

From ‘Intersex’ to ‘DSD’: a case of epistemic injustice

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Abstract The 2005 International Consensus Conference on Intersex resulted in a substantive revision of the lexicon and guidelines for treating intersex conditions. The speed with which the new treatment protocol has been adopted by healthcare practitioners and providers is considered unprecedented. However, a number of intersex people and advocacy groups have complained that the recommended revisions are inadequately informed by the testimony of intersex people. In this paper, I argue that such complaints are valid and that, despite the conference conveners stated intention, the revisions perpetuate the epistemic injustice long endured by intersex people. By analyzing the Consensus Conference and its results as a failed attempt to redress the epistemic marginalization of intersex patients and advocacy groups, I am able to identify lingering institutional hurdles to cultivating the virtue of epistemic justice in biomedical practice.

Keywords Epistemic injustice · Intersex · Consensus conferences · Disorders of sex development · Patient activism

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1 Introduction

In 2005, the International Consensus Conference on Intersex was held in Chicago. This was the culmination of years of advocacy by intersex¹ people and their allies calling for revisions in the then dominant treatment paradigm for intersex patients. The conference resulted in the “Consensus Statement of Management of Intersex Disorders” promoting a new standard of care. Included among revisions was a nomenclature change from ‘intersex’ to ‘disorders of sex development’ (DSD). According to a 2010 impact study, the conference and subsequent publications have led to “the complete overhaul and adoption of a new medical lexicon pertaining to DSD” (Pasterski et al. 2010, p. 193). The authors report that such a “rapid uptake” of a lexicon “is unparalleled in clinical medicine” (Ibid.).

Despite high hopes for the 2005 conference, a number of intersex people and advocacy groups expressed bitter disappointment in the outcome. According to the Consensus Statement, the reasons for convening the conference included “recognizing and accepting the place of patient advocacy” and the need to “review the management of intersex disorders from a broad perspective” (Lee 2006, p. e488). Critics, however, charge that the composition of the conference and especially the shift in nomenclature reveal that intersex advocates had little voice in shaping the so-called consensus. For these complainants, the conception of intersex promulgated in the revised lexicon is not adequately informed by the testimony² of intersex people and so is a poor resource for understanding their lived experience.

In her well-researched account of North American perceptions of intersexuality from the 1950s up through the conference, medical anthropologist Katrina Karkazis notes the tremendous hermeneutical authority accorded to healthcare lexicons:

[T]he power of medicine and science lies in their ability to define what is natural, to name nature and human nature, and in their claim or hope to return individuals to a more natural state or way of being. (2008, p. 11)

Having experienced this power firsthand, aggrieved intersex advocates insist that the decision to replace ‘intersex’ with ‘*disorders of sex development*’ reinscribes the assumption of the prior treatment protocol that intersex bodies are generally unnatural and require a biomedical or surgical fix restoring them to a more nat-

¹ ‘Intersex’ is an umbrella term for variations in the biological markers of sex identity—chromosomes, gonads, hormones or anatomical structure—such that they do not line up under a rigid male or female classification (Arboleda and Vilain 2014; UKIA Guide to Intersex). Incidence figures of intersex births vary depending on the conditions classed as intersex. That said, the global incidence rate is reported as ranging “between 1.7 and 4%” (Sanders et al. 2011, p. 2220), and the World Health Organization estimates that five children are born in the United States each day who are visibly intersex (“Gender and Genetics”).

² ‘Testimony’ is a philosophical term of art with a corresponding body of literature on how it should be defined. Here I use ‘testimony’ as does Zagzebski (2012, p. 121), to refer to “all cases in which a person A says that p to another person, B, who then believes p at least partly on the say-so of A”. This usage captures what Fricker (2007, p. 60) has in mind when developing her account of testimonial injustice as an intellectual and moral vice. She too uses ‘testimony’ in “its broadest sense to include all forms of telling” and where the hearer’s perception of the teller’s credibility plays a crucial role in believing what they are being told.

ural, i.e., binary, sexed and gendered way of being (“Why not ‘Disorders of Sex Development’”).³

Here I argue that the charges of disappointed intersex advocates are valid and hence the revised guidelines and lexicon fail to satisfactorily redress the epistemic injustice long suffered by intersex patients. First, I show that the decision to adopt and retain the nomenclature change perpetuates hermeneutical injustice as described by Fricker (2007, 2010). Second, I examine why this injustice occurred. According to Fricker, hermeneutical and testimonial injustice are intellectual vices towards which individuals and institutions are exceedingly prone. Correcting for this propensity and cultivating the relevant virtues at the individual level often demands identifying and correcting institutionalized prejudicial attitudes and procedures (Fricker 2010; Anderson 2012). By treating the 2005 Consensus Conference as a failed attempt to extend epistemic justice to intersex patients and advocacy groups, I am able to identify two institutional hurdles stymying such efforts: (1) the tendency to conceive of disability through a strictly individualistic framework;⁴ and (2) a resistance to broadening the perspective of treatment management beyond that considered standard for a western medical professional.

2 From ‘Intersex’ to ‘DSD’: a case of hermeneutic injustice

Fricker defines hermeneutical injustice as:

³ Beauvoir’s ‘One is not born, but rather becomes, woman’ is often credited with introducing the sex and gender distinction, and how to characterize this distinction has been debated ever since. For the purposes of this paper, ‘sex’ refers to a biological classification and indirectly to the criteria used by healthcare professionals in making birth sex and gender assignments. An XY newborn with relatively high testosterone levels, a penis and descended testes typically receives a ‘male’ assignment, whereas an XX newborn with a clitoris and ovaries is designated ‘female’. Intersexed biological markers problematize these birth assignments. ‘Gender-identity’ refers to a person’s self-representation or internalized identity as a female, a male or perhaps neither one exclusively. ‘Gender-role’ refers to behaviors and modes of presentations functioning as phenotypic or societal markers of gender assignment within the culture at large. Given these definitions, for me to say a treatment outcome takes a binary sexed and gendered way of being to be natural and hence normative is to say that it aims for an alignment of biological sex markers, gender-identity and gender-role whereby the assignment of ‘male’ or ‘female’ is unambiguous, stable, exclusive and exhaustive.

⁴ Since I will be arguing that using the term ‘disorder’ to describe intersex bodies constitutes a case of epistemic injustice, one might be concerned about my use of the term ‘disability’. Disability theorist Nancy Eiesland notes that modifiers referencing nonconventional bodies are often lacking in clarity and rich in marginalizing effect. She thus recommends the following terminological distinctions. ‘Impairment’ refers to an atypical bodily configuration constituting the actual loss of a physiological form or function. ‘Disability’ refers to the inability to perform some task or role because of an impairment. ‘Handicap’ refers to a social disadvantage that occurs because of an impairment or disability (1994, p. 27). In the body of the paper, I explain how Eiesland draws upon these distinctions to highlight the need for a minority-group analysis of disability. For introductory purposes, it suffices to note that while some intersex bodies are impaired in this technical sense, I support the position of intersex patient activists that most disabilities and handicaps experienced by intersex people are due to discriminatory attitudes. My claim here is that because biomedical institutions tend to conceive of disability and handicaps via an individualistic lens, they also tend to be blind to the way that accommodating these attitudes results in disabling, handicapping and even medically impairing those with atypically sexed bodies. I am grateful to an anonymous referee for suggesting I clarify my use of ‘disability’.

the injustice of having some significant area of one's social experience obscured from collective understanding owing to a structural identity prejudice in the collective hermeneutical resource. (2007, p. 155 italics in the original)

To illustrate, she draws from Edmund White's autobiographical novel about growing up in the United States in the fifties. White writes of his confusion in trying to make sense of the love and desire felt for a schoolmate:

The medical smell, that Lysol smell of homosexuality, was straining the air again as the rubber-wheeled metal cart of drugs and disinfectants rolled silently by.... I never doubted that homosexuality was a sickness; in fact, I took it as a measure of how unsparingly objective I was that I could contemplate this very sickness. But in some other part of my mind I couldn't believe that the Lysol smell must bathe me, too, that its smell of stale coal fumes must penetrate my love for Tom. (Cited in Fricker 2007, p. 164)

In her use of this example, Fricker, like Karkazis, underscores the power of extant healthcare taxonomies to determine the collective understanding of bodies and embodied experiences. Fricker goes further, however, in analyzing their capacity to cause discriminatory harm.

Of course, there were many authoritative institutions, texts and lexicons that would have named White's desires 'unnatural' or indicative of 'sickness', but Fricker notes that it was the prevailing medical or psychiatric understanding of homosexuality that caused his confusion. Moreover, it is this confusion that constitutes the primary harm of hermeneutical injustice (Ibid., pp. 163–167). The ability to clearly articulate the significance of certain experiences and relate them to one's identity is crucial in terms of becoming and being recognized as a competent epistemic agent. Since White could not square the "objective" psychiatric understanding of his experiences with the experiences themselves, he could not make them "communicatively intelligible" (Ibid., p. 162). Failures of communicative intelligibility can give rise to additional harms, including a general lack of epistemic confidence or self-doubt concerning the reliability of one's own cognitive and interpretive capabilities, which may thwart the development of epistemic virtues like intellectual courage and steadfastness.⁵

⁵ Dotson (2012) and others have criticized Fricker's description of the unintelligibility caused by hermeneutical injustice. There may be cases, as the adolescent White depicts, where agents are disabled or handicapped from rendering their experiences coherently intelligible to themselves. But as Dotson points out, the socio-epistemic power working to create hermeneutically marginalized groups is rarely effective in completely quashing knowledge of their situation. Resistant discourses emerge, and "there is always more than one set of hermeneutical resources available" (Ibid., p. 31). By foregrounding the availability of alternative resources, Dotson is able to introduce a type of epistemic injustice that Fricker's concept of epistemic injustice fails to capture, namely, contributory injustice. Contributory injustice occurs when perceivers of testimony willfully refuse to acknowledge or utilize resources enabling them to better comprehend and lend more credence to what a speaker is trying to communicate. Perpetrators of contributory injustice continue to deploy biased resources that distort, erase or discount a speaker's words when an alternative resource, one which would treat the testimony as an act of shared knowledge, is available (Ibid., pp. 32–35). Throughout this paper, I focus on the hermeneutical and testimonial injustice perpetuated by the Consensus Conference. It will become evident, however, that contributory injustice is also at work. I am indebted to an anonymous reviewer for recommending Dotson's work as an insightful supplement to Fricker's analysis of epistemic injustice.

Given the nature of these harms, hermeneutical and testimonial injustice create a vicious cycle. Testimonial injustice occurs when speakers are perceived as less credible because they are identified with a group persistently and systemically viewed as ‘less rational’ or ‘untrustworthy’ (Ibid., p. 29). On Fricker’s account, the assessment of another’s credibility is a spontaneous, perceptual type of judgement. These judgments are strongly influenced by the pre-reflective, socially situated interpretive resources that hearers bring to bear on the communicative exchange and their feelings of trust or empathy for the speaker (Ibid., p. 72).⁶ Actual and potential victims of testimonial injustice are members of groups that have often been barred from fully participating in the institutions tasked with generating the culturally dominant hermeneutical resources. For example, the American Psychiatric Association’s *Diagnostic and Statistical Manual* (DSM-I) was first published in 1952 and classified homosexuality as a “sociopathic personality” disorder. It was not until 1972 that a psychiatrist candidly spoke at an APA annual conference about his experiences as a gay man, and he did so wearing a disguise (Drescher 2015). From 1952 to the early 1970s, gay and lesbian people were effectively excluded from crafting a hermeneutical resource invested with substantial socio-epistemic power for deciding whether their embodied experiences were pathological or not.⁷ Now consider the harms of hermeneutical marginalization—an apprehensive expression of cognitive or communicative skills and underdevelopment or perceived underdevelopment of intellectual virtues. Consider too Kristi Dotson’s observation that epistemic hermeneutical frameworks pick out certain behavioral traits as reliable markers for distinguishing trustworthy from untrustworthy conveyors of knowledge (Dotson 2012, p. 38). It follows that those harmed by hermeneutical injustice are more likely to be perceived as less credible testifiers, resulting in future credibility deficits and continued hermeneutical marginalization.⁸

Fricker thus rightly describes testimonial and hermeneutical justice as *corrective* virtues. Structural-identity prejudice of one sort or another is so pervasive that hearers must cultivate testimonial justice by trying to neutralize this prejudice whenever judging a speaker’s credibility (Fricker 2007, pp. 91–92). For individuals to succeed in these attempts, societal and institutional remedies are also required (Alcoff 2010, pp. 132–133; Fricker 2010, pp. 166–167; Anderson 2012). Policy setting bodies must also cultivate this virtue and correct for adverse dialogical effects due to hermeneutical marginalization. Fricker characterizes these efforts as practicing a particular form of silence:

[This] is the active, attentive silence of those who are listening, perhaps trying to make out a voice that is seldom heard. This kind of silence belongs with a moral

⁶ In addition to the sources Fricker cites to support her account of testimonial credibility judgments, see Zagzebski (2012) on the critical role that trust plays in accounting for testimonial knowledge.

⁷ Although Fricker treats White’s obscured self-understanding as a classic case of hermeneutical injustice, she does not identify the structural identity prejudice occurring within the relevant hermeneutical resource causing this obscurity. I take this to be the answer.

⁸ It is only fair to note that this vicious cycle has been well-documented by feminist philosophers and critical race theorists for quite some time. Fricker’s contribution is expanding on their insights and relating them to current discussions in analytic philosophy on testimonial knowledge and virtue epistemology.

attitude of attention to others—an openness to who they are and what they have to say. (2012, p. 287)

Notice that for this silence to combat prejudice and marginalization, institutions must not only be open to hearing from previously discredited voices, but also to transforming the hermeneutical resource from which the institution's and its members' self-understanding as a class of privileged knowers is derived. That is, practicing biomedical epistemic justice implies being genuinely open to enlarging the class of knowers entitled to name what may be a natural state or embodied way of being. In the words of Rae Langton, addressing hermeneutical injustice requires a “conceptual revolution” (cited in Dotson (2012), p. 30). And as I see it, launching the revolution will involve having privileged epistemic agents and relevant institutional bodies cultivate Fricker's virtue of silent attention. My thesis that the 2005 Consensus Conference failed in its attempt to extend epistemic justice towards intersex patients is thus equivalent to the claim that intersex patient advocates were not actively and openly listened to in this sense. So while the revised clinical guidelines and lexicon go some way in addressing the epistemic injustice perpetuated in the prior protocol, they do not go far enough.⁹

What structural-identity prejudice existed in the pre-2005 hermeneutic of intersexuality and what obscured self-understandings did it produce? Beginning in the early 1990's, advocacy groups like the Intersex Society of North America (ISNA) and UK Intersex Association (UKIA) formed to provide support for intersex people and lobby for modifying the medical care many of them had undergone. This treatment model—referred to in biomedical literature as the “optimal gender” approach—held that socialization was the predominant factor in determining gender identity (Rosenfield et al. 1980, p. 16; Karkazis 2008, pp. 52–55, Sanders et al. 2011, p. 2220). The protocol, implicitly and in practice, subscribed to a heteronormative, binary sex and gender model of care. That is, the optimal outcome for patients was a lifelong identification with their birth sex assignment, living out the corresponding gender role and experiencing satisfying heterosexual attraction and intercourse. For a male assignment, the gender role included not only adopting traditional boy behavior and dress

⁹ On Dotson's account, hermeneutical injustice is a second-order epistemic injustice that can only be addressed by a second-order reform like the conceptual revolution described by Langton or by cultivating a virtue such as I have described, a virtue capable of altering the prevailing “socioepistemic structure” and recognizing hitherto marginalized knowers as full-fledged contributors in amassing shared epistemic resources (Ibid., p. 31). In contrast, contributory injustice is a third-order injustice manifesting itself in the fact that alternative resources fail to “gain uptake so as to influence dominant hermeneutical resources” (Ibid., p. 40). The willful refusal of the APA to avail itself of extant alternative resources for understanding homoerotic desire is a paradigm case of contributory injustice. Similarly, the fact that the testimony of intersex people and the treatment recommendations initially proposed by intersex patient advocacy groups had a limited influence on the protocol and lexicon subsequently endorsed by the Consensus Conference is an instance of contributory injustice. Responding to contributory injustice requires a third-order reform: becoming fluent in both dominant and resistant hermeneutical resources. Developing this fluency further requires establishing mutually trusting “embodied engagement” that crosses the border of distinct epistemic communities and “extends beyond conversation and dialogue” (Ibid., p. 35). Given that overcoming the two institutional hurdles to practicing epistemic justice that I identified constitute only first and second order reforms, more will be needed to address all forms of biomedical epistemic injustice experienced by intersex people.

codes, but such things as the ability to urinate standing up. As one intersex patient reports:

I spent many years in surgery whose purpose was to make me pee at the end of my penis. If they had just left my urinary meatus [pee-hole] where it was, at the base of my penis right by the scrotum, I could have avoided at least twelve of those surgeries. (McClintock 1997)

Surgical decisions related to projected sexual satisfaction also reflected societal gender norms, as evidenced by a 1980 guide on *The Diagnosis and Management of Intersex*: “Psychosexual pressures in our society are such that the male role in sexuality seems to require that he have a more perfectly formed sexual structure than the female” (Rosenfield et al. 1980, p. 40). A penile size large enough for vaginal penetration and the capacity for sexual arousal were critical factors in deciding for a male assignment. Given the difficulty of phallic reconstruction, infants with atypically small penises or enlarged clitorises often received a female assignment and surgery to standardize clitoris size (see Rosenfield et al. 1980, pp. 39–40; Karkazis 2008, pp. 138–139; Dreger 2015, pp. 21–24).

The structural-identity prejudice expressing itself in the optimal gender hermeneutic of intersex bodies is threefold. First, there was the preemptive discrediting of patient testimony when it came to determining and evaluating medical care. The specialized education and training of healthcare professionals certainly justifies a level of deference to their authority in biomedical decision-making. That said, recognizing pediatric endocrinologists, urologists and surgeons as relevant experts in the treatment management of intersex does not imply intersex patients have little knowledge to share about that management. A systemic devaluing of the patient’s voice is not a legitimate recognition of medical professional expertise. Rather, it is an egregious form of medical paternalism and prevalent enough to support the thesis that patients as such “are particularly vulnerable to epistemic injustice” (Carel and Kidd 2014, p. 529). In the case of intersex patients under the optimal gender protocol, the fact that this type of epistemic injustice occurred is undisputed, for the Consensus Statement concedes that progress in recognizing the rightful place of patient advocacy was a motivating factor in deciding to review and revise the protocol (Lee et al., p. e488).

Second, there is the marginalization of the female voice and perspective, a long-standing problem in western biomedicine and much discussed topic in feminist philosophy of science (Anderson 2015). The androcentric bias in this case manifested itself most starkly and harmfully in surgical directives aimed at “normalizing” infant genitalia. Surgeons routinely reduced or eliminated a clitoris in order to construct more typically appearing female genitalia, even at the cost of orgasmic sexual functioning (Triea 1997; Dreger 2015, pp. 28–29). In 2009 and in recognition of the work of patient advocacy groups, the NIH reported an emerging awareness among clinicians about this underlying bias: “Greater respect for the complexities of female sexual functioning has led them to conclude that suboptimal female genitalia may not be inherently better than suboptimal male genitalia, even if the reconstruction is ‘easier’” (“Intersex”).

The third type of prejudice is intricately intertwined with societal and hermeneutical marginalization of gay, lesbian, and transgender people. As mentioned in the case

of Edmund White, anything other than exclusively heterosexual erotic attraction was classified as abnormal psychosexual development until 1973. And it was not until 2013 that the APA asserted: “gender nonconformity is not in itself a mental disorder” (“Gender Dysphoria Fact Sheet”). Medical lexicons classifying homosexual attraction and transgender identity as abnormal or disordered pathologies are rightly considered hermeneutically unjust, not because of the classifications per se, but because the people whose attractions and identities were being so classified did not have a voice in generating those lexicons. The same holds for the hermeneutical resources of other institutions and communities. To the extent that these resources are the legacy of testimonial injustice or the marginalization of certain groups, they are conduits for epistemic injustice and our collective understanding of one another is obscured. Because of the persistent and ubiquitous marginalization of groups designated “homosexual”, “transgender” or one of their cognates, we should expect inherited and extant resources for understanding these groups to be prejudicially inadequate. We should also expect well-intentioned clinicians and parents will want to spare children the stigmatization and communal shaming directed at those identified with these groups.

Widespread prejudice against those with a homosexual orientation or nonconforming gender identity explains why the optimal gender approach employed infant reconstructive surgeries, hormonal therapy and even silence as means for achieving the treatment goal of a straight, cisgender, typically appearing boy or girl. Surgery and other medical means were recommended to make a child appear as if they met societal expectations of heterosexual sexual function and a stable, binary sex and gender identity (Rosenfield et al. 1980, p. 44; Karkazis 2008, pp. 137–142; Sanders et al. 2011, p. 2220) Parental silence concerning the diagnosis was encouraged so as not to induce gender confusion on the part of their child or have it reflected back at them by those whom they encountered (Morris 2006, p. 4; Karkazis 2008, pp. 188–191).

Once again, the Consensus Statement contains an implicit acknowledgement of this structural-identity bias in its recommendation that treatment outcomes ought to be disentangled from traditional expectations of heteronormative behavior and stereotypic cisgender identities:¹⁰

It is important to emphasize the separability of sex-typical behavior, sexual orientation, and gender identity. Thus, homosexual orientation (relative to sex of rearing) or strong cross-sex interest in an individual with DSD is not an indication of incorrect gender assignment. (Lee 2006, p. e489)

The problem, as we will see, is that the revised protocol does not sufficiently incorporate the insights and recommendations of intersex advocates and so cannot adequately respond to the secrecy and shame too often surrounding intersex bodies.

When the ISNA and other advocacy groups began the campaign to revise the optimal gender approach, they had three primary changes in mind. First, quit classifying an intersex body as “a rare anatomical **abnormality**”, viewing it instead as a somewhat common “**variation**” from the typical male and female anatomy: “Intersexed genitals are **not** a medical problem. They may signal an underlying metabolic concern, but they

¹⁰ By ‘cisgender identity’, I am referring to a gender identity that matches one’s birth sex assignment.

themselves are not diseased; they just look different (“Shifting the Paradigm of Intersex Treatment” emphasis in the original). Second, use surgery and medical intervention only for a patient’s health concerns, not to alleviate parental or communal anxiety: “Social distress is a reason to change society, not the bodies of children” (Ibid.). Third, end the practice of concealing the diagnosis from the patient and promote their participation in decision-making: “Secrecy and lack of information lead to shame, trauma, and medical procedures that may be dangerous to the patient’s health” (Ibid.).

Recall that the primary harm of hermeneutical injustice is the inability to make one’s experience or sense of self communicatively intelligible. Because of the prejudicial presuppositions of the prior treatment protocol and general stigmatizing of bodies failing to conform to male or female standard, many intersex people grew up without a clear understanding of their own embodiment. Sherri G. Morris, an attorney with androgen insensitivity (AIS),¹¹ describes her confusion and severe communicative isolation:

[M]y diagnosis was considered a tragic mistake of nature by both my physicians and my parents. Given that I looked normal, however, my parents undoubtedly took solace in that they did not ever have to reveal the truth about my body to friends or relatives and could keep it a secret even from immediate family members. ... [T]hey were advised by my pediatric endocrinologist to tell me I had a simple hernia when, as a young child, I discovered the abdominal scar just about my pubic region. They were then to say nothing again until the eve of puberty, at which time they should tell me that I had “twisted ovaries”, which had been removed at birth to prevent them from becoming cancerous. (Morris 2006, p. 4)

Morris recounts how, from age 11 until her mid-thirties, the negative silence surrounding her body made it the subject of worrisome half-truths,¹² shocking revelations,¹³ and embarrassing ignorance.¹⁴ This epistemic harm was commonly experienced by those whose bodies were interpreted via the optimal gender hermeneutic (see MacDonald 2009; Karkazis 2008, pp. 217–234). For Morris, as for others, the fog of isolation and self-alienation only began dissipating when she discovered an intersex support group:

¹¹ The frequency rate of XY individuals with androgen insensitivity is estimated at 1:20400 live births (Arboleda and Vilain 2014, p. 366). Because androgen is a testes-deriving hormone crucial in the development of internal and external, these children are genetically, chromosomally male, but with phenotypes ranging from a typically appearing female body to bodies of increasing degrees of ambiguity. In Morris’s case, the androgen insensitivity is complete, resulting in the birth of a typically appearing baby girl with internal, undescended testes (Morris 2006, p. 3).

¹² “I recall the day my mother told me the ‘twisted ovaries’ lie. ... I was worried that my ‘ovaries’ were not removed as a prophylactic measure to prevent cancer, but that I instead actually had cancer and my parents just weren’t telling me” (Morris 2006, p. 4).

¹³ “I was shaking as I steeled myself to inquire about whether I did indeed have [a uterus], and [the college doctor] said ‘no’ without further explanation” (Ibid., p. 6).

¹⁴ “I know that I could never share the truth about myself with any friend, much less a romantic partner.... [Men might] ask questions I was unequipped to answer.... I was afraid that [female friends] would discover my nonexistent knowledge about periods, and both marriage and children, topics that inevitably would come up in conversation seemed completely beyond my reach” (Ibid., p. 7).

[F]or the first time I stood side by side with someone who knew—knew what it was like to have a body that looked and felt like mine, and knew the same secrecy and silence and lies and shame that had been the hallmarks of my existence. My life in earnest had begun. (Ibid., p. 9)

It is important to highlight the impact this meeting had on Morris's estimation of herself as a competent knower and interpreter of her lived experience. For the first time, she was able to effectively communicate this experience to an empathic listener. As a recipient of testimonial justice, Morris was enabled in becoming an articulate advocate for herself and other intersex patients.

Having argued the optimal gender approach unwittingly perpetuated hermeneutical injustice against intersex people, I turn to my claim that this injustice persists under the revised approach, particularly in deciding to adopt 'disorders of sex development'. The Consensus Statement maintains that the reason for the nomenclature change was that term 'intersex' was "perceived as potentially pejorative by patients" and "confusing to practitioners and parents alike" (Lee et al., p. e488). This rationale is routinely cited in biomedical publications when introducing or defending the change:

The impetus for revising the terminology itself emanated from affected families and patient advocacy groups; while specialists in the field recognised that a new classification system was overdue and that changes needed to reflect scientific advancements in diagnostic procedures. (Pasterski et al. 2010, p. 189; see also Arboleda and Vilain 2014, p. 351)

I show there is scant evidence that intersex patients themselves find 'DSD' to be any less pejorative than 'intersex'. I argue that the nomenclature change does little to address parental concerns about the societal shaming or exclusion that their child may face due to an atypically sexed body or fluid gender identity. I conclude that the deliberations resulting in the new nomenclature did not exemplify biomedical testimonial justice. For when all was said and done, the voices and perspectives of healthcare practitioners and providers trumped those of intersex advocates.

Both the ISNA and UKIA acknowledge that labeling someone 'intersex' causes psychosocial distress for parents and society as a whole. They also recognize that fears of a child's stigmatization often prevent parents from accessing the medical, educational and communal support necessary to ensure a positive treatment outcome. Yet, nowhere in UKIA literature and nowhere in the ISNA's literature prior to 2005 is there any suggestion that the source of the stigmatization is the label itself.¹⁵ Rather, the source is located in the biomedical assumption that an intersex body is a pathological abnormality and that parents and their respective communities generally share this assumption ("Shifting the Paradigm"). The ISNA thus contrasts the belief underlying the pre-2005 protocol—"that our society can't handle genital ambiguity or non-standard sexual variation"—with the belief motivating their proposed patient-centered approach—

¹⁵ It is true that the ISNA explicitly did not advocate for use of 'intersex' as third gender birth assignment, advocating instead that the child be provisionally assigned as either 'male' or 'female' based on parental and doctor consultation and with the understanding the child will later determine what term best accords with their gender ("Shifting the Paradigm"). This recommendation was not referring to 'intersex' as the standing umbrella medical term and cannot be construed as a recommendation to replace it with 'DSD'.

“that a person with an intersex condition has a right to self-determination where her or his body is concerned” (Ibid.). According to this analysis, the locus of the problem is not with connotations associated with the term ‘intersex’, but with cultural attitudes stigmatizing any “sexual variation which blurs the line between male and female” (Chase 2003, p. 240). The solution is thus not eliminating use of the term ‘intersex’ and certainly not eliminating intersex bodies “via improved medical and scientific technologies” (“Shifting the Paradigm”). Instead, the ideal outcome envisioned by intersex advocates is “[s]ocial acceptance of human diversity and an end to the idea that difference equals disease” (Ibid.). Given their analysis of the problem with the optimal gender approach and the stated aims of their proposed patient-centered approach, it is hard to imagine that the impetus for deciding on ‘disorders of sex development’ actually arose from advocacy groups.

One might think the fact that the founder of the ISNA, Bo Laurent aka Cheryl Chase, participated in the Consensus Conference and that ISNA board member, Alice Dreger, edited *Clinical Guidelines for the Management of Disorders of Sex Development* proves advocacy groups did have sufficient testimonial input. However, this is not the case. While it is true that the ISNA commended the Consensus Statement as “an important inroad” to providing care for intersex people and went so far as to publish and promulgate the new DSD protocol, these actions must be understood within the context of the ISNA’s rationale for shutting its doors and passing the torch to the newly created Accord Alliance:

This is ISNA’s dilemma: we finally have consensus on improvements to care for which we have advocated for so long, but we lack a consistent way to implement, monitor, and evaluate them.... [T]here is concern among many healthcare professionals, parents, and mainstream healthcare system funders that ISNA’s views are biased or that an association with ISNA will be frowned upon by colleagues and peers. (“Dear ISNA Friends and Supporters”)

As explained here, the term ‘intersex’ was not viewed as particularly pejorative by intersex advocates, but by parents, healthcare professionals and the funders of major healthcare providers.

Dreger confirms that use of the term ‘DSD’ was a price paid to get a hearing from powerful biomedical stakeholders suspicious of the socio-political aims of the ISNA and other self-identifying ‘intersex’ groups. In 2007, she defended her use of the term as follows:

A new system based on the central term “intersex” was never going to fly. By then not only could the docs not agree on what it meant clinically, not only was the term heavily politicized, the term had started to be used by people who were transgendered but who weren’t intersex in any of the conventional ways. (Dreger 2007)

By employing the purportedly depoliticized ‘DSD’, Dreger saw hope of attaining the ISNA’s goals: “as I used ‘DSD’ instead of ‘intersex’, the medical professionals providing pediatric care immediately got past the usual defensiveness they had and got to talking with me about how to make things better” (Ibid.). Still, she supported the efforts of others to replace the word ‘disorder’ with ‘variation’ or ‘divergence’, so

long as “the big players” in biomedicine might be convinced to accept it (Ibid.). In the 2011 update on her 1998 Hastings Center Report, Dreger places less of an emphasis on the use of ‘DSD’ to effect change and credits the “success of the gay, lesbian, bisexual and transgender rights movements” with altering “how the public and clinicians think about atypical sex” (Dreger 2011). Dreger would thus have to agree that the political efforts of LGBT activists proved more effective than the nomenclature change when it comes to lessening the “shame, secrecy, homophobia and transphobia” attending the biomedical treatment of intersex people.

It is worth noting too that Laurent’s most recent advocacy and education efforts retain the term ‘intersex’ and parse ‘DSD’ not as “*disorders* of sex development”, but rather “*differences* of sex development” (Kinsman 2014, my emphasis). Similar terminology is endorsed by the UKIA. The UKIA immediately challenged the so-called consensus and vehemently opposed the shift in nomenclature. It continues to employ ‘intersex’ in public forums and proposes ‘variations of sex development’ for use in medical discussions (“Why Not ‘Disorders of Sex Development’”). In sum, whatever advocacy support there was for the nomenclature change was not the result of the biomedical community exercising testimonial justice towards intersex patients and their allies, but a concession on the part of certain members of the ISNA in order to get a hearing at all.

So what about parents or family members? Do they attach less negative connotations to the term ‘DSD’ and if so, does this promote the care standards of the revised protocol? Defenders of the nomenclature change initially thought the answer was yes (Dreger 2007). The Consensus Statement made several recommendations of special interest to patient advocacy groups: (1) more open communication between patients, families and practitioners; (2) encourage informed and collaborative decision making in treatment management; and (3) discourage medically unnecessary infant surgeries aimed at relieving parental stress (Lee 2006, p. e490-1). Though the data is far from conclusive, preliminary studies on parental decision-making indicate that the nomenclature change does little to alleviate anxiety. Consequently, secrecy and immediate surgical intervention are still viewed as go to options for ensuring a child can meet societal expectations of binary sex and gender alignment.

A qualitative study reports: “Many parents reflected that ‘not telling anyone’ became a mechanism, by which they could protect their child’s genital uncertainty from scrutiny and curiosity yet conversely this secrecy increased their anxiety” (Sanders et al. 2011, p. 2224). Even when parents recognize that secrecy increases their own anxiety and internalized sense of isolation, not to mention that of their child, they still feel pressured to employ a ‘don’t talk about it’ strategy to avoid being publically ostracized. Consider this testimony from a mother of an intersex child:

If people accepted that everybody’s different, it isn’t a problem. But people don’t accept that everybody’s different. You have to conform to the way that the public says you should be (Andrea). (Ibid., p. 2225)

Andrea decided to postpone surgery until her child could participate in the decision, but she echoes the generally expressed concern that postponing or foregoing surgery will subject a child to shaming and exclusion. For other parents, this concern makes early reconstructive surgery the obvious choice: “There’s no way in my mind we’ve

done the wrong thing and that I ever think ‘I wish we’d left him to make his own decisions when he was older’. Definitely not” (Ibid., 2225).

Two recent quantitative studies confirm that parents opt for normalizing infant surgeries despite the lack of evidence that this contributes to the long-term health and well-being of their child. Based on a survey of the biomedical literature, [Streuli et al. \(2013\)](#) conclude most parents choose surgery without waiting for child consent, even when made aware of the lack of data concerning positive outcomes and informed of chances of negative ones (Ibid., p. 1954). [Binet et al. \(2016\)](#) conducted a retrospective case study of patient and parent experiences of early versus late feminizing genitoplasty. The study consisted of 20 parents and 21 patients, all of whom were diagnosed with congenital adrenal hyperplasia (CAH)¹⁶ and underwent surgery between 1970 and 1999. The patients were divided into two groups: those who had only undergone genitoplasty prior to age 3 and those who had a redo or their first genitoplasty during adolescence (Ibid., p. 466). The study found no significant differences between the two groups with respect to their reported sexual activity, sexual satisfaction or “general quality of life and well-being” (Ibid., p. 468). Yet, 90% of the patients and 100% of the parents as compared to 52% of a control group maintained that surgery should be performed in the first year of life (Ibid., p. 466).¹⁷ Binet et al. supports the findings of the qualitative study that, for parents, making sure their child has an unambiguous, publically recognized male or female identity is a primary concern. 21% of parents and 0% of patients mentioned “getting back to ‘normality’/being like everyone else” as a reason for the surgery (Ibid., p. 467). The authors report: “In fact, it is not really the anatomy of their child with DSD that unsettled the families but rather the initial doubt about their child’s gender” (Ibid., p. 468). These initial studies on parental deliberations disconfirm Dreger’s hypothesis that use of the term ‘disorder of sexual development’ would make parents feel they “could afford to do less medical intervention on affected children” ([Dreger 2007](#)).

Although the focus of Binet et al. study concerns patient and parent responses to early normalizing surgeries, the article itself is especially telling about physician responses to the testimony of intersex patients and advocacy groups. The authors are pediatric surgeons and place their study within the context of debate between the medical-surgical community and advocacy groups:

Whereas for physicians it is obvious and unequivocal that a person with CAH-related DSD and XX karyotype has a female gender identity, some patient associations are in fact advocating to qualify CAH-DSD patients in the intersex category. They underline that ambiguous genital organs are not disease but rather one of its consequences not requiring treatment. (Ibid., p. 465)

¹⁶ CAH results in atypically high levels of androgen. Infants with an XX karyotype and a severe classic or virilizing form of CAH often display ambiguous external genitalia, e.g. an enlarged clitoris. Approximately 75% of individuals with virilizing CAH will also be diagnosed with a salt-wasting form. Immediate medical attention is required for these infants, since they can suffer from life-threatening dehydration. No immediate attention is required to treat the simple virilizing aspects of CAH. Feminine genitoplasty are surgeries aimed at making external genitalia appear more typically female and enabling penetrative vaginal sexual intercourse. These are not considered life-saving procedures, and so when or if to perform them is debatable.

¹⁷ It is unclear whether the study and control groups were given the option not to perform the surgery.

First, one should note that the ISNA never advocated using ‘intersex’ as an assigned gender identity, though it certainly did recommend depathologizing ambiguous genitalia in and of itself and postponing medically unnecessary reconstructive surgery. Second, given the broad consensus among their medical colleagues that there is “no evidence showing which timing of surgery is better” (Mouriquand 2016, p. 6) and that the study itself finds no significant difference in terms of patient health and well-being, the authors’ conclusion is startling: “The results of this study promote, in our opinion, the early surgical management of DSD in CAH-DSD females” (Binet et al. 2016, p. 468). Upon what do they base this opinion? “[P]arental stress and well-being are positively impacted during adolescence” (Ibid.). Here then Binet et al. reject not only intersex advocate concerns about irreversible nonconsensual surgeries, but also the care recommendations of the Consensus Statement encouraging patient participation in treatment decisions and discouraging surgeries aimed at alleviating parental distress. In fact, it is not too much of a stretch to read them as implicitly affirming the belief underlying the pre-2005 protocol, namely, that since parents and society cannot handle genital ambiguity or non-standard sexual variation, medical intervention is required to bring children’s bodies into alignment.

Third, Binet et al. ignore or discredit intersex patient testimony when it does not comport with their previously held beliefs. The study shows, for instance, a significant difference in the evaluation of physicians and patients with respect to gender appearance; patients “saw themselves as significantly more masculine” than did physicians (Ibid., p. 466). Yet, this result receives no further discussion, and there is no suggestion that physicians might want to reconsider the position that a CAH individual with an XX karyotype is obviously and unequivocally female. Furthermore, when accounting for why only 52% of the control group favored early surgical intervention, the authors allude to the influence of “patients’ associations” and their support for a child’s consent. They go on to reject this position on grounds that it fails to appreciate “the underlying difficulties for a person in dealing with the discordance gender sex/anatomical sex” (Ibid., 468). It is difficult not to read this remark as anything other than a striking failure to exhibit testimonial justice, since most of the members of patient associations are in fact intersex people and that Bo Laurent herself is a CAH patient.

Final support that the Consensus Conference did not fulfill its intention of broadening the biomedical perspective by virtuously listening to intersex advocates is found in the impact study’s defense of the nomenclature change. While acknowledging lingering complaints over the word ‘disorder’, Pasterski et al. dismiss the proposal of replacing it with ‘difference’ or ‘variation’:

[M]any of these conditions can be traced to gene mutations causing pathophysiological consequences.... As with all of medicine, it is of vital importance to remember that patients are individual people who happen to have a disease or disorder, rather than a person intertwined with or defined by the disorder. Nevertheless, from a medical perspective these conditions represent an abnormal pathophysiology, rather than simple variations within the normal range and should be considered as such. (Pasterski et al. 2010, pp. 189–190)

This response shows that, at the end of the day, the “medical perspective” eclipsed all others in deciding whether intersex bodies should be generally conceived as different or disordered, and it opted for the latter. Fortunately, there are also physicians examining how the dominant “medical perspective” may be inhibiting implementation of the DSD guidelines, particularly the call for “multilateral approaches” and “different perspectives” (Streuli et al. 2013, p. 1954).

3 From ‘Intersex’ to ‘DSD’: why it happens

Binet et al. legitimately bristle at the idea that physicians should be blamed for the secrecy and shame endured by intersex patients (Ibid., p. 467). I have argued that the Consensus Conference and its proceedings perpetuate hermeneutical and *institutional* testimonial injustice precisely because I am not interested in questions of blame. Hermeneutical injustice is strictly structural, which is to say that “no agent perpetuates it” (Fricker 2007, p. 159).¹⁸ Moreover, institutions can exhibit testimonial injustice irrespective of the doxastic states of their members. This occurs due to procedures resulting in discriminatory outcomes or the enactment of certain practical identities (Fricker 2013, p. 297). A practical identity is the constellation of commitments, values, and obligations one holds because they are a member of a certain profession or community. Practical identities “generate role-specific reasons for action” (Ibid., p. 296). In other words, individuals may have reasons for acting to which they feel obliged that conflict with personally held beliefs (Ibid., p. 296). Recognizing the epistemic and motivational force of practical identities explains how someone can be viewed as exemplifying testimonial injustice even though we would be reluctant to attribute the vice to the individual per se. In this section, I identify a few of the procedural and practical identity elements hindering the cultivation of biomedical epistemic justice on behalf of intersex patients and advocacy groups.

Critical race and disability theorists agree that systemic negative prejudice and discrimination remains hidden from view so long as individualistic explanations are institutionally prized. In her seminal work in disability liberation theology, Nancy Eiesland points out that many well-intentioned religious institutions issue double-minded policies about those with nonconventional bodies (Eiesland 1994, p. 75). Her case in point is the General Convention of the American Lutheran Church (ALC). In 1980, the ALC passed a resolution to “address the attitudinal, architectural, and communication barriers that prevents full access by persons with disabilities” (Ibid, p. 76). Five years later, the ALC stated that people with significant physical and mental disabilities were not eligible for ordination. Eiesland lists the following reasons why the ALC could not carry out its intention of granting complete access to people with disabilities: (1) it failed to examine the extent to which hermeneutical resources, e.g. extant Lutheran understandings of scripture and the sacraments, were responsible

¹⁸ As a reviewer of my paper noted, Fricker’s claim here is too strong, since at the very least individual agents perpetuate hermeneutical injustice insofar as they willfully or unintentionally draw only upon prejudicial conceptual resources for understanding what a speaker is trying to communicate. Dotson thus puts Fricker’s point better when she writes that, in the case of hermeneutical injustice, “an agent is only a tool within a socioeconomic structure” (2012, p. 29).

for marginalizing those with nonconventional bodies; (2) it continued locating “able-bodied people at the ‘speaking-center’”; and (3) it perpetuated an individual model of disability, “rather than incorporation of a minority group approach” (Ibid., p. 77).

I contend the 2005 Consensus Conference on Intersex is the biomedical analog of the General Conference of the ALC. Besides continuing to locate intersex patients and advocates outside of the speaking-center, it failed to incorporate a minority group model of disability. Individual models conceive of disability primarily as a dysfunctional or malformed property of a particular person. Therefore, providing care means providing a person with the biomedical, psychological and vocational resources needed for remedying or managing their dysfunction and affording them access to societal goods (Ibid., pp. 51–53). Such an approach is limited insofar as it neglects the fact that much of the social exclusion experienced by people with nonconventional bodies is due to persistent and pervasive prejudice. To address this limitation, Eiesland proposes a minority-group framework distinguishing between impairment, disability and handicap. ‘Impairment’ refers to an atypical bodily configuration constituting an actual loss of a physiological form or function. ‘Disability’ refers to the inability to perform some task or role because of an impairment. ‘Handicap’ refers to a social disadvantage occurring because of an impairment or disability. Drawing this distinction helps us to see that some disabilities and handicaps do not directly result from impairment, but from prejudicial societal attitudes concerning that impairment. The minority group approach thus allows for crafting care strategies aimed at navigating, challenging or eliminating discriminatory attitudes and practices (Ibid., p. 27).

Now consider the psychosocial management plan presented in the Consensus Statement. Its goal is “positive adaptation”, initially on the part of parents and ultimately on the part of intersex patients (Lee 2006, p. e492). Management teams are urged to screen families, identifying those “at risk for maladaptive coping with a child’s medical condition” (Ibid.). Intersex children are encouraged to undergo regularly scheduled psychological evaluations to assess their developing gender identity. The impact study rehearses the need to manage parental “anxieties and desperation” and identify “unstable familial relations” in order to devise “coping strategies” and strengthen “communication between medical staff and families” (Pasternaki, Prentice, Hughes, 2010, p. 190). Providing such resources is certainly beneficial, but there is no mention of equipping practitioners, parents or patients with the skills and strategies necessary for redressing the handicaps imposed on intersex people because of prejudicial cultural attitudes or practices. In short, the initiatives of the Consensus Conference continue locating the dysfunctional aspects of DSD on the bodies or psyches of intersex individuals and their immediate family members without ever referencing the larger body politic.

The failure to incorporate a minority group model of care is not just a problem associated with the new DSD protocol. Parents generally complain of the lack guidance in crafting strategies for addressing societal handicapping and consider developing these strategies to be part of a sufficiently complete treatment plan: “What I find most striking is that, when I reflect on the good interventions that I have brought to my son, most have been recommendations from other mothers. Doctors don’t offer many ideas for navigating the world of disability” [cited in Carel and Kidd (2014), p. 534]. Incorporating a minority group model of disability is thus one step biomedical institutions

could take towards enriching their hermeneutical resources for better understanding the various ways society handicaps intersex people and other atypically embodied people.

Enriching the notion of what it means to be a healthcare professional would also help cultivate biomedical epistemic justice by moving patients and nonmedical allies towards the center of care management. [Streuli et al. \(2013\)](#) set out to understand why parents continue to quickly choose infant reconstructive surgery in spite of inconclusive data regarding outcomes and the Consensus Statement's recommendation of a more careful, collaborative deliberative process. They found that medical professionals bring a distinct perspective to informing and counseling parents: “[M]edical professionals tended to medicalize, defining the child and its condition or behavior as a medical problem or illness that mandated or licensed the medical professional to offer a specific treatment” (Ibid., p. 1955). As viewed from this professional perspective, the child is a “passive agent in defining the problem” and any dysfunction is strictly biologically determined, thus dictating a strictly biomedical remedy. This perspective contrasts with the perspective of psychologists, intersex advocates, and parents, according to which the child and family are “active agents” and DSD-related dysfunctions are “context-dependent” and “subject to multifactorial influences” (Ibid.). The study also found that those counseled by means of the medical professional approach were almost three times as likely to choose early surgical intervention (Ibid., p. 1956). While admitting the preliminary nature of the study, I believe it supports the claim that the prevailing perspective or practical identity of a western healthcare professional is not entirely well-suited for virtuously listening to patients or their non-medical advocates.¹⁹ If I am right and if Fricker is right that cultivating institutional testimonial justice involves making this virtue part of the ethos of an institution, then cultivating biomedical testimonial justice will involve making respect for a patient's epistemic agency and interpretive competence part of the practical identities of healthcare practitioners and providers.

4 Conclusion

Conveners and participants of the 2005 Consensus Conference should be commended for acknowledging the structural-identity prejudices contained within the optimal gender protocol and for consulting with intersex patient advocates on how to revise it. As I have tried to show, however, consulting with intersex patients is not the same as exercising testimonial and hermeneutical justice on their behalf. For this reason, the biomedical epistemic injustice continues and the care recommendations of the Consensus Statement, let alone those initially proposed by the ISNA, have not been fully enacted. My aim in analyzing where the Conference failed in its intention is not to assign blame, but to identify hurdles confronting healthcare organizations in their efforts to extend epistemic justice to patients. Given this aim, I have foregrounded the

¹⁹ The modifier ‘western’ is added because the study focused on clinicians trained in European medical schools. For more on the overrepresentation of North American and European trained medical professionals at the Consensus Conference, see “Why not ‘Disorders of Sexual Development?’”.

discriminatory harm suffered by intersex patients. However, as Karkazis and Fricker suggest, medical treatment paradigms are hermeneutical resources with the power to influence cultural understandings quite broadly. So, to the extent that these resources are inadequately informed by the testimony of intersex people, everyone suffers epistemic harm, for our collective understanding about the variations of human sex and gender is unjustly obscured and impoverished.

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