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Tightening the tourniquet in the rights of vulnerable intersex people

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Introduction

'Intersex' is a general term that refers to the state of being born with biological sex characteristics that vary from what is typically thought of as exclusively male or female.[1] Intersex bodies are healthy bodies and, save in cases involving salt-wasting congenital adrenal hyperplasia,[2] there is no medical urgency involved that requires immediate intervention to safeguard the life or physical health of the person with the intersex variation. Yet intersex bodies are transgressive, in that they do not adhere to the conventional norm of biological human bodily configuration as expected by society and accepted by law. Thus, interventions are permitted on bodies with intersex variations that are explicitly prohibited on other bodies,[3] in order to facilitate the restructuring of the intersex body so that it more closely resembles the acceptable norm. This chapter argues that it is in this moment of intervention that the intersex body is rendered vulnerable. The protections and safeguards that people with an intersex variation might ordinarily expect to enjoy by virtue of their humanity are denied once law 'sees' the intersexness of their bodies. A visceral example of this is demonstrated in the decision of *In the Marriage of C and D (falsely called C)*.[4] Here the Brisbane Family Court annulled the marriage of the parties on the basis that under *Hyde v Hyde*[5] marriage is the union of one man and one woman. The putative husband in this case being 'neither man nor woman but a combination of both' was found to be incapable of contracting a valid marriage.[6] This

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[1] The author would like to acknowledge funding from the Irish Research Council under the COALESCE 2019 scheme. 'Intersex' is a highly contested term. Since 2006, medical professionals have employed the term 'disorders of sexual development' or 'DSD'. Peter A. Lee, Christopher P. Houk, Ieuan A. Hughes and S. Faisal Ahmed, 'Consensus Statement on Management of Intersex Disorders' (2006) 118(2) Pediatrics e 488. However, the use of the term 'DSD' has not found favour with some intersex activists and patients: see Elizabeth Reis, 'Divergence or Disorder: The Politics of Naming Intersex' (2007) 50(4) Perspectives in Biology and Medicine 535; and Georgiann Davis, *Contesting Intersex: The Dubious Diagnosis* (New York University Press 2015).

[2] Gerard S. Conway and Pierre D.E. Mouriquand, 'Congenital Adrenal Hyperplasia' in Adam H. Balen, Sarah M Creighton, Melanie C. Davies, Jane Macdougall and Richard Stanhope *Paediatric and Adolescent Gynaecology: A Multidisciplinary Approach* (Cambridge University Press, 2004), 310.

[3] Criminal Justice (Female Genital Mutilation) Act 2012.

[4] *In the Marriage of C and D (falsely called C)* (1979) 35 FLR 340.

[5] *Hyde v Hyde* (1866) LR 1 P&D 130.

[6] *In the Marriage of C and D (falsely called C)* (n 4).

chapter contends that adopting a vulnerability approach would enable the creation of spaces within the legal order wherein the innate human dignity and rights of people with intersex variations can be vindicated.

The importance of a recognisable body

In order to come *sui juris*, one must be legally recognisable as either male or female. This binary conception of corporality is evident in the list of required particulars of which the State must be informed when registering a birth. In Schedule 1 to the Civil Registration Act 2004, sex features as the third item for notification before name of the child or details of the parents. Thus, official recognition of sex is of primary importance in establishing legal identity. Sex has assumed this importance in relatively recent times. Writing in the 1600s, Coke CJ noted that '[e]very heire is either a male, or female or an hermaphrodite, that is both male and female. And an hermaphrodite … shall be heire, either as male or female, according to that kind of the sexe which doth prevaile'.[7] This historic acknowledgement of intersex variations contrasts sharply with the virtual invisibility of intersex in the twentieth century.[8] This disappearance of intersex from public and legal consciousness was necessitated by the prioritisation of heteronormativity.[9] In promoting the social and legal acceptability of heterosexuality, people whose bodies did not adhere to strict understandings of male and female, or whose sexuality did not orientate in a heterosexual manner, were outcast.[10]

Against this background, it is not surprising that the birth of a child with visibly ambiguous genitalia would be regarded as a 'social emergency'.[11] Legal definitions of male and female were formally stated by Ormrod J in *Corbett v Corbett*,[12] where it was held that legal sex and gender were determined by the congruence of the chromosomes, gonads and genitals at the moment of birth.[13] Notwithstanding this formal legal test, in reality gender assignment, and the

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[7] Sir Edward Coke, *The First Part of the Institutes of the Law of England* (Robert H. Smith 1853), 225.

[8] Alice Domurat Dreger, *Hermaphrodites and the Medical Invention of Sex* (Harvard University Press 1998).

[9] Tanya Ní Mhuirthile, 'Building Bodies: A Legal History of Intersex in Ireland' in Jennifer Redmond, Sonia Tiernan, Sandra McAvoy and Mary McAuliffe, *Sexual Politics in Modern Ireland* (Irish Academic Press 2015) 154. See also Anne Fausto-Sterling, *Sexing the Body: Gender Politics and the Construction of Sexuality* (New York: Basic Books 2000).

[10] Offences Against the Person Act 1861 and the Criminal Law (Amendment) Act 1885. Homosexual behaviour between consenting adults was finally decriminalised in the Criminal Law (Sexual Offences) Act 1993.

[11] American Academy of Pediatrics, 'Evaluation of the Newborn with Developmental Anomalies of the External Genitalia' (2000) 106 Pediatrics 138.

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

[13] Ibid, at 48.

recording of this information of a birth certificate, is a presumption determined by the appearance of the genitalia and investigations as to an individual's chromosomal and gonadal make-up only occur where there is genital ambiguity.[14] Thus, when a baby is born with ambiguous genitalia, social, medical and legal expectations are confounded such that the baby becomes culturally unintelligible. We have no pronouns in the English language to encapsulate this situation. To refer to such a child by the gender-neutral pronoun 'it' is to dehumanise that child. Viewed from this perspective, bodies with intersex variations may be considered grotesque.

Shabot argues that the grotesque body is one that is has an open subjectivity that defies clear definitions and borders.[15] As such it is unrepresentable by any system of knowledge governed by rational principles that aims for a clear framing of the objects of research. A postmodern realisation of the embodied subject, Shabot contends that the 'grotesque body is inherently ambiguous: it is not an isolated body, but at the same time it does not lose itself in the homogeneity of undifferentiated wholeness'.[16] Thus it is, in Bakhtin's words, incomplete.[17] According to this understanding of grotesque bodies, they are completed by their interactions with the outside world. It is when the grotesque body touches the outside world through childbirth, defecation, eating and drinking that it becomes complete – this is a fleeting achievement, as the grotesque body is ever unfinished and ever creating.[18] Thus Shabot argues that acknowledging the grotesque inherently creates anxiety, as the grotesque world is one which is 'a fragmentary, complex reality … where clear hierarchal relations derived from well-defined binary oppositions are not viable'.[19] Prior to interrogating law's response to the intersex body, this chapter will first explore the manner in which intersex variations are medicalised.

Pathologisation of intersex bodies

It is difficult to assess with precision the rate of intersex variations in society. This is partly due to the tendency to 'hide' the intersex diagnosis and partly due to the lack of diagnostic labels to cover every possible permutation of intersex corporeal configuration. A study published in

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[14] Tanya Ní Mhuirthile, 'Foy v An tArd Chláraitheoir' in Máiréad Enright, Julie McCandless and Aoife O'Donoghue (eds.) *Northern/Irish Feminist Judgments: Judges Troubles and the Gendered Politics of Identity* (Oxford: Hart Publishing 2017) 587, 292–293.

[15] Sara Cohen Shabot, 'The Grotesque Body: Fleshing Out the Subject' (2007) 15 Thamyris/Intersecting: Place Sex and Race 57.

[16] Ibid, at 59.

[17] Mikhail Bakhtin, *Rabelais and His World* (Bloomington: Indiana University Press 1984) 317.

[18] Ibid, at 26.

[19] Shabot, 'The Grotesque Body' (n 15) at 60.

2000 of eleven different intersex diagnoses estimated that approximately 1.7 per cent of the global population are intersex to some degree.[20] Of these, Lee et al. estimate that 1 in 4,500 births evidence genital ambiguity.[21] This is a problematic statistic, as there is no agreement as to what constitutes unambiguous genital appearance.[22] In the absence of an agreed standard, 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.[23] There is no universal medical or surgical treatment protocol for engaging with a body with intersex variations. It is worth restating that there is nothing inherently problematic or dangerous about a body configured intersex.

Early surgical interventions have been subject to criticism, as they do not exclusively impact upon the body with intersex variations but also have far-reaching consequences in terms of that person's development and life experience.[24] They have been the subject of much commentary: the physical aspects are much discussed in medical writings, whereas the psychological/emotional harm is more commonly discussed by sociologists, intersex support groups and intersex activists.[25]

A variety of surgical interventions are routinely performed on children with intersex variations to create gendered genitals. Such procedures include: clitoroplasty, phalloplasty, vaginoplasty, labioplasty and gonadectomy. The side effects of these interventions can include: pain, scarred tissue, pain during erection,[26] loss of sexual sensation,[27] blood clots,[28] colitis,[29] the elimination

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[20] Melanie Blackless et al., 'How Sexually Diamorphic Are We? Review and Synthesis' (2000) 12 American Journal of Human Biology 151.

[21] Lee et al., 'Consensus Statement on Management of Intersex Disorders' (n 1) at e 488.

[22] K. W. Feldman and D. W. Smith, 'Fetal Phallic Growth and Penile Standards for Newborn Male Infants' (1975) 86(3) Journal of Pediatric*s*, 395; S. E. Oberfeld et al., 'Clitoral Size in Full-Term Infants' (1989) 6(4) American Journal of Perinatology 453; and Susanne Kessler, *Lessons from the Intersexed* (Rutgers University Press 1998).

[23] Kessler, *Lessons from the Intersexed* (n 22) at 44–46.

[24] Dreger, *Hermaphrodites and the Medical Invention of Sex* (n 8); Fausto-Sterling, *Sexing the Body* (n 9); Kessler, *Lessons from the Intersexed* (n 22); M. Diamond and H. K. Sigmundson, 'Management of Intersexuality: Guidelines for Dealing with Persons with Ambiguous Genitalia' (1997) 151(10) Archives of Pediatric and Adolescent Medicine 1046.

[25] Ida Ismail and Sara Creighton, 'Surgery for Intersex' (2005) 5 Reviews in Gynaecological Practice 57; Sharon E. Preves, *Intersex and Identity: The Contested Self.* (New Brunswick, NJ: Rutgers University Press 2003); Kessler, *Lessons from the Intersexed* (n 22).

[26] Ian A. Oyama, Adam C. Steinberg, Adam S. Holzberg and Joseph L. Maccarone, 'Reduction Clitoroplasty: A Technique for Debulking the Enlarged Clitoris' (2004) 17 Journal of Pediatric and Adolescent Gynecology 393.

[27] Ismail and Creighton 'Surgery for Intersex' (n 25).

[28] Ibid.

[29] Ibid.

of the natural contour and pigmentation of the labia minora[30] and infertility. As a result of complications such as these, frequently bodies with intersex variations will require more than one surgical intervention to correct the after-effects of previous surgeries.

Commentary on intersex variations is not confined to the physical impact of gender assignment surgery but the impact on the lives of people with intersex variations is also much discussed.[31] In particular, criticisms centre on the sense of shame and stigma evident in personal narratives from those with intersex variations. In her study, Preves reports that repeated 'corrective' medical and surgical interventions decreased their sense of autonomy and undermined the development of a solid sense of self, and that those with intersex variations felt treated as objects of medical research, and as a result they felt freakish. Finally, she notes that medical interventions impaired their ability to engage in healthy sexual relationships due to both physical and psychological trauma.[32]

The second criticism of the medical approaches centres on the guidelines medical professionals use to determine gender assignment. These guidelines, which have developed organically through the publication of results of various surgical attempts in peer-reviewed journals, are prescriptive. Meyers-Steifer and Charest identify the three criteria underpinning the guidelines: 'the potential for (1) an ambiguous appearance of the genitalia before and after puberty, (2) adequate sexual functioning, and (3) fertility'.[33] Of these three criteria, it is the appearance of genitalia which garners most commentary, as Hendricks states: '[i]n truth, the choice of gender still often comes down to what the external genitals look like'.[34] This could be because the indicia of success in the creation of female genitalia might be held to a lower standard than those for the creation of male genitalia. An analysis of the guidelines reveals that what is important is that, once fertility has been preserved if possible, female genitalia can function as a site for heterosexual intercourse.[35] However, for males, it is important that the penis can function properly, i.e. permit urination while standing and engage in penetrative intercourse,

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[30] S. M. Maas and J. J. Hage, 'Functional and Aesthetic Labia Minora Reduction' (2000) 105(4) Plastic and Reconstructive Surgery 1453.

[31] Katrina Karakazis, *Fixing Sex: Intersex, Medical Authority and Lived Experience* (London: Duke University Press, 2008); Kessler, *Lessons from the Intersexed* (n 22); Preves, *Intersex and Identity* (n 25).

[32] Preves, *Intersex and Identity* (n 25) 62.

[33] C. H. Meyers-Steifer and N. J. Charest, 'Diagnosis and Management of Patients with Ambiguous Genitalia' (1992) 16(5) Seminars in Perinatology 332, 336–337.

[34] M. Hendricks, 'Is It a Boy or a Girl?' (1993) (November) Johns Hopkins Magazine 10, at 15.

[35] Oberfeld et al., 'Clitoral Size in Full-Term Infants' (n 22); Kessler, *Lessons from the Intersexed* (n 22).

but appearance is also prioritised.[36] Thus, if the phallus is deemed to be too small, the child will be assigned female.[37]

Response of law to issue of surgeries on those with intersex variations

Law is largely silent on the issue of surgical interventions on intersex children. There has never been a case on this point in Ireland or the United Kingdom. A case directly on point is currently *sub judice* before the North Carolinan courts.[38] Were such a case to come before the Irish courts, it is unlikely that a complainant would be successful.[39] This is not true of all interventions on the genitalia of children. The Criminal Justice (Female Genital Mutilation) Act 2012 ('FGM Act') specifically outlaws the cutting of genitalia of girls and women in any cultural context. The protection created by this legislation does not extend to those with intersex variations.[40] Recently, various UN bodies have specifically addressed the issue of interventions on intersex bodies and like the case of FGM have repeatedly considered them to amount to torture.[41] It is difficult to defend the accusation that domestic laws which do not protect the rights of intersex people to choose whether, how and when their bodies should be cut tacitly collude in the violation of their rights.

When introducing the Gender Recognition Act 2015 ('GRA'), the then Minister for Social Protection hailed it as guaranteeing the rights of intersex people.[42] Although the GRA has been welcomed for divorcing legal rights from medical treatment pathways, it does not implode the

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[36] K. W. Feldman and D. W. Smith, 'Fetal Phallic Growth and Penile Standards for Newborn Male Infants' (1975) 86(3) Journal of Pediatrics, 395; S. Y. C. Tong, K. Donaldson and J. M. Hutson, 'When is Hypospadias not Hypospadias?' (1996) 164 (5 February) Medical Journal of Australia 153; Kessler, *Lessons from the Intersexed* (n 22).

[37] Kessler, *Lessons from the Intersexed* (n 22.

[38] *M.C. vs. Medical University of South Carolina*, filed 14 May 2013 in County of Richland Common Pleas http://interactadvocates.org/wp-content/uploads/2016/03/050714_Crawford_Complaint_Release_FINAL_FINAL.pdf.

[39] According to *Dunne v National Maternity Hospital* [1989] IR 91 and *Bolitho v Hackney Health Authority* [1998] AC 232, once evidence can be adduced that a reasonable body of professionals would use the same technique/approach, then a medical practitioner will not be found to have been negligent.

[40] Nancy Ehrenreich and Mark Barr, 'Intersex Surgeries, Female Genital Cutting, and the Selective Condemnation of "Cultural Practices"' (2005) 40(1) Harvard Civil Rights – Civil Liberties Law Review 71; Isabelle R. Gunning, 'Arrogant Perception, World-Travelling and Multicultural Feminism: The Case of Female Genital Surgeries' (1992) 23 Columbia Human Rights Law Review 189.

[41] UN Committee on the Rights of the Child, *Concluding Observations on the Combined Third and Fourth Periodic Reports of Ireland* (Geneva: United Nations 2016) UN Doc: CRC/C/IRL/CO/3–4, paras 39 and 40; UN Committee on the Elimination of Discrimination Against Women, *Concluding Observations on the Combined Sixth and Seventh Periodic Reports of Ireland* (Geneva: United Nations 2017) UN Doc: CEDAW/C/IRL/CO/6–7, paras 24 and 25.

[42] Press Release, 'Minister for Social Protection Publishes Revised General Scheme for Gender Recognition Bill 2014' (Dublin: Department of Social Protection, 18 June 2014) www.welfare.ie/en/pressoffice/Pages/pr180614.aspx (last accessed 14 December 2020).

binary gender paradigm that underpins the recognition of people before the law. Rather, it further entrenches the primacy of the categories 'male' and 'female' by confirming they are the only acceptable ones. The scheme established by the GRA pertains to adults only. There is an exemption to the minimum age criterion for young people between the ages of 16 and 18 pursuant to an application to the Circuit Court and supported by medical evidence of transition.[43] However, the GRA contains no provision for the under-16s; thus, it does nothing to alleviate pressure on parents to consent to procedures on their intersex children. As an alternative, intersex people might seek to use the provisions contained in Section 63(2) of the Civil Registration Act 2004 ('the 2004 Act') to correct a clerical error or an error of fact in the recording of a birth. The question then becomes whether such an amendment would be permissible. Consideration of this section in *Foy v An tArd Chlaraitheoir (No 2) (2007)* suggests that, as the system of birth registration is a matter of historic importance and not intended to establish the present identity of any person interacting with the law in Ireland, it cannot. Being, then, a snapshot of 'observable characteristics of the newborn' as they appeared at the moment the birth was registered, it seems unlikely that the 2004 Act would permit an alteration of the record.[44]

Neither the GRA nor the 2004 Act overtly exclude people with intersex variations. Yet, read together, this is the net effect. These statutes control how a person comes *sui juris*. In order to avail of the protections of law and to fully enjoy inalienable human rights, one must present oneself to the State as either male or female. Where one's body inherently defies such categorisation, law delays active protection of one's rights as in the case of interventions on intersex bodies. The protection of the FGM Act 2012 to guard against non-consensual genital surgeries does not extend to those with intersex variations. Neither does law intervene to prevent or to limit parental proxy consent to such surgeries. Yet it could by adopting the approach in *Re J (Child's Religious Upbringing and Circumcision)*, where the Court refused to permit the circumcision of a boy on the basis that the procedure was not medically indicated, would cause pain and distress, was irreversible and the immediate harm to the child outweighed the speculative future benefits should he subsequently identify as Muslim.[45]

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[43] Section 12 of the Gender Recognition Act 2015.

[44] *Foy v An tArd Chlaraitheoir (No 2)* (2007) IEHC 470, at para 73.

[45] *Re J (Child's Religious Upbringing and Circumcision)* [2000] 1 FCR 307. Tanya Ní Mhuirthile, *Realising Gender Recognition: Rendering the Vulnerable Visible or Further Vulnerabilising the Invisible?* UCD Working Papers in Law, Criminology and Socio-Legal Studies, Research Paper no. 41/2010 http://ssrn.com/abstract=1680899 (last accessed 14 December 2020).

Sharpe convincingly argues that homophobia is the unconscious subconscious of law.[46] Despite the introduction in 2015 of both gender recognition and marriage equality,[47] this criticism, refined to heterophilia, continues to be valid. The categories of male and female are limited and cannot encapsulate the entirety of human existence. Intersex bodies are inherently ambiguous. They are at their most grotesque when questions of medical or surgical interventions arise, as this is the moment when they 'touch' the outside world. They demonstrate the non-viability of the oppositional binary gender paradigm underpinning law. Law uses its internal dogma to look the other way and does not activate protections for the rights of those with intersex variations. From a doctrinal perspective all aspects of formal equality have been met: parents give lawful proxy consent, children may be too young to participate meaningfully, interventions are construed as being in their best interests and, if necessary, the child can activate rights under the GRA at a later stage in life. Thus for the rational, reasonable man the correct procedures have been followed. The vulnerability thesis advanced by Martha Fineman and others offers a way to disrupt this doctrinal dominance and consider the question from a fresh perspective, one that might enable the activation of the protections of human rights law for those with intersex variations.[48]

Adopting a vulnerability approach

For Fineman, vulnerability is not an exceptional disadvantage. Rather, it is a universal experience which may be occasional or enduring. It arises 'from our embodiment, which carries with it the ever present possibility of harm, injury, and misfortune from mildly adverse to catastrophically devastating events whether accidental, intentional or otherwise'.[49] Thus we are all interdependent: this is the foundation of society. She argues that 'It is the recognition and experience of human vulnerability that brings individuals into families, families into communities, and communities into societies, nation states and international organisations.'[50] Consequently, she contends that there is an obligation on the State to reduce, ameliorate and compensate for vulnerability.[51] The need to make institutional change to arrangements that

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[46] Andrew N. Sharpe, *Transgender Jurisprudence. Dysphoric Bodies of Law* (Cavendish Publishing 2002).

[47] Marriage Act 2015.

[48] Martha A. Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (2008) 20(1) Yale Journal of Law and Feminism 1.

[49] Ibid, at 9.

[50] Martha A. Fineman, 'Equality, Autonomy and the Vulnerable Subject in Law and Politics' in Martha Albertson Fineman and Anna Greer (eds.) *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics* (Farnham: Ashgate Publishing 2013) 13, 22.

[51] Fineman, 'The Vulnerable Subject' (n 48), at 8–15.

create privilege and perpetuate disadvantage is evident when viewed through the lens of vulnerability theory.

Fineman argues that the liberal subject is at the centre of law making.[52] The liberal subject is always an adult,[53] and thus the laws produced reflect only a percentage of embodied human experience and do not account for moments of vulnerability such as dependency or childhood.[54] Kohn identifies three ways that vulnerability theory helps to support and further understanding of social policy.[55] First, articulating the universal condition of vulnerability highlights the importance of the role of the State in this regard and justifies the interventions necessary for the State to discharge that obligation – for example, introducing social welfare provisions. Second, the focus on a universal vulnerability helps to reduce the stigma experienced by members of particular minority groups. Finally, acknowledging that vulnerability is universal encourages a holistic, rather than piecemeal, response to its reduction.

Adopting such an approach in the context of intersex variations necessitates a shift away from considering intersex as exceptional or grotesque. Rather, it requires us to refine what it is about the moment of intervention that has universal applicability. It is widely acknowledged that there is a paucity of longitudinal studies proving the efficacy or otherwise of medical and surgical intervention on people with intersex variations.[56] Indeed Lee et al. expressly acknowledge this and call for research to be conducted in this area.[57] Given this lack of authoritative information on its impact, Cheryl Chase argues that each individual procedure was effectively an experiment.[58]

Although the terms ‘research’ and ‘experimentation’ are often used interchangeably, Mason and Laurie opine that they are not in fact the same thing.[59] Research implies a predetermined protocol with a clearly defined end point, whereas experimentation involves a more speculative, ad hoc approach to an individual subject. This is an important distinction, as the researcher cannot deviate from the predetermined protocol, whereas when conducting an

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[52] Ibid, at 10.

[53] Ibid, at 11.

[54] Ibid, at 12.

[55] Nina A. Kohn, ‘Vulnerability Theory and the Role of Government’ (2014) 26(1) Yale Journal of Law and Feminism 1, at 9.

[56] American Academy of Pediatrics, ‘Evaluation of the Newborn with Developmental Anomalies of the External Genitalia’ (n 11); Dreger, *Hermaphrodites and the Medical Invention of Sex* (n 8); Fausto-Sterling, *Sexing the Body* (n 9).

[57] Lee et al., ‘Consensus Statement on Management of Intersex Disorders’ (n 1).

[58] Cheryl Chase, *ISNA’s Amicus Brief on Intersex Genital Surgery* www.isna.org/node/97 (last accessed 14 December 2020) at point 12.

[59] J. Kenyon Mason and Graeme T. Laurie, *Mason & McCall Smith’s Law and Ethics* (7th edn, Oxford University Press 2006) 651.

experiment it can be altered and modified to take into account the individual response of the subject.[60] Additionally, the aims of research and experimentation are usually different. Research is defined as 'the attempt to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods' and thus its aim is not directly related to the research subject.[61] By contrast, experimentation is focused on the diminishing health of the patient and therefore responds to any changes in the individual patient.

There are a variety of approaches to the treatment of intersex variations.[62] Yet, while some advocate introduction of a formal treatment protocol,[63] others decry such a step as 'too prescriptive'.[64] Nonetheless, there is some guidance regarding suggested interventions for particular intersex variations, which suggests that treatment can be considered research. However, as each intersex child is treated individually and the treatment evolves as the child grows, develops and responds to previous interventions, it could be argued that the treatment should be considered experimentation. Thus, whether treatment would be considered research or experimentation depends on the particular circumstances of each individual case.

International ethical guidelines on research and experimentation were developed in the aftermath of the Second World War[65] and subsequently endorsed by the medical professions in the Declaration of Helsinki (1964). These principles have been restated by national authorities.[66] At a regional level, in 2005, an Additional Protocol to the Council of Europe's Convention on Human Rights and Biomedicine (1997) was opened for signature.[67] All these guidelines share an appreciation for the need for human research subjects while simultaneously accepting that, in order to produce scientifically accurate research, the right to self-determination of the individual research subject will necessarily be sacrificed. It is for this reason that the importance of the informed consent of the research subject is emphasised.[68] They all include specifications regarding the inclusion of children and mentally disordered

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[60] B. M. Dickens, 'What is a Medical Experiment?' (1975) 113 Canadian Medical Association Journal 635.

[61] Department of Health, *Research Governance Framework for Health and Social Care* (London, UK: Department of Health 2005) at 3.

[62] Ní Mhuirthile, *Realising Gender Recognition* (n 45) at 6–8.

[63] Lee et l., 'Consensus Statement on Management of Intersex Disorders' (n 1).

[64] N. R. Maharaj, A. Dhai, R. Wiersma and J. Moodley, 'Intersex Conditions in Children and Adolescents: Surgical, Ethical, and Legal Considerations' (2005) 18 Journal of Pediatric and Adolescent Gynaecology 399, at 401.

[65] George J. Annas and Michael A. Grodin (eds.) *The Nazi Doctors and the Nuremberg Code: Human Rights in Human Experimentation* (Oxford University Press 1992).

[66] www.mrc.ac.uk/Ourresearch/Ethicsresearchguidance/MRC002578.

[67] Available online at http://conventions.coe.int/treaty/EN/Treaties/Html/195.htm.

[68] Declaration of Helsinki, paras 19–25, Additional Protocol Articles 13–17.

research subjects. Generally speaking, in such circumstances the informed consent of a legally authorised representative is required in accordance with the applicable domestic law.[69] Furthermore, children and other medical incompetents can only become research subjects where such research is necessary to promote the health of the population represented and the research cannot be conducted on legally competent persons.

For those conducting research/experimentation, the protection afforded by the common law test will not be forthcoming.[70] By definition, if the procedure is research or an experiment, it is not endorsed by a reasonable body of medical opinion. Yet, if the deviation for normal practice is deemed to be logical in all circumstances of the case, it may not offend legal principles. As stated in the Declaration of Helsinki:

> In the treatment of a patient, where proven interventions do not exist or have been ineffective, the physician, after seeking expert advice, with informed consent from the patient or a legally authorized representative, may use an unproven intervention if in the physician's judgement it offers hope of saving life, re-establishing health or alleviating suffering.[71]

Thus the importance of informed consent is clear. However, even in situations where informed consent is not possible, experimental treatment may be legal if it is deemed to be in the best interests of the patient.

Simms v An NHS Trust concerned two teenagers suffered from advanced stages of variant Creutzfeldt-Jakob disease (vCJD), a degenerative, incurable and terminal brain condition.[72] Both sets of parents sought a declaration that it would be lawful to undertake a highly experimental course of treatment, the risks and benefits of which were unknown, but which had shown some marginal varying success in mice, rats and dogs in Japan. It was accepted by all parties that the minors would not recover from the disease and that this treatment was a 'last chance'. The Court applied the best interests test and ruled that the experiment was justified, as there was no witness who was willing to rule out the possibility that some benefit might accrue to the children in question. However, the permission to conduct the experiment was qualified by the fact that the disease was invariably progressive and fatal, there was no

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[69] Ibid, para 24, Additional Protocol 15–17.

[70] *Dunne v National Maternity Hospital* [1989] IR 91 and *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582 (n 39).

[71] Declaration of Helsinki (n 68), para 37.

[72] *Simms v An NHS Trust* [2002] EWHC 2734.

alternative treatment and, so long as the experiment did not increase the suffering of the children, then it would not be unlawful to try. Finally, because there was evidence that did not entirely rule out some chance of benefit, Dame Butler-Sloss held that the Bolam test had been complied with. From this case, it becomes evident that a fine balance must be maintained between the child's rights and the interests of progress.

The situation with interventions on intersex children is different to that in *Simms*. Applying Butler-Sloss's qualifications: there are alternative treatment options to performing surgery in infancy, the available evidence indicates that being treated in this manner does increase the physical suffering of the intersex child, and finally a substantial number of medical professionals would contend that performing surgery does not benefit the child.[73] As interventions on bodies with intersex variations meet the criteria for the qualifications to the best interests test in the context of undergoing an experimental and/or research procedure, proxy consent cannot be given to these procedures. In this way, the right of children with intersex variations to develop without restriction or impediment, and to participate in decisions about interventions, is vindicated.

Conclusion

Recent leaps forward in LGBT rights in Ireland have left those with intersex variations behind. In permitting movement between legally recognised genders, the Gender Recognition Act 2015 has further embedded the primacy of the binary gender paradigm underpinning the law. Thus, it fails to protect those with intersex variations from unnecessary interventions. In this way, law becomes complicit in rendering healthy bodies vulnerable. Adopting the vulnerability lens enables law to refocus from the obvious doctrinal dogma around negligence and to consider instead the question of interventions on intersex bodies from the perspective of experimentation. Applying directly the doctrinal law on consent to experimentation carves out a space where children with an intersex variation can be enabled to determine for themselves what, if any, interventions they should undergo.

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[73] See *supra* (n 24).