tiffany Jones, ‘Intersex and Families: Supporting Family Members With Intersex Variations’ (2017) 17 Journal of Family Strengths <https://digitalcommons.library.tmc.edu/jfs/vol17/iss2/8>.

[314] Amy Ellard-Gray and others, ‘Finding the Hidden Participant: Solutions for Recruiting Hidden, Hard-to-Reach, and Vulnerable Populations’ (2015) 14 International Journal of Qualitative Methods 1609406915621420 <https://doi.org/10.1177/1609406915621420> accessed 10 December 2020.

[315] Nita GM de Neve–Enthoven and others, ‘Psychosocial Well-Being in Dutch Adults with Disorders of Sex Development’ (2016) 83 Journal of Psychosomatic Research 57 <https://www.sciencedirect.com/science/article/pii/S002239991630040X> accessed 14 March 2022.

since a sampling risk may emerge because all potential participants are networked into Intersex Ireland's national support group hence the voices of those who may not be interested in affiliating themselves with a support group continue to remain excluded as will the voices of undiagnosed intersex people. This is a concern even in clinical-based research. Nonetheless, two large clinical-based intersex studies in Europe employed the use of self-help groups,[316] and support groups[317], as part of their recruitment strategies. Elsewhere, using a qualitative approach, van Lisdonk reports that all six of her intersex/DSD in-depth interview cohort "are or have been in contact with a patient organisation or support group" whilst all six of her focus group participants "are active in patient organisations or interest groups".[318]

Institutional Support

We engaged with our university's Marketing and Communications throughout our study. They were instrumental in operationalising national-level publicity campaigns for four important elements of our work (1) the development of our website, (2) launch of our online survey in July 2020, (3) our *Ireland Turns Purple* campaign in November 2020 (4) our online conference *Intersex 2021: A Vision For The Future* in April 2021. They also supported our online presence on Twitter and any other public engagement our team undertook such as interviews through traditional media channels (e.g. radio, magazine) to raise awareness about our research.

Public Awareness and Engagement

We undertook two significant national and international events that raised awareness about our research which we briefly outline here. For a more detailed account of our #IrelandTurnsPurple campaign and our conference, please see the Impact section below.

(1) #IrelandTurnsPurple, 8th November 2020

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[316] Lux and others (n 24).

[317] Robert Röhle and others, 'Participation of Adults with Disorders/Differences of Sex Development (DSD) in the Clinical Study Dsd-LIFE: Design, Methodology, Recruitment, Data Quality and Study Population' (2017) 17 BMC Endocrine Disorders 52 <https://doi.org/10.1186/s12902-017-0198-y> accessed 5 January 2021.

[318] van Lisdonk (n 19).

Purple and yellow are internationally recognised as intersex colours and feature on the intersex flag designed my global intersex activist, Morgan Carpenter.[319] To mark Intersex Solidarity Day, on 8th November, we embarked on an all-island campaign to have as many buildings across the country turn purple. Our intention was to raise awareness about what it means to be intersex. Seventy buildings turned purple and *#IrelandTurnsPurple* was trending on Twitter that day. Numerous publicity events were undertaken with the support of the DCU Marketing and Communications Department. We used all opportunities to promote our research.

(2) Intersex 2021: A Vision For The Future

Our international online conference was a key output from the project. It attracted enormous interest and was opened by the EU Commissioner for Equality, Ms. Helena Dalli. We also used this opportunity to promote our research.

Media Engagement and Social Media

On numerous occasions throughout the lifetime of the project our team members engaged in interviews for radio; the traditional print media (newspapers, magazines) and podcasts.

We established a Twitter account to position ourselves in the online social media space with the intention of raising awareness about what it means to be intersex. We actively promoted our work on Twitter through the creation of regular content such as highlighting a book an intersex person may have written, promoting a national event or supporting other key initiatives that were taking place. We also engaged in novel activities such (1) curating the Mother Fócloir Twitter account for one week and (2) hosting a 'Trans-Atlantic Tweet Chat' through the Irish language (*as gaeilge*) between our PI and an international intersex activist academic, Dr Janik Bastien-Charlebois, Université du Québec à Montréal. We used all opportunities to promote our research. Our efforts on Twitter were invaluable for raising awareness about our #IrelandTurnsPurple campaign.

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[319] Morgan Carpenter, 'The Intersex Flag' (4 June 2019) <https://morgancarpenter.com/intersex-flag/> accessed 14 March 2022.

Networking

We also reached out to our professional networks to promote our work. We expected this would facilitate recruitment of medical professionals but this sample was achieved via our recruitment advertising on Twitter and then by snowballing.

Sampling Challenges

The Intersex Community - A hidden population

No official register exists in Ireland recording the population and this has the potential to limit all types of investigations, particularly non-clinical ones. At best we have the broad UN estimate of intersex population variation being between .5 - 1.7%. Given the significant complexities and realities of intersex, we believe it would be an almost impossible task to put an accurate estimate on a total intersex population for the purposes of sampling. Conversely, records for every child diagnosed with an Austistic Spectrum Disorder (ASD) are held by medical and educational professionals in Ireland. Consequently, just by being known they can be provided for. When registers are available for an intersex population it has the potential to significantly impact on participant recruitment as clinical based studies have shown.[320] [321]

However, even when registers do exist, they may not fully capture a population. For example, in the case of restricted growth, Shakespeare and colleagues[322] in the UK noted that a person may have simply carried on with their life believing they were short without ever being given an official diagnosis of restricted growth. This means they remain invisible and would never feature on any official list or register such as the one held by the UK Restricted Growth Association (RGA). In their clinical evaluation of intersex people in Germany, Lux et al. acknowledge that the “rareness of a condition creates a serious challenge for research and patient care” because it further

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[320] Röhle and others (n 317).

[321] Lux and others (n 24).

[322] Tom Shakespeare, Sue Thompson and Michael Wright, ‘No Laughing Matter: Medical and Social Experiences of Restricted Growth’ (2010) 12 Scandinavian Journal of Disability Research 19.

compounds recruitment.[323] van Lisdonk's exploratory study of the "social situation" of being intersex in The Netherlands explained that "information was only obtained about people who were aware of their condition".[324]

Personal and social factors add further weight to our position that our main target population is indeed very much hidden – ninety-three per cent of intersex people who participated in the World Bank study in southeastern Europe said they are "never or rarely open about their identity"[325] and only two per cent "reported that they are completely open about their gender identity of being intersex"[326] Much of this careful, management of one's self, "is likely related to an overall feeling of unsafety that LGBTI respondents expressed"[327] in the research and their perceptions that intolerance is high,[328] acceptance is low,[329] and discrimination is "either fairly common or very common".[330] Moreover, the fear of violence is very real. The very real and hidden nature of our participants was an important finding in our work which we discuss later.

Ethics

Ethical Approval

Ethical Approval was granted for the study by the DCU Research Ethics Committee (REC) in 2019. The COVID-19 pandemic restrictions meant we had to conduct interviews online using zoom and/or telephone. Our submission to the DCU REC for an amendment to facilitate this was approved in May 2020. The following outlines how we adopted our procedures and protocols.

DCU Research Ethics Committee Amendment

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[323] Lux and others (n 24).
[324] van Lisdonk (n 19).
[325] World Bank (n 13) 2. At p2.
[326] World Bank (n 13). At p18.
[327] ibid 2. At p13.
[328] ibid. At p28.
[329] ibid. At p31.
[330] ibid. At p34.

The purpose of this was to establish a new protocol to conduct online/telephone interviews with our population given that the COVID-19 pandemic prevented in-person meetings.

Do you wish to amend your approved study?
If so, please provide details of the proposed amendments and a justification for why this is requested.

Yes.

COVID-19 social distancing measures have had an enormous impact on our fieldwork. In-person interviews have stopped completely, and no progress has been made on this unit of work for more than two months. No further work of this nature can proceed until social distancing measures ease and it is deemed safe to meet. Furthermore, the University, as a 'safe space' in which to conduct interviews remains closed further limiting our efforts at engaging with our sample population.

We wish to open up alternative technology-based channels of communication to facilitate conducting interviews with our key sample group – specifically, the intersex population.

We request approval to conduct Zoom/Skype or telephone calls (inc. using WhatsApp) to facilitate our fieldwork.

To ensure potential participants can give informed consent, we propose the following protocol:

1. Participants express interest in participating via email.

2. Team replies and attaches a copy of Plain Language Statement with instructions about the study and communicating any queries.

3. Participants then email Team members and confirm they have understood what is involved and are agreeable to interview via Zoom/Skype/phone (inc. WhatsApp) – whatever their preferred medium may be. This email will be accepted as their

informed consent in the absence of not being able to provide their actual written signature on paper.

4. As per previously approved protocol, after the interview concludes, the participant will receive an email from the Team and containing the contact details for Trish Toal (Counsellor), if they choose to avail of this follow-up service.

Follow-Up Procedures

We knew our intersex sample were a vulnerable group. We also knew our interviews could have a trigger effect. In order to safeguard our participants' welfare, we established a follow-up procedure. We engaged with a counsellor who had expertise in working with sexual minority clients. This counsellor had also completed Masters'-level research on the subject of intersex. We had business/contact cards printed with the counsellor's details on them. These would be given to participants at the end of each interview if the participants felt the need to speak confidently to the counsellor after their interview. When face-to-face interviews were impossible to conduct due to COVID-related restrictions, we provided the counsellor's contact details to participants in an email. We can confirm the counsellor's services were used following interviews. Participants were very grateful for this service.

Researcher safety during research

Sometimes intersex can be a highly-charged topic. As noted previously, the terminology can be subject to debate. Multiple groups have vested interest in the area such as academics like ourselves, intersex people, their families, activists, medical professionals, and legal professionals. Consensus is not always the reality.

We wish to acknowledge that the overwhelming majority of our public and academic engagements have been positive. However, and regrettably, we feel obliged to detail some negative experiences relating to our work on the Intersex Mapping Project.

We were 'trolled' on social media and so were our supporters and, by association, an intersex activist who has made a significant contribution to Irish intersex studies. This 'trolling' involved harmful and deeply personal attacks launched against our PI and the intersex activist on social media. This took place over multiple social media platforms.

Moreover, through our Twitter account, some of our corporate supporters of our #IrelandTurnsPurple campaign were identified. Our supporters were trolled, and our reputations were called into question. Social media trolls ridiculed their support of our research and the campaign. The trolls also asked our supporters for money for their own causes and charities which were based in another country. Supporters contacted us asking if we were affiliated with these individuals and also asked for help in terms of how they should respond. This was a professionally embarrassing situation we found ourselves in and it was harmful for us and our supporters. We were persistently 'trolled'. When we posted our 'Conference Programme', attendees' abstracts were targeted and subject to fierce commentary on social media. We consulted with our DCU Communications colleagues for advice in terms of how to deal with the social media negativity. After much consideration, and with regret, we withdrew from social media.

Furthermore, on a number of occasions we received threatening and intimidating emails demanding that we withdraw/reformulate our research. It was clear to us that our work was not 'being read' in its proper context and subject to the trolls' limited interpretation of what constitutes intersex.

The Impact of COVID-19 on our research

We launched our online survey in mid-February 2020 as the world began to take serious note of the coronavirus spread. We completed our first in-person interview in early March. The participant took away a hard copy of the survey and noted that they would follow-up with us at a later date. A meeting was held with our University's Marketing department on 2nd March to discuss (1) development of an official DCU website which would provide us with greater visibility and reach, (2) a plan to formally launch our online survey and (3) a plan to launch our conference – scheduled for November 2020 – in September 2020. Our team had an informal meeting on 3rd March and on the 5th March one team member elected to remain at home due to their vulnerable status. One week later, our University closed under instruction from the Irish Government as did all primary and post-primary schools in addition to cultural institutions (i.e. museums).

As was the case with most other education institutions, teaching and learning moved online overnight. This was an intense and stressful transition given that most staff and students were untrained in online teaching and learning technologies and fora. Moreover, all higher education students were expected to commence learning from home. Many staff and students were ill-resourced (e.g. poor WiFi) to adapt to the immediate changes to teaching and learning. Staff who were parents now found themselves at home caring for and schooling their own children whilst trying to work from home. This was the reality for two team members. A third team member was involved in the Government's public health response. At that point, uncertainty was the only thing we were certain of.

Plans to develop our own official University website no longer existed since our University's IT support services were now redirected to support teaching and learning efforts. In-person interviews ground to a halt. Ireland gradually commenced its unprecedented 'lockdown' and healthcare workers, one of our sample populations, were called to the frontlines.

On 23rd April 2020, we were notified that our University's Research Ethics Committees were working to "develop a comprehensive set of requirements to support researchers who wish to move their research to online platforms". With immediate effect we commenced our application to submit an 'amendment' to our original ethics application. However, we did not arrive at this decision lightly. We held numerous online meetings to discuss this prospect. We wondered about how to ensure we would safeguard our participant's welfare while not being present in their company. How would we pick up on cues? Would we be able to read a person's uncomfortableness? We also had to consider the more official aspects of our research – how would we obtain a signed consent form? How would we get a consent form to the potential participant? Following much discussion and decision making we arrived at a new working protocol for obtaining consent and interviewing people (See Appendix 1). Our amendment was approved in June 2020. The reality of this meant that for almost three full months we could not engage in any in-person interviews, including our follow-up interview with our first participant.

Given that medical professionals were called to the frontlines and were working in unprecedented circumstances, we determined it would be unethical to attempt to engage in a targeted recruitment campaign of medical/healthcare professionals who have experience working in the intersex field. We did however continue with our ongoing and general efforts on social media. Our first medical professional engaged with us having seen a recruitment notice we posted on Twitter.

In an attempt to facilitate greater reach with potential participants, we commenced work on developing our official DCU website. Work on this commenced in July 2020 and was an ongoing effort. The conference launch we scheduled for September 2020 was cancelled. Our Conference was also postponed until April 2021 and we had to begin planning for a 'hybrid' conference given the likelihood of ongoing COVID-19 restrictions. For example, one room in our chosen conference could accommodate 120 delegates according to pre-COVID capacity standards. Applying COVID-19 social distancing measures meant it could accommodate 16. Moreover, we now were faced with a significant bill, in excess of five thousand euro, for costs-related to providing the technology and IT support in our conference venue so we could move proceedings online in order to reach out to our international delegates who would no longer be able to travel. Before COVID-19 upended life as we knew it, delegates from eighteen countries around the world had registered to attend our conference in Dublin. As of January 2021, we were faced with the reality that international travel would still be restricted in April 2021 and our entire conference proceedings moved online.

In July 2020, we commenced online interviews using Zoom and were successful by the 'new normal' standards through which we were navigating. We were also able to re-engage with our first participant. Suspension of inter-county travel within Ireland meant our team members could not travel to meet that participant in a safe space of their choice and the University still remained closed to such activity. The second interview with our first participant took place over Zoom as did all other interviews for the remainder of our research.

Due to the enormous challenges brought about by the pandemic we were granted a one-year, cost neutral extension by the Irish Research Council to complete our work.

6

The Power of Phenomenology

Chapter 6: The Power of Phenomenology

At the heart of our study was an invitation to people to tell us their story of being intersex. We ask one question: can you please tell me your expereince of being intersex? This is the creation of a space by which the person is free to tell their story about being them. There are no preconceived ideas or notions entailed in the question. There are no questions that we seek or require to be answered. It is a free canvas through which the storyteller paints their own picture, their reality for the listener. For many of us we are never really asked, who are you? Or tell me about yourself? We may indeed be familiar with the: Who do you think you are? But to be genuinely interested in the person as they present themselves to us is the central aspect of hermeneutic phenomenology. Gray states '[f]for him [Heidegger] the spoken word is greatly superior to the written.'[331]

It is within the spoken word that the nuances of life are articulated. The hearer is welcomed into the life of the speaker where the hidden is revealed precisely through the way it is spoken. The hearer that is the interviewer navigates the teller's journey with the teller traversing the highways and byways of their life. As researchers we immerse ourselves in the story as told of the lived experience of the phenomena under investigation. Later the interviewer will reflect upon the story and transform it for wider public consumption while remaining true to the storyteller.

At the *Intersex 2021 - A Vision For The Future* (21 & 22 April 2021) conference, we gave a paper with a similar title to this chapter. The paper centred on the concept of Being Human from a Heideggerian perspective. Indeed the question raised was: what was it like to be human? A few days after the conference the team received an email from a participant who attended the paper. Commenting on their own life, they revealed:

> This has been one of the challenges for me; how to express what it's like to be me [correspondent]

In the context of being human, the correspondent continues

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[331] Glenn J Gray, 'Introduction' in Glenn J Gray (tr), Martin Heidegger, *What is called thinking?* (Perennial, Harper and Row 1976). At piv.

> Throughout my life including my encounters with the medical world I was never asked, "How do you feel?" or " Tell me about yourself ". It seems almost too obvious to miss this critical question because our inner world is as important as our physical outer world [correspondent].

Indeed, few are asked in a medical setting to reveal who they are from their perspective. In other settings we may upon greeting someone ask them: How are you? If the person begins to respond they may have broken the social norms of greeting. The response in an Irish setting may be to say, I am doing fine or great, thank you but never revealing the true nature of how we are. But a detailed response is not what is socially expected. We have social cues for interaction. There are some settings in which these cues are not relevant, for example when a doctor asks, 'how are you?', there is an expectation that the patient/client will respond relating to the reason why they are in a consultation in the first place. Heidegger regarded languages '[a]s that sphere in which man can dwell aright and make clear to himself who he is.'[332]

By the doctor asking the question, the patient/client is provided with an opportunity to not only make themselves known to the doctor but to themselves. When you are asked the question 'how are you' from an interest and invitation to speak, the responder has the opportunity to reflect on themselves and to make themselves known. This is why Heidegger considers language the gateway to understanding of oneself and for others to insight into who we are.

Indeed, Ward and Savulsesu indicate that a service based on patient-centred care where a simple question enquiring about how one is leads to trust and mutual respect.[333] This may lead to the incorporation of the patient-as-person and doctor-as-person,[334] therefore, being human embraces both parties in the encounter. It is through language that we articulate who we are which may not be what a medical profession wants to

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[332] ibid. At pvii.

[333] Michael Ward and Julian Savulescu, 'Patients Who Challenge' (2006) 20 Best Practice & Research. Clinical Anaesthesiology 545 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7185597/> accessed 27 March 2022.

[334] N Mead and P Bower, 'Patient-Centredness: A Conceptual Framework and Review of the Empirical Literature' (2000) 51 Social Science & Medicine (1982) 1087.

know; rather it might be easier for them to deal with the ailment presented. The correspondent suggests that they were never invited in a healthcare setting or indeed any other settings to articulate who they were. Through this the self is never revealed to the other but more importantly as Heidegger suggests that it is in the articulation that we come to know ourselves. It is the negation or the unrevealing of the self when it really matters that leads to a hiddenness of the truth of who we are to both ourselves and others. Indeed, in a health care setting, when the health care provider does not ask how the patient is or how they experience the condition that they are presenting with, it removes the possibility for the health care provider to review, reflect and through thinking make changes, in how they as professionals engage with intersex people or indeed any other person they encounter in their practice. This level of engagement is something that our correspondent would have welcomed and indeed all the participants in this study.

Hermeneutic phenomenology is centred on the task of thinking.

> We come to know what it means to think when we ourselves try to think. If the attempt is to be successful, we must be ready to learn thinking.[335]

Our correspondent observations reflect Heidegger's remarks that thinking creates a road of discovery of who we are as well as the nature of our Being.[336] This is in keeping with the method as it requires us to think, to uncover and to bring forth that which needs to be thought about. Through the interviews thinking brings forth that shared meaning(s) and understanding(s) of how the phenomenon of being intersex as they come to know it. A few participants in our study returned to their story a second and a third time. In returning to the story the participant reflected upon what they had shared and, in some cases, sought to clarify, adding to their story. The going back and forth of the participants is akin to Heidegger's hermeneutic circle. While the hermeneutic circle is commonly articulated as the method chosen as

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[335] Martin Heidegger, *What Is Called Thinking?* (Glenn J Gray tr, Perennial, Harper and Row).

[336] Gray (n 331). At pvi.

> analysis [it] is a continuous circular and reflexive process where themes emerge, and the researcher returns to the data and starts to re-read it.[337]

We suggest that some participants in our study engaged in their own hermeneutic circle through a reflective process, returning to their story, further sharing their understanding and meanings with us. They dwelled with their story they had imparted to add illumination later. For example, Darcy returned to their story twice with a few emails in between. Prior to the ending of the third interview, they were asked if there was anything else they wished to further explore their story in any way, they stated:

> No, I can't really think of anything. I think I am good, I have covered everything. But that really is everything now. I don't think there is any more that I can possibly tell but if there is I will come back to you and tell you but thank you for giving me the opportunity to come back and tell more of it. [Darcy]

It is in the dwelling with the story of the self that Darcy could make clear to themselves who they are. In the telling of their story, the reflective process opened up avenues through which the self was explored and shared. It gave meaning and understanding to their life as an intersex person. Meaning and understanding as they had come to know it through the articulation of this life.

While Darcy had come to tell their story in their own way and in parts, there was also an underlying reason why they felt they could come back

> Part of the reason why I am committed to doing this and doing it so fully is because I appreciate the fact that you guys want to do it for fully and you are being led by intersex people. I have never done a research study that is so led by intersex people like myself and that is why I am happy to do it. [Darcy]

Returning to the story reflected the trust that was placed in us to reveal their story to others in ways that were true to their meanings and

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[337] Dibley and others (n 299). At p127.

understandings. We are in effect “bearing witness to their stories’[338] through the opportunity to ‘review, reflect and inspire new thinking’.[339]

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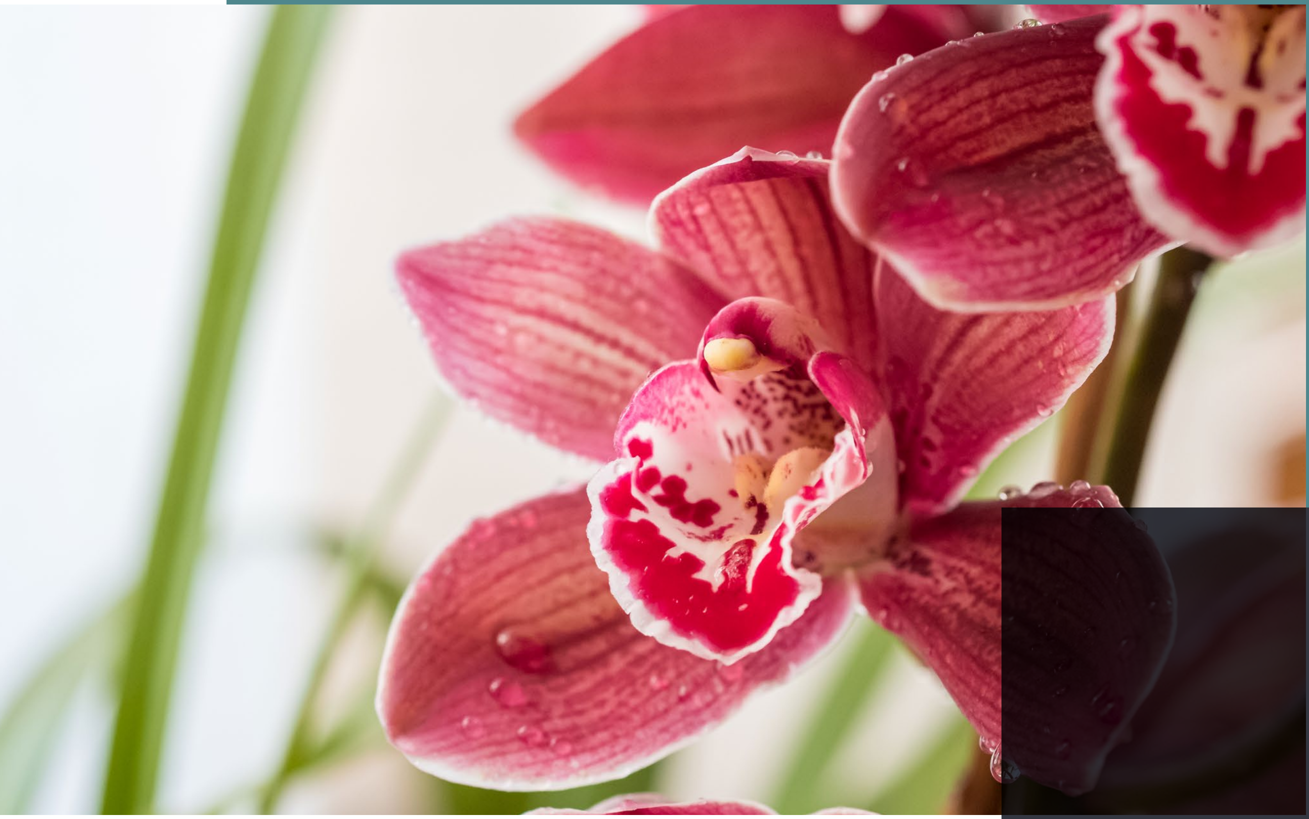
[338] Susan Crowther and Elizabeth Smythe, ‘Open, Trusting Relationships Underpin Safety in Rural Maternity a Hermeneutic Phenomenology Study’ (2016) 16 BMC Pregnancy and Childbirth 370 <https://doi.org/10.1186/s12884-016-1164-9> accessed 27 March 2022. At p2.

[339] ibid. At p2.

7

Intersex people in Ireland - a hidden population



Chapter 7: Intersex People in Ireland - a hidden population

Hidden participants are considered 'hard-to-reach' from both qualitative and quantitative perspectives across multiple disciplines.[340] However, hidden populations can also refer to those who do not wish to be found or contacted (e.g. illegal drug users or migrants or homeless people)".[341]

Hidden populations are usually without a sampling frame such as membership lists,[342] or other "centralised sources of information"[343] further compounding (quantitative) efforts to obtain a sample that will deliver data with statistical power.[344] The absence of a sampling frame is acknowledged by the World Bank in relation to the LGBTI population.[345] As we noted earlier, no official register of intersex individuals exists in Ireland thus problematising access. Interestingly, if the UN intersex prevalence estimate of .5 - 1.7% is applied to Ireland's total population of 4,761,865 million,[346] it would reflect a potential intersex population (sampling frame) of between 23,809 – 80,952.

We interpret our own sample – intersex people and their parent(s)/partner(s) – as hidden participants. Considering intersex people in this way is not new. In Australia, Jones et al. specifically explain that

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[340] Nadia von Benzon and Lorraine van Blerk, 'Research Relationships and Responsibilities: "Doing" Research with "Vulnerable" Participants: Introduction to the Special Edition' (2017) 18 Social & Cultural Geography 895 <https://doi.org/10.1080/14649365.2017.1346199> accessed 22 March 2022; Ellard-Gray and others (n 314); Sue Thompson and David Phillips, 'Reaching and Engaging Hard-to-Reach Populations with a High Proportion of Nonassociative Members' (2007) 17 Qualitative Health Research 1292; Robert Magnani and others, 'Review of Sampling Hard-to-Reach and Hidden Populations for HIV Surveillance' (2005) 19 AIDS S67 <https://journals.lww.com/aidsonline/Fulltext/2005/05002/Review_of_sampling_hard_to_reach_and_hidden.9.aspx> accessed 15 December 2020; John K Watters and Patrick Biernacki, 'Targeted Sampling: Options for the Study of Hidden Populations' (1989) 36 Social Problems 416 <https://www.jstor.org/stable/800824> accessed 4 January 2021.

[341] Abdolreza Shaghaghi, Raj S Bhopal and Aziz Sheikh, 'Approaches to Recruiting "Hard-To-Reach" Populations into Re-Search: A Review of the Literature' (2011) 1 Health Promotion Perspectives 86. At p87.

[342] ibid; Douglas D Heckathorn, 'Extensions of Respondent-Driven Sampling: Analyzing Continuous Variables and Controlling for Differential Recruitment' (2007) 37 Sociological Methodology 151 <http://www.jstor.org/stable/20451134> accessed 10 December 2020.

[343] Thompson and Phillips (n 340).

[344] Watters and Biernacki (n 340).

[345] World Bank (n 13). At p8.

[346] Central Statistics Office (CSO), 'Census 2016 Summary Results – Part 1' (Central Statistics Office (CSO) 2017) <https://www.cso.ie/en/media/csoie/newsevents/documents/pressreleases/2017/prCensussummarypart1.pdf>.

historically, intersex people have been a difficult to reach population.[347] Recent research from the USA acknowledges that intersex people are "… often an invisible and forgotten group."[348] Being hidden in this way can cause vulnerability.[349] Furthermore, findings from a phenomenological study involving ten parents of intersex children documented other reasons such as secrecy and shame that compound intersex people's invisibility,

> …the silence that surrounds the phenomenon of intersexuality, including the surgical solutions, results in secretiveness and invisibility (cf. Boyle et al., 2005). Down's syndrome on the contrary is well known to everybody and there is a vocabulary to discuss the condition and the experience of living with it. If intersexual phenomena were not associated with silence and shame, parents and doctors could possibly talk and think more freely about intersex, and thus be able to consider different possibilities and even alternatives to infant and child surgery.[350]

Unsurprisingly, the hidden nature of the intersex population, corresponds to lengthy recruitment stages and small sample sizes in both quantative and qualitative research. In the German/Austria and Switzerland DSD study, Lux et al. reported that recruitment commenced in December 2004 and data collection ceased in December 2007 when a total sample of 439 participants was achieved.[351] In another six-country European study, note that recruitment of 1,161 DSD patients to their clinical evaluation study took nineteen months (02/2014 – 09/2015).[352] In the Netherlands, de Neve-Enthoven et al. had a sample of 120 and research was undertaken from 2007-2012.[353] Crucially, researchers in these studies had access to their patient registers (sample frames), nonetheless, data collection was a years' long process. Similarly, qualitative data collection (narrative interviews) with twenty-two parents of intersex children in the German-Israeli study took approximately five years (2009-2016) and was facilitated through the

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[347] Jones and others (n 87). At p56.

[348] Rosenwohl-Mack and others (n 307).

[349] EU Fundamental Rights Agency (n 39). At p7.

[350] Zeiler and Wickstrom (n 9). At p373.

[351] Lux and others (n 24).

[352] Röhle and others (n 317).

[353] de Neve–Enthoven and others (n 315).

use of support groups.[354] Schützmann and colleagues in their small pilot study in Germany recruited thirty-seven participants.[355] A qualitative study in the Netherlands generated a sample size of seven intersex participants plus one focus group of intersex activists.[356] Another small phenomenological study in the USA examining intersex people's expereinces of academic and careers guidance, generated a sample size of ten individuals and a small scale study in New Zealand engaged with three intersex people.[357] The non-clinical Australia survey had a sample of N=272 intersex participants from a total Australian population of approximately 23.8 million.[358] And the non-clinical USA intersex survey had a valid sample of N=198 from a total population of approxaimatley 329.5 million.[359]

Our research is in keeping with this international situation. We had a sample size of seven intersex participants for interviews, two of whom were not from Ireland. Our survey returned thirty-eight (n= 38) valid responses from a total of 58 engagements.

37 individuals responded 'Yes' to the following item

Were you born with congenital differences in your sex characteristics?

One person replied 'Unsure' but we determined that their identification with the intersex variation "gonadal dysgenesis (partial & complete" warranted inclusion. This individual further supported their variation by writing "streak ovaries" in the optional text box response. This person's inclusion as intersex the number of valid response to 38. Twelve responses selected 'No' to the above question. They were not included in our valid responses. A further seven engagements with the survey were left blank. These were not included in our analysis.

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[354] Limor Meoded Danon and Anike Krämer, 'Between Concealing and Revealing Intersexed Bodies: Parental Strategies' (2017) 27 Qualitative Health Research 1562.

[355] Karsten Schützmann and others, 'Psychological Distress, Self-Harming Behavior, and Suicidal Tendencies in Adults with Disorders of Sex Development' (2009) 38 Archives of Sexual Behavior 16 <https://doi.org/10.1007/s10508-007-9241-9> accessed 8 January 2021.

[356] van Lisdonk (n 19).

[357] Drew MacKenzie, Annette Huntington and Jean A Gilmour, 'The Experiences of People with an Intersex Condition: A Journey from Silence to Voice' (2009) 18 Journal of Clinical Nursing 1775 <https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2702.2008.02710.x> accessed 6 January 2021.

[358] Jones and others (n 87).

[359] Rosenwohl-Mack and others (n 11).

As noted earlier, some intersex variations are very rare and their frequency in the population may be very low. For example, some variants of Klinefelter (e.g. 48, XXXY, 49, XXXXY) can occur at a frequency of 1 in 50,000 - 85,000 or fewer newborns. This compares to MRKH which is more prevalent affecting approximately 1 in 5,000.[360] The reality of rarity emerged in our findings as it pertains to ambiguous genitalia thus demonstrating its low prevalence. One health professional gave an example of this when they drew on their experience of the number of births in the hospital in which they work. When discussing this rarity, they also noted the overall, general frequency that they meet their patients. Interestingly, they too noted the absence of a "better database" and that formulating one is a future goal.

> I think babies born with ambiguous genitalia at birth I'd say there is maybe one or two a year. We deliver in (Irish Maternity Hospital) maybe 8,500 babies a year. Again the paediatricians they'd give you a better indication but I'd say maybe one or two a year in our population. Then thinking about the older girls - the other thing I am interested in, and I know the terminology is a big discussion but DSD is what I would have been taught and at all the meetings I go to that is what it would be referred to, and again looking at the Chicago consensus, the classification - if I was to include the XY, the XX and the other DSDs I think I am probably seeing a patient every week with some form of DSD. Again Turner's patients are included in that. So probably one a week, I would imagine. It would be nice to have a better database where we could collect information and those are goals for the future. (Healthcare Professional 2).

And when drawing on their own international experience, Healthcare Professional 2 also noted that case incidences were "relatively small". Health Professional 1 noted that in terms of "new babies" being seen with intersex characteristics/VSC "we could probably see up to five a year". They noted that it was "extremely rare" for an older child to be referred - "there may be one to less than one a year". When asked about the frequency of case incidences, Healthcare Professional 3 explained that

> So maybe 5 per year in total on the ward. So the answer is no we don't get many.

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[360] Herlin and others (n 6).

Moreover, the issue that also arises is that in addition to very low incidences, each child that presents is unique. Healthcare Professional 1 noted

> I have never seen any two DSD the same. They are all so individual. You can't read one from one book because they are so different, each and every one of them. (Health Professional 1)

Similarly, Healthcare Professional 3 noted

> when it comes to the child born with DSD each child is different, like each child is different no matter what they have. But in this particular scenario every single child would represent a new challenge for each person involved in their care.

The rarity issue also has implications in another way in terms of being known here in Ireland and seeking support as Healthcare Professional 2 also explained. This example further demonstrates why registers and support groups are limited here in Ireland.

> I think it is easier nowadays to reach out and to get that support. Even though for some of these conditions if they are very rare the support might not be in Ireland. Sometimes the support groups are through the UK or through the States. I have patients that have flown over to America to join a support group and who have then become advocates for local support groups after that. (Healthcare Professional 2)

Furthermore, it is also important to acknowledge that some intersex adults may not realise that they are intersex. While some intersex variations may be detected before birth (e.g. Klinefelter Syndrome and Turner Syndrome), it is not unusual for some people to learn they are intersex as adults through what is termed an 'incidental diagnosis' when engaged with healthcare services relating to a separate issue/concern. This happens because some intersex variations, such as chromosomal ones, may not be identifiable at birth (e.g. some forms of Turner Syndrome may be subtle and not discovered until adulthood). Lux et al. acknowledge that the "rareness of a condition creates a serious challenge for research and patient care".[361] van Lisdonk's exploratory study of the "social situation" of being intersex in The Netherlands explained that "information was only obtained about people who were aware of their condition".[362] It is clear from the literature and indeed from our own research here in Ireland that engaging with such a hidden and vulnerable population presents enormous challenges.

Who are our intersex/VSC population?

Our intersex population emerged from two data-sets. Our interviewees (n= 7) and our survey respondents (n= 36). Both groups are detailed separately in the following tables.

Four of our interviewees also completed our survey and are included in the survey sample of n= 36. Given the entirely different nature of the data-collection methods and research instruments used, and due to the fact that we cannot entirely identify these four individuals from the anonymous survey data-set, they feature in our total survey sample.

Intersex variations identified by our interview participants

Table 7.1 Intersex variations identified by our interview participants

Pseudonym & Age	**Intersex Variation**	**Location of Experience**
Alan (40+)	Hypospadias	Ireland
Becca (30s)	Androgen Insensitivity Syndrome (AIS) ("Undescended Gonads", no uterus, no ovaries)	International

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[361] Lux and others (n 24).
[362] van Lisdonk (n 19).

Claire (40+)	Ambiguous Genitalia	Ireland & International
Darcy (20s)	MRKH Mayer-Rokitansky-Küster-Hauser Syndrome	International
Emma (40+)	Unknown/variation not disclosed	Ireland
Frankie (40+)	Unknown/variation not disclosed	International
Gina (40+)	PCOS Poly Cystic Ovarian Syndrome	Ireland

Intersex variations identified from our survey sample

A total of 21 intersex variations were identified among our survey sample (N= 36). Ten respondents selected more than one variation.

Table 7.2 Intersex Variations identified by our survey participants

	Intersex Variation	Number or respondents with this variation
1	XXY/ 47	3
2	5-alpha reductase deficiency (5-ARD)	1
3	Clitoromegaly (large clitoris)	2

4	Congenital Adrenal Hyperplasia (CAH)	3
5	Complete Androgen Insensitivity Syndrome (CAIS)	5
6	Gonadal dysgenesis (partial & complete)	2
7	Hypospadias	2
8	Jacobs/ XYY Syndrome	1
9	Kallmann Syndrome	1
10	Micropenis	3
11	Mosaicism involving "sex" chromosomes	1
12	MRKH (Mullerian agenesis; vaginal agenesis; congenital absence of vagina)	2
13	Ovo-testes (formerly called "true hermaphroditism")	2
14	Partial Androgen Insensitivity Syndrome (PAIS)	3
15	Polycystic Ovarian Syndrome	1
16	Progestin Induced Virilization	1
17	Swyer Syndrome	1
18	Turner's Syndrome (one X chromosome)	2

19	XY-Turner’s Syndrome	1
20	Unknown	3
21	Other*	8
	Total	48

* 8 respondents selected ‘Other’ and three individuals further supported their response by providing additional information in the space provided.

> I was born without a womb and my ovaries were testes in which one developed a cancerous tumour. Apologies I don't know the correct medical terms for this as none were given 32/33 years ago when the diagnosis was made (22)
>
> Small underdeveloped vagina and severally delayed puberty (10)
>
> Hermaphroditism (6)

Our Healthcare Professionals

Four healthcare professionals agreed to participate in our research. They are members of a very small team of healthcare professionals caring for intersex people/those with VSC in Ireland. Our sample has a breadth of medical and mental health expertise. Some also have experience from internationally renowned hospitals. To ensure their anonymity we do not identify them by specialism. We simply refer to them as Health Professional 1, 2, 3 and 4.

Identifying with terminology usage here in Ireland

As noted in the introduction, the use of terminology around intersex variations can prompt highly-divise and emotionally-charged debate that can be harmful for some. While we have used the term intersex throughout this report we wish to acknowledge that this is not the preferred terminology for some of our participants, in fact two were deeply opposed to it as the survey data demonstrates. Yet, as Table 7.3 illustrates, intersex was the term most frequently selected by our sample as the one researchers should use.

Table 7.3. Terminology researchers should use

What terms should researchers use for people born with congenital sex variations. Tick any/all that apply.	Frequency
Intersex people	8
People with variations in reproductive development	5
People born with congenital sex variations	4
People with diverse sex development	4
People with atypical congenital sex characteristics	3
People with atypical sex development	3
People with a Disorder in Sex Development (DSD)	2
People with congenital reproductive development conditions	1
Other:	3
Other suggestions detailed: "Variations of Sex Development"	2

When invited to offer suggestions as to other terms researchers should use, some participants suggested the following:

> Please don't use intersex as it hurts so many of us, especially those who don't engage in activism and hate the way we are misrepresented. I use AIS or difference of sex development (18 - variation, Complete Androgen Insensitivity Syndrome (CAIS))

> I personally think the word Intersex, suggests the person is confused about their sexuality. In my opinion, it sounds like a negative word. I think there should be a word that reflects the loss of sexual identity eg like miscarriage when a woman looses a baby. I think congenital sex variations is a good definition as it goes back to the womb... it is not the persons choice, it is just how they were made. (22 - variation, Ovo-testes (formerly called "true hermaphroditism"), Other)
>
> Male (incomplete) not fully virilized (24 - variation, Hypospadias,Micropenis)
>
> Variations of sex development. Please stop using intersex as I find it really upsetting. (28 - variation, Complete Androgen Insensitivity Syndrome (CAIS))
>
> Intersex people, People who are intersex, the intersex community, persons of intersex experience. The pathologicalisation of my body and identity is not anyone else's to define. (32 - variation, MRKH (Mullerian agenesis; vaginal agenesis; congenital absence of vagina))

The issue of terminology emerged again in responses to a final item on the questionnaire asking if there was anything else participants would like to share with us. Two participants with CAIS believe that the term intersex is inappropriate.

> Please stop calling me intersex and misrepresenting who we are (18 - variation, Complete Androgen Insensitivity Syndrome (CAIS))
>
> Please stop calling us intersex. Please stop conflating us with gender identities. AIS is not to do with gender. Please stop saying that this has nothing to do with a medical issue - it is a medical issue and not something that you can identify as - people with CAH have lifelong medical issues that are dangerous to ignore. (28 - variation, Complete Androgen Insensitivity Syndrome (CAIS))

Interestingly, one of our international participants noted that they too had AIS but does identify with and embraces the word intersex. They are married to a man and on Intersex Awareness Day they “came out” as being intersex to their family and friends. Becca explained

> I finally came out [on] October, 26th for the Intersex day as well as that November date as well. So I came out on October 26th 20XX officially to all my family, all my friends, I told them I was intersex. I had no choice, I was born this way and it's who I want to be and who I want to explore. And I am not comfortable with binary roles and standards for people and I just want to be myself. And any information or any education I can find on intersex people I love to read, I love to spread it around. When I started getting into the research of intersex people I couldn't believe how many intersex people there actuallly were on the planet. It just blows my mind. I've never personally met another intersex person, ever, so it just blew my mind. (Becca)

Both Becca and Darcy were in favour of the term 'intersex' as one that is easily identifiable.

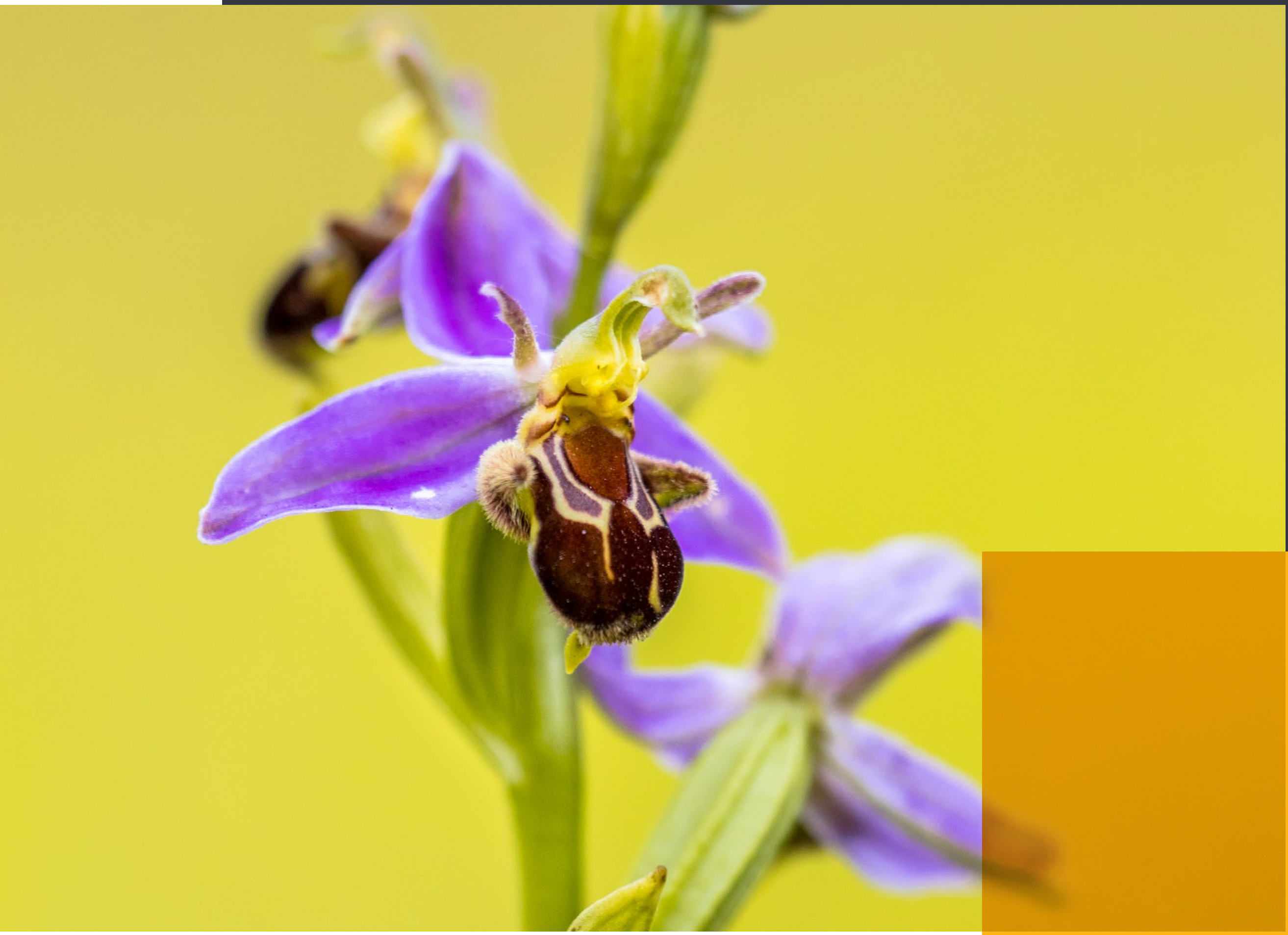
> I prefer the term intersex. In fact I am very firm on that. I know some people have different terms that they prefer. I also identify as intergender because of that and I feel quite strongly that that should only be a term that intersex people can use. That is just my personal experience. If I met somebody that told me Oh i'm intergender I'm not intersex' I'm going to jump down their throat. But you know internally I feel quite a strong sense of that. … And there is debate around whether MRKH fits in as an intersex condition as well. That is frustrating too. It is under the DSD umbrella and some people say it is intersex, some people say it is not. But as far as I am concerned most of the literature that I have read considers it as such. And so I will use the word. But that really annoys me as well, the discrepancies in what people consider is intersex and what isn't. That makes you feel even more othered. And the reason I don't think other people consider MRKH as intersex sometimes is because there is not a chromosome issue but actually the definition of intersex or DSD is chromosomes, reproductive organs external and or internal genitals, so that covers everything. MRKH should absolutely be considered as an intersex condition. And I think more literature considers it one than not. But there is still literature that doesn't consider it, and I find that quite offensive really. I find that really, really quite offensive and annoying. … There is a huge discrepancy as to whether it is considered an

> intersex condition or not. Some of the literature I have read lists it as one. Some of the shows that I've watched list it as one. And some of them don't. There's so much discrepancy around all the research that has been done because there is so little of it I think, I get frustrated by the lack of it all the time as well. (Darcy)

We do appreciate that the debate about terminology will remain an ongoing one. Through all our engagements with those who have variations of sex characteristics, we used their preferred terms and respect that it is everyone's individual right to choose terminology most appropriate to them.

8

Knowing and Understanding Oneself



Chapter 8: Knowing and Understanding Oneself

Learning and knowing about oneself

Intersex is a complex umbrella term that encompasses more than thirty ways the human body can differ according to its sex characteristics. Enormous variation exists relating to this range of differences. It is generally accepted that while some variations may be evident in-utero and at birth, others may become known until later in the life-course. While many people become aware of their difference during adolescence, other people may live their lives never knowing about their variation.[363] Consequently, learning about oneself becomes a complex process. Interestingly, twenty-five of our survey participants responded to an item asking

> *At what age did you start to learn about/become aware of being intersex / your congenital variation?*

Only 4 participants (16%) reported that they "Always Knew". Almost half (12/25, 48%) learned during their adolescence. Eight individuals (32%) learned about their variation in their twenties and one person (4%) learned about their variation in their sixties. Furthermore, the way in which our participants learned about their variation also differs with 58.3% (n= 14) reporting that "someone told me" and 41.7% (n= 10) reporting that "I discovered this myself".

Some participants elaborated on their responses and these too vary.

Participants who learned about their variation themselves provided further insight about this experience. They explained:

> I found divergence in my birth certificate and later my mom told me. (33 - intersex variation, PAIS)

> first heard the term in a law lecture around gender at the time of the same sex marriage referendum in Ireland and more recently heard Dr.

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[363] Dreger (n 221).

> Tanya being interviewed on radio. (19 - intersex variation, micropenis)
>
> I started googling the medication I was put on as well as other differences I had noticed about myself (10 - intersex variation, unknown/other ‘underdeveloped vagina’)
>
> I knew I had TS (Turner’s Syndrome…because I read it on a doctor's notes. I learnt the word intersex at 19 because I was engaging in LGBT+ activism and so researching queer topics. Then I realised it applied to me. (35 - intersex variation, Turner’s Syndrome (one X chromosome)).

For those who were told about their variation, this involved a medical diagnosis. They describe their experiences

> First made aware that I was different at 14 but was not told anything or informed about what was going on. Was older when formally diagnosed in (Maternity Hospital) when trying to have kids, no diagnosis before that but I knew things weren't right, from when I was young. (26 - intersex variation, Polycystic Ovarian Syndrome).
>
> The consultant told me I have streak ovaries when I was diagnosed at 21. I was a student at university in (another country) so went through all the diagnosis etc. on my own. The consultant was a nice man but I got the final diagnosis after the laparoscopy at the hospital bed in a public ward with just the privacy of a curtain. I had no time to think and ask any questions. That was it. I would be given a prescription for HRT and a follow up appointment to see if the HRT was not causing problems etc. I think one of the other patients overheard and as a result took pity on me and gave me a lift back to my accommodation which I was grateful for the kindness. I was never specifically told that streak ovaries was an intersex condition though. I have used the internet in recent years to find info on streak ovaries etc myself. (21 - intersex variation, Gonadal Dysgenesis (Streak Ovaries)).
>
> After medical investigation once menstruation did not begin. Heavily invasive medical examinations and investigations that included a laparoscopic surgery. (32 - intersex variation, MRKH)

Interestingly, it also emerged that finally learning and knowing about oneself can be a very positive experience. One survey participant explained how they felt when they learned about their variation

> I was overjoyed, officially knowing what I had long suspected (27 - intersex variation, XXY/47).

Navigating Officialdom to Know

It is important to note that engaging with 'officialdom' is often a reality for intersex people as they search for information about themselves or seek to have official records (e.g. passport) reflect who they are and not necessarily what a birth certificate states. Fifteen survey participants responded to an item asking if they had sought to obtain their medical records. Their responses are recorded in the following table:

Table 8.1 Accessing Medical Records

Response	**Number of respondents**	**%**
Yes, Full Access	2	13.3
Yes, Partial Access	5	33.3
No Access	2	13.4
I have never tried to get this information	5	33.3
I attempted access but I was denied	1	6.7
Total	15	100.0

Five respondents (5/15, 33.3%) reported 'Yes' they have 'Partial Access' to their medical records. Three provided further insights

> I would like to access all my medical records including birth & post-natal. I had some surgeries done as an infant but I have never been told what they were. My mother knew of Y condition but my father only found out when I was 17 & had to change schools (go to girls school from boys) (15 - intersex variation 'Other' - hermaphrodite).

> I do have access to some of my records but my MRI scan records I don't have access to as in distress I threw them away. I have my hospital records filed including details of my dilation treatment and my gender identity clinic appointments for my hormones. (5 - intersex variation, MRKH)

> As of now it is clear to me that I am intersex and I want to know more about it. (13 - intersex variation, Cliteromegaly, Micropenis, Unknown, Other i.e. "*I have 2 sex characteristics of hermaphrodism I have micro penis and vagina. I registered as female, my body part developed both male and female but my prefer gender is male.*)

Two participants reported 'No access' with only one offering a response. Their response highlights the very nuanced and limiting ways in which the internal machinations of the health system can inhibit learning about oneself.

> In my mid / late 20s I came home from (another country) to speak with the Professor in the (Maternity Hospital) just before he retired to understand more about my body. I got more specific information but with his retirement my access ceased. (22 - intersex variation, Ovo-testes)

One person reported that they attempted and were denied access and explained why they were denied

> Made few attempts to get hospital records, was informed all old records before digitalisation were lost in flooding of storage facility years ago. (24 - intersex variation, Hypospadias, Micropenis).

Not knowing about oneself

Our in-depth interviews have demonstrated the depth of feeling that participants have about not fully knowing what happened to them, and not fully understanding why certain medical interventions/treatments were given. Having access to information about oneself is crucial for understanding what has happened to them. Not being able access information in this way has been a major issue for intersex people and has the potential to exacerbate their trauma.[364] These realities are evident in the literature.

Most participants in Jones and colleagues' Australian study were given no information/option to decline/defer the intervention.[365] One-fifth were given no information at all about any intervention/treatment.

We observed a similar trend in our own survey data. Twenty-four participants responded to the item

Were you always given adequate information on the treatment/surgeries by medical professionals?

Eighteen respondents (75%) reported that they were not always given adequate information. Moreover, when asked if their parents/legal guardians were given adequate information about their treatments/surgeries, two-thirds (16/24, 66.7%) of our respondents said 'No'.

In the Australia study, the majority also noted at least one negative impact from the treatment(s) which were life-threatening for some.[366] Moreover, twenty-one comments offered by participants linked negative well-being to

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[364] Fausto-Sterling (n 174); Preves (n 97); Kessler (n 175); Sytsma (n 274); Davis (n 97).

[365] Jones and others (n 87).

[366] ibid.

> the impact of having under-gone medical intervention including a traumatising or unwanted surgery and grieving the physical parts or sense of autonomy that were lost.[367]

In Poland, Bajszczak and colleagues report that the development of mental health problems

> has been attributed to improperly carried out hormone substitution: poorly selected hormonal preparation, incorrect dose, unsatisfactory route of administration, and side effects.[368]

It is evident that negativity associated with medical intervention is problematic and has the potential to have a catastrophic impact for some. Interestingly, intersex respondents in Norway reported significantly lower psychological distress among the group who had positive experiences about the information given to them prior to their intersex surgeries compared to the group who reported negative experiences.[369] Falhammar and colleagues also noted the importance of providing information to patients "promptly" and including knowledge about health issues that "might occur in the different diagnoses" in patient education programmes.[370]

Our participants' stories reflect similar realities. Neither Alan, Claire or Frankie fully understand what happened to them as children. Frankie does not know why she has scars in their thigh/groin area. She explained

> I have no idea what they are caused by. I have no idea if they are surgeon scars or what they would be. But they are almost like 3 scars, lines the same and they are deep. They are on both sides. (Frankie)

At the time of writing Alan is almost fifty-years old. He is unsure about what exactly happened to him as child in terms of two intersex surgeries. It was never spoken about at home. Alan struggled to obtain this information about himself and eventually was granted access to his school attendance

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[367] Jones, 'The Needs of Students with Intersex Variations' (n 99). At p609.

[368] Katarzyna Bajszczak and others, 'The Risk of Mental Disorders in Patients with Disorders/Differences of Sex Differentiation/Development (DSD) and Y Chromosome' (2020) 71 Endokrynologia Polska 168 <https://journals.viamedica.pl/endokrynologia_polska/article/view/EP.a2020.0005> accessed 22 March 2022. At p174.

[369] Wæhre and others (n 85). At p11.

[370] Falhammar and others (n 80).

records which allowed him to examine his long absences from school as a child. He used this information as a proxy to calculate how long he spent in hospital. He believes "There is no doubt that if I got my medical file it would be completely redacted anyway." He is traumatised by what happened to him and offered a profound acknowledgement of what 'not knowing' has meant in his life.

> I was living in complete ignorance even of my own medical position that I couldn't voice any concern or I couldn't voice it in a coherent manner. I didn't know anything. How can you be heard when you don't even know your own story? I didn't just not know my story, I didn't know a single part of it. Not one single part of it could I accurately or fully own because I just didn't know. (Alan)

A survey participant noted a similar experience

> Treatment was not correct - e.g. progesterone introduced too late. I would not have consented to treatment plan with full correct info. It's also been difficult to get honesty re my medical history - I had a surgery at 3 that I cannot remember and nobody will tell me about it. (35)

As a child growing up in Ireland, Claire was instructed to take "vials" when she was in late childhood. She did not know what they were for or why she was taking them.

> I don't know that I was given hormones. I know it is very common. I don't know for a fact that I was but I suspect I was. I was given, at one point I was given a lot of medications for my 'asthma'. (Claire)

Similarly, Becca's hormone treatment was not discussed with them by their parents. Becca explained that

> my parents didn't exactly go into huge detail about why I am taking this. … after a while I was just a little curious so my Junior year in X School which is my 11th year in X School, I asked my father. I was like 'Well you know I'm just curious why am I taking all these pills and having all these doctors' visits?' He kind of just gave me a very archaic explanation and he used the term pseudo-male hermaphrodite, I'm

> pretty sure that is really old and archaic and no one uses that anymore. So that was a shock to me (Becca).

While Becca understands that her parents did not mean to cause harm by not telling her information about herself, she believes that withholding information and not addressing her circumstances was harmful. None of these participants, aged between 30 and 55, grew up in family environments that were prepared to openly discuss their intersex variation. Claire and Frankie's family background were pathologically dysfunctional and abusive and this only compounded their experience of growing up different.

Another participant, Darcy, described how not being fully informed about the potential side effects of their hormone treatment and vaginal dilation has been incredibly traumatic. Darcy has deep distrust of the medical treatment due to their experiences. Darcy was never informed about the catastrophic mood changes hormone treatment would induce. Consequently, they remain very troubled by the reality that they did not give their fully informed consent to this treatment. Moreover, Darcy believes that vaginal dilation, to stretch their vagina, was "this fairytale ideal that they sell you". At the time of interview Darcy had requested their medical records. There is much they wish to learn about what happened to them because Darcy does not remember everything that happened.

> Accessing my medical records has been challenging due to the centre not receiving my documents and not communicating this to me. Thankfully I chased them, they've been lovely and all sorted now but it now means an even longer wait for my medical records which I requested two months ago. This is deeply traumatic as I had to push myself to get my records in the first place and there's a lot I don't remember. (Darcy)

Our findings correspond to other international and European ones.[371] Limited knowledge and information about treatment and information has the potential to be harmful and traumatic. Our participants were unable to consent to treatment that was undertaken on their bodies when they were children. Moreover, when information is not given fully, they are unable, as Darcy was, to give fully informed consent. This has prompted distrust of

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[371] Jones and others (n 87). Wæhre and others (n 85).

medical professionals and the medical system. Such experiences are further compounded by the difficulties intersex people experience when trying to access their medical records. Our qualitative interview data is further supported by our survey data.

Twenty survey participants offered a response when asked to explain their experience of not being given adequate information. Thirteen (13/20, 65%) reported a problematic experience in terms of: "never told", "never had full explanations", "never received full information", "never given any explanation".

In addition to documenting problematic experiences relating to a lack of information, four survey responses also noted negative experiences with medical professionals

> I was never told that it was a common occurrence. One doctor in (Irish Hospital - centre of excellence) as much as told me that I was a freak and she wanted to study me for a paper which was massively distressing. I found the whole situation in Ireland awful! I was 25 before I even heard the term intersex and it was through my own research. (34 - intersex variation CAIS)
>
> Things were never properly explained to me - there's a lot of pressure put on me to go along with doctors' suggestions, no information as a child - was kept to a very strict diet by my parents (when I was back at home). (26 - Intersex variation, Polycystic Ovarian Syndrome)
>
> I was told if I didn't maintain the standard treatment of testosterone that my life would not be worth living, when it became obvious the hormone was causing harm, my doctor released me from his care, saying there was nothing more he could do for me. (27 - Intersex variation, XXY/47)
>
> multiple doctors refused hormonal treatment which I wanted (29 - Intersex variation, CAH & Hyperandrogenism)

Seven respondents (7/20, 35%) specifically documented issues relating to their status as a child/their young age as being related to why they were not given adequate information. One noted that their parents were given the information “not me”. Another wrote that at seventeen years old, “I was given a childish explanation…”. While another explained “…never received information on my childhood surgery”.

Learning and Knowing Through Education and School

We have documented our participants’ experiences of learning and knowing about themselves and their bodies with a particular focus on medicine. However, learning and knowing about oneself also occurs through another ‘official’ channel - education. We examine two aspects of our survey participants’ educational experience (1) Learning from the curriculum and (2) Personal experiences of education

Learning from the curriculum

From a socio-cultural perspective, learning about bodies and sexuality was restricted and associated with shame, stigma and sin in Ireland not least due to the strong grip the Catholic Church had over education.[372] The formal introduction of official guidelines for *Relationships and Sexuality Education (RSE)* in 1996 was not without controversy. Provision of the programme at school was at the discretion of the school. Based on schools’ assessments of their students’ needs and in keeping with their ethos, they decided on what was taught. This varied within and across schools even in recent times.[373] It was not until 1999 and 2000 that RSE became a mandatory part of the primary and post-primary junior-cycle curriculum.[374]

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[372] Tom Inglis, *Lessons in Irish Sexuality* (University College Dublin Press 1998a) <http://capitadiscovery.co.uk/dcu/items/98814>; Tom Inglis, *Moral Monopoly: The Rise and Fall of the Catholic Church in Modern Ireland, 2nd Ed.* (University College Dublin Press 1998b) <http://capitadiscovery.co.uk/dcu/items/77890>.

[373] Mel Duffy, Maria Feeney and Anne Lodge, ‘Let’s Talk about Sex, Baby’..... Second-Level Students, Parents/Guardians, Teachers and Principals Talk about the Relationships and Sexuality Programme Publication Description’ [2020] Proceedings of the Annual Conference of the Educational Studies Association of Ireland (ESAI) Opening Up Education: Options, Obstacles and Opportunities.

[374] National Council for Curriculum and Assessment, ‘Report on the Review of Relationships and Sexuality Education (RSE) in Primary and Postprimary Schools’ (National Council for Curriculum and Assessment 2019) <https://ncca.ie/media/4462/report-on-the-review-of-relationships-and-sexuality-education-rse-in-primary-and-post-primary-school.pdf>.

In some schools, learning about one's body is a rather limited and haphazard affair as it relates to to RSE.[375] For example, on the post-primary curriculum, learning about the body occurs through certain subjects such as biology, home economics, religion and, if offered, through Social, Personal and Health Education (SPHE). At Junior-Cycle,[376] RSE was housed within Social, Personal and Health Education (SPHE). However, SPHE was not mandated for senior-cycle but there was an expectation that schools should provide RSE to pupils as noted in the Department of Education's review of RSE in 2013

> In accordance with Department of Education and Skills Circular 0037/2010, Relationships and Sexuality Education, post-primary schools are obliged to develop an RSE policy and to implement a programme in this area for all students from first year to sixth year. Junior cycle RSE should be taught as an integral component of SPHE. In senior cycle, schools are required to teach RSE, even in the absence of a timetabled SPHE class. The RSE Interim Curriculum and Guidelines outline the expected content of an RSE programme under the following three key themes. • Human growth and development • Human sexuality • Human relationships[377]

Learning about sexuality then remains even more limited since exposure to this type of learning will not necessarily be found in other, non-RSE, curricular spaces. A key finding from the NCCA review of RSE was that "additional topics" needed to be taught to address the "contemporary challenges" young people experience.[378]

We asked about individuals experiences of (1) Puberty Education and (2) Sex Education in order to learn about their learning experiences at school.

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[375] Duffy, Feeney and Lodge (n 373).

[376] Junior Cycle is years 1-3 of post-primary education in Ireland. 4th Year, known as Transition Year, is optional in many schools. Senior Cycle covers the final two years of post-primary school education (5th & 6th). A high-stakes examination, the 'Leaving Certificate', is undertaken by pupils at the end of 6th year. Grades in these exams are converted into points and third-level education places are awarded based on points achieved.

[377] Department of Education and Skills, 'Looking at Social, Personal and Health Education Teaching and Learning in Post-Primary Schools' (Evaluation Support and Research Unit Inspectorate, department of Education and Skills 2013) <https://assets.gov.ie/25284/6d006de035c8437f9e8de363343941e6.pdf>. At p3.

[378] National Council for Curriculum and Assessment (n 374). At p69.

The following table outlines the number of participants who responded to these items. The majority did receive puberty and sex education.

Table 8.2 Puberty education and Sex education

Were you offered…	**Puberty Education**	**Sex Education**
Yes	11 (73.3%)	12 (85.7%)
No	4	2
Total (n=)	15	14

When asked during what lessons/classes these lessons were offered, our participants' full responses are in the following table.

In terms of Puberty Education science subjects (n= 5) featured in half of the responses. SPHE featured in four responses. Religion was noted in only one response. In terms of Sex Education, science subjects were noted in one-third (4/12) responses and SPHE was noted in another one-third. Religion was noted in a quarter (3/12) of responses.

Table 8.3 Recalling lessons/classes in Puberty education and Sex Education

Puberty Education Lessons/Classes (n= 10)	**Sex Education Lessons/Classes (n= 12)**
6th Class primary school	Religion (n= 2)
Biology (n= 3)	A special Sex Ed class in 1st year
I believe Inter Cert Year 3, but I stayed at home on day of subject because I could not relate to pictures shown in diagrams	Biology (n= 2)

Science and PHSE[379]	Religion in secondary school
Science and SPHE	Combined with puberty education of just one class
Religion	Biology & PSHE
Junior Cycle: SPHE Senior Cycle: Relationships and Sexuality	Junior Cycle: SPHE Senior Cycle: Relationships and Sexuality
SPHE	Science & SPHE
	As one class in the 8th grade. It was just, if u have sex u will get diseases kind of class.
	SPHE

We also wanted to specifically know if participants' experiences of Puberty and Sex Education include lesson(s)/information about diverse congenital sex and development variations?

Unsurprisingly, all participants reported 'No'. We argue that this has significant implications for the general public's lack of awareness and understanding of intersex.

Table 8.4 If puberty and sex education classes included lessons about intersex variations

Did Puberty Education include lessons/information about diverse congenital sex and development variations?	**Puberty Education**	**Sex Education**

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[379] PHSE - Personal, Social and Health Education

Yes	-	-
No	11	12
Total	11	12

These findings are further supported by Alan's recollection of his biology text book in post-primary school. He spoke of his gradual realisation that his body was not normal.

> ...the realisation is that I wasn't dealing with what was normal anatomy, I was dealing with something that wasn't within the parameters of normal. But I have to say in every aspect of it I had to take it on board being completely normal. I did not recognise my anatomy. I knew my anatomy did not, wasn't comparable with the male anatomy in the biology book they were giving us in secondary school. I could not relate to it. (Alan)

This inability to relate to curricular content showing images of 'normal' anatomies is exclusionary because there is no recognition of difference. Alan has similar experiences as they relate to the medical literature he has researched.

Memories of Puberty Education in Ireland

> Very sex specific no talk or acknowledgement of non-standard development (10 - intersex variation, Unknown, Other)
>
> Very basic (13 - intersex variation, Complete Androgen Insensitivity Syndrome (CAIS))
>
> It was basic (18 - intersex variation, Complete Androgen Insensitivity Syndrome (CAIS))
>
> Yes I had puberty education in 6th class. I went to a convent national school. The puberty education was given by a lay teacher. It focussed

more on womanhood being a class of girls. (22 - intersex variation, Ovo-testes (formerly called "true hermaphroditism"), Other)

I was petrified of doing the class. I was sure my awkwardness & discomfort with the subject would be noticed. (24 - intersex variation, Hypospadias, Micropenis)
It was basic (28 - intersex variation, Complete Androgen Insensitivity Syndrome (CAIS))

Memories of Sex Education in Ireland

2 or 3 classes in first year provided by the vice principal. Abiding by the rules of the catholic Church with no contraceptives mentioned. Only heterosexual relationships. Body parts mentioned but only male and female without any variations. (12 - intersex variation, Congenital Adrenal Hyperplasia (CAH))

Putting condoms on bananas (13 - intersex variation, Complete Androgen Insensitivity Syndrome (CAIS))
Minimal received in all male religious order school. (19 - intersex variation, Micropenis)

It was given by a Nun and we watched a video during Religion class. I went to a mixed secondary school. It was mortifying. Everyone was half looking at the TV and there were a few smart comments from some of the lads toward the lads. We couldn't wait to get out of the class. (22 - intersex variation, Ovo-testes (formerly called "true hermaphroditism"), Other)

nothing like this was ever discussed (26 - intersex variation, Polycystic Ovarian Syndrome)

It was basic (28 - intersex variation, Complete Androgen Insensitivity Syndrome (CAIS))

The need for informed curricular content

A general consensus exists across both our sample populations that greater awareness of what intersex/VSC means is required. Informative curricular content appears limited in people's experiences and its inclusion on the curriculum would serve to inform all pupils/students of a natural human variation and identity. Some participants suggested

> More information and knowledge… (26)
>
> Mention that intersex people exist to all students, offer support for intersex students. (29).
>
> Consider your reading material. Include diverse bodies/ experiences in your discussions - there are more than two chromosome combinations! Use inclusive language. Do not enforce gender norms e.g. around uniform. Foster a safe environment for queer people (35)

Such content could potentially feature across multiple curricular platforms at both junior and senior cycles at post-primary level: Social, Personal and Health Education (SPHE), Relationships and Sexuality Education (RSE), Home Economics, Science, Biology and all other places where students can be presented with opportunities to learn about intersex/VSC.

Personal experiences of education

Another important area that warrants consideration is young people's experience of school and the impact this can have on their development. While schools are for the most part places of learning and prosocial development, this is not the experience for all. Indeed, schools are places of stress, bullying and exclusion and can be hostile environments with little meaningful support, particularly for sexual minority adolescents. Schools can expose young people to risk factors (e.g. academic stress, bullying, peer victimisation, aggression) that can lead to anxiety, anger, shame and helplessness.[380] Moreover, bullying is linked to mental ill-health among

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[380] Kim-San Lim and others, 'Global Lifetime and 12-Month Prevalence of Suicidal Behavior, Deliberate Self-Harm and Non-Suicidal Self-Injury in Children and Adolescents between 1989 and 2018: A Meta-Analysis' (2019) 16 International Journal of Environmental Research and Public Health 4581 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6888476/> accessed 6 January 2022. At p17.

adolescents and is a "major contributor" to an adolescent's decision to engage in self-harm behaviour,[381] and was experienced by 50% of intersex youth (15-17 years) at school across Europe.[382] Similarly, Jones' survey of intersex people in Australia found that "many" of the 272 respondents experienced bullying at school and only one quarter of those who responded rated their education experiences positively.[383] Moreover, intersex respondents provided 102 responses about their overall school experiences in which 77 (75.5%) commented "about being bullied, ranging from daily to occasional incidents" from name-calling, rude questions to "physical violence".[384] Similarly, in another global survey of intersex people (n= 86), respondents also reported being bullied, feeling depressed and having suicidal thoughts at primary and high-school level.[385] They described not fitting in, and feeling isolated and different to their peers.

Findings about our Irish cohort are aligned with these international findings. Almost one-third of our participants (N= 7/23, 30.4%) reported that they (1) experienced discrimination at school and (2) 'other issues" related to their intersex variation. The following table outlines how often they experienced discrimination.

Table 8.5 Frequency of experiencing discrimination while in education

Always	Often	Sometimes	Rarely	Never
1	1	3	1	1

When asked to explain this experience, some participants described very negative experiences of discrimination from not being permitted to use the correct toilets, to being shouted at and witnessing hostile and offensive lectures. Our participants described their experiences in their own words.

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[381] Nicholas W Bakken and Whitney D Gunter, 'Self-Cutting and Suicidal Ideation among Adolescents: Gender Differences in the Causes and Correlates of Self-Injury' (2012) 33 Deviant Behavior 339. At p342.

[382] European Union Agency for Fundamental Rights (EU FRA) (n 90).

[383] Jones and others (n 87).

[384] ibid.

[385] Henningham and Jones (n 84).

> Not being allowed use correct toilets. Not being addressed repeatedly by my name or correct sex in 3rd level. My student ID was regularly wrong. (11, intersex variation 'Other')

> In college, the inability to socialise with girls as age appropriate level. The heightened awareness of being underdeveloped in physical, emotional and sexual development. (24 - Hypospadias, Micropenis)

> Hated anything at school where you had to expose the body e.g. PE its makes its easier to bully. (26 - intersex variation, Polycystic Ovarian Syndrome)

> I've had a student scream in my face that I'm mentally ill; had lecturers give very hostile, ill-informed, damaging and offensive lectures in front of me related to trans and intersex matters. (30 - intersex variation, hypospadias)

> Bullying from other students due to "looking different" which is a result of my differing development path through being intersex. Delayed puberty. (32 - intersex variation, MRKH)

> Because I looked like a girl and had Asperger I was prime target for bullying. I looked (like a) 13 year old girl when I was 18 and that kind of phenotype made me be bullied constantly. I suffered rape while in the boy scouts because I told that one of the boys peed from fear of a big dog and he and his friends decided to give me a lesson. (33 - intersex variation, PAIS)

One person documented a positive, supportive experience

> I found the Head of my Department very supportive while studying in [Big Irish City]. (22, intersex variation, Ovo-testes (formerly called "true hermaphroditism"),Other)

We also asked our participants about their experience of "other" issues or problems arising from their variation while at school. 15 people responded to this question with 7 stating 'yes' they did experience other issues pertaining to their education. Two people reported that they experienced such issues "Often", and three individuals noted they experienced these types of issues “sometimes”. Another two said they “Rarely” experienced such issues.

We offered participants a text box response to document these issues. The following responses are what they recalled.

> People/tutors often asked if I was male or female. (11 - intersex variation, ‘Other’)
>
> The changing room (19 - intersex variation, Micropenis)
>
> While studying in [Big Irish City]. Going through the dramatic menopause, missing time off college for surgery, I got some support from the college to get me through my first year exams. I found the students in my class were very unpleasant toward me. Even into second year following my radiation treatment, I felt bullied. They didn't know about the chromosome issue, just that I was sick - couldn't have kids and had cancer. I think it was jealously over the assistance I was receiving. (22, intersex variation, Ovo-testes (formerly called "true hermaphroditism"),Other)
>
> The awareness of difference in genital appearance in compulsory showering communal after PE. At least 35 yrs ago no one had 'google' to highlight differences. (24 - Hypospadias, Micropenis)
>
> There are no gender-neutral bathrooms so I use the men’s room. It’s often uncomfortable and fills me with apprehension for me if not vacant. Threatened and yelled at by one student. Heard phobic discriminatory comments from others. Derogatory lectures and comments from a couple of lecturers. (30 - intersex variation, hypospadias)
>
> Issue getting time out of class for the many many medical appointments without disclosing my emerging intersex status, following on was falling behind in class and the stress from that. I was undergoing these medical appointments in full swing in my final two years of secondary school. (32 - intersex variation, MRKH)

Education in Ireland has offered little opportunity to learn about oneself through the official curriculum. No participant has an educational experience or memory of learning about intersex through puberty or sex education lessons/classes. This absence represents total non-recognition of intersex people on any formal curriculum and has the potential to be harmful. Similarly, in Ireland, Traveller culture was absent from the formal curriculum and this too has been implicated in their negative experiences of education in Ireland and it is also set within the broader oppression and discrimination they experience as a minority group in a system designed and geared towards the majority population.[386] Furthermore, our intersex participants provided experiences of how schools and other educational institutions can also be constraining and hostile environments through regular procedures governing the intimate body such as rules for toilet use and showering. Moreover, painful experiences were recalled when some described being bullied. Given this 'mapping' of their educational experiences, it was unsurprising to also learn that the overwhelming majority of our participants (13/14) reported that their schools (both primary and post-primary) did not offer counselling services that discussed intersex/affirmed people born with a congenital sex and development variation. Only one person noted that their schools did offer such a service. We invited participants to share their comments on this which are outlined below:

> It was not done at that time. (11 - intersex variation, 'Other)
>
> We are pretty rare and need specialist services, not someone with little bits of inaccurate knowledge being preset in schools. (13 - intersex variation, Complete Androgen Insensitivity Syndrome (CAIS))
>
> I would have been upset if they called me intersex, especially at school. (18 - intersex variation, Complete Androgen Insensitivity Syndrome (CAIS))
>
> I was in secondary school from 1983 - 1988. We had a chaplin and a career counsellor and our school was ahead of its time. (22 - intersex

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[386] National Council for Curriculum and Assessment, 'Traveller Culture and History in the Curriculum: A Curriculum Audit' (National Council for Curriculum and Assessment November 2019b) <https://ncca.ie/media/4324/ncca_draftaudit_travellerculturehistory_0919.pdf>.

> variation, Ovo-testes (formerly called "true hermaphroditism"), Other)
>
> If there was a nurse available to talk privately, I might have approached even if only to discuss bed wetting still at 15 years of age. (24 - intersex variation, Hypospadias, Micropenis)
>
> nothing like this was ever discussed (26 - intersex variation, Polycystic Ovarian Syndrome)
>
> I would have been very distressed if a counsellor called me intersex, especially during my teens - how horrible to tell a teenage girl without a uterus that she is neither male or female. (28 - intersex variation, Complete Androgen Insensitivity Syndrome (CAIS))
>
> No mention across the board, I am trying to be clear that I received (what i believe) was the most comprehensive sexual health education I could have, in Ireland, in its education system. I was very fortunate to receive such high quality sexual education - and to this day recall the information I learned it has been invaluable. With that said and imposed, there was *0* mention at any point in my education about variations of sex characteristics in any meaningful way. The solitary mention it got was during my own young social innovators project where we focused on LGBTI issues. At no point in curriculum. (32 - intersex variation, MRKH)
>
> This would have been enormously helpful as would have encouraged my parents to seek support for themselves/ me rather than insisting there was 'nothing wrong with me'. (35 - intersex variation, Turner's Syndrome (one X chromosome))

We asked if, in the absence of this type of school counselling, if schools provided a link/contact for similar services elsewhere. 15 people responded: two-thirds (66.6%, 10/15) said 'No', 3 reported "Non-applicable" and 2 reported "Don't know". We asked people to comment on their responses to the issue of counselling in their schools or lack thereof.

> Not done at that time (11 - intersex variation, 'Other)

> We need specialist services and funding for groups that support children and families (13 - intersex variation, Complete Androgen Insensitivity Syndrome (CAIS))
> This was a big gap in education at that time. (19 - intersex variation, Micropenis)
>
> In the 80's the possibility of even being gay wasn't discussed never mind Intersex. Nothing outside of the normal was referred to or educated in secondary school. (22 - intersex variation, Ovo-testes (formerly called "true hermaphroditism"), Other)
>
> I don't remember any awareness of counselling services before mid-nineties. Almost 9 years after secondary school & 3 years after leaving college. (24 - intersex variation, Hypospadias, Micropenis)
>
> I was under a specialist clinic and saw a specialist psychologist. (28 - intersex variation, Complete Androgen Insensitivity Syndrome (CAIS))
>
> Unclear what this is asking. ? Maybe the last question? My school had a Chaplin and a counselor, neither of whom ever mentioned intersex to me in any meaningful way. (32 - intersex variation, MRKH)

Regrettably, education and schools in Ireland did not provide a learning or knowing space for our participants to learn about themselves and their bodies. Our findings provide evidence of two important aspects of the state apparatus, specifically medicine and education, limiting opportunities for intersex people to fully know and learn about themselves. It also limited opportunities for all students to learn about intersex/VSC.

9

Intersex Trauma

Chapter 9: Intersex Trauma

Trauma

Trauma is the Greek word for 'wound'. Trauma can be used in the physical (injury) and psychological contexts (emotional response to distress).[387] It also takes three main forms: acute, chronic and complex (ibid). It can be a single event or a series of events and/or a chronic condition and "frequently produced a sense of fear, vulnerability, and helplessness."[388]

Psychological trauma is now a common concept in medical and popular fields.[389] Understanding trauma is important for public mental health and while we may have a familiarity with traumatic events such as war, violence, loss and serious illness, Kleber explains that

> Phenomenologically such an event can be characterized by an extreme sense of powerlessness as well as a disruption of beliefs and expectations. The individual has lost control over the situation and is to a large extent a victim of the circumstances and/or other people (i.e. the perpetrator).[390]

Traumatic events cause trauma and younger age at the time of trauma experience is an additional risk factor.[391] It is now widely accepted that children have the capacity to perceive trauma,[392] and the capability to understand what is happening even if they are to be told they have a

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[387] Shaziya Allarakha, 'What Are the 3 Types of Trauma?' (*MedicineNet*, 8 February 2021) <https://www.medicinenet.com/what_are_the_3_types_of_trauma/article.htm> accessed 6 May 2021.

[388] Substances Abuse and Mental Health Services Administration (SAMHSA), *Understanding the Impact of Trauma*, vol TIP-57: Trauma-Informed Care in Behavioral Health Services (Substance Abuse and Mental Health Services Administration (US) 2014) <https://www.ncbi.nlm.nih.gov/books/NBK207191/> accessed 6 May 2021. At p7.

[389] Rolf J Kleber, 'Trauma and Public Mental Health: A Focused Review' (2019) 10 Frontiers in Psychiatry <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6603306/> accessed 6 May 2021.

[390] ibid. At p1.

[391] Y Auxéméry, 'Posttraumatic stress disorder (PTSD) as a consequence of the interaction between an individual genetic susceptibility, a traumatogenic event and a social context' (2012) 38 L'Encephale 373.

[392] Harvard Health Publishing (HHP), 'Past Trauma May Haunt Your Future Health' (*Harvard Health*, 1 February 2019) <https://www.health.harvard.edu/diseases-and-conditions/past-trauma-may-haunt-your-future-health> accessed 25 May 2021; Kristen E Buss, Jeffrey M Warren and Evette Horton, 'Trauma and Treatment in Early Childhood: A Review of the Historical and Emerging Literature for Counselors' (2015) 5 The Professional Counselor 225 <http://tpcjournal.nbcc.org/category/pdf-articles/volumes/volume-5/volume-5-issue-2/> accessed 13 May 2021.

terminal illness.[393] Historically, society did not acknowledge early-childhood trauma and this fits within the broader social landscape where children and their rights were not afforded the same recognition they are today. However, recent decades of research has demonstrated that young children are "especially susceptible" to trauma exposure and rates of abuse and neglect are "staggering" against young children.[394] As a society, we remain unaware of the true extent and prevalence of childhood trauma.[395] Medical experiences in childhood can be frightening, traumatic and confusing.[396] The American Psychological Association (2011) identifies medical trauma as a traumatic event implicated in PTSD and Trauma in Childhood and Adolescents.[397] We believe this is of critical relevance for explaining what we identify as intersex trauma.

Intersex trauma

Violations of intersex people's rights and their bodies often relate to unnecessary medical treatment they endured as non-consenting children but which was most likely consented to by their parents,[398] otherwise known as "proxy consent".[399] Some parents of newborn intersex babies may feel fear, shock, chaos, uncertainty and in the midst of this highly-charged emotional experience have agreed to medically unnecessary interventions on their non-consenting babies' bodies.[400]

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[393] Kevin G Behrens, 'A Principled Ethical Approach to Intersex Paediatric Surgeries' (2020) 21 BMC Medical Ethics 108 <https://doi.org/10.1186/s12910-020-00550-x> accessed 24 May 2021.

[394] Buss, Warren and Horton (n 392). At p225.

[395] Amanda E Berg, 'Trauma in Schools: Identifying and Working with Students Who Have Experienced Trauma' 68.

[396] Nancy Kassam-Adams and Lucas Butler, 'What Do Clinicians Caring for Children Need to Know about Pediatric Medical Traumatic Stress and the Ethics of Trauma-Informed Approaches?' (2017) 19 AMA Journal of Ethics 793 <https://journalofethics.ama-assn.org/article/what-do-clinicians-caring-children-need-know-about-pediatric-medical-traumatic-stress-and-ethics/2017-08> accessed 13 May 2021. At p793.

[397] Presidential Task Force on Posttraumatic Stress Disorder and Trauma in Children and Adolescents American Psychological Association, 'Children and Trauma: Update for Mental Health Professionals' (*https://www.apa.org*, 2011) <https://www.apa.org/pi/families/resources/children-trauma-update> accessed 13 May 2021; Buss, Warren and Horton (n 392). At p225.

[398] Behrens (n 393); Jemma Tosh, 'The (In)Visibility of Childhood Sexual Abuse: Psychiatric Theorizing of Transgenderism and Intersexuality.' (2013) 2 Intersectionalities: A Global Journal of Social Work Analysis, Research, Polity, and Practice. 71.

[399] Matteo Cresti, Elena Nave and Roberto Lala, 'Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment' (2018) 15 Journal of Bioethical Inquiry 557 <https://doi.org/10.1007/s11673-018-9880-7> accessed 14 March 2022.

[400] Limor Meoded Danon, 'The Parental Struggle With the Israeli Genital Socialization Process' (2021) 31 Qualitative Health Research 898 <https://doi.org/10.1177/1049732320984420> accessed 28 March 2022; Behrens (n 393); Cresti, Nave and Lala (n 27); Davis, DEWEY and MURPHY (n 22).

Such interventions can have significant, and unknown, implications on the person's mental and physiological wellbeing in later life and studies addressing such life outcomes are "scarce".[401] Interestingly, Greenberg explains that prior to the 1950s intersex babies were not subjected to medical intervention.[402] It was the development of surgical techniques and ideas about gender identity (nurture not nature) that resulted in increased medical intervention on intersex infants.[403] Since then, intersex people and their bodies "have been objects of intense medical scrutiny."[404] Carpenter explains

> In practice, intersex bodies remain "normalized" or eliminated by medicine, while society and the law "others" intersex identities.[405]

Negative experiences abound in some intersex people's stories such as; dealing with childhood intervention; accepting a later diagnosis, chronic health issues and infertility are some that were noted in van Lisdonk's work from the Netherlands.[406] Similarly, the UN reports that

> irreversible procedures can cause permanent infertility, pain, incontinence, loss of sexual sensation, and lifelong mental suffering, including depression. Regularly performed without the full, free and informed consent of the person concerned, who is frequently too young to be part of the decision-making, these procedures may violate their rights to physical integrity, to be free from torture and ill-treatment, and to live free from harmful practices.[407]

Moreover, research also attests to the fact that intervention on a person's body, and not necessarily their intersex trait, has created chronic health and disability issues,[408] and trauma which are particularly problematic in an

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[401] Cresti, Nave and Lala (n 399).

[402] Julie A Greenberg, *Intersexuality and the Law: Why Sex Matters* (NYU Press 2012). At p856.

[403] Morgan Carpenter, 'Intersex Variations, Human Rights, and the International Classification of Diseases' (2018) 20 Health and Human Rights 205 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6293350/> accessed 3 October 2019. Greenberg, *Intersexuality and the Law* (n 69).

[404] FEDER (n 77).

[405] Carpenter, 'Intersex Variations, Human Rights, and the International Classification of Diseases' (n 403).

[406] van Lisdonk (n 19).

[407] United Nations for LGBT Equality, 'Fact Sheet Intersex' <https://www.unfe.org/wp-content/uploads/2017/05/UNFE-Intersex.pdf> accessed 15 February 2022.

[408] Kessler (n 175); Fausto-Sterling (n 174).

ableist society.[409] The UN recognises that many intersex adults "emphasize the shame and stigma … as well as the significant physical and mental suffering" that has resulted from unnecessary surgery which often only compound their suffering.[410] Ireland has a notorious reputation for the way in which it cultivated secrecy and shame – particularly around bodies and sexuality so it is not surprising that this broader socio-cultural issue was noted by some participants when they shared their stories with us.[411] In fact, as we demonstrate, it compounds their trauma.

When applying the concept of childhood medical trauma to intersex children, it is also worth remembering that unnecessary medical intervention on intersex people has been considered a form of 'Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment'.[412] Research attests to the fact that intersex surgery on infants can be deeply traumatic.[413] Waterworth identified the type of trauma arising from cosmetic and other surgeries on intersex infants as *biopsychosocial.*[414] In a discussion about intersex vaginal dilation, Tosh argues that it has the potential to be conceptualised as abuse and explains it is not only painful and distressing for the child but also for parents who have to subject their young child to this type of 'treatment'.[415] Furthermore, this type of trauma can be further compounded if the child has not been informed about what is/has happened to them.[416] Cultures of secrecy and shame existed around intersex issues and their medico-social management. Often parents feel compelled to proceed with medical advice without question. Indeed, this was the reality for some of our survey participants.

> They (parents) were encouraged to normalise and never really questioned medical staff, I hope they would have made different

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[409] Stephen Kerry, 'Intersex Individuals' Religiosity and Their Journey to Wellbeing' (2009) 18 Journal of Gender Studies 277 <http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=44263692&site=ehost-live> accessed 26 May 2021.

[410] United Nations for LGBT Equality (n 3).

[411] Inglis, *Lessons in Irish Sexuality* (n 372); Inglis, *Moral Monopoly: The Rise and Fall of the Catholic Church in Modern Ireland, 2nd Ed.* (n 372).

[412] Bauer, Truffer and Crocetti (n 20).

[413] Cresti, Nave and Lala (n 399). Greenberg, *Intersexuality and the Law* (n 69).

[414] Kai Tiaki, 'Surgery on Intersex Infants "causes Unnecessary Trauma" in News & Events Section' (2016) 22 Kai Tiaki Nursing New Zealand 9 <http://search.ebscohost.com/login.aspx?direct=true&db=ccm&AN=114616549&site=ehost-live> accessed 26 May 2021. At p9.

[415] Tosh (n 398).

[416] Behrens (n 393).

> choices with full info and acceptance/support to let me be. (35 - intersex variation, Turner's Syndrome: One X Chromosome)
>
> ...they were never even told of my chromosome difference. (34 - intersex variation, CAIS)

What these practices did in the past was to create "a 'conspiracy of silence' and a 'paradigm of deceit'."[417] that intersex adults attempt to navigate in order to understand what happened to them as children.[418] Truth is sometimes inconvenient and withholding it can permit people, and indeed professionals, to fall into beliefs based on false narratives or in the case of the latter, serve to support such narrative. Given that medical records often serve as written proof of truth, patients often had their medical histories withheld "[t]o ensure normative psychological development".[419] They were denied access to their data that could potentially assist them with learning about themselves, their bodies and what happened to them.

Here in Ireland we have enormous familiarity with similar conspiracies of silence and deceit as they relate to children's and women's experiences of incarceration, abuse and illegal/forced adoptions relating to industrial schools, Magdalene Laundries and Mother and Baby Homes.[420]

What our data tells us

Trauma is a multi-faceted part of some intersex people's stories that emerged strongly in three interviews. We document how trauma features in the lives of intersex people. It emerged in two distinct ways that are directly related to what it means to be intersex.

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[417] Groveman Morris, Sherri, 'DSD But Intersex Too: Shifting Paradigms Without Abandoning Roots | Intersex Society of North America' <https://isna.org/node/1067/> accessed 5 January 2022. At p27.

[418] Kerry (n 409). At p277.

[419] Carpenter, 'Intersex Variations, Human Rights, and the International Classification of Diseases' (n 28).

[420] Adoption Rights Alliance, 'Mother & Baby Homes Commission Report' (20 January 2021) <http://adoption.ie/commission-report/> accessed 21 March 2022; Emmet Oliver, '3,000 Ex-Industrial School Residents Apply to See Files' *The Irish Times* (13 July 2002) <https://www.irishtimes.com/news/3-000-ex-industrial-school-residents-apply-to-see-files-1.1088399> accessed 21 March 2022; UN Committee on the Elimination of Discrimination Against Women (n 181); Justice for Magdalenes Research (JFMR), 'About the Magdalene Laundries' (*Justice for Magdalenes Research*, 16 March 2017) <http://jfmresearch.com/home/preserving-magdalene-history/about-the-magdalene-laundries/> accessed 21 March 2022.

Firstly, we identified 'Historical Trauma' as relating to the memories of the past concerning previous surgeries, non-surgical treatments and other negative and disturbing aspects of a person's story. Implicated in this trauma is the reality that some people are not, or at least were not, fully informed about what happened to them as intersex children and minors which we have outlined in the previous chapter of the report. This 'not knowing' has been harmful and its harmful effects are represented in the second type of trauma that we identify and that is Current Trauma. Some of our participants experience immensely difficult circumstances in their 'here-and-now' present-day lives. The trauma that they experience today, can be 'triggered' by memory of the past, or by something new that they have to endure and navigate as an intersex person whether it relates to their healthcare or personal relationships.

It is widely known that surgical and non-surgical healthcare interventions can be deeply traumatising for people, even adults who give their fully, informed consent to such treatments. However, interventions in childhood can be a significant source of trauma when adults believe that as children they (1) did not know about what was happening to them, (2) were never told about what had happened to them at a later stage in their life by their parents/doctors and spend their lives unsure about their bodies and (3) did not in fact give *informed* consent to certain treatments.

Being intersex means that their bodily realities do not 'go away' as such despite the socio-medical rationale that the body has been fixed or corrected. For example, if we have our appendix removed, it usually means the end of the problematic appendix. This was not necessarily the case with our participants. Firstly, what has been done to their bodies is irreversible. Secondly, their bodies require frequent interventions and this is difficult for a whole host of reasons (e.g. ongoing hormone therapy, dilation, pain, time required). Moreover, forming a coherent concept of oneself has been impossible feat for some of our intersex participants following medical intervention on their bodies. This finding is aligned with recent research that uses an interpretative phenomenological approach. Hart and Shakespeare-Finch in their work exploring intersex trauma, explain that

> experiences of systematic pathologisation of intersex bodies were negatively internalised and affected sense of self.[421]

One participant, Darcy, endures extraordinary pain as result of vaginal dilation to the point where they have passed out. Contrary to the belief that this non-surgical intervention is better than surgery, this person believes that they were not invited to contribute to any meaningful discussion about the type of vagina that they were being instructed on creating. Instead, through dilation, the vagina that was created was based on its ability to accommodate a man's erect penis. The treatment was described by the person as "genital lengthening" pitched as "minimally invasive". Darcy noted their vagina was Size 2. The 'aim' of a Size 4-5 vagina corresponds to the "imaginary relationship" they would have with a man. This intersex participant understood that their treatment – dilation and hormones - was very much embedded in a heteronormative process of healthcare delivery whereby their body was highly objectified.

The reality of what being intersex is and how it has impacted their life has been profoundly troubling and distressing. And realising as an adult that they did not give informed consent to interventions/treatments as a minor aged seventeen years, is deeply distressing and firmly embedded in their current trauma narrative. Darcy explained

> I've recently come to the realisation that I have PTSD as a direct result of being intersex [3] and have had PTSD, unknowingly, for about 10 years. … this includes severe sleep disturbances, extremely distressing images which are debilitating, becoming extremely agitated and distressed incredibly quickly and extreme bereavement/grieving (Darcy)

Darcy acknowledged that there are some "good doctors" out there, they have a deep general distrust of doctors due to their experience. While they accept that at the age of 17, they did give consent to taking blue pills, they do not believe that they gave informed consent and they do not remember the name of the medication or recall exactly what the pills were for. They

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[421] Bonnie Hart and Jane Shakespeare-Finch, 'Intersex Lived Experience: Trauma and Posttraumatic Growth in Narratives' (2021) 0 Psychology & Sexuality 1 <https://doi.org/10.1080/19419899.2021.1938189> accessed 15 March 2022. At 1.

were never told how those pills would affect their mood. They are currently working through the issue of being a victim of trauma with a therapist despite their initial reluctance to see themselves as being deserving of the 'trauma' label. Having reflected on their experience, they realise now that their experiences are worthy of being interpreted as trauma.

The present-day realities of what childhood interventions have done are traumatic. Our intersex participants have developed coping strategies to deal with this, primarily mal-adaptive ones, such as non-disclosure of issues to those in their networks, avoidance (avoiding/burying their pain and trauma) and even deliberate self-harm ideation and behaviour.

Alan explained that he never disclosed details about what happened to him to his network. He buried his trauma. As a young child he had been subjected to surgery. He was never really told what was done to him, why it was done to him but he was always aware that something had happened to him. Alan's story demonstrates that medical experiences in childhood can be frightening, traumatic and confusing.[422]

He explained that from the age of four, he was aware that there was "something missing". He recalls having had surgery as a child, when he was five and half years old, but does not know exactly what was done or why. He remembers

> I always had memories of surgery and how poorly it went. ... at five and a half (years) it is too old. It's completely the wrong age to have surgery of that nature because it is neither too young to forget or too old to understand. It really is a horrible age. I do believe that surgery was necessary in my case and again because nobody ever spoke to me and I never asked questions. I have absolutely no way of knowing what the original op, the original condition could have been or was. ... there was no conversation about it in any shape or form. ... I know the surgery did not go right when I was a child because I was in hospital for way longer than I should have been. (Alan)

This historical trauma also becomes part of the current trauma he grapples with as he continues to navigate his adult life in a body he is unsure of and at

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[422] Kassam-Adams and Butler (n 396). At p793.

pains to keep from further harm. Burying his historical trauma has meant he could 'carry-on' with life however, having never had the knowledge, care or support to understand and learn about himself means that the current trauma he experiences - specifically the prospect of more surgery - is deeply problematic and preventing him from fully engaging with medical professionals. Alan explained

> …there was an issue there from an early age. From 4 and a half or 5 years of age but it was just a question of putting up with it like, more or less. So, there was a medical issue erupted a few years ago where it became quite difficult to go to the toilet etc. … and that just kicked off all the mental issues as well. 'Cause it brought up the memories of hospitalisations and all sorts of things. Which I had done a very good job of keeping covered and buried over the years … so I had to get help and it would have been primarily I suppose, … I wasn't overly impressed by medical approach but I certainly, it would have been from going to counselling and going to psychologists that the whole, the broader picture like in terms of intersex would have been on the table. (Alan)

As a five-and-a-half-pound newborn, Claire was subjected to intersex genital surgery. A penis was constructed on her ambiguous genitalia and she was reared a boy. Her parents were deeply ashamed of their intersex child and Claire grew up in the most dysfunctional family circumstances. Claire makes a direct link between the torment they have endured throughout their life and being an intersex child.

Claire struggled to conform to their assigned gender. They were beaten and bullied by their parents for asking Santa for the wrong types of toys at Christmas. Much of their story is told through a narrative of trouble – trouble at home, in school, on the street, in relationships – they got in trouble for the length of time it took them to urinate. They were also a victim of rape. They were being molested by adults as they tried to escape their family home which they compared to a "haunted mansion" that was joyless and miserable. They were eventually thrown out of the family home – they were smoking at aged 7 to be tough so as to fend off bullies. Claire said

> I look back and realise how much those things affected my self-efficacy through life. Because I looked at how I was bullied into certain

> life changing situations as an adult, how I was bullied, I allowed someone to bully me into being pimped … I had a terrible childhood as an LGBTQIA plus child … I had no self-efficacy because I was a f**king intersex child. I didn't have, I didn't get to grow up as a little girl and have the normal childhood I would have wanted. … I was never meant to be a boy. (Claire)

Claire has struggled to identify with their altered intersex body. She describes her penis as "man-made" and is disgusted by it.

> I still don't know what I am supposed to call them (genitalia). I don't like really referring to it as a penis because I didn't really start life with a penis. I started life with basically a large clitoris. And they re-routed the urethra and it's like now you have got a penis but then your brain is supposed to hook in with it (Claire)

She has dissociated from her surgically altered body and has othered herself. Her self-concept and way of being in the world - essentially who she is - has been disrupted as a result of the intersex surgery and trauma she has endured.

> … me and my reflection went two different ways and not only did I not like my reflection I lost my ability to relate to it. It was weird. To the point my reflection became somebody that you see some person on the bus every single day, … I didn't relate to my body so I wasn't taking care of it. I was drinking really heavily for a child. … as a kid you are trying to figure out what the f**k are you doing? You're a monster. Ok, I accept that I am a monster, I'm an abomination. Why am I this way? (Claire)

The evidence we present here demonstrates that intersex trauma is a complex phenomenon that is directly related to childhood medical intervention/treatment and individuals not fully understanding what happened to them as children. Evidence also suggests that intersex people like the ones we have spoken to and incredibly resilient despite their trauma. So much of what they deal with in their everyday lives has become their 'normal' and they have navigated that without much support – whether it is hurtful hospital communication or verbally abusive taxi drivers telling them they should have been aborted. Our participants are remarkable and we are indebted to them for sharing their deeply personal life stories with us.

10

Intersex Care in Ireland

Chapter 10: Intersex Care in Ireland

PART 1: Mapping the Approach to Care

In order to map how people with intersex variations are cared for in Ireland, we must recall the four potential approach to the medical management of intersex outlined in Chapter 4. As outlined in that Chapter, one of the main distinctions between the approaches is in how a decision about whether a medical and/or surgical intervention will take place. For the Optimum Gender of Rearing (OGR) approach it is the treatment team which decides and informs the parents about what will take place. Using the Modified Approach, both parents and the treating team together come to a decision about the most appropriate route forward. The pool of decision-makers potentially grows when the Consensus Approach is followed. Here is the child with the intersex variation is sufficiently grown to particpate in the decision, they may be involved in an age appropriate manner. The Moratorium Approach prohibits unnecessary interventions until the person with the intersex variation is capable of making an informed decision about their treatment plan.

There is no formal statement from any professional body guiding practitioners about the most appropriate approach for the Irish context. Neither are there guidelines from the Government, the Department of Health nor the Health Services Executive on this issue. In line with this, there is an absence of formal support structures for people with intersex variations of their sex characteristics, their familes and the healthcare professionals who practice in the area in Ireland. Similarly, there are no formal oversight mechanisms charged with focusing on intersex/variations of sex characteristics here.

It is for this reason that the stories that those healthcare professionals practising in this space in Ireland shared with us are invaluable. They confirmed that they do not see many people with intersex variations of their sex characteristics each year. From them we understand that there is an informal group of professionals in a variety of disciplines who, as part of their practice, treat people with intersex variations of their sex characteristics. This informal group is a multi-disciplinary team, which they call the National Forum. Although not formally recognised, the Forum is resourced. Pasterski et al noted that the ideal multidisciplinary team consists of paediatric endocrinologist, paediatric surgeon/urologist, plastic surgeon, paediatric psychiatrist/psychologist, gynaecologist, clinical geneticist, histopathologist and neonatologist. Ideally, there should also be a social worker, specialist nursing staff and a medical ethicist.[423] The healthcare professionals we spoke with informed us that the National Forum in Ireland consists of endocrine consultants, a urologist, at times a genetic consultant, a gynaecologist, an obstetrician, a psychologist, a social worker, specialist nurses, radiologists, and has recently included a medical ethicist. Not all the members are Dublin-based and health care professionals from all regions of the country participate in the Forum. In addition, a UK based endocrine consultant also attends meetings on occasion. The membership of the Forum closely reflects the ideal composition of a multidisciplinary team as identified by Pasterski.

This Forum has a focus on paediatric health. Complicated cases from across the country are referred to this Forum for discussion. However, those we spoke with confirmed that there may be other children whose cases do not get referred to this Forum and whose variations are managed locally. Generally speaking, the medical professionals we spoke with clarified that in current practice in Ireland, a patient-centred approach is adopted. It is not unusual for parents to meet with all the team. The National Forum holds a 'consensus meeting' to discuss each case which is referred to it, and agree a plan on how best to manage each case based on its individual facts. There is no designated Centre of Excellence for the management of variations of sex characteristics in Ireland. However, those we spoke to consider this is a strength:

> So there is a lot of focus, of expertise in one forum. Which makes it a really amazing system. Because I think we are privileged in one way, because we are a small country, that when we have a baby that is born with a sort of sex development or a query we can all come together, and now we are doing it on Webex, and that means that there are no rush decisions made. In other countries different centres are doing it but even in Ireland a child born in Cork or Galway or wherever can be brought to that Forum. So I think that makes it very cohesive and very fair because no child is denied that expertise and no

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[423] Pasterski, Prentice and Hughes (n 265). At p620.

> consultant is denied that opportunity to discuss. (Health Professional 3)

The Forum meets quarterly to discuss the ‘difficult cases’.

> It is a very good format. Often patients will come to the hospital on that day and can be seen by whichever experts need to see them. So rather than having multiple visits they can see everybody on the one day. (Health Professional 1).

There is no typical trajectory for the care of people with intersex variations of their sex characteristics. The healthcare professionals repeatedly stressed that they respond to each person as that individual requires. All the healthcare professionals we spoke with mentioned that there is a preference within practice in Ireland for postponing interventions until the intersex person can be part of the decision making process where possible, even up to adulthood. Health Professional 2 described this to us:

> But generally the consensus is to avoid surgery unless it is necessary. Medically or in terms of reducing cancer risk. I think it can be difficult as well, I have one particular patient who I suppose in years gone by she probably would have had genital surgery as a child but now she is a teenager and she hasn't had it. But it is something that she is very conscious of and she herself now is expressing a wish to have the surgery. But the consensus of the whole team was that the surgery should be deferred until she’s 18. And the patient is very disappointed about this. She finds it hard to understand. But I think that is out of cautiousness. For her being an adult and making a big decision like that herself. And obviously she is linked in with the psychologist and is getting good support around that. (Health Professional 2)

Thus it is clear that healthcare professionals in Ireland currently follow the Consensus Statement approach to the medical management of intersex variations. However, it is also important to recall that there are intersex adults living here who were treated under the OGR approach. Health Professional 1 and Health Professional 3 told us:

> when I would have been a student, a while back, I would have overheard doctors consulting, not with parents, that it will be

> anatomically easier to raise this chid as this, I would say. But in my present experience I would say no, it is more a collaborative discussion with parents and that. It is better now. (Health Professional 1)
>
> I know there are patients out there that maybe in the past may feel that they didn't have a say and that is absolutely valid. It is how they feel that is most important. But I guess it is just to reiterate there is no child going for surgery in Ireland without absolute necessity and detailed discussion with the whole team, cross disciplines and the parents. And obviously when it comes to consent of a baby that is a huge issue. And that is why we have an ethicist and all this huge discussion. But surgery is only done if absolutely necessary. (Health Professional 3)

A particular feature of historic management of intersex variations involved limited disclosure about both the particular variation and precisely which interventions had been experienced and why. Health Professional 2 described the impact which this lack of knowledge may have on patients, identifying that it can be a cause for patients becoming lost to follow-up. The healthcare professionals who spoke to us emphasised the need to move away from the secrecy of the past which was ‘a level of concern from all angles.’ (Health Professional 3) They identify the support of psychologists in the Forum as being very important in facilitating disclosure. Key to this was maintaining a good rapport and open door policy with both patients and parents alike. Healthcare professionals told us that they would not be comfortable with patients transitioning into the adult services while still not being fully aware of their variation and its implications. The also reported that parents can often ask them to facilitate informing their child about the intersex variation of their sex characteristics.

> Sometimes the parents might ask us to do it and I am not saying ‘the difficult conversation’. The parent might not be able to do it themselves but they might ask the child to ask us to do it in front of them. Which I think is fine because medicalising it but you are giving the parents an out. So obviously the child can talk to their parents after and I think that is when patient information leaflets and websites can be very helpful. (Health Professional 3)

Analysing the stories the intersex people, an intersex person's partner and the healthcare professionals who care for them have shared with us, three key issues about the experience of the medical management of intersex in Ireland emerge. We have called these ageing out, stepping out and turning out.

Ageing Out

Mirroring the dominance of academic writing and activist advocacy focused on intersex children, so too the experiences of medical professionals of intersex in Ireland was predominantly paediatric. The medical professionals spoke to us of the problems of ageing out of the system. The National Forum is a paediatric one. There is no comparable holistic multi-disciplinary team for adult intersex people in Ireland. Thus people age out of joined up care once they turn 18.

Some of the healthcare professionals we spoke to were acutely aware of the paediatric nature of their service, and the inevitability of turning 18. Healthcare professionals discussed the detailed plans and support they provide for young people with intersex variations of their sex characteristics as they moved towards accessing adult services. Health Professional 4 describes the

> But I suppose it is like any transition, you prepare the young person for it. If you have a working relationship for the last year we have been preparing for the transition on to adult services. So this young person, I was working with them if they had any expanding questions for the medical team. So, we sat down with the endocrinologist and the Urologist who had done surgery, this person had a complex medical history, not just the intersex condition but a complex medical history and Urology, Surgery, Endocrinology and myself and I had worked with the young person to come up with all the questions they had around their treatment and decisions that were made and we sat down together so that they could ask all their questions in preparation for moving on to adult services and then we had questions afterwards to process the information and then they were ready to go. That young person needed a lot of input whereas someone else, they might

> not need as much input as that to transition on to adult services. It is on an individual basis. (Health Professional 4)

However, they were also aware that there is no central hub, or coordinated wrap-around care for adults with intersex variations of their sex characteristics. As Health Professional 3 told us:

> the transition planning is huge. They may have been treated by us as one service all the way through and now maybe their issues are gynecological and endocrinological so you have to tee up different people in different hospitals. So it can be a little bit messy trying to figure out what is the priority. (Health Professional 3)

From an intersex person's perspective, Claire described in visceral detail the realities of the absence of a lifelong, informed and coordinated healthcare support system for adults with intersex variations of their sex characteristics when she told us about reaching out for help when suicidal.

> The psychiatrist I got never called me back. I was like, so I called the GP, got his number, phoned him, got his secretary and she was like [Secretary] 'but you are intersex and transgender'.
> [Claire replies] 'I know, I'm trying to see you to talk about that'.
> [Secretary] And 'you are intersex and transgender'.
> [Claire replies again] 'I know. I am a suicidal intersex and transgender person'. And she was like 'You need to go to [Mental Health Hospital]'. I am on the waiting list for [Mental Health Hospital] but 'let me see what I can do' and I still didn't get a call back. I called them again and they were like 'you are intersex and transgender' and I'm [like] 'I know, just trying to see you about antidepressants'… and they said 'No, we won't see you here, you need to go to [Mental Health Hospital'. 'I'm on the waiting list for [Mental Health Hospital]'. They refused to see me while I was suicidal. (Claire)

Claire's experience reveals that adult patient care at present fails to properly support patients who have intersex variations of their sex characteristics. Where healthcare providers cannot see beyond a gender question when a patient with an intersex variation presents, this may result in a refusal of treatment as Claire experienced.

In recognition of the need for continuity of care, some of our healthcare professionals told us that they can involve practitioners with practices who see both adolescent and adult patients as their paediatric patients grow up. This ensures that there are some familiar faces as patients age out of the Forum's coordinated service. As Health Professional 2 told us:

> we give continuity of care for women who would have been diagnosed with Androgen Sensitivity or Congenital Hypoplasia in adolescence. Even just once a year to touch base with them. I think patients appreciate that. (Health Professional 2)

This commitment to remain meaningfully engaged with patients, and encourage the development of peer-support, prompted the development of one particularly innovative and patient-led initiative with one of our health professionals. In the absence of Irish-based support for certain variations, one of their patients travelled to another country to seek support and then with our health professional initiated a patient-support meeting which our health professional described as a transformative day for patients their own professional self.   Health Professional 2 explained

> We would often say wouldn't it be great to have a support group or to bring these women together. So that happened. And it was through a patient advocate who had travelled to [another country] and who got involved in a support group in [that country] and she became an advocate for support groups [here]. I suppose she was the person who brought us all together and I would have a database of women attending my service. And I basically sent them out an invitation, just this meeting is happening and if you are interested we'd love to see you there. So the age group of the women who came they were mostly probably in their 20's and 30's and some of the parents of the teenagers came. So that was helpful. But we had a general overview talk about the condition. The advocate spoke about her experience and telling her story, the woman who had the baby through surrogacy with the condition shared her story and then the parents all got together in one room and the patients got together in another room. And basically swapped stories and it was really very emotional listening to the parents. The girls themselves spoke privately without any medical people or anybody. They just got together, themselves and swapped numbers, created a What's App group. But the parents

> spoke openly, some didn't want to speak. Some just cried. And they spoke about what it was like when their child received this diagnosis in the 80’s, 90’s, 70’s and how difficult that was and how alone they felt. How unsupported. And I think just for those parents to meet other parents and the women to meet other women it was really powerful. We felt like we had done something good. I mean our vision would be to do that for other [intersex] conditions as well. So perhaps to have something like that for Intersex or DSD patients. I think a lot of good could come from something like that. (Health Professional 2)

This innovative and patient-centred initiative is perfectly aligned to a consensus-based approach and is evidence of best practice in an Irish healthcare setting.

Stepping Out

In the absence of specific transition from paediatric to adult care services and in addition to the lack of coordinated adult services, it is not surprising that some patients may be lost to follow-up. When such people reemerge to medical attention, there can be many sensitivities to navigate as Health Professional 2 told us:

> and sometimes I come across women who have been lost, to follow up. So for example they were diagnosed as teenagers. And I think these women have had very difficult and traumatic experiences I suppose. So you are talking about women maybe in their 40’s who were diagnosed I guess 20 or 30 years ago. And some of these women I think in those days, in times gone by, it was very much a secret if there was any DSD, an XY karotype. If they didn't have a uterus. I think they weren't told very much as patients, as teenagers or children. I think it was very much things were covered up. They were told they had a hernia or they had a cyst removed. Those kinds of things. So I think the system isn't perfect now but I think in those days it was very different. And it was definitely, I think there wasn't a lot of disclosure to patients what their diagnosis was. So I have had women who have come in and literally just cried in my consultation room and I think for many years they haven't had support or known who to go to. It has been quite

> rewarding to help some of these women. Sometimes it is just talking to them. There are lots of issues. (Health Professional 2)

Given the trauma that some adults with intersex variations of their sex characteristics experienced with medicalisation in childhood coupled with the difficulty they had accessing informed and appropriate healthcare as adults; it is not surprising to hear that some of the people with intersex variations that we spoke with told us they avoid doctors as much as is possible.

Alan was very open about his distrust of medical professionals. He felt that medical professionals in adult settings defaulted to responses that were not appropriate for a person with an intersex body. That they do not take the time to listen to him and his explanations about himself and his body. He also noted that the short appointment times worked against healthcare providers gaining an understanding of why he is reluctant to undergo more surgery. This has had an impact on his willingness to engage. You can see this wish to avoid healthcare professionals in the following exchange:

> Interviewer I am talking about now, sorry, your recent, when you said in your 40’s you needed to go back and you needed to be hospitalised it resurrected again. Did any family members know then that you were in hospital? With your recent stint in hospital
>
> Alan I haven't been in hospital since I was 5 I haven't been to hospital. Because again I have not gone to medically for anything.
>
> Interviewer Stay well away from them.
>
> Alan In all circumstances. I wouldn't even go for a doctors check up in a year.
>
> Interviewer Ok, so you have stayed well away from everything since t hen.
>
> Alan As much as absolutely possible, yes. Again until I was forced into it.

Emma tells us of stepping sideways, to find an alternative healthcare provider when her initial provider was not responding to her in a manner she felt met her medical needs. Emma's life-course was very much aligned to a heteronormative script - Emma married a woman and they had children. As a teenage boy, Emma played football but felt uncomfortable with "lads' culture". Their male body did not resemble those of their football team mates and Emma noted "I was constantly trying to hide my body from other people". It was only when Emma was undergoing surgery as part of their "medical transition" from man to woman that their intersex variation was discovered and confirmed. This discovery helped Emma to understand, albeit retrospectively, their experiences of growing up and puberty. Having initially learned about their variation post-surgery, Emma wanted to learn more. The initial "wait and see" approach by her doctors then was not helpful and Emma did recall a time where she had an "argument" with a medical professional who she believed was not caring properly for her given the lack of monitoring of her hormone levels. However, Emma now meets with a different doctor, who is committed to helping inform Emma about herself and her variation. When speaking about her experience of medical professionals Emma explained

> They've helped definitely in understanding of where I am and where I've been and what my condition is. I suppose they haven't been very helpful in the sense that they still don't know what the problem is that I am dealing with. Because it is very much a wait and see. It doesn't seem to be bad or it doesn't seem to be a problem. But if there is no problem we'll keep monitoring you. So therefore I go in once a year for a test and then I get ultrasounds and I get scans and I get all sorts of stuff done over the period, which I am due in November. And I haven't got an appointment for it yet. But I am paying for it privately so that I can make sure that it is done. But I still haven't got an appointment so they should have scheduled and they haven't done yet. Which is fine, I'll try and contact them soon. But the clarity about what they then gave me a diagnosis about actually they've been very clear and very helpful about that. I don't know that everyone necessarily was before this particular consultant I am dealing with. In fairness she has gone out and gone looking for information, even stuff that she wasn't even 100% aware of I think. That has been reasonably helpful. But it is also therefore helped me come to terms a little bit on why things have

> happened in particular ways over the last not only 12 or 15 years or 20 but over the last 50+ years. (Emma)

Experiences of engaged and supportive medical professionals has been beneficial for Emma to continue learning not just about the physiological characteristics of her variation but rather, learning about herself and who she is and piecing together this information to assemble a coherent and informed self-concept. Thus demonstrating the importance of a consensus-approach from the intersex person's perspective.

From the perspective of our participants with intersex variations of their sex characteristics, evidence is mixed as to whether a consensus-approach is actually a reality for all, particularly those who have aged-out of the current care framework our healthcare professionals describe.

We find evidence from Alan's story to suggest that barriers exist in the current Irish public healthcare model preventing him from experiencing what we identify as practice aligned to the consensus approach. Alan's intersex variation is hypospadias - when the opening of the urethra is not located at the tip of the penis, rather on the side or underside (see glossary note for a full description). Alan is unsure as to what surgeries were performed on him as a young child. He does not dispute that he needed surgery but the reasons for the surgeries were never explained to him. His experiences in this regard correspond to "The Modified Approach". Open and transparent engagement with children about their bodies was not a feature of Ireland's socio-cultural milieu in the 1960s. He has not been "overly impressed with the medical approach" since.

However, even now, as our medical professionals and Emma point to evidence of the consensus approach in action, this is not something Alan can relate to. Alan's experience is a fine example of his "opting out" of the healthcare provision due to (1) the trauma of his past experiences and (2) his current belief that the medical professionals caring for him appear to have a preference for taking the "default" position and only offering him a cystostomy ("the surgical creation of an opening into the bladder")[424] -

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[424] John Samuel Fisher (MD) and Edward David Kim, 'Suprapubic Cystostomy: Background, Indications, Contraindications' [2021] Medscape <https://emedicine.medscape.com/article/1893882-overview> accessed 25 March 2022.

another surgical solution to the problem he experiences as a result of the childhood interventions. Alan obtained a second option advising that "under no circumstances was it suitable" for him to undergo a cystostomy and this confirmed his own doubt that a cystostomy was the most appropriate pathway of healthcare. Alan believes other options of care are available but the constraining nature of Ireland's public health system, such as specifically very short appointment times, prevent meaningful engagement with medical professionals and time to discuss and explore all possible pathways of care. Not having his voice heard and/or having his preferences for alternative healthcare solutions dismissed and relegated to second position below those of the medical profession makes for discriminatory healthcare experiences which further fuel his opting-out.

> the interpretation of the situation is always your own opinion afterwards. I have had a lot of medical experience in the last 4 or 6 years. I would have said they were all discriminative but I couldn't pinpoint how or where, do you follow? Because it was always along the way, it is what their opinion was [that] takes precedence and their expertise takes precedence over what my opinion is or what I feel needs to be done or corrected. ... I have no credibility going to medical people now. ...Because medical people will only listen to medical people. They don't listen to the patient. ... I know it is that way. Ten minutes of a public consultation is not enough in my situation. So, I know it is that way. And, again, it comes back to that default setting. They will do absolutely nothing and you can't get a single word out of them except cystoscopy. That is it. There is no deviation from that default setting. None. And that is a bugbear of mine. And I am still traumatised from the surgery I had forty-five years ago and that is all they want to do for me. (Alan)

When asked at interview if he thought he would be re-traumatised by a cystostomy he replied

> I don't think it, I know it. Because of the influences of family and because of other influences as well. Like, I don't have support. I don't have enough support. Never had. There is no medical person interested in that. They never even ask. No medical person ever asked 'What support do you have?'. Not once. (Alan)

While he believes that change is happening and we are in a more open, transparent society, he does not believe that the system has kept apace. He noted a specific failure of 'the system' that inhibits meaningful patient-professional dialogue and it is the fact that the operationalisation of the 'system' of care is binaried.

> I feel like the hardest people to get on line are the medical [professionals] because they are really, really stuck on binary male and female (Alan)

Moreover, this experience also extends to the medical literature that Alan has himself read and researched. Once again those are discriminatory experiences because they are exclusionary and only serve to reproduce a binary-based value system.

> I still have issues with those biology books and have even more issues with the modern medical. They can write books on hypospadias but they always have to use the perfect shape and size and I can't see how [that] is that relevant to the variation in the species? What are they trying to prove? Just thinking beggars believe. And all it is doing is heightening the unease in the patients that don't have the perfect anatomy again because they don't fit perfectly into the binary. And there isn't any scope in the medical for that. And there even in very recent publications like and they still haven't shifted from that. (Alan)

There is no room for appreciation of difference or alternative approaches to patient engagement in this binaried framework of care. However, Alan also recognises that medical professionals are also affected by the public healthcare constraints which ultimately have a knock-on effect on patient care.

> I am not necessarily angry with the situation and I am not necessarily resentful of anything but I know everybody is operating, all medical people are operating within a framework that they have to work within. And it is not conducive to, certainly not people with these kinds of difficult and awkward situations like. So like, I am not taking issue on the medical side of things in that regard. I know they are time limited and I know they are finance limited and I know there are all sorts of limitations. Because you have to accept that into the

> equation as well. So like it is all well and good like to shout that you haven't got heard enough or you haven't had enough time or you haven't had enough time to answer all questions etc. but you have to accept that there are limitations on the medical side as well. (Alan)

Alan recognises that this is another “system” issue in the same way he recognises that the system is built around a binary notion of male and female which impacts on the delivery of care all of which collectively impact on the structure and delivery of intersex healthcare in Ireland. Alan’s ideal option for meaningful care is perfectly aligned to the consensus approach. His preference is for open and transparent engagement whereby all options of care are presented to him and discussed so he can make informed decisions about his care offered by a ‘system’ with a joined-up, holistic approach to him as a human. Heretofore, based on his lived experience, Alan has not realised the human aspect of himself. When asked at interview “When did you get a sense of you as a human being then?, his response was profound, he said “I’m still looking. Still waiting.”

Turning Out

The third issue that emerged in our analysis was that of turning out. In other words, circumstances where an intersex person was required to travel abroad in order to access the healthcare they need. Some of this was mandated due to the small size of the Irish population there may be procedures required by patients that Irish based doctors are not familiar with. As Health Professional 3 explained:

> We have to acknowledge we are a very small population so when it comes to rare diseases and rare conditions with specific anatomical issues that might need expertise there may just not be the surgeons or gynaecologists there that have the experience or the willingness to start doing, because they don't have that footfall there, that number of patients. And there is an acknowledgment of the treatment abroad scheme patients do have access to care that is not available in Ireland which I do think is quite fair. Because you do want to be sending your patients to somewhere that has got expertise. You don't want to be doing it on your own. (Health Professional 3)

Changes in medical practices and delaying surgical interventions may partly explain why it can be necessary to travel to access expert care. Health Professional 2 told us:

> And the other issue that we are encountering now is a lot of this surgery was done by paediatric surgeons in times gone by and now the surgery is being deferred until they are older, as adults, there's really a scarcity of people who are skilled in that kind of surgery. At that age group. So most of these, if a girl needs surgery for the most part it is quite complex surgery. It is not something that a general gynaecologist or urologists would be familiar with. This is reconstructive surgery so we would end up referring our patients to the UK. (Health Professional 2).

One of the big issues identified by healthcare professionals was the preservation of fertility when at all possible. This featured in discussion about initial decision making when first encountering a patient with a variation of their sex characteristics. They told us about the importance of discussing fertility issues with parents when the variation was identified in early childhood, and more importantly, ensuring that patients understood any impact on their fertility when disclosing about their intersex variation of sex characteristics. Health Professional 2 told us:

> The other thing we talk about if it is appropriate, depending on the age group or if the parents want to talk about it is we talk about fertility. And I would work closely with my colleagues in [a fertility clinic]. I will try and emphasise the positive. So many of these girls will have normal ovaries so although they might not have a uterus they'll have normal ovaries so egg freezing may be an option. And we would discuss possibilities like surrogacy for example. In the past adoption was the only option for a lot of these women but surrogacy may be an option now. For those that have a uterus but don't have normal gonads they can carry a normal pregnancy with a donor egg. Or donor sperm. Again there are positive things that we can discuss with patients. And I would tend to focus on that. (Health Professional 2)

To obtain a sense of whether or not people with an intersex variation in their sex characteristics experienced fertility issues, we included the following item on our questionnaire

Does your variation impact your ability to reproduce your own (biological) children?

Seven of the fourteen respondents noted that they could not reproduce either due to their congenital sex variation (n=6) or due to treatments/surgeries related to their congenital sex variation (n= 1). The following table provides a breakdown of their responses.

I cannot reproduce due to my congenital sex variation	42.9% (6)
I cannot reproduce due to treatments/ surgeries related to my congenital sex variation (e.g. I was sterilised)	7.1% (1)
I can reproduce with difficulties	14.3% (2)
I can reproduce but need assistance of reproductive technologies (21.4%, 3/14)	21.4% (3)
There is no impact on my reproduction (I can reproduce without problems) (14.3%, 2/14)	14.3% (2)
Total respondents	14

Nine of our survey participants reported that they did not have children.

Some survey participants shared their feelings about this.

> Heartbreaking, devastating (13)

> Very upset about this as always wanted to have children (18)

> As I said, it has affected my self esteem. It is a very difficult conversation to have with a partner. I guess everyone would like to have that experience and see what their offspring would look like. I guess because I found out at 17, I had a few years to come to terms with it myself. I can imagine it being a lot more tough had I been married and finding out having tried to conceive with my husband/partner. (22)
>
> The fear of passing the same trait/condition to male child is/was main reason for not wanting children (24)
>
> I was devastated - and still very sad about this (28)
>
> I couldn’t reproduce now due to HRT, but I have patented biological children. (30)
>
> Learning this in the way that I did (by connecting a few dots in the car ride home from the doctor) as a young person was deeply troubling, then being offered no age appropriate supports was deeply traumatic. I have worked on both this trauma and the underlying issue of parenthood, its ongoing. (32)

The impact on her fertility was the most upsetting aspect of her intersex variation for Gina.

> I think for me the hardest thing for me was my fertility and like as same sex couples we weren't allowed to use the [local maternity hospital], we weren't allowed to use any public funded facility. We had to pay everything private. We wouldn't be monied people so we did the fertility here and we did it in [European City] because it was cheaper. And I’ll tell you doing fertility in a foreign country, if you are doing IVF here it is fucking tough but if you are doing IVF in [European City] it is really, really tough. But we did 8 rounds of it and 4 IUI and 4 IVF. It was an absolutely horrendous experience. (Gina)

She talked about how the stresses of undergoing IVF were compounded by the need to book flights and accommodation, while waiting to ovulate and waiting for optimum blood test results. The financial, physical and emotional stresses of the situation were compounded by their feeling that they could not share their fertility struggles with friends or family.

> And you couldn't tell anyone. I remember going to [European City] going through IVF and my boss is a lovely woman and probably she would have understood but she thought I'd gone on holidays. And she was like do you know what I don't know why you are going over there? The weather is lovely here now this week. And I was like she actually thinks we are on holidays and we should be coming back totally refreshed. And I worked from the time I came back because you couldn't, I couldn't take time off cause I couldn't tell anyone. (Gina)

Gina and her partner describe a profoundly upsetting human experience as they tried to fulfil their lifetime desire of having a child. This was an emotionally exhausting experience compounded by the fact that key institutions in Irish society such as law and medicine do not have the flexibility to support and protect an intersex person like Gina in the same way it offers support and protection to the non-intersex population.

Our data demonstrates that the aging out, stepping out and turning out realities that our participants discussed, describe an Ireland that is not enabling people with variations of their sex characteristics to exercise their right to the highest attainable healthcare in an equivalent manner to everyone else in society. Our healthcare professionals acknowledge that the system in Ireland is not perfect. Additional support is needed to enable the delivery of lifelong, coordinated, informed and expert healthcare. Health Professional 3 described initiatives to create transition pathways towards informed adult healthcare:

> I am trying to set up a CAH transition process in [Large Public Hospital 1] because two of my colleagues there have reached out and we have a working relationship and naturally I would have transitioned lots of patients to them. Same with Turners and I would have seen a lot of Turner's patients in the [Large Public Hospital 2] and [Large Public Hospital 3]. So there is no issue finding an endocrinologist to be honest. The endocrinologists themselves are very good at accepting some patients with some DSD as long as we explain what it is. They find it fascinating. They would probably be less

> knowledgeable on it because they wouldn't have had to go through the nitty gritty work up in the diagnostics stage. They wouldn't have any experience of the infant stage and they'd have trainees to come and do a bit of paediatrics, I think they find it really useful. When it comes to the rare cases you have to figure out what are their pressing needs for adulthood. If they are female reared, then they may need some gynaecology so that is critical. Sometimes a urologist might be needed. And if it is an endocrine disorder they'll need an endocrinologist. So they are not under the same roof unfortunately but there are very few with that that would have a rare condition of this, that and the other. So the main thing is planning with it and discussing with the child and the parent as to what their needs are. (Health Professional 3)

The healthcare professionals we spoke with demonstrate patient-centred care, adopting the Consensus Approach and describe a commitment to delay medically unnecessary interventions and provide as much assistance to help patients and their families understand and come to terms with varied diagnoses whether it is with the use of advanced genetic testing or counselling. They also are concerned to ensure that as their patients age out of paediatric services, they are properly supported. In this way they attempt to reduce stepping out. Unfortunately, our research has revealed that given the small size of the Irish population generally, with the 'lack of footfall'[425] to build sufficient expertise nationally, turning out has the potential to continue to be a feature of healthcare provision in Ireland.

PART 2: The Irish Experience of Intersex Healthcare

At the time of completion, twenty-three of our survey participants reported that they were living in the Republic of Ireland. Four of our interviewees were living in Ireland at the time.

Our survey contained a number of items asked about the reality of our participants' healthcare experiences. We obtained some demographic,

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[425] Health Professional 3

health-related, data about our survey participants to map their health-related status.

Healthcare Capital

We were interested to learn about various different aspects of a person's overall health status and experience. Ireland's public health system offers people with certain long-term health conditions assistance in terms of having a (1) GP Visit Card which entitles the cardholder to free visits to see their GP or (2) a full Medical Card which covers almost all healthcare and medicine costs. Medical cards are also held by a proportion of the population who, following a means test, are deemed eligible for this form of social assistance. Almost one-third of the Irish population had medical cards in 2018, one in ten people had a GP Visit Card,[426] and by 2021, 47.1% of the total population had private health insurance with the average adult premium costing €1, 470.[427] Insurance coverage rates like this are not necessarily the norm. In fact, insurance coverage is relatively low in the United States.[428]

Twenty-two intersex participants, living in Ireland, responded to an item asking about their 'healthcare capital' status. Despite our very small sample size, the results are aligned to the national trend for having health insurance – 45.5% of our sample had health insurance. However, the majority did not have this form of healthcare capital. Approximately one-fifth (22.7%) had a full medical card and 31.8% did not have either a GP Visit card or medical card.

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[426] Central Statistics Office (CSO), 'Ireland's UN SDGs 2019 - Report on Indicators for Goal 3 Good Health and Well-Being' (*Ireland's UN SDGs 2019 - Report on Indicators for Goal 3 Good Health and Well-Being*, 2021) <https://www.cso.ie/en/releasesandpublications/ep/p-sdg3/irelandsunsdgs2019-reportonindicatorsforgoal3goodhealthandwell-being/healthcare/> accessed 16 March 2022.

[427] Health Insurance Authority (HIA), 'HIA Quarterly Bulletin: Market Statistics for Irish Health Insurance Q4 2021' (*Market Statistics*) <https://www.hia.ie/publication/market-statistics> accessed 16 March 2022.

[428] Rosenwohl-Mack and others (n 307).

Table 10.1 Healthcare capital

Healthcare	**Number of Responses**	**%**
GP Visit Card	-	-
Full Medical Card	5	22.7
Neither GP or Full Medical Card	7	31.8
I have Private Health Insurance	10	45.5
I do not have Private Health Insurance	-	-
Other	-	-
Total	22	100.0

Health Status and Self-Reported Health

Ireland has the highest self-perceived health status in the EU, with 82.9% of people rating their health as good or very good.[429] The number of people reporting a chronic illness or health problem is also better than the EU average, at around 27.7% of the population (Table 2.2). Yet, along with trans people, intersex people reported the lowest life-satisfaction scores among the EU LGBTI surveyed as part of the EU FRA survey in 2019.[430]

Interestingly, the majority of our sample (9/15) rated their physical health positively (either good or excellent). This is similar to Australian findings where 79% "considered themselves moderately to extremely healthy".[431] Similarly, 91% of intersex participants (n= 1040) reported "good or fair in general health" and less than 9% reported "bad or very bad general health"

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[429] Department of Health, 'Health in Ireland - Key Trends 2019' (Government of Ireland 2019) <https://assets.gov.ie/45117/6a4f970018d6477bac38f4539f80e927.pdf>. At p19.
[430] European Union Agency for Fundamental Rights (EU FRA) (n 90). Ar p30.
[431] Jones and others (n 87).

across 14 European sites.[432] Furthermore, no one in our sample rated their physical health as very poor yet two respondents rated their mental health as being very poor. No one rated their mental health as excellent. Just under half our sample rated their mental health as 'good' and this is not too far removed from the 2015 intersex Australia survey that noted 59% of participants "rated their mental health as good or better".[433] Notwithstanding the general and positive overviews of intersex people's health, it is important to remember that both European and American studies have noted that their intersex people still have poorer health outcomes and physical health compared to control populations.[434]

How our intersex participants living in Ireland rated their physical and mental health.

Table 10.2 Self-reported physical and mental health

Self-Reported Health Ratings	**Physical Health (n= 15)**	**Mental Health (n= 15)**
Excellent	3	-
Good	6	7
Fair	4	4
Poor	2	2
Very Poor	-	2
Total	15	15

Fifteen participants living in Ireland responded to items asking if they had physical and mental health conditions. Just over half (8/15) reported they had a physical diagnosis and six reported that they had a mental health diagnosis. We detail their diagnosis descriptions in the table below.

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[432] Falhammar and others (n 80). At p470.

[433] Jones and others (n 87).

[434] Rosenwohl-Mack and others (n 307). Falhammar and others (n 80).

Table 10.3 Self-reported physical and mental health diagnosis

Physical Health Diagnoses (n= 6)	**Mental Health Diagnoses (n= 7)**
Psoriasis (13 - Complete Androgen Insensitivity Syndrome (CAIS))	Post-surgery, due to hormonal imbalance after losing male bits, I was suicidal & referred to Mental hospital for evaluation. I would not admits myself though, as I realised that it was due to hormonal imbalance & it was a physical cause & effect. Once on temporary HRT I did not feel suicidal or depressed (11 – Other – Hermaphroditism, born with Male & female genitalia, plus other extra body parts; extra kidney, larger than normal liver, 2 sets of adult teeth, two sets of tonsils, extra bone density, etc.) (11 - 'Other')
Blood pressure (19 - Micropenis)	Anxiety/PTSD/Trauma (24 - Hypospadias, Micropenis)
I avoid attending doctor, unless absolutely necessary to sudden increased frequency to urinate! I use acupuncture & homeopathy to maintain fair health status. Urinary issues - i refuse the medical default investigation – cystoscopy (24 – Hypospadias, Micropenis)	No formal diagnosis but have attended counselling for survivors of institutional abuse (26 - Polycystic Ovarian Syndrome)

obesity, asthma, underactive thyroid, PCOS (26 – Polycystic Ovarian Syndrome)	I have some issues related to AIS, such as low bone density (28 - Complete Androgen Insensitivity Syndrome (CAIS))
hyperandrogenism, hypothyroidism, acne, iron deficiency, vitamin d deficiency (29 - Congenital Adrenal Hyperplasia (CAH),Unknown ,Other)	Depression, sleep disorders (30 - Hypospadias)
DVT, Asthma, major depressive disorder, narcolepsy, insomnia. (30 - Hypospadias)	PTSD related to the trauma of medical interventions previously mentioned, Depression (unrelated), anxiety, gender identity disorder (I contest the need for this to be a medical diagnosis) (32 - MRKH (Mullerian agenesis; vaginal agenesis; congenital absence of vagina))
"Psoriasis, High blood pressure, Hypogonadism, Hypothyrodism, Myopia Lymphodema, Vitamin D deficiency" (35 - Turner's Syndrome (one X chromosome))	Depression, Anxiety, BDD, Panic Attacks (33 - Partial Androgen Insensitivity Syndrome (PAIS))

Ours was a very small sample but it did detect mental ill-health diagnoses. Similarly, the USA survey noted that "found high prevalence of self-reported lifetime anxiety disorders (62.6%), PTSD (40.9%), and depressive disorders

(61.1%), as well as positive screening for current depressive symptoms (61.7%)."[435]

Disability Status

We were also interested to know if our participants had disabilities related, and unrelated, to their intersex variation. For the purposes of this report, we detail the responses from the 23 individuals living in Ireland.

- 5 participants (21.7%) reported that they had a disability related to their intersex variation.

This compares with Australia's only intersex survey which reported that 27% of their respondents had disabilities.[436] The USA survey did not report specifically in relation to 'disability' rather they examined self-reported "functional health" and specific physical and mental health diagnoses.[437]

Our participants' disabilities are outlined as follows:

Table 10.4 Self-reported disabilities related to one's intersex variation

ASD*[438] (1 - Kallmann Syndrome, Partial Androgen Insensitivity Syndrome (PAIS))
I am unable to bear my own children (22 - Ovo-testes (formerly called "true hermaphroditism"),Other)

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[435] Rosenwohl-Mack and others (n 307).

[436] Jones and others (n 87). At p56.

[437] Rosenwohl-Mack and others (n 11).

[438] ASD = Autism Spectrum Disorder

Have impediments, incompetent in, incapable, impotent, powerless inability to, hindrance to, interference, obstruction, disadvantage, damaged, awkward with..... (24 - Ovo-testes (formerly called "true hermaphroditism"), Other)
I've battled a severe hormonal imbalance all my life which affects my sleep, mood, etc., (30 - Hypospadias)
"Hearing loss, Non-verbal learning difficulties" (35 - Turner's Syndrome (one X chromosome))

- 4 participants (17.4%) reported that they had a disability unrelated to their intersex variation.

Table 10.5 Self-reported disabilities unrelated to one's intersex variation

Autism, dyslexia, dyspraxia (10 - Unknown ,Other)
Dyspraxia (26 – Polycystic Ovarian Syndrome)
Dyspraxia, ADD, Diagnosed depression and anxiety disorders (32 - MRKH (Mullerian agenesis; vaginal agenesis; congenital absence of vagina)

Asperger and Klippel Feil Syndrome (33 - Partial Androgen Insensitivity Syndrome (PAIS))

Discrimination in healthcare based on intersex variation

We examine experiences of discrimination in healthcare based on two items in our questionnaire:

(1) Experiences of discrimination when availing of Health/Medical Services and
(2) Experiences of discrimination when availing of Other Health-Related Services (e.g. Counselling, Physiotherapy etc.)

Availing of Health/Medical Services

Twenty-three of our participants reported that they were living in the Republic of Ireland. Sixteen of those (69.6%, 16/23) reported that they had experienced discrimination when availing of health/medical services based on their variation.

Only six offered details about the frequency of this occurrence: Always (n= 1), Often (n= 4) and Sometimes (1).

We also offered different examples of experiences that intersex people may have experienced. Respondents could tick as many as were relevant to them. In the following table we illustrate their frequency. *Lack of referral to social support groups related to my variation* was the most commonly identified reality for our participants.

Table 10.6 Experiences when using health/medical services

Experiences when using health/medical services	**Frequency**

Lack of referral to social support groups related to my variation	13
Feeling excluded when medical staff discussed my variation (and/or potential treatments)	8
Not enough attention on my needs related to my congenital sex variation after childhood	8
Medical staff talking about my variation in a negative way (stigma)	5
Too much attention on my congenital sex variation around the time of diagnosis	4
Other*	3
None of the above	1

*Three respondents identified selected 'Other' and offered the following, additional responses:

> Health professionals getting confused between trans and intersex and making assumptions about my needs (13 – CAIS)
>
> The female gynaecologist who first diagnosed I had was born without a womb said that not having kids wasn't such a big thing. She was a woman and didn't want kids so it's not for everyone. I was so shocked and upset by what she said. There was no definition of my condition and no support was offered. (22 - Ovo-testes (formerly called "true hermaphroditism", Other)
>
> Because I don't present with 2 obvious forms of addictions or maladaptive coping strategy. "I look to healthy for presenting with underlying trauma" (24 – Hypospadias, Micropenis)

We were also interested to learn about some of the problems/issues they experienced when availing of health/medical services. We document those experiences here:

> Denied transition related care (10 – intersex variation, 'Unknown, Other)
>
> Sometimes I get labelled as male despite my Records having been amended to female. This causes confusion & embarrassment; for example when an anaesthetist doesn't perform pre-surgery consultation because they expected a male and this delayed surgery for 3 days until it was clarified (2017 broken collarbone) Or X-ray dept won't x-ray Me for similar reason. (11 – intersex variation, 'Other')
>
> CAH is not included as a condition that requires a medical card which I find disappointing since we will always have to take medication and attend medical clinics. (12 - intersex variation, 'Other')
>
> Lack of knowledge. People conflating my medical history with trans identities and asking for my pronouns, which is more than a little offensive (13 – intersex variation, CAIS).
>
> I feel medical personnel don't hear my concerns, fears, challenges in relation to my variation because I am still unable to express myself coherently enough in the short time available! (24 – intersex variation, Hypospadias, Micropenis)
>
> being refused testosterone lowering medication despite wanting to present feminine (29 – intersex variation, CAH, Unknown, Other).
>
> Ignored, offered and given inappropriate care. (30 – intersex variation, Hypospadias)

Moreover, two respondents offered a further insight into their experiences of the discrimination they experienced.

> Whenever I let a medical person know of my intersex status they immediately panic and either 1) only want to treat intersex and fix me or 2) jump to fear and stop treating me (32 – MRKH).
>
> Interestingly, one person stated "No discrimination - I have the same rights as everyone else" (13 – CAIS).

Availing of Other Health-Related Services (e.g. Counselling, Physiotherapy etc.)

> Experiences of discrimination when availing of Other Health-Related Services (e.g. Counselling, Physiotherapy etc.)

Of the 23 respondents who were living in Ireland at the time of questionnaire completion, only three noted 'Yes' they had experienced discrimination when availing of other health-related services. One individual noted "I have never used these services".

Table 10.7 Experiences of discrimination when using other health-related services

	Yes	No	I have never used these types of services
Counsellor/Psychotherapist	3	11	1
Clinical Psychologist	-	12	2
Physiotherapist	-	8	4
Occupational Therapist	-	7	6
Other:	1	6	5
I did not use these types of services			

For those that reported 'other', they offered the following additional details

> In psychotherapy and alternative field labelled resistant to change because I don't conform to their narrow scope of training and zero training in congenital sex variations of anatomy. (24 – Hypospadias, Micropenis)
>
> They don't always know about intersex. You end up wasting almost a whole appointment trying to explain to them what it is before you get started on why you're there. Then you run out of time and nothing properly has been discussed - it's costing money I don't have a lot of for nothing until they get their heads around things. (26 - Polycystic Ovarian Syndrome)
>
> Refused care, told to present more typically female, told i was just trying to attract my father. (30 – hypospadias)
>
> Only sought out these interventions for trans-related issues (32 - MRKH)

14 people living in Ireland noted the frequency of experiencing this type of discrimination which we outline in the following table.

Table 10.8 Frequency of discrimination experience in relation to other healthcare services

How often discrimination was experienced in relation to other healthcare services (e.g. counsellor)	Number of responses	%
Often	3	21.4
Sometimes	2	14.3
Rarely	1	7.1
Never	8	57.1
Total	14	100.0

Some participants documented their experiences of discrimination.

> Consultants regularly reduced to treat me as my condition was not their field. For example, I am trying to see a urologist about an ongoing issue, and the 2 urologists I have seen so far refused to deal with me because of my medical history & condition not being their field. (11 – Other,
>
> I have thought about disability and how there are services for people with different disabilities and felt that just because my is hidden shouldn't mean that there should be no support. (22 – Ovo-testes (formerly called "true hermaphroditism"),Other)
>
> How can one have normally developed interpersonal relationships with atypical physical, mental and emotional anatomy development, normal development pathways begin and continue in maladaptive manner. (24 – Hypospadias, Micropenis)
>
> As above. Felt like an outsider (26 - Polycystic Ovarian Syndrome)
>
> No discrimination (28 - Complete Androgen Insensitivity Syndrome (CAIS))
>
> None (29 - Congenital Adrenal Hyperplasia (CAH), Unknown, Other)
>
> It was frustrating being told I was wrong, ignored. (30 – Hypospadias)
>
> Its more intersectional than this form allows. (32 – MRKH)
>
> Q39e: once through university i was provided with an understanding counselor who understood intersex. this interaction lasted roughly 4 sessions.
>
> Counsellor focused on my fertility - became convinced I was mourning the children couldn't have .. (35 - Turner's Syndrome (one X chromosome))

Some participants also provided evidence of support when engaging with healthcare services.

> No discrimination - all supportive. Most of the discrimination I have faced has been from trans activists who call me neither male or female and share pictures of people like me online. I feel used and misrepresented. (18 – CAIS).
>
> The most authentic support I have received from acupuncturist(s), homeopath & why, because they are not hiding behind perceived medical expertise or the psychotherapist training, who can pretend to cover sexual issues from a few personal development 40/50 PDC Hrs. (24 – Hypospadias, Micropenis)
>
> if I didn't tell them about intersex I might get better results. (26 - Polycystic Ovarian Syndrome)
>
> None (29 - Congenital Adrenal Hyperplasia (CAH), Unknown, Other)
>
> I have yet to encounter supportive mental health care (30 – Hypospadias)
>
> once through university I was provided with an understanding counsellor who understood intersex. this interaction lasted roughly 4 sessions. (32 – MRKH).
>
> My uni OT was a godsend - he helped me access services in college and communicate needs around my disabilities to future employer (35 - Turner's Syndrome (one X chromosome))

These few examples and their content offer little in terms of describing what supportive Irish healthcare services might look like. However, some evidence of best practice, centres of excellence and expertise emerged in interviews with our international participants and are insightful for considering how healthcare practices and systems could be improved by being more accessible and inclusive.

Having been treated locally in the area where she was from, Becca describes their experience of visiting a more distant centre of excellence and the ways in which it differs from the smaller, more local health system and how it impacted on her sense of self-empowerment.

> Like last year I think last summer before I came out in October I was seeing the (Expert Clinic). It is a really big hospital in (large state expert hospital) and they have a really big endocrinology department that deal with trans people, intersex people. That level of health care was an eye opener just to see how much knowledge was available within the healthcare system at such a facility. They had like pride flags on their scrubs, they had trans flags, intersex flags, it was like instant inclusivity where you felt like you were in the right place. It wasn't something that I needed to hide. Like people wanted to talk about it. That was awesome. That is something I definitely noticed. But again the (Expert Clinic) clinic is the leading hospital when it comes to certain medical steps so you would probably see it there instead of like a smaller hospital. That was very good to see that. That added to my empowerment of wanting to come out and having a good place to have more knowledge and have more medical attention if I needed it. And in fact when I went to them the first time the oral oestrogen that I had been taking they said was much more for a post-menopausal dose. Like for women to take at a post-menopausal dose so that was prescribed by a rural smaller doctor and then I go to the (Expert Clinic) clinic and they say I am getting too little oestrogen. And then they switch me over to these patches. And I change those like every 4 days so that has been awesome too. So I don't have to take pills every day anymore and I've been switched over to a patch. (Becca)

Darcy also explained why being treated in a centre for excellence has been beneficial. It has been beneficial to speak with medical professionals who are experts and obtain a diagnosis.

> I got to (Centre of Excellence) in 2013 and that is when I was 20. And finally MRKH was confirmed by the people that knew what they were talking about. … I then went through the Gender Alliance Clinic in (Capital City) and finally got those hormones. And I have been on

> them nearly two years now and I am a very, very happy bunny on them. And I am in a much better psychological place. (Darcy)

At interview, our team-member asked Darcy if it felt different by being at this centre of excellence and they replied

> 110%, yes, 110%. And as I say there was one particular doctor there at the hospital who I absolutely adore. I really like her, I've watched her on lots, I'm not going to name her, but I've watched her on lots of things. She's done documentaries about it, she's done a lot of awareness stuff as well. And when I came back to her for my final check-up from when I'd been having maintenance, she did examine me but it was gentle. And she very much understands the trauma that people may have been through before. (Darccy)

It is clear that having access to meaningful, expert-led healthcare has the power to have a transformative effect on intersex people's health and wellbeing including their sense of self.

11

Conclusion

Chapter 11: Conclusion

This study is the first of its kind in Ireland that sheds light on what it means to intersex/be born with a variation in one's sex characteristics. No data set like this previously existed that would facilitate our thinking about how we interrogate aspects of Irish life and society that adversely affect the lives of those born with variations in their sex characteristics.

Our findings demonstrate that intersex people/those born with VSC are a hidden, vulnerable and extraordinarily diverse and resilient group. Our interview participants are all over forty and their stories document lived experiences of struggling to understand who they are, negative experiences of childhood healthcare, trauma, and attempts at advocacy as they navigate Irish officialdom through health, education and life more generally. In many incidences, the law is not on their side as they seek meaningful and holistic care that is not delivered through a rigid adherence to the male-female binaried way of thinking about bodies or as they try to learn about themselves in order to assemble a coherent self-concept. There is much room for improvement in terms of health, education and law and our survey participants attest to this also.

However, more hopeful evidence of a patient-centred approach exists. Our healthcare professionals also speak to the rarity of intersex/those born with VSC, nonetheless, they describe a multi-disciplinary approach to caring for their patients that is different from much of what our intersex participants/those with VSC described at interview. While our professionals acknowledge that the current system of care is not perfect and requires additional supports, they do describe a commitment to delay medically unnecessary interventions and provide as much assistance to help patients and their families understand and come to terms with varied diagnoses whether it is with the use of advanced genetic testing or counselling. Moreover, they also describe the challenging realities of their roles when parents withhold information from children and young people the healthcare professionals believe should be disclosed or when they recalled having to have difficult and traumatic discussions with parents.

We have learned that that learning about being intersex/being born with VSC is important for all. Ireland's general public lack awareness about variations of sex characteristics - how people are affected by them, how common/rare some variations are and how society adversely affects intersex people/those with VSC through its failure to recognise and protect them through things like the school curriculum and accessing appropriate and respectful healthcare. We have made two important contributions in this area thus far with our #IrelandTurnsPurple campaign and our online, international conference. Both events were extraordinary successes and the support we received surpassed our expectations.

This report is an important contribution that offers numerous recommendations that will assist policy-makers in working towards a more equal society by recognising the ways in which we can confer greater rights and protections on those who have variations of their sex characteristics in Ireland. We will make further contributions to the field in the near future. Furthermore, we hope that this study will become a starting point for more detailed work on intersex experiences and intersex studies in Ireland.

Regularly throughout the pandemic we have heard our Taoiseach, Micheál Martin, remind us that 'ar scáth a cheile a mhaireann na daoine', an old Gaeilc saying that translates as 'people live in each other's shadows' or more accurately, we shield each other from the sun, we shelter each other. People need other people. By sharing their stories with us, our participants, and we, hope that their stories will enable others to learn about their experiences. In turn, we hope that this increased awareness will result in the introduction of laws, policies and guidelines which will make living life in Ireland a healthier, more respectful and dignified experience whereby being human will be the determining factor for the life a person can achieve rather than have their opportunities at life limited by the way their bodies differ.

We are indebted to all our participants for sharing their stories with us.

12

Recommendations

Chapter 12: Recommendations

Law

1. Provide information about the registration options for registering a child's birth before the birth takes place. This should include information about the option of indeterminative and information about amending birth registrations as regards naming and also section 63 of the *Civil Registration Act, 2004* to amend errors on the face of the Register.

2. Issue a clarifying Ministerial Order that section 63 of the *Civil Registration Act, 2004* facilitates applications, at any age, for correction of birth registration based the sex characteristics of a person.

3. Strengthen human rights protections through the introduction of clear practice guidelines for healthcare practitioners in this area delivering both paediatric and adult services to those with variations in their sex characteristics.

4. Implement the recommendations of the Committee on the Rights of the Child in their Concluding Observations to Ireland in 2016:
    a. Ensure that no one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to children concerned, and provide families with intersex children with adequate counselling and support;
    b. Undertake investigation of incidents of surgical and other medical treatment of intersex children without informed consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation;
    c. Educate and train medical and psychological professionals on the range of sexual, and related biological and physical, diversity and on the consequences of unnecessary surgical and other medical interventions for intersex children.

5. Formally establish two specialised, multidisciplinary teams to care for and support those with variations of their sex characteristics, one focused on paediatric care and one focused on adult care. This will ensure that people with intersex variations have access to lifelong healthcare and should include guaranteed full access to their medical records.

6. Introduce a formal legal definition of 'sex characteristics'. We recommend that the definition contained in the Maltese *Gender Identity, Gender Expression and Sex Characteristice Act, 2015* provides a good example of such a definition.

7. Introduce a statutory definition of privacy.

8. Introduce legislation regulating surrogacy and in particular clarifying the rights of those who become parents through surrogacy, regardless of their biological connection to the child.

Healthcare

1. Key staffing gaps need to be addressed in relation to providing specialist psychological support for patients and their families especially for those that are out of the children's hospital age group. The need for an adolescent nurse specialist was also noted to support the care of adolescents as they transition through the care system.

2. Multiple different types of support are required.
    a. Increased psychological support services in our healthcare system are required.
    b. Support, at all levels, is required for those who will experience infertility. This affects those who have learned that they are infertile and require counselling support to cope with such realities.
    c. Assistance with the cost of fertility treatment is required for those who may not have means financial or otherwise to pay for fertility treatments and/or surrogacy.

    d. Support groups where patients can benefit from meeting one another.

3. Continued commitment to the holistic, multi-disciplinary approach that places the patient front and centre. The provision of emotional/psychological support is key.

4. Access to meaningful, peer-support opportunities.

5. Ensure timely access to all services.

Education

1. Need to develop informed and objective curricular content to explain intersex/VSC

2. Need for a nationwide, ongoing public awareness campaign about intersex/VSC

Recommendations for future research.

When designing our research study we were interested to meet with family members of those who are intersex/who have VSCs. We were also expecting to have some engagement with a child and adolescent population to capture some of their lived experiences to address this gap in knowledge. We did not have this opportunity. The COVID pandemic did create enormous challenges for our data collection but we do recognise that a more targeted approach may be necessary in future to identify this child and adolescent sample population and their family members who wish to share their experiences with us.

We were commended by some participants for undertaking the current research and offering intersex people/those born with VSC themselves the opportunity to participate. In keeping with the spirit of "nothing about us, without us", our recommendations about future research are founded upon what our participants told us. We invited our survey participants to respond to an item asking them *What further research should be conducted for/about people born with congenital sex variations?* Twelve people responded. One person simply wrote “Don’t know” (11) and another participant wrote “I don't feel qualified to answer that question” (22). Ten others elaborated a little more. These are their recommendations about the type of future research that is required.

> We don't need further research, we need funding for peer, psychological and family support (13)
>
> No more internet surveys as more trans people complete these than people with DSDs. Research into fertility and sexual function and need to psychological support and support for families (18)
>
> Any research that brings greater public awareness to congenital sex variations benefits all (24)
>
> Research should focus on finding out what people need. There needs to be more legal information and ways to combat intersexphobia, there needs to be legislation to protect - upgrade equality laws so we are included in the words, there needs to be more information for counsellors, parents, teachers, all sorts of doctors. There needs to be proper support for parents. Doctors etc need to give proper information, including about support groups and about not doing things to intersex people, so that there is proper informed consent. Consent is not real, there is no consent, when people, whether intersex people themselves or parents of intersex people, are emotionally vulnerable. (26)
>
> More about psychological and medical needs (28)
>
> The medical system needs to learn about helping us to make us happy. Whether that is treatment or no treatment, we all need to make our own choices. (29)
>
> Semi-structured interviews with us and with those that push for continued surgery and stigmatisation of us. Anything that stops future non-consensual intersex surgeries and creates a better world for us. (30)

> Research into the impact of encouraging people of any sex/ gender but specifically those of varied sex/ gender to live non intervention-ed and fulfilled lives with support to engage in the world unchanged, unaltered, and unknowing of intersex associated shame. (32)
>
> I think that history of intersex people and how we are natural. (33)
>
> Prevalence of surgeries. Cancer risks as this is often used to argue for gonadectomy. Research around the impact of growing up without gender (35)

We also obtained our participants' level of agreement with the following statement

> The Irish Government should make a strong statement against killings of people with intersex / congenital sex variations around the world.

The majority of respondents (80.0%, 12/15) agreed. Two people neither agreed/disagreed and only one disagreed with the statement.

13

Impact

Chapter 13: Impact

#IrelandTurnsPurple Campaign, 8th November 2020

#IrelandTurnsPurple was our campaign to turn Ireland purple in a show of support for the Intersex community here and abroad, on International Intersex Solidarity Day on 8th November 2020.

On November 8th, 2019 the Mansion House in Dublin turned its lights purple in a show of solidarity for the intersex community. The Mansion House is the official residence of the Lord Mayor of Dublin. It is a site of historical significance because it is where the First Dáil (Irish Parliament) met on 21st January 1919 and one hundred years later it became the first public building in Ireland to turn purple in solidarity with the intersex community. We were indebted to Lord Mayor of Dublin, Paul McAuliffe, for his support of our efforts in 2019. That day, Dublin City University became the first Irish university to turn purple. We were very grateful to DCU President Brian MacCraith for supporting our work. We were delighted to be able to make such an impact with our campaign. After this success we embarked on a challenge to turn Ireland purple in 2020!

On social media, we invited individuals, businesses, and institutions to join our #IrelandTurnsPurple 2020 campaign by having as many buildings/monuments as possible turn purple for Intersex Solidarity Day on November 8th.

From the beginning, our campaign had the support of the Minister of State for the Office of Public Works, Mr. Patrick O'Donovan, TD. who pledged his support to have landmark OPW buildings and monuments turn purple.

We are delighted to say that 70 buildings in 20 counties across the island of Ireland turned purple - including: one fountain, two courthouses, three bridges, three castles, 17 colleges/institutes of technology/universities, a cluster of medieval monuments, four museums, a concert hall, numerous other city halls and a barracks, and we even have one very dedicated supporter turning their house purple!

And in a further important show of solidarity, Ireland's Minister For Foreign Affairs, Mr. Simon Coveney, TD. pledged his support, and that of his Department, to #IrelandTurnsPurple.

#IrelandTurnsPurple - Our Supporters

We are indebted to the following groups and organisations for their support in offering to turn their buildings and monuments purple.

Mr. Patrick O'Donovan, TD. Minister of State with Responsibility for the Office of Public Works. Department of Public Expenditure and Reform.

Minister for Foreign Affairs and Minister for Defence, Mr. Simon Coveney, TD. at Ireland's Department of Foreign Affairs.

Intersex Ireland | Irish Research Council | Prof. Daire Keogh | Dr. Sindy Joyce | The Union of Students in Ireland | Irish Universities Association | Higher Education Authority | Comfort Keepers | Siobhán McSweeney | GCN Gay Community News | Michelle Heffernan | Image Magazine | BeLonG To | Dr. Caroline West & Glow West Podcast | Hannon Media | Robert Wade Photography |

City and County Councils in: Cavan, Clare, Cork, Derry, Dublin, Donegal, Galway, Kerry, Kildare, Laois, Louth, Monaghan, Waterford, Wexford
Lord Mayors' Offices in Cork and Dublin

An Garda Síochána - Ireland's National Police Force

SIPTU | EPIC - the Irish Emigration Museum CHQ Building | the Convention Centre, Dublin | Shannon Heritage - King John's Castle | George's Quay Plaza | Irish Rail | Linenhall Arts Centre, Castlebar | National Museums of Ireland: Collins Barracks, Dublin & Turlough Park, Mayo | Teach Solais LGBT+ Resource Centre, Galway | McCann Fitzgerald |

Irish Universities, Institutes of Technology & Colleges: Dublin City University | University College Cork | Ulster University - Magee | Letterkenny Institute of Technology | Cork Institute of Technology | Griffith College | Royal College of Surgeons Ireland | University of Limerick | Trinity College Dublin | Galway-Mayo Institute of Technology | National University of Ireland - Galway | National College of Ireland | Institute of Technology - Tralee | Athlone Institute of Technology | Maynooth University | Waterford Institute of Technology | Sligo Institute of Technology |

We also wish to acknowledge the support from our colleagues in DCU across the following schools and units:

School of Law and Government | School of Nursing, Psychotherapy and Community Health | Centre of Excellence for Diversity and Inclusion | Communications and Marketing | Information Systems and Support

#IrelandTurnsPurple

in numbers

Nov. 8th - Intersex Solidarity Day

70 Buildings
20 Counties
17 Colleges
14 Councils
4 Museums
3 Bridges
2 Government Ministers
& more @IntersexMap !

Ulster University – Magee, Derry. Image: Prof. Malachy Ó Néill

Image source: CHQ Building Dublin

Map Image: https://www.google.com/maps/d/u/0/edit?mid=1dOYlfErXsAl1rA4-cbrW2VakXWlfdE9I&ll=53.41530250450295%2C-11.974662174999999&z=7

Intersex 2021 - A Vision For The Future

INTERSEX 2021 - A Vision For The Future

Online Conference: 21st & 22nd April 2021

Hosted by The Intersex Mapping Study, Dublin City University

Contact: intersex@dcu.ie @IntersexMap

Our interdisciplinary conference, brought together a multiplicity of discourses about intersex/variations of sex characteristics in society. The conference continued on an important path that takes intersex out its historical confines in the medical space where babies, children, adults and their bodies have been problematised in the quest to "normalise" difference. Contemporary understandings of intersex/variations of sex characteristics demand more informed and multidisciplinary perspectives. *Intersex 2021 - A Vision For The Future* aimed to provide an inclusive and diverse platform through which to listen and discuss intersex for the new decade.

Intersex 2021 was an enormous success. 122 delegates, from nineteen countries, joined us online for the event. Thirty-eight keynote addresses, conference presentations and panel discussions were held over our two-day event. The EU Commissioner, Ms. Helena Dalli, opened the conference and gave a commitment to ensure the intersex community would be recognised and protected through legislation across Europe.

Overall, 87.9% (29/33) of those who responded to our online evaluation rated the conference as 'excellent' or 'very good'. The following comments represent some of the positive feedback we received about the event.

Intersex 2021 was the best online event I've attended in a year. I only wish we could have all been together in real life.

Friendly, inclusive, vibrant, interesting - not often one attends an event where every session grabs the attention so well. Everyone was welcomed, and valued. Great organisation - easy to move from one room to another, well-structured, clear and simple instructions; great to have pre-recorded videos to reduce stress on presenters and keep things efficient.

It was incredibly well organised and thought out. It was the first event I have attended where the videos all played and no one seemed to experience technical glitches. I liked the fact the speakers were pre-recorded which meant everything ran on time and there was plenty of opportunity for Q&A's to take place.

The inclusivity; the willingness to listen and learn - everyone was welcome, be they part of the intersex community, researcher, clinicians or not formerly associated with the group. Tolerance if pronouns misused, or issues misunderstood - a desire across the intersex community to help others udnerstand. I had the great pleasure of chairing one of the parallel sessions - and throughly enjoyed it.

I felt inspired and energized to improve myself as an intersex ally. I particularly enjoyed that we got beyond the heavy medical focus, and were able to speak about social issues. Centering on intersex voices and experience was really powerful.

The diversity of topics, the friendliness and warmth and feeling valued. Becoming more aware of the range of work that’s going on to raise the profile of intersex and generate change.

Hearing some really interesting new research. Being around intersex people, allies, and scholars. The graphics etc for the conference portal eg the opening show.

> I really have to pay a compliment here, because not only the technical support was excellent, but also the moderation by the people in charge. I found the communication very appreciative and inclusive. The exchange was lively despite the digital format. Many thanks to all organizers!

Some feedback also illustrated that is was an important opportunity for intersex people to meet with other intersex people. These four comments were offered by participants who were describing the most enjoyable aspect of the conference.

> The discussion and connection with other intersex people

> The fact that the topics were very relatable and very relevant to our current narratives.

> Being around intersex people

> Meeting other intersex people

This was an important aspect of the conference because it was the first time some intersex actually had the opportunity to meet other intersex people. Consequently, ensuring a safe and inclusive atmosphere was of paramount importance to us as organisers. The following data demonstrates that we achieved this goal. 86.7% (26/30) of respondents agreed that the event (1) had an inclusive atmosphere and (2) another 86.7% (26/30) agreed that it felt like a safe space.

What our participants told us about the impact the research had for them

> Firstly, I would like to thank you for having had this opportunity to share my experience. I actually found the process of completing the questionnaire quite therapeutic to sum up the last 33 years of my life since I found out at 17 years. I realise that I have had no support and been very alone in all of this. Reflecting on my life, it has been tough but I have always put my best foot forward. I never felt ashamed of

my congenital variation until that day my sister passed the chromosome test around the dining table to show that she didn't have the gene. It was like a kick in the stomach and a rejection of who and what I am. I was extremely hurt. I would hate anyone to ever feel like that. I wish you the best in your research and I hope the outcome can make life easier for young people finding out for the first time. I hope they can have the much needed support and be properly informed. (22)

It's really important that you are doing this work. You need to share our stories so people understand, so what happened to me never happens to anyone else. (26)

14

Glossary and Bibliography

Glossary

5-Alpha Reductase Deficiency (ARD)

5-alpha reductase deficiency is an inherited condition that primarily affects male sexual development before birth and during puberty. People with this condition are genetically male, with one X and one Y chromosome in each cell, and they have male gonads (testes). Their bodies, however, do not produce enough of a hormone called dihydrotestosterone (DHT), which is critical for male sexual development. Most are born with external genitalia that appear female. In other cases, affected individuals may have ambiguous genitalia. Others may have genitalia that appear predominantly male, often with an unusually small penis (micropenis) and the urethra opening on the underside of the penis (hypospadias). This condition is caused by mutations in the *SRD5A2* gene and is inherited in an autosomal recessive pattern.[439]

Ambiguous Genitalia

Ambiguous genitalia is a rare birth defect in which a baby's external genitals aren't clearly male or female. The genitals may not be well formed, or the baby may have characteristics of both sexes. The outer genitalia may not match the internal sex organs. The condition, a disorder of sexual differentiation, affects an estimated 1 in 4,500 infants.[440]

Androgen Insensitivity Syndrome (AIS) [can be complete (CAIS) or partial (PAIS)]

Androgen insensitivity syndrome (AIS) occurs when someone is genetically male but is insensitive to androgens (male sex hormones). This means the person has male sex chromosomes (one X and one Y chromosome) but may have female genitals. AIS is a disorder of sex differentiation. It was previously called testicular feminization syndrome. It affects male fetuses as they develop in the womb, as well as sexual development during puberty.

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[439] National Institutes of Health (NIH) Genetic and Rare Diseases Information Center (GARD), '5-Alpha Reductase Deficiency' (*NORD (National Organization for Rare Disorders)*, 2021) <https://rarediseases.org/gard-rare-disease/5-alpha-reductase-deficiency/> accessed 22 March 2022.

[440] Jennifer Bercaw-Pratt and Jennifer Dietrich, 'Ambiguous Genitalia' (*Texas Children's Hospital: Ambiguous Genitalia*, n.d. (no date)) <https://www.texaschildrens.org/health/ambiguous-genitalia> accessed 22 March 2022.

AIS prevents male genitals from developing as they should. It almost always results in infertility during adulthood.[441]

Complete Androgen Insensitivity Syndrome (CAIS)

Complete Androgen Insensitivity Syndrome (CAIS) is a condition that affects sexual development before birth and during puberty. People with this condition are genetically male (one X and one Y chromosome) but do not respond to male hormones at all. As a result, they generally have normal female external genitalia and female breasts. However, they do not have a uterus or cervix so are unable to menstruate or conceive children. Other signs and symptoms may include undescended testes and sparse to absent pubic hair. Gender identity is typically female. Complete androgen insensitivity syndrome is caused by changes (mutations) in the AR gene and is inherited in an X-linked manner. Treatment and gender assignment can be a very complex issue, and must be individualized with each affected person. In general, surgery may be required to remove testes that are located in unusual places and estrogen replacement therapy can be prescribed after puberty.[442]

Congenital Adrenal Hyperplasia (CAH)

Congenital adrenal hyperplasia (CAH) is a group of rare inherited autosomal recessive disorders characterized by a deficiency of one of the enzymes needed to make specific hormones. CAH affects the adrenal glands located at the top of each kidney. Normally, the adrenal glands are responsible for producing three different hormones: 1. corticosteroids, which gauge the body's response to illness or injury; 2. mineralocorticoids, which regulate salt and water levels; and 3. androgens, which are male sex hormones. An enzyme deficiency will make the body unable to produce one or more of these hormones, which in turn will result in the overproduction of another type of hormone precursor in order to compensate for the loss. Many individuals with CAH present with abnormally enlarged adrenal glands (hyperplastic adrenomegaly) that produce excessive amounts of androgens (male steroid hormones) leading to abnormal sexual development in females affected with the disease. Females with severe or

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[441] Cleveland Clinic, 'Androgen Insensitivity Syndrome: Complete & Partial' (*Cleveland Clinic*, 14 December 2021) <https://my.clevelandclinic.org/health/diseases/22199-androgen-insensitivity-syndrome> accessed 22 March 2022.

[442] ibid.

classic virilizing CAH due to 21-hydroxylase deficiency will most likely have ambiguous or atypical external genitalia (masculinization or virilization), although they are genetically female and will have normal internal reproductive organs. Males with this type of CAH will not have ambiguous genitalia. Both genders can experience other symptoms such as early onset of puberty, fast body growth, and premature completion of growth leading to short stature, if they are not diagnosed and treated in early life.[443]

Gonadal Dysgenesis (partial & complete)

Complete or partial gonadal dysgenesis is a congenital disorder affecting the development of external genitalia. The results of these anomalies vary from genetically male individuals having either nearly complete female genitalia or nearly complete male genitalia, both with a lack of the secondary sex characteristics that normally develop at puberty, along with complete infertility.[444]

Hypospadias

In hypospadias, the opening of the urethra is located on the underside of the penis instead of at the tip. In most cases, the opening of the urethra is within the head of the penis. Less often, the opening is at the middle or the base of the penis. Rarely, the opening is in or beneath the scrotum.[445]

Jacobs/XYY Syndrome

XYY syndrome is a rare chromosomal disorder that affects males. It is caused by the presence of an extra Y chromosome. Males normally have one X and one Y chromosome. However, individuals with this syndrome have one X and two Y chromosomes. Affected individuals are usually very tall. Many experience severe acne during adolescence. Additional symptoms may include learning disabilities and behavioral problems such as impulsivity.

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[443] National Organization for Rare Disorders (NORD), ‘Congenital Adrenal Hyperplasia’ (*NORD (National Organization for Rare Disorders)*, 2018) <https://rarediseases.org/rare-diseases/congenital-adrenal-hyperplasia/> accessed 22 March 2022.

[444] Ann & Robert H. Lurie Children’s Hospital of Chicago, ‘Complete or Partial Gonadal Dysgenesis’ (2022) <https://www.luriechildrens.org/en/specialties-conditions/complete-or-partial-gonadal-dysgenesis/> accessed 22 March 2022.

[445] Mayo Clinic, ‘Hypospadias - Symptoms and Causes’ (*Hypospadias*, 29 March 2018) <https://www.mayoclinic.org/diseases-conditions/hypospadias/symptoms-causes/syc-20355148> accessed 10 August 2021.

Intelligence is usually in the normal range, although IQ is on average 10-15 points lower than siblings. Characteristics of XYY syndrome are often subtle and do not necessarily suggest a serious chromosomal disorder. Thus, males with this condition are often undiagnosed or misdiagnosed. The most common physical difference is increased height, which usually becomes apparent after the age of five or six, and results in an average height of about 6 feet, 3 inches by adulthood. Some individuals with XYY also develop severe cystic acne during adolescence. Fertility and sexual development are normal.[446]

Kallman Syndrome

Kallmann syndrome (KS) is a condition that causes hypogonadotropic hypogonadism (HH) and an impaired sense of smell. HH affects the production of the hormones needed for sexual development. It is present from birth and is due to deficiency of gonadotropin-releasing hormone (GnRH). KS is often diagnosed at puberty due to lack of sexual development. It may first be suspected in infancy in males with undescended testicles or a small penis. Symptoms in untreated, adult males may include decreased bone density and muscle mass; small testicles; erectile dysfunction; low sex drive; and infertility. Untreated adult females with KS usually do not have menstrual periods (amenorrhea) and normal, little, or no breast development. Rarely, a person with KS will have failure of kidney development (renal agenesis); hearing impairment; cleft lip or palate; and/or dental abnormalities. Most cases of KS are sporadic (not inherited) but some cases are inherited. The mode of inheritance depends on the gene involved. Treatment includes hormone replacement therapy for sexual development. Fertility can be achieved in most cases.

Males with KS may have signs of the condition at birth, such as undescended testes or a smaller than average penis. However, most cases are diagnosed at the time of puberty due to lack of sexual development. Males usually have no growth of facial or body hair, and decreased growth of pubic hair and genitals. They also have a delayed pubertal growth spurt in comparison

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[446] National Organisation for Rare Disorders (NORD), 'XYY Syndrome/Jacob's Syndrome' (*NORD (National Organization for Rare Disorders)*, 2012) <https://rarediseases.org/rare-diseases/xyy-syndrome/> accessed 22 March 2022.

to their peers. If not treated, adult males may have decreased bone density and muscle mass; decreased testicular volume; erectile dysfunction; low sex drive; and infertility.

Females with KS usually have absent breast development, an attenuated growth spurt, decreased pubic hair growth, and no initiation of menses (primary amenorrhea). However, some females partially undergo puberty with the beginning of breast development that fails to progress. Very occasionally, affected females have onset of menses at an appropriate age, but it stops after a few cycles.

In both males and females, development of pubic hair can be normal because it is controlled by secretion of androgens from the adrenal glands, which are not affected by the condition. Almost all untreated people with KS are infertile, but fertility can be restored in those that respond to certain treatments. Some people with KS have any of various non-reproductive features. These may include: cleft lip and palate | renal agenesis (one kidney does not develop) |hearing impairment | dental abnormalities | eye movement abnormalities | poor balance | scoliosis (curvature of the spine) | synkinesis of the hands, in which the movements of one hand are mirrored by the other hand.[447]

Klinefelter syndrome (KS) also known as XXY/47

Klinefelter syndrome (KS) is a condition that occurs in males when they have an extra X chromosome. Some males with KS have no obvious signs or symptoms while others may have varying degrees of cognitive, social, behavioral, and learning difficulties. Adults with Klinefelter syndrome may also have primary hypogonadism (decreased testosterone production), small and/or undescended testes (cryptorchidism), enlarged breast tissue (gynecomastia), tall stature, and/or inability to have biological children (infertility), as well as an abnormal opening of the penis (hypospadias), and a small penis (micropenis). KS is not inherited, but usually occurs as a random event during the formation of reproductive cells (eggs and sperm) that results in the presence of one extra copy of the X chromosome in each cell (47,XXY). KS treatment is based on the signs and symptoms present in each person.[448]

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[447] National Institutes of Health (NIH) Genetic and Rare Diseases Information Center (GARD), 'Kallmann Syndrome | Genetic and Rare Diseases Information Center (GARD) – an NCATS Program' (2016) <https://rarediseases.info.nih.gov/diseases/10771/kallmann-syndrome> accessed 22 March 2022.

[448] 'Klinefelter Syndrome | Genetic and Rare Diseases Information Center (GARD) – an NCATS Program' (n 8).

Mayer-Rokitansky-Küster-Hauser (MRKH)

Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome is a rare disorder that affects women. It is characterized by the failure of the uterus and the vagina to develop properly in women who have normal ovarian function and normal external genitalia. Women with this disorder develop normal secondary sexual characteristics during puberty (e.g., breast development and pubic hair), but do not have a menstrual cycle (primary amenorrhea). Often, the failure to begin the menstrual cycle is the initial clinical sign of MRKH syndrome. The range and severity of MRKH syndrome can vary greatly and the disorder is generally broken down into type I, which occurs as an isolated finding, and type II, which occurs with abnormalities of additional organ systems including mainly the kidneys and the skeleton. Because of the nature of the disorder, MRKH syndrome can cause significant psychological challenges and counseling is recommended. The exact cause of MRKH syndrome remains largely unknown, but there is now no doubt of a genetic origin.[449]

Micropenis

Micropenis is defined as a normally structured penis that is below the normal size range for an infant. Normally, the length of a newborn boy's penis is between 2.8 to 4.2 centimeters (1.1 to 1.6 inches) with a circumference of 0.9 to 1.3 centimeters (0.35 to 0.5 inches). This measurement is taken by carefully stretching the penis and measuring from the tip of the penis to the base of the penis. A penis length of less than 1.9 centimeters (0.75 inches) is usually considered micropenis. Micropenis can occur alone, but usually occurs in combination with other disorders. Hormone disorders that cause an abnormal level of the hormones involved in the development of the sexual organs may be seen in combination with micropenis. This can involve the pituitary gland or the hypothalamus.[450]

Mosaicism involving “sex” chromosomes

Mosaicism occurs when a person has two or more genetically different sets of cells in his or her body. If those abnormal cells begin to outnumber the normal cells, it can lead to disease that can be traced from the cellular level

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[449] ‘Mayer-Rokitansky-Küster-Hauser Syndrome’ (*NORD (National Organization for Rare Disorders)*) <https://rarediseases.org/rare-diseases/mayer-rokitansky-kuster-hauser-syndrome/> accessed 28 March 2022.

[450] Children’s National Washington, ‘Pediatric Micropenis | Children’s National Hospital’ (2022) <http://childrensnational.org/visit/conditions-and-treatments/urology/micropenis> accessed 22 March 2022.

to affected tissue, like skin, the brain, or other organs. (Yale Medicine, 2022). Most people have 46 chromosomes in each of their cells, and two of those 46 chromosomes are sex chromosomes. Most girls and women have two X sex chromosomes (so we say their chromosomal component is "46,XX"). Most boys and men have an X sex chromosome and a Y sex chromosome ("46,XY"). But some people have "mosaic" chromosomes, meaning that not all their cells have the same component of chromosomes. This is called "mosaicism" because it is sort of like the body is made up of a varied set of colored tiles, rather than a single-colored set of tiles. When a person has more than one component of sex chromosomes, the person is said to have "sex chromosome mosaicism." So, some people have 46,XX in some cells with 46,XY in other cells. Some may have 46,XY in some cells and 47,XXY in other cells. Some may have 45,X in some cells and 46,XX in others.[451]

Ovo-testes (formerly called "true hermaphroditism")

Ovotesticular disorder of sex development (ovotesticular DSD) is a very rare disorder in which an infant is born with the internal reproductive organs (gonads) of both sexes (female ovaries and male testes). The gonads can be any combination of ovary, testes or combined ovary and testes (ovotestes). The external genitalia are usually ambiguous but can range from normal male to normal female.[452]

Partial Androgen Insensitivity Syndrome (PAIS)

Partial androgen insensitivity syndrome (PAIS) is genetic condition that affects the sexual development of a male fetus. During pregnancy, male fetuses with PAIS are unable to properly respond to male sex hormones (androgens). As a result, this affects the development of the genitals. The appearance of the genitals may vary from person to person. Some males have an unusually small penis (microphallus), undescended testes, hypospadias (urethra located on the underside of the penis), and/ or bifid scrotum (scrotum split in two). Others may have more female-appearing genitals and physical features, including a large clitoris (clitoromegaly),

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[451] Accord Alliance, 'What Is Sex-Chromosome Mosaicism? | Accord Alliance' (2013b -08-01T17:59:58+00:00) <https://www.accordalliance.org/faqs/what-is-sex-chromosome-mosaicism/> accessed 22 March 2022.

[452] National Organisation for Rare Disorders (NORD), 'Ovotesticular Disorder of Sex Development' (*NORD (National Organization for Rare Disorders)*, 2016) <https://rarediseases.org/rare-diseases/ovotesticular-disorder-of-sex-development/> accessed 22 March 2022.

male breast development (gynecomastia), undescended testes, and/ or fusion of the labia. Individuals with PAIS typically have infertility. PAIS is caused by a change in the AR gene, which is located on the X chromosome. It is inherited through an X-linked recessive pattern and typically affects males. It is recommended that parents and caretakers work with an experienced healthcare team to evaluate a child with PAIS before assigning their sex. If the individual is reared as male, they may be given testosterone therapy to improve fertility and surgeries to repair structures of the penis and to reduce the size of the male breasts. If the individual is reared as female, they may be offered surgery to remove the male reproductive organs after puberty, followed by estrogen (female sex hormone) therapy.[453]

Polycystic Ovarian Syndrome

Polycystic ovarian syndrome (PCOS) is a hormonal imbalance caused by the ovaries (the organ that produces and releases eggs) creating excess male hormones. If you have PCOS, your ovaries produce unusually high levels of hormones called androgens. This causes your reproductive hormones to become imbalanced. As a result, people with PCOS often have erratic menstrual cycles, missed periods and unpredictable ovulation. Small cysts may develop on your ovaries (fluid-filled sacs) due to lack of ovulation (anovulation). However, despite the name "polycystic," you do not need to have cysts on your ovaries to have PCOS. PCOS is one of the most common causes of female infertility. It can also increase your risk for other health conditions.[454]

Progestin Induced Virilisation

“Virilization” is a medical term for development that is male-like. “Progestin-induced virilization” refers to a situation in which a woman who is pregnant with a female fetus (46,XX) ingests drugs called progestins that cause the female fetus to be virilized, i.e., to develop more along the male pathway. This can result in the child’s clitoris being larger than usual and may cause the labia to join together, like a scrotum. The child may also develop in such

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[453] Cleveland Clinic (n 441).

[454] Cleveland Clinic, ‘Polycystic Ovarian Syndrome (PCOS): What Is It, Causes, Symptoms & Treatment’ (*Cleveland Clinic*, 21 September 2021) <https://my.clevelandclinic.org/health/diseases/8316-polycystic-ovary-syndrome-pcos> accessed 22 March 2022.

a way that her urethra and vagina are joined into something called a urogenital sinus.[455]

Swyer Syndrome

Swyer syndrome is a rare disorder characterized by the failure of the sex glands (i.e., testicles or ovaries) to develop. Swyer syndrome is classified as a disorder of sex development (DSD), which encompasses any disorder in which chromosomal, gonadal or anatomic sex development is abnormal. Girls with Swyer syndrome have an XY chromosomal makeup (as boys normally do) instead of an XX chromosomal makeup (as girls normally do). Despite having the XY chromosomal makeup, girls with Swyer syndrome look female and have functional female genitalia and structures including a vagina, uterus and fallopian tubes. Girls with Swyer syndrome lack sex glands (ovaries). Instead of sex glands, women with Swyer syndrome have "gonadal streaks", in which the ovaries do not develop properly (aplasia) and are replaced by functionless scar (fibrous) tissue. Because they lack ovaries, girls with Swyer syndrome do not produce sex hormones and will not undergo puberty (unless treated with hormone replacement therapy). Mutations in several different genes are known to cause Swyer syndrome.[456]

Turner's Syndrome (one X chromosome)

Turner syndrome is a rare chromosomal disorder that affects females. The disorder is characterized by partial or complete loss (monosomy) of one of the second sex chromosomes. Turner syndrome is highly variable and can differ dramatically from one person to another. Affected females can potentially develop a wide variety of symptoms, affecting many different organ systems. Common symptoms include short stature and premature ovarian failure, which can result in the failure to attain puberty. Most women with Turner syndrome are infertile. A variety of additional symptoms can occur including abnormalities of the eyes and ears, skeletal malformations, heart anomalies, and kidney abnormalities. Intelligence is usually normal, but affected individuals may experience certain learning disabilities. Turner syndrome may be diagnosed before birth or shortly after birth or during early childhood. However, in some cases, the disorder may not be diagnosed until well into adulthood, often as an incidental finding.

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[455] Accord Alliance, 'What Is Progestin-Induced Virilization? | Accord Alliance' (1 August 2013) <https://www.accordalliance.org/faqs/what-is-progestin-induced-virilization/> accessed 22 March 2022.

[456] National Organization for Rare Disorders (NORD), 'Swyer Syndrome' (*NORD (National Organization for Rare Disorders)*, 2019) <https://rarediseases.org/rare-diseases/swyer-syndrome/> accessed 22 March 2022.

Most cases do not run in families and appear to occur randomly for no apparent reason (sporadically).[457]

XY-Turner's Syndrome

In Turner syndrome, an individual does not have the usual pair of two complete X chromosomes. The most common scenario is that a girl has only one X chromosome in all of her cells. However, some girls with Turner syndrome have a full or partial absence of the X chromosome in only some of their cells. When an individual has a different chromosomal content in his/her cells, it is called mosaicism. When some of the cells have one X chromosome and no other X or Y chromosome, and other cells have either the usual two sex chromosomes (two X's or one X and one Y) or other chromosomal differences, it is called mosaic Turner syndrome. Mosaic Turner syndrome, like Turner syndrome, is not typically inherited. It occurs as a random event during cell division in early fetal development. Other sex chromosome abnormalities are also possible in individuals with X chromosome mosaicism. Mosaicism of both the X and the Y chromosome is a common finding in Turner syndrome. The features of mosaic Turner syndrome can vary considerably from individual to individual. In females, they can range from mild to severe signs and symptoms of Turner syndrome. In males, they can range from a seemingly normal male to the presence of a variety of features which can include dysmorphic (abnormally formed) features, mild intellectual disabilities, infertility, Ulrich-Turner stigmata (drooping of upper eyelid, extra "webbing" on the neck), gonadal dysgenesis, infertility, low testosterone levels, and azoospermia (having no sperm).[458]

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[457] 'Turner Syndrome' (n 7).

[458] National Institutes of Health (NIH) Genetic and Rare Diseases Information Center (GARD), 'Turner Syndrome' (*NORD (National Organization for Rare Disorders)*) <https://rarediseases.org/rare-diseases/turner-syndrome/> accessed 14 March 2022.

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intersex@dcu.ie

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