

## Making the State Responsible: Intersex Embodiment, Medical Jurisdiction, and State Responsibility

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*Through consideration of new developments in the United Kingdom's intersex policy, this article traces the ways in which responsibility is produced, naturalized, and avoided by individuals, institutions, and the state. Jurisdiction is identified as a barrier to the attribution of responsibility that must be overcome to achieve progress in relation to the needs of intersex people. By bringing together jurisdictional analysis and vulnerability theory, this article demonstrates how the state has traditionally abrogated responsibility by compartmentalizing specific practices as governed by medical authority. It highlights that such accounts mask the role of the state in the creation of jurisdiction and the ways in which governance is conducted. Challenging these boundaries allows vulnerability theorists to move the state towards greater levels of responsibility. By combining these theoretical tools, the article enhances the practical utility of vulnerability theory and advances an important agenda for intersex people.*

### INTRODUCTION

This article is born out of a concern that despite growing research evidence and international condemnation from supranational bodies such as the United

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Nations,<sup>1</sup> the Council of Europe,<sup>2</sup> and the European Parliament,<sup>3</sup> states are failing to prohibit medical professionals from performing non-consensual and unnecessary gender-normalizing interventions on intersex children.<sup>4</sup> Our previous work in this area has clearly identified key areas of challenge for intersex-embodied people,<sup>5</sup> using a vulnerability lens to engage with notions of harm, state responsiveness, and resilience.<sup>6</sup> Yet, despite this work, in the intersex context, the majority of states remain largely unwilling to legislate on this area.<sup>7</sup> As the United Kingdom's Government begins to consider policy developments with regards to intersex,<sup>8</sup> we are accordingly concerned that its response may similarly fail to engage with the issues identified by empirical research with the intersex community.<sup>9</sup> This article therefore interrogates the ways in which responsibility is produced, naturalized, and dismissed by

- 1 J. Mendez, UN Human Rights Council, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment* (2013), at [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.;](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.;) United Nations, 'Joint UN Statement on Ending Violence and Discrimination against Lesbian, Gay, Bisexual, Transgender and Intersex People' (2015), at <https://www.ohchr.org/en/issues/discrimination/pages/jointlgbtstatement.aspx>.
- 2 Council of Europe Commissioner for Human Rights, *Human Rights and Intersex People* (2015), at <https://wcd.coe.int/ViewDoc.jsp?Ref=CommDH/IssuePaper%282015%291&Language=lanEnglish&Ver=original>.
- 3 European Parliament, 'European Parliament Resolution on the Situation of Fundamental Rights in the EU in 2016' (2018) para. 68, at <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P8-TA-2018-0056+0+DOC+XML+V0//EN>.
- 4 Malta (2015) and Portugal (2018) are exceptions to this, with Iceland rejecting a similar bill in 2018.
- 5 F. Garland and M. Travis, 'Legislating Intersex Equality: Building Resilience through Law' (2018) 38 *Legal Studies* 587; S. Monro et al., *Intersex, Variations of Sex Characteristics, and DSD: The Need for Change* (2017) University of Huddersfield; M. Travis, 'Accommodating Intersexuality in European Union Anti-Discrimination Law' (2015) 21 *European Law J.* 180.
- 6 M. Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (2008) 20 *Yale J. of Law and Feminism* 1; M. Fineman, 'The Vulnerable Subject and the Responsive State' (2010) 60 *Emory Law J.* 251; M. Fineman, 'Elderly as Vulnerable: Rethinking the Nature of Individual and Societal Responsibility' (2012) 20 *The Elder Law J.* 101; S. Marvel, 'The Evolution of Plural Parentage: Applying Vulnerability Theory to Polygamy and Same-Sex Marriage' (2014–2015) 64 *Emory Law J.* 2047; B. Clough, 'Vulnerability and Capacity to Consent to Sex: Asking the Right Questions?' (2014) 26 *Child and Family Law Q.* 371; M. Travis, 'The Vulnerability of Heterosexuality: Consent, Gender Deception and Embodiment' (2018) 28 *Social and Legal Studies* 303; Garland and Travis, id.; J. Mant and J. Wallbank, 'The Mysterious Case of Disappearing Family Law and the Shrinking Vulnerable Subject: The Shifting Sands of Family Law's Jurisdiction' (2017) 26 *Social and Legal Studies* 629.
- 7 Garland and Travis, op. cit., n. 5.
- 8 Government Equalities Office, 'Variations of Sex Characteristics Call for Evidence' (2019).
- 9 Garland and Travis, op. cit., n. 5.

individuals, institutions, and the state. In particular, it focuses on the methods employed by states to absolve themselves of responsibility for intersex issues.

To achieve this, the article brings together jurisdictional analysis and vulnerability theory. While our previous work demonstrated how vulnerability theory clearly demands a state response in this area,<sup>10</sup> this article builds on that work by exploring recent theoretical engagements with jurisdiction<sup>11</sup> to reveal and disrupt the ‘natural’ barriers that have traditionally prevented such responses. Jurisdiction in this context is thus decoupled from the state and instead used to explore the ways in which power and authority are enunciated through law.<sup>12</sup> Most notably, this analysis highlights that one reason for dismissing the legal concerns of intersex-embodied people has been that their ‘conditions’ come under the jurisdiction, and thus the responsibility, of the medical profession. As one Government official from the United Kingdom recently said in response to allegations of abuse from the UN Committee on the Rights of the Child, ‘[National Health Service] England are responsible’ for intersex issues.<sup>13</sup> This belief exemplifies the way in which much policy development and potential legislation in this area stalls because of an assumption that the medical profession is best placed to define its own jurisdictional remit. Such an assumption, however, fails to trace the ways in which responsibility is, in turn, avoided by the medical profession. In the past, this has led to policymakers being largely deferential to medical expertise not only on intersex issues but also on wider issues of disorder and diagnoses, leading to either state silence or ineffective reform.

Thus, this article demonstrates how a (state-constructed) medical jurisdiction is a potential barrier to the proper attribution of responsibility and explains how it can and should be reframed at state level to enable political and legal development. This jurisdictional analysis draws upon vulnerability theory to redirect responsibility away from an individual level and towards the state. In doing so, this article offers a more enriched understanding of vulnerability theory. It allows vulnerability theorists to understand the constructed nature of such jurisdictional boundaries and expands upon the theory’s understanding of the state and its relationships with institutions. Moreover, dismantling these jurisdictional boundaries further empowers

10 *Id.*

11 M. Valverde, ‘Jurisdiction and Scale: Legal “Technicalities” as Resources for Theory’ (2009) 18 *Social and Legal Studies* 139; M. Valverde, *Chronotopes of Law: Jurisdiction, Scale and Governance* (2015); S. Dorsett and S. McVeigh, ‘Questions of Jurisdiction’ in *Jurisprudence of Jurisdiction*, ed. S. McVeigh (2007) 3; B. de Sousa Santos, ‘Law: A Map of Misreading – Toward a Postmodern Conception of Law’ (1987) 14 *J. of Law and Society* 279; C. Dietz, ‘Jurisdiction in Trans Health’ (2020) 47 *J. of Law and Society* 60; J. Harrington, *Towards a Rhetoric of Medical Law* (2016).

12 Dorsett and McVeigh, *id.*, p. 3.

13 F. Taylor Goldhill, 72nd Session of the UN Committee on the Rights of the Child, 23 May 2016, at <<http://stop.genitalmutilation.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-the-Child>>.

justifications for state responsiveness and so enhances the practical utility of vulnerability theory.

This article first outlines recent theoretical work on the nature of jurisdiction<sup>14</sup> and the ways in which medical jurisdiction has framed responsibilities to intersex-embodied people before turning to vulnerability theory to offer an alternative – state-based – articulation of responsibility. The article then applies these theoretical insights to the United Kingdom, where policy developments in this area are at an embryonic stage and could progress in a number of directions. The article then considers Malta as an example where medical jurisdiction has been successfully challenged and responsibility redirected towards the government. Here we argue that similar reforms in the United Kingdom could lead to positive changes for intersex-embodied people. Finally, the article concludes by reaffirming the need for the United Kingdom and other states to take responsibility for intersex people through the destabilization of traditional jurisdictional boundaries. Ultimately, it highlights that such jurisdictional boundaries can (and, in this case, should) be ruptured but that this will require states like the United Kingdom to take a normative stance on gender-normalizing interventions on intersex-embodied children and to accept responsibility for this area.

## JURISDICTIONAL ANALYSIS

Over the past decade, there has been an increasing focus on the theoretical underpinnings of jurisdiction.<sup>15</sup> These approaches have moved away from more traditional understandings of jurisdiction where analysis has failed to account for the multiple and contested nature of governance and law, with a tendency to characterize the state as monolithic rather than as an assemblage. The relative recency of these socio-legal investigations can be compared with legal practice, which, in contrast, has long been invigorated by interrogations of jurisdiction and what this may mean for authority and governance.<sup>16</sup> In this socio-legal sense, jurisdiction can be understood as the ways in which power, responsibility, and authority are enunciated through law.<sup>17</sup> This approach decouples jurisdiction from the state and can account for multiple jurisdictions that can exist within a singular territory or area, subject or object. As Dorsett and McVeigh write, incorporated within jurisdiction is the ‘authorisation and ordering of law as such as well as determinations of authority within a legal regime’.<sup>18</sup> Jurisdiction therefore encompasses the abilities of law but, in articulating these abilities, also creates the limitations

14 Valverde, *op. cit.* (2009), n. 11; Valverde, *op. cit.* (2015), n. 11; Dorsett and McVeigh, *op. cit.*, n. 11; de Sousa Santos, *op. cit.*, n. 11; Dietz, *op. cit.*, n. 11.

15 *Id.*

16 Dorsett and McVeigh, *op. cit.*, n. 11, p. 3.

17 *Id.*

18 *Id.*

and boundaries of law. Engaging with notions of jurisdiction is crucial to allow us to critique the ‘naturalness’ of authority and instead reframe jurisdiction as a technology of governance.<sup>19</sup> Such an approach moves from considering the law as abstract towards a contextual approach attentive to the ‘identity of the speaker’<sup>20</sup> or ‘the who of governance’.<sup>21</sup> This is a helpful shift when evaluating governmental non-response and the allocation of responsibility.

Questions of jurisdiction are the building blocks of jurisprudence. They form the basis for questioning whether a particular law is appropriate, or indeed whether a law is a suitable response at all.<sup>22</sup> Moreover, jurisdiction not only concerns the ‘who’ of law but also asks fundamental questions about where governance is located, what it organizes, and how it operates.<sup>23</sup> Understanding the instrumentality of jurisdiction allows us to better map the operation of power and knowledge in legal governance.<sup>24</sup> For Valverde, each legal jurisdiction has a different notion of what (or whom) is subject to governance and how they are to be governed. Thus, jurisdiction can prove an effective tool for mapping power and understanding its dynamic inter-subjectivities in the context of ‘the plurality of state and non-state jurisdictions’.<sup>25</sup> Moreover, jurisdiction helps us to think through the ways in which legal governance mechanisms are organized and (in some instances arbitrarily) divided, enabling us to better question the benefits and pitfalls of such distributions of power (including the methods through which responsibility can be avoided). Indeed, such an approach sheds new light on the complex interactions that take place between institutional mechanisms within any given legal territory. Accordingly, the supposedly ‘natural’ separation between different jurisdictions can be further exposed as artificial, while ‘the simultaneous operation of quite different, even contradictory, rationalities of legal governance’ can be explored.<sup>26</sup> These contradictory rationalities of governance highlight the existence of multiple sites of power; the plural knowledges that these institutions create can also expose gaps in responsibility.<sup>27</sup> As institutions draw on differing knowledge bases justified through distinctive modes of power, we can better interrogate the disconnection between, for example, the state-scale or global ‘rights’ and the day-to-day legal experiences of individuals that animate this article. As Valverde notes:

19 Dorsett and McVeigh (id.) use the term ‘technologies of government’. This article moves beyond government to consider governance more generally. For a sophisticated discussion of governance, see, for example, B. Sokhi-Bulley, ‘Government(ality) by Experts: Human Rights as Governance’ (2011) 22 *Law and Critique* 251.

20 Harrington, op. cit., n. 11.

21 Valverde, op. cit. (2009), n. 11, p. 144.

22 Dorsett and McVeigh, op. cit., n. 11, p. 4.

23 Id.

24 Id., p. 140.

25 Id., p. 9.

26 Valverde, op. cit. (2009), n. 11, p. 142.

27 Id., p. 143.

Theoreticians have not yet noted that governing projects and the power-knowledges that make them work are differentiated from one another and kept from overtly clashing by the workings of the machinery of ‘jurisdiction’, which instantly sorts governance processes, knowledges, and powers into their proper slots as if by magic, and sets up a chain by which (most of the time) deciding who governs where effectively decides how governance will happen.<sup>28</sup>

Through this ‘black boxing’, the machinery of jurisdiction also apportions responsibility in particular ways and makes this seem natural or inevitable. The next section considers the ways in which responsibility has been understood in the medical context.

## HEALTHCARE, RESPONSIBILITY, AND INTERSEX EMBODIMENT

The power and jurisdiction of the medical profession has expanded in recent years, led by a genomic turn in biomedicine that has greatly increased the scope of diagnoses and promises new preventative methods of dealing with disorder and disease.<sup>29</sup> Importantly, this extension has vastly increased the number of subjects governed by healthcare. These moves, however, continue to place the responsibility for management on the individual, with patients expected to be actively involved in researching and understanding their own somatic variances.<sup>30</sup> This expansion of medical governance has led to all of us being ‘asymptomatically, presymptomatically ill – and perhaps all suitable cases for treatment’.<sup>31</sup> A shift towards preventative medicine has seen the medical profession extending its authority into spheres to which it would not traditionally have access; issues such as obesity are now understood in terms of a ‘health crisis’,<sup>32</sup> highlighting the (perhaps) unlimited potential of medicine to colonize other areas and knowledge bases. Pickersgill has traced similar shifts in relation to psychiatry. Discussing changes in the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders (DSM)*, he notes an increasing medicalization of everyday or routine experiences.<sup>33</sup> Evidently, the jurisdiction of healthcare now exists far beyond its traditional clinical and hospital-based settings. This expansion

28 Id.

29 N. Rose, ‘Normality and Pathology in a Biomedical Age’ (2009) 57 *The Sociological Rev.* 66.

30 N. Rose and C. Novas, ‘Biological Citizenship’ in *Global Assemblages: Technology, Politics and Ethics as Anthropological Problems*, eds. A. Ong and S. Collier (2005) 439.

31 Rose, op. cit., n. 29, p. 71.

32 Id.

33 M. Pickersgill, ‘Diagnoses and the Sociology of Critique’ (2014) 40 *J. of Medical Ethics* 521, at 522. However, Pickersgill does highlight some boundaries to the increasing scope of the medical profession. The negative reception to the potential inclusion of grief in the *DSM-5* indicated the lines in the sand that can be drawn around the jurisdiction of medical authority.

of jurisdiction has not led to concomitant increases in medical responsibility, however, and this article traces the gaps in responsibility produced by medical knowledge around intersex-embodied people.

Intersex people are born with chromosomal, hormonal, or genital variances that place them outside of, or in between, commonplace understandings of male or female. Thus, 'intersex' is an umbrella term that includes a range of different variances, each of which presents differently and at a different time of an individual's life course. Over the past century, and despite the benign nature of the vast majority of intersex variations,<sup>34</sup> the medical profession has increasingly claimed 'intersex' within its jurisdictional remit 'in the name of correcting nature's mistakes'.<sup>35</sup> While intersex variations are predominantly benign, a number of variations lead to the appearance of ambiguous internal and external reproductive organs. The appearance of this type of ambiguity has led to medical professionals performing aesthetic 'normalizing' interventions to ensure that children are raised within the gender binary.<sup>36</sup> Thus, the expansion of this jurisdiction has been particularly problematic for the intersex community, who have long contended that such a medical framing 'changes something which is a natural variation of humanity through to illness'.<sup>37</sup>

The efficacy of these medical interventions has been heavily questioned, as they lead directly to a range of negative consequences, including reduced sexual sensitivity,<sup>38</sup> sterilization,<sup>39</sup> vaginal stenosis,<sup>40</sup> being assigned to a gender with which the individual does not identify,<sup>41</sup> and reliance on artificial

34 K. Zillén et al., *The Rights of Children in Biomedicine: Challenges Posed by Scientific Advances and Uncertainties* (2017) 42, at <<https://rm.coe.int/16806d8e2f>>.

35 A. Fausto-Sterling, *Sexing the Body: Gender Politics and the Construction of Sexuality* (2000) 37.

36 These interventions include genitoplasties, gonadectomies, clitorectomies, and labioplasties.

37 Garland and Travis, op. cit., n. 5, p. 9 per Respondent 7.

38 S. Creighton et al., 'Objective Cosmetic and Anatomical Outcomes at Adolescence of Feminising Surgery for Ambiguous Genitalia Done in Childhood' (2001) 358 *The Lancet* 124; N. S. Crouch et al., 'Sexual Function and Genital Sensitivity Following Feminizing Genitoplasty for Congenital Adrenal Hyperplasia' (2008) 179 *J. of Urology* 634; C. Minto et al., 'The Effects of Clitoral Surgery on Sexual Outcome in Individuals Who Have Intersex Conditions with Ambiguous Genitalia: A Cross-Sectional Study' (2003) 361 *The Lancet* 1252.

39 S. Creighton et al., 'Childhood Surgery for Ambiguous Genitalia: Glimpses of Practice Changes or More of the Same?' (2014) 5 *Psychology and Sexuality* 34.

40 L. Wang and P. Poppas, 'Surgical Outcomes and Complications of Reconstructive Surgery in the Female Congenital Adrenal Hyperplasia Patient: What Every Endocrinologist Should Know' (2017) 165 *The J. of Steroid Biochemistry and Molecular Biology* 137.

41 In a clinical review, Cohen-Kettenis found that children with certain intersex traits changed from their assigned gender in between 39 and 64 per cent of cases; see P. Cohen-Kettenis, 'Gender Change in 46 XY Persons with 5 $\alpha$ -Reductase-2 Deficiency and 17 $\beta$ -Hydroxysteroid Dehydrogenase-3 Deficiency' (2005) 34 *Archives of Sexual Behavior* 399.



hormones (leading to conditions such as osteoporosis).<sup>42</sup> Moreover, these surgical procedures remain experimental, so there is a likelihood of indirect negative consequences, including sepsis, infection, and multiple follow-up surgical procedures;<sup>43</sup> it is not unusual for intersex people to have multiple non-consensual gender-normalizing surgical procedures on their genitals before they are able to engage with the decision-making process.

Surgery is not the only type of medical intervention that affects intersex people. Intersex people also report vaginal dilation (the stretching of the vaginal canal to accommodate a 'normal' penis) during childhood either by parents, carers, or healthcare professionals as a deeply traumatic experience.<sup>44</sup> Hormone replacement regimes that do not relate to the gender with which the intersex person identifies can also be extremely problematic.<sup>45</sup> The rarity of these variances mean that intersex people are also subject to a higher level of medical interest, which leads to medical photography and extra attention from junior medical professionals during 'rounds'.<sup>46</sup> These medical interventions lack therapeutic value and are based on healthcare practitioners' subjective assessments of best interests. This is confirmed by Lee and colleagues, who note in the 2006 Consensus Statement on the Management of Intersex Disorders that 'minimizing family concern and distress, and mitigating the risks of stigmatization and gender-identity confusion of atypical genital appearance', are key priorities for medical intervention.<sup>47</sup> This valuation of best interests determines that the physical and psychosocial risks identified above are outweighed by the perceived benefits of intersex people fitting into society (which include the ability to take part in heterosexual sex).<sup>48</sup> As outlined below, the surprising lack of follow-up studies means that there is a corresponding lack of medical data supporting the need for or benefits of

- 42 C. Benetti-Pinto et al., 'Factors Associated with the Reduction of Bone Density in Patients with Gonadal Dysgenesis' (2002) 77 *Fertility and Sterility* 571; K. Rubin, 'Turner Syndrome and Osteoporosis: Mechanisms and Prognosis' (1998) 102 *Pediatrics* 481; S. Mora et al., 'Effect of Estrogen Replacement Therapy on Bone Mineral Content in Girls with Turner Syndrome' (1992) 79 *Obstetric Gynaecology* 747.
- 43 Wang and Poppas, op. cit., n. 40; I. Hughes et al., 'Consequences of the ESPE/LWPES Guidelines for Diagnosis and Treatment of Disorders of Sex Development' (2007) 21 *Best Practice & Research Clinical Endocrinology & Metabolism* 351, at 363; P. Hegarty and C. Chase, 'Intersex Activism, Feminism and Psychology: Opening a Dialogue on Theory, Research and Clinical Practice' (2000) 10 *Feminism & Psychology* 117.
- 44 Monro et al., op. cit., n. 5; Wang and Poppas, op. cit., n. 40.
- 45 A. Spurgas, '(Un)Queering Identity: The Biosocial Production of Intersex/DSD' in *Critical Intersex*, ed. M. Holmes (2009) 97; Cohen-Kettenis, op. cit., n. 41.
- 46 S. Creighton et al., 'Medical Photography: Ethics, Consent and the Intersex Patient' (2002) 89 *BJU International* 67.
- 47 P.A. Lee et al., 'Consensus Statement on the Management of Intersex Disorders' (2006) 118 *Pediatrics* 488, at 488, 490.
- 48 Fausto-Sterling, op. cit., n. 35.



these interventions; indeed, there is a growing body of evidence that disputes their necessity.<sup>49</sup>

However, despite this lack of evidence supporting non-therapeutic medical interventions, medical professionals remain unwilling to accept responsibility for the negative consequences associated with these interventions due, in part, to the governing logics of healthcare. Although the state has the power to regulate medical practice, in reality much of the detail around medical governance is left to healthcare practitioners to determine.<sup>50</sup> However, this abdication of governance is contingent upon the 'professional' nature of medicine ensuring the maintenance of clear divisions between 'scientific' medicine and more holistic, traditional, or complementary medicines.<sup>51</sup> Nonetheless, medicine itself cannot be thought of as monolithic, with differing degrees of societal value and esteem afforded to the expertise of, for example, surgeons/urologists, geneticists, pharmacologists, psychologists, nutritionists, and midwives. Governmental and legal deference to traditional medical power/knowledge is premised on the historical understanding that medicine is a science and thus objective. Diseases and disorders are *discovered* by scientists rather than *created* by them;<sup>52</sup> similarly, they are properly 'fixed' through healthcare techniques rather than social change.<sup>53</sup> Moreover, certain medical professionals, through their training and vocation, are better placed to identify diseases and disorders than other institutions, individuals, and indeed other actors within healthcare.

These governing logics of healthcare point towards negligence, inaction, and failure to diagnose as issues that are the responsibility of the medical professional at both an individual and an institutional level. Although misdiagnoses might result in some claim of professional responsibility, diagnosis in and of itself would not. Diagnosis is understood as a process of scientific classification, responsibility for which rests with either the individual 'patient's' genetic make-up or bacterial/molecular accounts. While the classificatory systems upon which medicine relies are understood as contestable, shifting, and in some sense promissory,<sup>54</sup> defining them remains solely the task of a small group of healthcare professionals. The remit of

49 Zillén et al, op. cit., n. 34, p. 43.

50 S. Devaney and S. Holm, 'The Transmutation of Deference in Medicine: An Ethico-Legal Perspective' (2018) 26 *Medical Law Rev.* 202, at 224.

51 E. Cloatre and N. Urquiza Haas, 'Healthcare, Well-Being, and the Regulation of Diversity in Healing' in *The Jurisprudence of the Body*, eds C. Dietz et al. (forthcoming).

52 However, this view is itself predicated upon medicine's (political) relationship to the epistemological primacy of science and/or biomedicine.

53 M. Oliver, *Social Work with Disabled People* (1983); M. Oliver, 'The Social Model of Disability: Thirty Years On' (2013) 28 *Disability and Society* 1024; T. Shakespeare, 'The Social Model of Disability' in *The Disability Studies Reader*, ed. L. Davis (2017) 195.

54 D. Griffiths, 'Shifting Syndromes: Sex Chromosome Variations and Intersex Classifications' (2018) 48 *Social Studies of Science* 125.

medical governance is thus established through classificatory regimes of disorder and disease which are rarely challenged at the state or legal level. As a result, the methods by which disorders and disease are managed are also rarely interfered with by the state, outside of limitations on resources, and subject to professional standards.<sup>55</sup> Thus, medical professionals have been somewhat insulated from voices outside of the medical profession that wish to challenge classificatory regimes or the abrogation of responsibility.<sup>56</sup>

Consequently, the medical profession has taken great care to establish its own jurisdictional remit while relying upon a clear hierarchy in order to solve its own internalized contradictions. As Griffiths notes, since at least the 1950s individuals who blur the boundaries between male and female, creating differing levels of social and medical emergencies, have led to ‘a need within the medical profession to purify, redraw and maintain strict boundaries’.<sup>57</sup> Medical professionals continue to advocate cosmetic, gender-normalizing medical interventions as ‘best practice’ while concomitantly failing to take responsibility for them. The continuing hierarchy between scientific knowledge and patient experience has meant that the governing logic of healthcare with regards to intersex people remains largely unchanged from the 1950s. Responsibility is thus largely avoided within the medical profession, aside from the key areas that we have already identified. This is important in relation to intersex variances as the logics of healthcare mean that practitioners tend to frame non-therapeutic medical interventions through a responsibility to act, as inaction can be equated with neglect. Such medical interventions are thus presented as an inevitable element of combatting faulty genetic pathways.

Symptomatic of the divide between medical professionals and the intersex community has been the struggle over terminology. In 2006, the Consensus Statement on the Management of Intersex Disorders introduced the term ‘disorder of sex development’ (DSD) to address ‘several aspects of the care of patients’.<sup>58</sup> It said:

Terms such as ‘intersex’, ‘pseudohermaphroditism’, ‘hermaphroditism’, ‘sex-reversal’, and gender-based diagnostic labels are particularly controversial. These terms are perceived as potentially pejorative by patients and can be confusing to practitioners and parents alike. We propose the term ‘disorders of sex development’ (DSD), as defined by congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical.<sup>59</sup>

In a relatively short amount of time, the terminology of DSD gained almost universal acceptance within the medical profession. In part, this

55 *Bolitho v. City and Hackney Health Authority* [1998] AC 232.

56 Oliver, op. cit. (1983), n. 53; Oliver, op. cit. (2013), n. 53; Shakespeare, op. cit., n. 53.

57 D. Griffiths, ‘Diagnosing Sex: Intersex Surgery and “Sex Change” in Britain 1930–1955’ (2018) 21 *Sexualities* 476, 489.

58 Lee et al., op. cit., n. 47, p. 172. For a contextual overview of the Consensus Statement, see G. Davis, *Contesting Intersex: The Dubious Diagnosis* (2015).

59 Lee et al., op. cit., n. 47.

may have been because the conference leading to the Consensus Statement was prestigious and well attended, enabling widespread coverage and dissemination. While many intersex activists have fundamentally rejected DSD terminology as inappropriately pathologizing, they have been unable to stop the rise of this nomenclature in the medical field. Davis argues that this is because ‘medical professionals have strategically used the terminology as a vehicle to reclaim their jurisdiction over intersex, just as intersex activism was seemingly beginning to successfully challenge that authority’.<sup>60</sup> Shifting the terminology used to discuss intersex people from ‘intersex’ to ‘disordered’ reifies the place of the medical professional in discovering and ‘reordering’ the disordered body while simultaneously moving responsibility away from the medical interventions (and categorizations) themselves.

Terminology here serves to justify medical intervention on the basis of ‘fixing’ the intersex child. Medical jurisdiction becomes further entrenched, with responsibility being framed in terms of the obligation to ‘fix’. Whereas ‘intersex’ can be mobilized as a political position or a legally protected characteristic outside of this fixing narrative, DSD terminology depoliticizes this state of embodiment and at the same time moves it from the public sphere into the private. This results in various responsibilities being depoliticized and ultimately privatized, reproducing existing inequalities.<sup>61</sup> DSD terminology thus ‘naturalizes’ the lack of responsibility taken for these medical interventions by framing them as ‘natural’ rather than social. Such manoeuvres draw strong jurisdictional boundaries around this area, preventing dialogue with legal and political institutions about the issue as well as re-establishing existing hierarchies between patients, parents, and medical professionals.

The difficulties in challenging medical jurisdiction have meant that even where practices are harmful, they are slow to be altered. Despite a severe lack of evidence as to the efficacy of gender-normalizing medical interventions on intersex children, they continue to be practised.<sup>62</sup> Moreover, notwithstanding criticism, the current iteration of the World Health Organization’s International Classification of Diseases continues to recommend surgical procedures for certain types of intersex variance.<sup>63</sup> Guidelines on the treatment of intersex children recommend surgical interventions on neonates, as their recovery time is quicker and mortality

60 Davis, op. cit., n. 58, p. 54. See also T. Lundberg et al., ‘Making Sense of “Intersex” and “DSD”’: How Laypeople Understand and Use Terminology’ (2018) 9 *Psychology & Sexuality* 161.

61 Dietz, op. cit., n. 11.

62 Zillén et al., op. cit., n. 34.

63 M. Carpenter, ‘The “Normalization” of Intersex Bodies and “Othering” of Intersex Identities in Australia’ (2018a) 15 *The J. of Bioethical Inquiry* 487; M. Carpenter, ‘Intersex Variations, Human Rights, and the International Classification of Diseases’ (2018b) 20 *Health and Human Rights* 1.

rates are lower.<sup>64</sup> Such guidelines fail to consider *why* particular responses are necessary in the first place but point towards social reasons (such as relieving parental anxiety) as a justification.<sup>65</sup> The absence of evidence-based medicine or longitudinal follow-up studies in this area further highlights a need for governments to cross traditional jurisdictional boundaries and to take responsibility in this area. However, much jurisdictional analysis reveals a general unwillingness to challenge established boundaries.<sup>66</sup>

For the most part, law and policy seem willing to defer to medical expertise<sup>67</sup> precisely because of healthcare's positioning as private technical issues requiring professional expertise rather than as public issues allowing disputes to be settled by parties with unequal bargaining power.<sup>68</sup> Indeed, Devaney and Holm note that deference towards medicine can be advantageous for policymakers as it presents an issue as an objective medical fact rather than as a political issue.<sup>69</sup> Even in instances where medical governance or authority is challenged through, for example, medical law, cases are usually decided on the basis of prevailing (medical) professional standards and norms.<sup>70</sup> Medical jurisdiction is thus further entrenched as these legal cases focus on the question of 'who has the authority to govern' rather than the (more pressing) 'what' question that would consider the facts and context. Thus, jurisdiction has prevented further scrutiny of medical practice in the context of intersex embodiment and instead justifies the state's relegation of responsibility into a purely medical setting. In these medical contexts, responsibility is then abrogated or 'naturalized' as belonging to the patient or as an inevitable outcome of 'fixing' a genetic 'disorder'. However, such arguments fail to consider the harm done by these interventions. As Pickersgill notes in relation to the *DSM*:

we might usefully consider whether scholars and other commentators ... could broaden out their arguments over whether diagnostic entities ... are 'right' or 'wrong' – or even 'good' or 'bad' – and reflect more fully on the kinds of rights and responsibilities that different diagnoses and diagnostic tools enable and constrain. By this I mean, for instance, where and how diagnoses are used both to facilitate and exclude individuals from accessing particular services and benefits, and indeed how they are employed in the actual design of services.<sup>71</sup>

Moving to this more holistic consideration of healthcare would be useful for intersex-embodied people, as it may be beneficial for considering responsibility and its production and distribution. Over the past decade,

64 Lee et al., op. cit., n. 47.

65 Id.

66 Dietz, op. cit., n. 11; Valverde, op. cit. (2015), n. 11.

67 Harrington, op. cit., n. 11.

68 Dietz, op. cit., n. 11.

69 Devaney and Holm, op. cit., n. 50.

70 Harrington, op. cit., n. 11.

71 M. Pickersgill, 'Diagnoses and the Sociology of Critique' (2014) 40 *J. of Medical Ethics* 521, at 524.

vulnerability theory has attempted to refocus attention away from individual responsibility towards state responsibility. The following section considers such an approach in relation to intersex embodiment in light of the above jurisdictional analysis. Combining these two theoretical tools, this article is able to advance an important agenda for intersex-embodied people by demanding that the state challenge jurisdictional boundaries and take responsibility.

## COMBINING VULNERABILITY THEORY AND JURISDICTIONAL ANALYSIS: INTERSEX EMBODIMENT

As with our previous work, this article engages with vulnerability theory to support the position that gender-normalizing interventions on intersex infants should be deferred until the child can consent. While this prioritizes one theoretical position, we would argue that very few theories of justice or understandings of children's rights could (or would attempt to) defend these medical practices.<sup>72</sup> Using a vulnerability analysis, the article suggests that the lack of responsibility taken by the medical profession means that state action is required to regulate this area.<sup>73</sup> This vulnerability lens therefore allows responsibility to be framed not as an individual issue but as a societal issue necessitating state monitoring. This section begins by outlining vulnerability theory, before going on to engage with intersex embodiment specifically. Finally, the section reflects on how jurisdictional analysis can enhance the practical utility of vulnerability theory.

Vulnerability theory offers a theoretical framework committed to decentralizing the liberal legal subject. This allows for the destabilization of foundational organizing principles of current Western legal systems such as autonomy, rationality, independence, and meritocracy.<sup>74</sup> Vulnerability theory offers the insight that we are all vulnerable to expose the fallacy that certain groups are 'more vulnerable' and thus naturally differentiated from wider society as a 'special class' of people in need of help (which they may or may not be constructed as deserving). Resilience is key to Fineman's conception of vulnerability. As no one can achieve a state of invulnerability, it does not make sense to talk in such terms, and as vulnerability is universal and constant, one cannot be more or less vulnerable. Consequently, Fineman uses the term 'resilience' to denote the particular differences between people – usually understood in terms of the gathering of social resources or capital.<sup>75</sup>

72 However, compare this with liberalism, which might argue that the state should not interfere in the private sphere of parental decision making or professional expertise.

73 Garland and Travis, op. cit., n. 5.

74 Fineman, op. cit. (2008), n. 6; Fineman, op. cit. (2010), n. 6; M. Fineman, 'Vulnerability, Resilience, and LGBT Youth' (2014) 23 *Temple Political & Civil Rights Law Rev.* 307.

75 Fineman (2008), id.; Fineman (2010), id.; Travis, op. cit., n. 6.

This insight highlights the unequal distributions of dependency, privilege, and resilience within our society and the ways in which they are constructed as natural.<sup>76</sup> One of the key components of vulnerability theory, therefore, is to challenge the naturalness of these inequalities.

Vulnerability is experienced in two different ways: as embodied (through the body) and as embedded (through our relationships with institutions and the state).<sup>77</sup> Understanding vulnerability as embodied allows us to consider its universality and the inevitability of dependency. All humans, no matter how privileged or resilient to illness, will be dependent at some point in their lives – through childhood, old age, and illness, at least.<sup>78</sup> Understanding vulnerability as embedded, in turn, focuses on the individual's relationships with institutions (such as the family, the workplace, and the healthcare system) and the state. These relationships can either attenuate or heighten the resilience of individuals. The state's distribution of resources and allocation of support, either by itself or through institutions, thus plays a crucial role in vulnerability theory.<sup>79</sup>

These decisions as to resources are not natural or inevitable. If the state chooses not to interfere in a particular area, this is still a choice<sup>80</sup> and it will impact upon the resilience of individuals. From a vulnerability theory perspective, however, our inherent vulnerability gives these decisions a normative dimension and places a moral imperative on the state to ensure its subjects' resilience. This normative dimension then changes the nature of state interference from responsiveness (which can be either positive or negative) to responsibility (which allows for a sense of justice to be built into the decision-making process). By repositioning responsibility at the state level, vulnerability theory offers a vital intervention into the relationship between intersex people and the medical profession that moves away from the complete abrogation of responsibility that we have identified.

Recently, Fineman has abandoned the notion of equality as a central part of vulnerability theory, instead positing the idea that inequalities may be inevitable and, in some cases, even desirable.<sup>81</sup> As she notes, 'vulnerability theory goes beyond the normative claim for equality, be it formal or substantive in nature, to suggest that we interrogate what may be just and appropriate mechanisms to structure the terms and practices of inequality'.<sup>82</sup> The facilitation of and responsibility for justice, therefore, is not achieved

76 Fineman (2008), id.; M. Fineman, 'Vulnerability and Inevitable Inequality' (2017) 4 *Oslo Law Rev.* 133.

77 Fineman (2008), id.

78 Fineman, op. cit. (2014), n. 74; Fineman, op. cit. (2017), n. 76.

79 Fineman, op. cit. (2008), n. 6; Fineman, op. cit. (2010), n. 6; Fineman, op. cit. (2012), n. 6; Marvel op. cit., n. 6; Clough, op. cit., n. 6; Travis op. cit., n. 6; Garland and Travis, op. cit., n. 5; Mant and Wallbank, op. cit., n. 6.

80 Clough, id.

81 Fineman, op. cit. (2017), n. 76.

82 Id., p. 134.

through measuring equality but through attentiveness to vulnerability and the constant monitoring of inequalities. As Fineman notes, through engagement with the universality of vulnerability, ‘I develop a normative, or theoretical, perspective on the just allocation of responsibility for individual and societal well-being. Such responsibility must be shared between the individual and the state and its institutions.’<sup>83</sup> The ways in which the state ought to respond are not proscribed by the theory, allowing law and policymakers to adopt differing solutions in response to their own political and legal contexts.<sup>84</sup> For vulnerability theorists, though, the state ought to be compelled by a ‘responsibility to establish and monitor social institutions and relationships that facilitate the acquisition of individual and social resilience’.<sup>85</sup>

Certainly, in the intersex context, the application of vulnerability theory as a heuristic device demonstrates the institutional and physical harms arising from medical interventions that limit the resilience of intersex people. Rather than helping intersex people to fit into society, these medical interventions often damage relationships with crucial institutions at an early stage, leaving individuals with lowered resilience and difficulties in obtaining the resources and relationships needed to become more resilient. Considering the interventions in this more holistic and contextual manner allows us to consider the effect of the interventions outside of the simple lens of physical harm and allows us to perceive the wider social harms that are perpetrated against intersex children, affecting their embeddedness within institutions and society. Rather than placing responsibility on the individual to ‘fit in’, focusing on the embedded nature of vulnerability highlights the systemic nature of the issues affecting intersex-embodied people. To adequately respond to systematic inequalities, Fineman posits that the state must take an active role in the monitoring of institutions that may affect an individual’s resilience, cutting across the sharp divide between the public and private sphere. In our context, given the lack of responsibility taken by the medical profession regarding the institutional and physical harms experienced by intersex-embodied people, state action is clearly required to regulate this area.

However, effective action requires states to be more than just responsive; they must become responsible for the harms experienced by intersex-embodied people, which requires them to challenge medical jurisdiction. This need has been highlighted in our own previous empirical work with intersex organizations which evaluated how states other than the United Kingdom – particularly Australia, Germany, and Malta – have reacted to intersex concerns.<sup>86</sup> This work set out a number of recommendations that could structure an effective state response to intersex embodiment.<sup>87</sup> Chiefly,

83 *Id.*, p. 141.

84 *Id.*, p. 134.

85 *Id.*

86 Garland and Travis, *op. cit.*, n. 5.

87 *Id.*



it recommended the prohibition of gender-normalizing medical interventions on intersex persons without the acquisition of their full informed consent as the primary state response that intersex research participants would like to see enacted; respondents wanted the state to intervene to redress the inherently unequal relationship between medical professionals, intersex ‘patients’, and their families. Our work also outlined the need for anti-discrimination legislation, hate-crime provisions, an easier-to-navigate process for making gender changes on official documentation (such as birth certificates), and educational reform across a multitude of institutions.<sup>88</sup>

While a growing number of states *are* responding to calls for reform in this area, a frustrating global pattern is developing whereby introducing a ‘status-based’ approach focusing on a ‘third gender’ is the predominant mode of state action. The pertinent question, then, is not whether states should respond, but rather why (and how) states are ignoring such clear evidence about the harmful nature of non-therapeutic medical interventions. Turning to jurisdictional analysis not only helps to answer this question but also enables barriers that have traditionally prevented governmental or legal response in this area to be overcome. The deeper consideration of the nature of jurisdiction offered by this article allows vulnerability theorists to understand the artificiality of such jurisdictional boundaries. As the broader state begins to recognize its responsibilities in this area, this form of analysis draws attention to the state’s previous failure to uphold its obligations to intersex citizens. Thus, considerations of jurisdiction are extremely useful for vulnerability theorists, as they are often proffered by the state as an explanation for non-responsiveness. The scrutiny offered by this article reveals some of the barriers to the creation of a more responsive state and so enhances the practical utility of vulnerability theory. The article now considers what lessons can be learned by policymakers in the United Kingdom.

### THE CONTEXT IN THE UNITED KINGDOM: VULNERABILITY, JURISDICTION, AND A RESPONSIBLE STATE

This section applies vulnerability theory and jurisdictional analysis to the context of the United Kingdom. As previously mentioned, parts of the United Kingdom have begun to consider potential avenues of reform in this area.<sup>89</sup> This section now outlines the growing momentum in the United Kingdom towards a state response, including a recent Call for Evidence

<sup>88</sup> Id.

<sup>89</sup> Scottish Government, *Review of the Gender Recognition Act 2004: Consultation Analysis* (2018), at <<https://www.gov.scot/publications/review-gender-recognition-act-2004-analysis-responses-public-consultation-exercise-report/>>; Government Equalities Office, *LGBT Action Plan: Improving the Lives of Lesbian, Gay, Bisexual and Transgender People* (2018), at <[313](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/721367/GEO-LGBT-</a></p></div><div data-bbox=)

specifically on intersex issues in England and Wales. This Call was wide-ranging and comprehensive and showed a willingness to at least investigate the potential need for disrupting a number of traditional jurisdictional boundaries. Nonetheless, the framing of some of the Call's questions may see a default return to focusing on individual rather than institutional responsibility. This would reaffirm the public/private divide and reify medical jurisdiction in this area. This section suggests ways in which such jurisdictional barriers can be circumvented to ensure that a growing legal consciousness leads to the disruption of the power imbalances currently found in the intersex–medical relationship.

Until very recently, the United Kingdom's Government remained non-responsive with regards to gender-normalizing surgical procedures, justifying this approach through deferral to the (state-constructed) medical jurisdiction. In 2016, for example, the United Nation's Committee on the Rights of the Child questioned the Government on the continued practice of gender-normalizing medical interventions on intersex children. The Government's response, articulated by Flora Taylor Goldhill (then Director for Children, Families and Communities, Department of Health), stated:

NHS England are responsible for specialised commissioning which covers this area. ... Where babies and children could be described as intersex, decisions about when and how to make medical interventions should be taken by clinicians in consultation with the parents of the child, and where possible and the child is older, seeking the views of the child himself or herself or themselves ... The commissioning of specialised services by NHS England is heavily informed by expert and stakeholder advice via the clinical reference group ... They use their specific knowledge and expertise to advise NHS England on the best way that specialised services should be provided.<sup>90</sup>

Taylor Goldhill's response clearly relegates responsibility for intersex issues solely to medical jurisdiction, in this case the National Health Service, thus displacing responsibility away from the broader state. Despite being challenged by the Committee over the National Health Service's continued breaching of children's bodily integrity without gaining the appropriate levels of consent, Taylor Goldhill is unable to understand intersex embodiment outside of a medical narrative. This privileging of medical power/knowledge continues to frame the intersex experience purely in terms of disorder and 'fixing', with responsibility again being understood as a responsibility to fix.<sup>91</sup> Throughout her statement are references to the 'specific knowledge

Action-Plan.pdf>; Government Equalities Office, op. cit., n. 8; Minister for Women and Equalities, *Reform of the Gender Recognition Act: Government Consultation* (2018), at <[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/721725/GRA-Consultation-document.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/721725/GRA-Consultation-document.pdf)>. Northern Ireland has yet to engage with this matter.

90 F. Taylor Goldhill, op. cit., n. 13.

91 Davis, op. cit., n. 58; K. Karkazis, *Fixing Sex: Intersex, Medical Authority and Lived Experience* (2008); Fausto-Sterling, op. cit., n. 36; M. Holmes 'Straddling Past, Present and Future' in *Critical Intersex*, ed. M. Holmes (2009) 1.

and expertise' required for such considerations and the 'specialised' nature of such services, alluding to a context of medical exceptionalism and hierarchy. While the statement includes the potential for engagement with charities and patient groups, this is yet to materialize in the intersex context.<sup>92</sup> Indeed, this is exacerbated by the wide remit of the clinical reference group to which she refers, which falls under the umbrella of 'specialised endocrinology', again framing intersex as a genetic or scientific issue rather than as a political one. This team is responsible for the management of specialist thyroid conditions, complex parathyroid conditions, pituitary/hypothalamic conditions, and familial endocrine conditions. This broad range of issues has meant that the group are yet to commission any policies on intersex variances. Consequently, expertise remains cast in generalist medical terms and patient knowledge continues to be marginalized. Responsibility is framed at the level of the individual practitioner, with overarching responsibility for medical policy being ensured by the clinical reference group. Moreover, responsibility for harm continues to be thought of in terms of inaction and inadequacy rather than in terms of responsibility for the decision to medically intervene in the first place.

However, since Taylor Goldhill's statement, there has been a shift in the Government's approach towards intersex embodiment that could disrupt these jurisdictional boundaries. Certainly, the Government has a growing awareness of the structural and systemic harms faced by intersex people. Regionally, intersex has already been included (although problematically, as a form of trans identity) within Scotland's Offences (Aggravation by Prejudice) (Scotland) Act 2009, and in 2016 the Scottish Government 'added intersex equality to its approach to sexual orientation and gender identity equality and now uses the acronym LGBTI to support the inclusion of intersex people in Scotland'.<sup>93</sup> Furthermore, the Scottish Government has indicated plans for a separate intersex-specific consultation.<sup>94</sup> Similarly, England and Wales has also begun to engage with intersex embodiment at a policy level, including intersex issues within its LGBT Survey (2017), its Gender Recognition Act (GRA) Consultation (2018), and the recent Call for Evidence on intersex-specific issues (2019).<sup>95</sup> These policy documents follow a series of meetings with stakeholders in an attempt to comprehend the issues affecting the intersex community.

Importantly, then, through active dialogue with the intersex community the Government is beginning to approach intersex matters in a way that could take account of the systemic nature of harm experienced by intersex-

92 National Health Service England, 'A03 Specialised Endocrinology', at <<https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-a/a03/>>.

93 Scottish Government, *Fairer Scotland Action Plan* (2016), at <<http://www.gov.scot/Publications/2018/05/4431/3>>.

94 Scottish Government, *op. cit.*, n. 89, para. 1.03.

95 Government Equalities Office, *op. cit.*, n. 8; Government Equalities Office, *op. cit.* (2018), n. 89.

embodied people. For example, the LGBT Survey (which examined access to health services in the last 12 months across all regions in the United Kingdom) specifically included questions related to intersex experiences and of 108,100 respondents, 1,980 identified as intersex (around 2 per cent). Not only are these findings significant in terms of the survey's size in an under-researched area,<sup>96</sup> but the report also rightly identified areas of weakened intersex resilience:

Intersex respondents were more likely to have been unsuccessful when trying to access mental health services ... (13%) than non-intersex respondents (8%), and were also more likely to say that accessing them had not been at all easy (37%) than non-intersex respondents (28%).

11% of intersex respondents said that accessing sexual health services ... had not been at all easy, compared to 5% of non-intersex respondents. Of those who had accessed or tried to access sexual health services ... 6% said their GP had not been supportive, compared to 2% of non-intersex respondents, and 5% said their GP had not known where to refer them, compared to 1% of non-intersex respondents.<sup>97</sup>

These findings are particularly important as the survey's results signpost the Government towards particular directions of policy and legislative response. However, the findings remain limited given that the survey was entitled 'LGBT'; intersex individuals may not have realized that it was also aimed at them and thus may not have taken part or may have refused to do so on the grounds that many do not identify with LGBT identities.<sup>98</sup> Furthermore, some respondents used the terms 'intersex' and 'non-binary' interchangeably and described themselves as intersex in ways 'other than a strictly medical sense'.<sup>99</sup> Moreover, as the survey's framing had the broader LGBT community in mind rather than being intersex-specific, questions focused on accessing services in the last 12 months rather than overall experiences of the medical profession;<sup>100</sup> intersex individuals had no designated space to raise concerns over gender-normalizing medical interventions. Consequently, this survey alone does not constitute adequate engagement with intersex matters on the part of the Government as it did not focus on key areas of concern nor ask

96 There have been very few large-scale studies of intersex experience due to the problems in accessing participants; see, however, T. Jones et al., *Intersex: Stories and Statistics from Australia* (2016).

97 Government Equalities Office, op. cit. (2018), n. 89, p. 235.

98 F. Garland and M. Travis, 'Queering the Queer/Non-Queer Binary: Problematizing the 'I' in LGBTIAQ' in *The Queer Outside in Law*, eds S. Raj and P. Dunne (forthcoming). These concerns are acknowledged within the report: 'the survey was not intended to gather robust data on intersex-specific issues because [it] was primarily targeted at people identifying as having a minority sexual orientation or gender identity. It is likely that intersex respondents who identify as such are overrepresented in the sample compared to the full intersex population.' Government Equalities Office, op. cit. (2018), n. 89, p. 234.

99 Id., p. 235.

100 See id., p. 271 for an appendix of the survey's questions and pp. 284–289 for the section on healthcare.

important questions about responsibility and structural change. Importantly, responsibility here was understood in quite a short-term way, around access to services, rather than with regards to the longer-term issues that might push people to use those services in the first place and the responsibilities that may arise from this.

However, the Government seems aware of its limited understanding in this area. In its *LGBT Action Plan* (2018), announced alongside the findings of the LGBT Survey, the Government showed a commitment to ‘improve our understanding of the issues faced by people who are intersex’<sup>101</sup> and accordingly launched a Call for Evidence in England and Wales on the issues faced by intersex people.<sup>102</sup> This Call (alongside Scotland’s promise for a separate consultation)<sup>103</sup> was a most welcome step in the policy development of the United Kingdom and showed promise for addressing the issues that limit the resilience of intersex-embodied people. Most reassuringly, the Call covered a broad range of topics relating to experiences and perceptions of the medical profession, support services, birth registration, education, and the workplace.<sup>104</sup> Significantly, the Government has paved the way for a state response that takes responsibility for gender-normalizing medical interventions on intersex individuals.<sup>105</sup>

This marks a significant advance for academic and intersex campaigners in the United Kingdom and indicates that the Government may be willing to listen to the overriding concerns of intersex-embodied people in the near future. Of course, listening and responding are two very different things, but it seems likely that the Government will intervene in this area in some way. However, a meaningful response must not only tackle identity-related issues but also address concerns surrounding the medical treatment of intersex bodies and the lack of responsibility that currently characterizes this area. The Government must move from simply responding to the issues to taking responsibility for them and stopping deferring such responsibility,

101 *Id.*, p. 4.

102 Government Equalities Office, *op. cit.*, n. 8.

103 Scottish Government, *op. cit.*, n. 89, para. 1.03.

104 As Scotland has yet to action an intersex-specific consultation paper, its framing remains to be seen.

105 In 2017, the United Kingdom also launched a consultation on reform of the Gender Recognition Act 2004 in England and Wales. Most of the GRA consultation relating to intersex focused on ascertaining how far diagnoses of ‘gender dysphoria’ are relevant to intersex people and how the GRA could be better improved to accommodate intersex people. The consultation’s discussion went further than the survey report, however, by acknowledging that ‘there are a range of issues pertinent to intersex people, some of which include unnecessary medical interventions performed on infants, correcting birth certificates, barriers in accessing healthcare services, psychosocial provision, support groups, as well as issues in education and in the workplace. These issues are outside of the scope of the GRA consultation.’ (Minister for Women and Equalities, *op. cit.*, n. 89, p. 56). The brief mention of the harms of gender-normalizing medical interventions on intersex people denotes the first official recognition of this within the United Kingdom.

as Taylor Goldhill did, to medical jurisdiction. Vulnerability theory demands that responsibility is shifted from an individual to a state level. Taking responsibility, however, requires the state to adopt a normative stance on gender-normalizing interventions on intersex-embodied children and to disrupt traditional jurisdictional boundaries between medicine and the state.

Yet, as previously mentioned, the disruption of jurisdictional boundaries may not be a simple task given that law and policy have historically been willing to defer to the medical profession. Even cases in which medical governance has been challenged have been decided on the basis of prevailing (medical) professional standards and norms.<sup>106</sup> Indeed, in the context of the United Kingdom this line is further blurred through the National Health Service's position within the state. Again, this may be seen as an example of the plural and multifaceted logics that can exist within a governing institution. It may be useful to think of state deference in terms of its established understandings of what counts as medical expertise and thus as worthy of consideration. It is therefore questionable how far the Government will actually go to challenge medical governance. Indeed, intersex variances are extremely difficult to disentangle from the medical profession, as some variances need continuing healthcare provision. Accordingly, this article identifies a significant danger of 're-institutionalizing' intersex embodiment with the broader state avoiding responsibility by constructing intersex embodiment as appropriately governed by the medical profession. States need to be convinced that the problems of the intersex community are their responsibility and that they are more than capable of challenging and overruling medical jurisdiction. Changing the state perspective on these issues will not be easy, however. In the United Kingdom, and more widely, the prevailing trend of neoliberalism has introduced a governing logic of self-responsibility.<sup>107</sup> Arguments for a more interventionist state are not currently in vogue, with much government policy being directed towards individual rather than institutional responsibility. This has certainly been reflected in the case law emanating from the United Kingdom, which has placed increasing emphasis on patient autonomy and self-determination in clinical decision-making processes. Most recently in *Montgomery v. Lanarkshire Health Board* (2015), the Supreme Court declared:

a doctor must take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative or variant treatments. The test of materiality is whether, in the circumstances of the particular case, a reasonable person in the patient's position would be likely to attach significance to the risk, or the doctor is or should reasonably be aware that the particular patient would be likely to attach significance to it.<sup>108</sup>

106 Harrington, *op. cit.*, n. 11.

107 W. Brown, *Undoing the Demos: Neoliberalism's Stealth Revolution* (2013); Mant and Wallbank, *op. cit.*, n. 6.

108 *Montgomery v. Lanarkshire Health Board* (2015) [2015] UKSC 11, para. 11.

This decision marked a considerable shift in medical power/knowledge surrounding non-disclosure of information; rather than it being left to the medical professional to decide how much information to share with the patient on clinical procedures, *Montgomery* 'enshrines in law an approach which is intended to ensure that consent is given only where the patient has been informed of risks in a way which meets her needs and has thus been hailed as the final step in a legal power shift from paternalism to patient autonomy'.<sup>109</sup> Of course, the problem here is that it is parents rather than intersex children who are consulted over treatment and that the medical risks are being weighed against social understandings of sex and gender.

A state response to intersex issues informed by these governing logics is likely to develop in two ways: first, placing responsibility on parents to make choices informed by medical guidance and information; and second, placing responsibility on individual doctors for making 'bad decisions' or failing to inform patients and parents of all available options. Certainly, the current framing of the Call for Evidence suggests that the Government may push towards reform that centres on informed consent, as Question 3b (aimed at parents/those involved with caring for intersex-embodied people) demonstrates: 'With regard to medical interventions/procedures, how could the care, support and information provided to people living with variant sex characteristics be improved?'<sup>110</sup>

This individualization and privatization of responsibility is hugely and inherently problematic as it fails to take into account the structural and systemic nature of the problems that intersex people face. Rather than challenging medical practice, it seemingly absolves the medical professional of responsibility for the intervention that takes place and instead places responsibility for procedures squarely onto the patient or, in most cases, their family. Additionally, it will reinforce existing structural inequalities as many people will find it difficult to bring a claim against the (comparatively) well-funded and state-backed healthcare practitioners. Moreover, it fails to prevent the surgical procedures from happening in the first instance and only provides a remedy once they have already happened. Indeed, this is rendered all the more problematic as medical professionals will be defended from such claims if they can show that their approach was in keeping with professional norms and standards.<sup>111</sup> Consequently, it is clear that the individualization of responsibility will not solve the problems faced in this area and we must move towards a more relational understanding of vulnerability and consent.<sup>112</sup> Part of the efforts of intersex campaigners and scholars sympathetic to their cause must revolve around shifting responsibility from the individual to the

109 Devaney and Holm, op. cit., n. 50, p. 207.

110 Government Equalities Office, op. cit., n. 8.

111 *Bolitho*, op. cit., n. 55.

112 E. Feder, *Making Sense of Intersex: Changing Ethical Perspectives in Biomedicine* (2014).



state – something that this article has sought to enable. Nonetheless, looking at global shifts in the relationship between intersex embodiment and medical jurisdiction, there is a significant opportunity at this political moment to reconfigure the relationship between intersex-embodied people, the medical profession, and the state.

## CHALLENGING JURISDICTION AND STATE RESPONSIBILITY

As recognized to an extent in recent Government policy,<sup>113</sup> children are being harmed by gender-normalizing medical interventions. This acknowledgement by the Government establishes a need not only for response but also to take responsibility for the issue. The medical profession, and its location within the apparatus of the state, highlights the multiple logics and jurisdictions that can compete over particular subjects. While the Government, for the most part, is deferential to medical expertise, this is a normative issue that clearly necessitates going beyond the traditional jurisdictional divides over knowledge – particularly where responsibility has so easily been avoided. The divide between the experiences of intersex-embodied people and prevailing medical norms is too stark and too wide, necessitating governmental intervention to build a bridge between them. By doing so, the Government could establish itself as a leader in addressing responsibility for intersex people; meaningful reform needs to disrupt the boundaries of medical jurisdiction but the Government has demonstrated a historical reluctance to do this when challenged.<sup>114</sup>

Unfortunately, the most common form of state response globally has been a model of recognition whereby ‘intersex status’ is enshrined in law either through ‘X’ markers on official documents and/or anti-discrimination law that specifically includes intersex people.<sup>115</sup> Such interventions are important in terms of symbolic recognition but have been criticized for mirroring broader (and more easily achievable) LGBT priorities rather than engaging with the specific demands of the intersex community.<sup>116</sup> In terms of responsibility, this model places a general duty on employers and service providers not to discriminate, but this is typically hard to enforce and could therefore be seen as a continued evasion of responsibility. In terms of challenging medical authority, these reforms are, ultimately, ineffective. More concerningly, such reforms could actually *strengthen* the remit of medical jurisdiction. Certainly,

113 Minister for Women and Equalities, op. cit., n. 89.

114 Harrington, op. cit., n. 11.

115 Garland and Travis, op. cit., n. 5, p. 5.

116 Carpenter, op. cit. (2018a), n. 63; Carpenter, op. cit. (2018b), n. 63; Garland and Travis, op. cit., n. 5; Garland and Travis, op. cit., n. 98. In fact, three years after passing anti-discrimination legislation, Australia’s Family Court held that parents could consent to gender-normalizing medical interventions on their children even if it resulted in sterilization; *Carla* (medical procedure) [2016] FamCA 7.

Germany has been criticized in this regard after introducing a ‘blank space’ on birth certificates.<sup>117</sup> While this space was introduced to allow parents and medical professionals more time to assess the ‘true sex’ of the child, it has led to gender-normalizing interventions being performed at earlier stages as parents are anxious to avoid their children being placed into this legal category.<sup>118</sup> Responsibility has remained with medical professionals as they determine who should be placed into the third gender category.

Yet these jurisdictional boundaries can be disrupted. In 2013, Maltese governmental officials participated in the International Intersex Forum, a large intersex conference attended by 30 global organizations and hosted in Malta. At this event, officials were able to hear first-hand accounts of the medical interventions and harms experienced by intersex people. As a result, in 2015 Malta introduced the Gender Identity, Gender Expression and Sex Characteristics Act (GIGESC). This revolutionary Act was the first piece of legislation to prohibit surgical interventions on intersex people without their prior consent and has been heralded as the current ‘gold standard’ of legislation.<sup>119</sup> Alongside provisions that now allow individuals to self-ascribe their own gender identity,<sup>120</sup> extend ‘hate crime’ legislation to incorporate sex characteristics, and set out sex characteristics as a protected category within Maltese anti-discrimination law,<sup>121</sup> Section 14 of GIGESC states:

It shall be unlawful for medical practitioners or other professionals to conduct any sex assignment treatment and/or surgical intervention on the sex characteristics of a minor which treatment and/or intervention can be deferred until the person to be treated can provide informed consent.

This holistic model of reform has been viewed by the intersex community to be an effective (although imperfect)<sup>122</sup> state response that makes a concerted

117 Gesetz zur Änderung personenstandsrechtlicher Vorschriften (Personenstandsrechts-Änderungsgesetz—PStRÄndG) 2013. A recent court case held that this blank space ought to be a ‘positive’ rather than a ‘negative’ identity; Order of 10 October 2017 – 1 BvR 2019/16.

118 Amnesty International, *First, Do No Harm: Ensuring the Rights of Children with Variations of Sex Characteristics in Denmark and Germany* (2017), at <<https://www.amnesty.org/download/Documents/EUR0160862017ENGLISH.PDF>>; Travis, op. cit., n. 5.

119 Garland and Travis, op. cit., n. 5, p. 5.

120 Section 4 of GIGESC 2015 allows individuals to change official records of their gender without any medical evidence being required to do so.

121 Section 4 allows individuals to request change of first name and recorded gender to reflect self-determined gender. No medical evidence is necessary. Section 10(3) amends Article 83B of the Maltese Criminal Code to include offences motivated on the basis of gender expression and sex characteristics. Section 14 prohibits any discrimination on the basis of sexual orientation, gender identity, gender expression, and sex characteristics.

122 The Maltese law in this area is still problematic as, for example, it does not prohibit travel to other countries for gender-normalizing medical interventions; Garland and Travis, op. cit., n. 5, p. 5.

effort to challenge medicalized narratives of intersex embodiment<sup>123</sup> while also addressing other substantive inequalities. The Act considers the temporality of intersex experience and focuses on the concept of ‘deferability’.<sup>124</sup> It forces healthcare practitioners to engage with a simple question: can this intervention be deferred? If not, then the medical intervention must take place. If yes, then the intervention must be deferred until such a point as it becomes necessary or the intersex person is capable of providing their informed consent.<sup>125</sup> Healthcare practitioners who do not adhere to this legislation face legal consequences such as fines or being struck off the medical register.<sup>126</sup> Such an approach recognizes the specialist medical knowledge of healthcare professionals but does not prioritize it over and above the lived experiences of intersex people. Nor does it seek to infantilize intersex persons by only considering them as children whose best interests must be decided without their input or consultation. Responsibility is thus helpfully shifted away from intersex-embodied people and healthcare practitioners towards the state. In particular, it challenges the medical profession’s lack of attributed responsibility in this area and subsumes such responsibilities into the corpus of the state.

While the Maltese provisions are less than perfect, they highlight an important and interesting shift in jurisdiction and governance. Crucially, in Malta intersex has moved from the private sphere of a medically defined disorder to the public space of a legally protected identity. Such a change demarks a huge shift in the governing rationalities that construct intersex embodiment. In particular, we see a contraction of the jurisdictional terrain of the medical profession and a shift in responsibility towards the state. Despite the growth of DSD nomenclature, medical power/knowledge – in this instance – has been unable to frame medical interventions as inevitable (and without responsibility) or to define its own jurisdictional limits. The difference between the Maltese example and that of other national and international provisions around intersex embodiment has been a political openness to state responsibility. This was marked by the willingness of governmental officials

123 Garland and Travis, id.

124 F. Garland et al., *Law and Intersex in Norway: Challenges and Opportunities* (2018), at <<https://bufdir.no/globalassets/global/law-and-intersex—final.pdf>>.

125 In Malta, children over 16 with ‘sufficient maturity and understanding’ can consent to medical treatment; s. 2(2) Health (Amendment) Act No. VII of 2017. Further consideration over the appropriateness of a fixed age limit is needed but is outside the scope of this article. A helpful starting point for discussions in the United Kingdom may be *Gillick* competency, which permits children under 16 with sufficient capacity to consent to medical treatment; *Gillick v. West Norfolk and Wisbech Area Health Authority* [1986] AC 112. However, safeguards are needed to protect intersex children from family pressures that could influence decision making.

126 However, the consequences were relatively minor; see Garland and Travis, op. cit., n. 5 for further critique. This has since been updated by the introduction of Act No. XIII of 2018. Practitioners can now face up to five years incarceration for breaching s. 14.

to *listen* to intersex testimonies and ensure that these experiences informed the drafting of legislation.

Here, the unproductive stand-off between intersex groups and healthcare practitioners has been avoided through the state subsuming responsibility into its own corpus. A clear prohibition, grounded in the language of temporality, allows these interventions to be understood as systemic structural inequalities that the state is ideally placed to respond to rather than individual ‘one-off’ situations that are best dealt with privately. Accordingly, Malta provides a good example to policymakers of a responsive state willing to overcome the traditional jurisdictional boundaries between healthcare and the state. An understanding of the role of jurisdiction is useful, therefore, in seeing why states have traditionally been hesitant to legislate on intersex issues. It is also helpful in dismantling notions of medical jurisdiction as a reason for the lack of a state response – particularly where there is such a clear normative motivation for the state to intervene. We hope therefore that this article can contribute to debates in this area and ensure that challenges to reform are considered in their appropriate jurisdictional context.

While this article has focused on policy development in the United Kingdom, the key messages transcend this particular context. An unwillingness to challenge medical jurisdiction has been a recurring feature of governmental regulation of intersex embodiment across the globe. Moreover, the fact that meaningful reform requires the Government to challenge these jurisdictional boundaries and to reappportion responsibility may provide important lessons for contexts other than the intersex experience; disability and trans activists and scholars, as well as those working in science and technology studies more broadly, may be able to learn from this example.

## CONCLUSIONS

This article has wide-reaching practical and theoretical implications. In terms of policy and practice, it has engaged with vulnerability theory to demonstrate that non-consensual, gender-normalizing medical interventions on intersex people are a structural and systemic issue that requires a state response. In doing so, it has highlighted the normative dimensions that underpin the need for a move from simple state response to state responsibility. These are not individual problems but ones that affect an entire subset of the United Kingdom’s populace and so require a sustained, multi-pronged, and structural response from the Government. Through a consideration of new developments in intersex policy in the United Kingdom, the article has highlighted jurisdiction as a potential barrier that must be overcome to effect progress in this area. The medical profession enjoys a high degree of autonomy in setting its own jurisdictional remit. The classificatory boundaries of disorder and disease are rarely challenged by the state. However, this article has argued that the overwhelming lack of medical evidence to support gender-

normalizing medical interventions and the breakdown in communication between medical professionals and intersex-embodied people justify and, indeed, necessitate a state response that disrupts these traditional jurisdictional boundaries around expertise.

This type of state response is not unprecedented; the article has pointed towards Malta as a state that has been willing to challenge the traditionally deferential relationship of state and medical expertise. This provides further support for the state's adoption of a critical approach to jurisdictional boundaries. Through this article, we have demonstrated that, despite progress in intersex policy in the United Kingdom, jurisdiction remains a potential barrier to effective reform. However, this barrier can be dismantled if the Government is willing to take responsibility for the structural and physical harms that affect intersex-embodied people. Fundamental change will require the state to go beyond liberal notions of public and private spheres to monitor and regulate inequalities. As a result, vulnerability analysis highlights the areas that need targeting to effect real progress for the resilience of intersex-embodied people – namely, an end to the state's deference to medical jurisdiction and improved communication with the intersex community.

Furthermore, this article has added to vulnerability theory by moving away from simply demanding a response from the state to analysing the reasons behind possible state non-response. The analysis has highlighted that the appeals to jurisdictional boundaries, often relied upon by the state, can be circumvented. It has demonstrated the efficacy of engaging with theories of jurisdiction in relation to vulnerability theory and laid the groundwork for more sustained use in the future. This article has therefore powerfully enhanced the utility of vulnerability theory and improved its potential for engaging with the state.