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Intersex: Intersectionality, Epistemic and Structural Violence

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ABSTRACT

Intersex people are recognized in Australian anti-discrimination law through an attribute of “intersex status”. At the same time, intersex variations are described by medicine as ‘Disorders of Sex Development’, implying that intersex persons collectively have individual disorders that can be ‘fixed’. While ‘fixing’ sex is increasingly understood as a human rights issue, the birth of an intersex infant remains a ‘challenging clinical emergency’. Surgical interventions on minors continue, addressing psychosocial rationales such as family distress, and even marriageability. This paper applies the concepts of intersectionality (Crenshaw, 1993), structural violence (Galtung, 1969), and epistemic injustice (Fricker, 2007) to the physical and mental health of people with intersex variations.

INTERSEX

Intersex people are born with atypical physical sex characteristics, including genetic, hormonal and anatomical differences. Intersex is not about gender identity; intersex people have a broad range of gender identities. Just like non-intersex people, there are intersex men and women, intersex people who are both, and those with other identities. Intersex is a lived experience of the body.

Many forms of intersex exist, mostly genetic in origin; it is a spectrum or umbrella term, rather than a single category. It can include differences in the number of sex chromosomes; and different tissue responses to sex hormones, or a different hormone balance leading to atypical sex characteristics. Some common intersex variations are diagnosed prenatally. Intersex differences may be apparent at birth. Some intersex traits become apparent at puberty, or when trying to conceive, or through random chance.

Intersex people face a range of health and human rights issues. These include deep-seated stigma, superstition, and medical interventions in infancy and childhood that are explicitly intended to make intersex bodies conform to social norms for a specific sex or gender. In recent times, people with intersex variations also face social expectations to identify as a third gender or sex, to challenge or transgress gender norms. These are weighty and contradictory social expectations, which inhibit disclosure and affect our public visibility.

Contradictory and powerful expectations date into Western pre-history. The Greek historian Diodorus Siculus wrote of “gods and monsters”, in the first century BC:

Hermaphroditus, as he has been called, who was born of Hermes and Aphrodite and received a name which is a combination of those of both his parents. Some say that this Hermaphroditus is a god and appears at certain times among men, and that he is born with a physical body which is a combination of that of a man and that of a woman... But there are some who

declare that such creatures of two sexes are monstrosities, and coming rarely into the world as they do they have the quality of presaging the future, sometimes for evil and sometimes for good.[1]

INTERSECTIONALITY

Intersectionality, a concept first developed by Kimberlé Crenshaw [2] describes an understanding of the multiple simultaneous influences of race, class and gender.

Intersex could itself be described as an intersectionality between the related areas of sex, gender and sexuality, and disability. In the weight of those multiple layered relations, it is arguably a domain of its own; indeed, in 2013, the Australian government created a new attribute, “intersex status” in anti-discrimination law, separate to sex, sexual orientation, gender identity, and disability.[3]

Rarely is the sexism and heterosexism seen so profoundly as in the latest of a recurrent sequence of articles with titles that can be paraphrased as, “Man finds out he’s really a woman”. [4,5] The man was treated for stomach cramps and found to have an intersex variation called CAH. A hospital spokesman said, “He was wearing men's clothes with short hair, so we didn’t think that he would be a female at the beginning”; they also said he was too old for effective medical treatment.[4] The Huffington Post said, "Mr Chen is reported to have told doctors that he and his wife have had intercourse - we can't help but wonder how that worked".[6]

In many times and places, sex assignments encapsulate cultural biases toward male and female sexes. Cultural, familial and medical attitudes govern to which sex we are assigned. In Malaysia, work has showed that assignments of infants with the same intersex variation differed depending on the parent's culture and attitudes towards dowries, with Malay parents far more willing to consider female assignment (and related surgeries) than Chinese or Tamil parents.[7]

The intersectionality with disability is often considered less obvious. The World Health Organization [8] defines “disabilities” as:

...an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.

Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers.

The WHO definition applies to intersex, in that the medical profession regards intersex people as having an impairment ("disorder") in body function or structure, “disorder of sex development”. These “disorders” are regarded as impairments in our body structures (genitals, gonads, chromosomes) or functions (adrenal glands, gonads, or other glands).

It is our superficial characteristics, and the concepts of what it means to be a real man, or a real woman, that underlie surgical and hormonal interventions on the bodies of intersex infants, children, adolescents and adults. Intersex people have non-heteronormative bodies. Surgical and other medical interventions are designed to erase intersex differences and interpret a “true” sex, constructing normative bodies and stereotypical gender identities. An Australian Senate committee reported on the Involuntary or coerced sterilisation of people with disabilities in Australia in 2013; a separate report on the Involuntary or coerced sterilisation of intersex people in Australia came out of the same inquiry. It said:

normalisation surgery is more than physical reconstruction. The surgery is intended to deconstruct an intersex physiology and, in turn, construct an identity that conforms with stereotypical male and female gender categories[9]

Historically, as described by biologist Anne Fausto-Sterling, “penetration in the absence of pleasure takes precedence over pleasure in the absence of penetration”. [9] More recently, the Australasian Paediatric Endocrine Group [10] states that surgeries are necessary for “psychosocial reasons such as to allow the child to develop without the psychosocial stigma or distress which is associated with having genitalia incongruous with the sex of rearing”.

Those same intersectionalities with issues of “real” and normative sex and gender result in entirely different outcomes for trans kids: no medical intervention is entertained before adolescence, and no surgical intervention until they can personally give fully informed consent.

We hear from doctors that parents want normal kids, we also hear from parents who have lost a certain expected future for their child. According to Pasterski et al, [11] parents are as traumatized by the birth of an intersex infant as they are by a cancer diagnosis in their child - but the clinical construction that birth as a “challenging clinical emergency” [11] contributes to that trauma. Other evidence [12] shows how the medicalized or non-medicalized information given to parents results in dramatically different outcomes for infants.

A key 2006 clinician document defined “psychosocial” therapeutic rationales as including “minimizing family concern and distress”, and “mitigating the risks of stigmatization and gender-identity confusion”. [13] A decision-making framework published by the Department of Health in Victoria, Australia, in 2013 defines such rationales as including “risk of social or cultural disadvantage to the child, for example, reduced opportunities for marriage or intimate relationships, or reduced opportunity for meaningful employment and capacity to earn an income, risk of social isolation”. [14] Psychosocial rationales for early surgery were criticized by the 2013 Australian Senate committee report:

There is frequent reference to ‘psychosocial’ reasons to conduct normalising surgery. To the extent that this refers to facilitating parental acceptance and bonding, the child’s avoidance of harassment or teasing, and the child’s body self-image, there is great danger of this being a circular argument that avoids the central issues.[9]

Intersectionalities with same sex attraction are well documented. 1950s medical reports that describe homosexuality and transvestism as forms of “psychological” intersex, [15]

and there are more disturbing recent documents. A 1990 peer-reviewed article by Heino Meyer-Bahlburg, member of a DSM5 Work Group,[16] entitled, "Will Prenatal Hormone Treatment Prevent Homosexuality?" considered how research on intersex differences could be used to explore the potential "prenatal hormone screening or treatment for the prevention of homosexuality".[17] While his research showed the "scientific groundwork" to be "insufficient" at that time, prenatal screening and treatment of intersex traits continues.

Dreger, Feder and Tamar-Mattis, in a paper[18] on the use of dexamethasone in pregnant women, at risk of carrying a female fetus affected by congenital adrenal hyperplasia (CAH)" found that dexamethasone, a steroid, is being used, off label, to prevent homosexuality, gender non-conforming behavior and physical masculinization – and these are considered to be of greater benefit than established cognitive and physical risks to the children concerned.

Some portrayals of intersex as monstrosity demonstrate an intersectionality with both sexual orientation and race:

as late as 1921, medical journals contained articles declaring that a physical examination of [female homosexuals] will in practically every instance disclose an abnormally prominent clitoris" and that this is "particularly so in colored women".[19]

Van Mens-Verhulst and Radtke describes "social positioning at the intersection of a complex set of social relations", "tied to one's identity and a sense of agency". Disadvantage provokes "feelings of powerlessness".[20]

Adults are vulnerable in multiple situations of low agency, including in situations that can be described as ones of domestic and family violence:

I was in a stable, long term relationship. Several years into the relationship, I became economically dependent on my partner: I went back to college to gain a qualification. At the same time, issues with my body became important to my partner, important enough to insist that I found out what those issues were, and did something about them.[21]

Medical authority can construct a powerful, and ultimately seductive, vision of normality. Michael Noble has documented his own experience:

Around the age of 23, an endocrinologist discovered that my body had never produced enough testosterone for me to undergo a full puberty. He therefore suggested I commence testosterone therapy. Initially, I resisted the pressures placed on me to commence therapy. Yet, eventually, I crumbled under the constant onslaught of threats and horror stories of what my future would be like if I didn't undergo therapy, which the doctors claimed would turn me into a 'real man'. It was insinuated, even blatantly stated on occasions, that my life would be worthless; that I would be a freak; that I would never achieve my potential, and that I would never have any self-esteem (apparently the self-esteem I already had was invalid as it existed outside of the predefined paradigm of being a real man). So, eventually, from the age of 28, after about 6

years of constant threats and 'counselling' by my medical specialists, I began testosterone therapy. And I found it to be a horrifying experience.[22]

In competitive sports, the IOC mandates that national sports authorities: "actively investigate any perceived deviation in sex characteristics" and remove women with "hyperandrogenism" from competition – women with elevated natural levels of testosterone[23] Other sports codes follow suit. The policy means that "butch" women in particular, and those who least conform to Western models of femininity, are most at risk of being singled out. This policing includes physical inspection of their genitals.

A British Medical Journal article in early 2014 documented how four unnamed intersex women athletes from developing nations were recently subjected to partial clitoridectomies – a form of Female Genital Mutilation – and removal of their gonads – in order to continue to compete, with no guarantee of continued access to medical treatment for the rest of their lives.[23] The context for such treatment is clearly coercive, yet an IAAF medical report published in mid 2014 tells us that there is "no clear scientific evidence proving that a high level of T [testosterone] is a significant determinant of performance in female sports".[24]

Those four athletes have a variation called 5 alpha Reductase Deficiency. Despite an atypical capacity for elite sports performance, as intersex women have a high representation in elite sports,[24] that variation is one of several that appears on a UK list of "sufficiently serious" traits meriting removal from the gene pool via IVF.[25] There are no special health risks from 5 alpha Reductase Deficiency,[26] simply a perceived non-conformity in sex characteristics and development.

The construction of intersex differences as major genetic defects also leads to high rates of pregnancy termination. A 2010 Consensus statement on diagnosis and clinical management of Klinefelter syndrome[27] reports "only 25% of estimated cases are diagnosed post-natally, and <10% are detected at or before birth". The health impacts of 47,XXY and 45,X0 (Turners) are typically considered to be cognitive differences, infertility and differences in stature and physical appearance. In some cases there are concurrent health problems.

However, the overwhelming majority of persons with 47,XXY do not come to the attention of clinicians because they do not meet the clinical parameters that indicate a need for karyotype testing. Despite these low rates of diagnosis, termination rates for 47,XXY once diagnosed during pregnancy are known to reach up to 88%.[28,29]

Behrmann and Ravitsky[30] comment on perceptions of "stark distinctions between sex, gender, and sexual orientation", saying "these concepts are actually intertwined on many levels. Parental choice against intersex may thus conceal biases against same-sex attractiveness and gender nonconformity".

THE RELATIONAL NATURE OF POWER

The relational nature of power is central to the concept of intersectionality. Hankivsky et al[31] describe how "power operates at discursive and structural levels to exclude particular knowledges and experiences". It is in the multiple axes, in feminism, queer and trans communities, and in the medical profession, where agency is repeatedly, systemically taken from people with intersex variations, that we see the distinctiveness of intersex as a distinctly separate intersectionality or domain.

Rose-tinted visions of intersex as a third gender or sex fail to acknowledge the power relations between each of the thirds in such societies.[32] Moreover, they miss the key issues. They focus on more comfortable, even salacious, gender identity issues, and the deconstruction of sex and gender, rather than “intersex as a site of intimate physical violation”,[33] human rights and social justice.

Koyama and others found this to be prevalent in education on women’s studies, gender and queer studies in the early 2000s; it remains the case today. As in most representations of the Norrie case, this privileges the needs of non-intersex people over the needs of people born with intersex variations.[34]

Some (not all) trans people and “Trans-Exclusionary Radical Feminists” throw intersex at each other, on Twitter and in the media, to prove points about either the social construction of sex or the social construction of gender.

On the one hand, “Genitals can be ambiguous at birth and many trans people get gender confirmation surgery to change them”.[35] On the other hand, “demands by intersex activists that children should not be forced by the administration of surgery or hormones to fit into a sex category, is diametrically at odds with the developing practice in western medicine of transgendering children“.[36]

Further, the core theoretical dichotomy of “cis” and “trans”, and in particular the concept of “cis privilege”, bear no useful relation to bodily experiences of diverse sex characteristics, nor experiences of coercive “normalizing” surgeries.

These are the voices that are most commonly heard, and the real issues of people with intersex variations are typically left behind.

Those of us that are queer or trans are more likely to become activists. Our multiple intersectionalities mean that we may more strongly experience the impact of societal pressures to conform to sex and gender norms; we are also more conscious of the misuse of intersex to pursue other agendas, and the removal of agency this entails. We are obliged to tread carefully to manage those intersectionalities, handle preconceived ideas of intersex constructively, and ensure that our own intersectionalities do not serve as a distraction.[37]

Miranda Fricker[38,39] describes a process of “epistemic injustice” where testimony is devalued due to the characteristics and powerlessness of the speaker. She describes “hermeneutical injustice” where a subject is hampered by a lacuna in collective due to the relative powerlessness of the subject’s social group:

An example of hermeneutical injustice might be the difficulty of making sense of homosexual desire as a legitimate sexual orientation in a cultural-historical context where homosexuality is interpreted as perverse or shameful.[38]

The disadvantage caused by hermeneutic injustice lies in “the lived experience of being unfairly disadvantaged in rendering one’s social experiences intelligible, to others and possibly even to oneself”. Social understandings of intersex clearly remain rudimentary, and intersex communities themselves are still coalescing, hampered by differences in

language and philosophical positions that confer hermeneutical inequalities on both disconnected patients of medical institutions and community activists.

Intersex activism itself stalled for multiple years after the introduction of “DSD”: opposition to the new language contrasted in other quarters with optimism for consequential changes to clinical practice. In reality, medical literature still tends to focus on surgical technique, and the numbers of clitoral surgeries on under-14s are known to have increased in the UK since 2006.[40] The secrecy that once pertained to an intersex diagnosis has been replaced by a careful curation of that knowledge, bound to different terms. Psychosocial rationales persist and are repeated. Human rights challenges to such practices are denied, Western civilizations don’t perform forced surgeries.[41]

Fricker also describes “testimonial injustice” where a subject is devalued or wronged due to their characteristics, such as their ethnicity or gender.[38] This is evident in comparisons of medical authority with that of intersex activists. Today, competing analyses see the dominant clinical voices make arguments from authority, such as this, by the Royal Children’s Hospital, Melbourne:

As part of our DSD multidisciplinary team we are fortunate to have highly skilled paediatric urologists with extensive experience in this area,[42]

The concerns of intersex community organizations are minimized: spokespeople are a vocal minority, sometimes just a few;[43] other times simply a group of dissatisfied individuals to be contrasted with satisfied patients. In 2013, the Australasian Paediatric Endocrine Group commented:

Some individuals are unhappy with their childhood treatment and have formed advocacy groups or pursued litigation. Other patients report satisfaction with early surgery.[10]

This can also be contrasted with the authority of the few dissenting clinical voices, such as Paediatric surgeon Mika Venhola who describes how:

The management of intersex conditions is based on expert opinion, and evidence on proper treatment is lacking. Intersex is also an ethical problem as full disclosure, informed consent, and children’s rights are not unquestionably respected.[44]

STRUCTURAL VIOLENCE

The construction of medical authority over people with intersex variations has been made possible by our heterogeneity and rarity - historically, an intersex person would rarely or never be able to meet someone else with the same diagnosis or characteristics - but also by the construction of intersex as monstrous and abnormal, creating stigma, secrecy, and shame. That rarity also means that many intersex people have an experience of unnecessary display to clinical teams, including physical display to clinicians unrelated to their health needs, and including photography.[45] It also includes clinical approaches that regard disclosure of an intersex diagnosis as too shocking to contemplate, particularly for children.[46]

Since 2005/2006, intersex people have been regarded by medicine as having “Disorders of Sex Development” (DSD).[13] This is claimed to reduce stigmatization but, whatever it is called, Professor Sonia Grover of the Royal Children’s Hospital, Melbourne was quoted in The Age newspaper stating:

We would never have one of our patients [with a disorder of sex development] as the face of a Good Friday appeal because of the stigma associated with the diagnosis.[47]

Diagnosis and treatment do not resolve stigma; they have a circular relationship. The collective term DSD reinforces the idea that intersex traits are individual medical conditions or disorders that need to be fixed. The term DSD and the disordering framework ensure that sterilizations and normalizing genital surgeries continue today, in Australia, the UK, and around the world, to make infants and children "appear" stereotypically male or female.

Intersex sociology professor Morgan Holmes states that the terminology shift “reinstitutionalises clinical power to delineate and silence those marked by the diagnosis”.[48] Another intersex sociologist, Georgiann Davis describes how, as the intersex movement first began to organize and provoke change:

Medical professionals needed to maintain their authority in the face of intersex activism, and they did so linguistically through a reinvention of the intersex diagnosis. The new DSD terminology constructs "sex" as a scientific phenomenon, and a binary one at that... This places intersexuality neatly into medical turf and safely away from critics of its medicalization.[49]

Structural violence, conceived by Johan Galtung is where social violence causes harm, preventing people from meeting their basic needs, it causes impairment of fundamental human needs.[50]

Galtung states that "violence is present when human beings are being influenced so that their actual somatic and mental realizations are below their potential realizations”.[50]

Australian clinicians state that early surgery is indicated despite "limited evidence reporting long-term outcomes of early surgical management for reasons of appearance", conflicting data on outcomes, and "particular concern" about post-surgical "sexual function and sensation".[10]

The Royal Children's Hospital states that "outcomes related to current approaches remain to be established".[42]

In contrast, Jordan-Young et al describe how clitoridectomy “is long eschewed because it has poor cosmetic outcomes and damages sexual sensation and function”.[23]

It is no coincidence, too, that surgeries on intersex infants and children are sometimes described as more successful than surgeries on adolescents and adults; necessitating early intervention. Adolescents and adults can differentiate their experience of sensation and sexual function before and after surgery.

Structural violence is built into the structure of our societies, our economies and our political systems. It recognizes that acts of violence are not individual, but repeated systemically, they are commonplace. And they are not intended to be violence. Galtung states that "ethical systems directed against intended violence will easily fail to capture structural violence".[50] Structural violence lies in the consequence of violence, rather than the intention; there is no personal guilt.

Doctors intend well, but it is the prevailing imposition of unthinking societal norms ahead of individual autonomy over our own bodies that makes the treatment of intersex people a case of structural violence.

Gilligan describes how structural violence may often be embedded in longstanding "ubiquitous social structures, normalized by stable institutions and regular experience"; the normality and ubiquity of sex and gender stereotypes.[51]

In fact, the evidence of medical understandings of what are "normal" female genitals was described by the Australian Senate as raising "disturbing questions": a Dutch study of physicians' views on the desirable size of women's labia minora found that male doctors were more likely to recommend reduction surgery than female doctors.[9,52] Alice Dreger reports of a German study showing that a majority of men don't meet strict clinical standards for normal genitalia.[53]

In Australia, the 2013 Senate committee report concluded:

The medical understanding of intersex is so strongly focussed on binary sex and gender ... Enormous effort has gone into assigning and 'normalising' sex: none has gone into asking whether this is necessary or beneficial. Given the extremely complex and risky medical treatments that are sometimes involved, this appears extremely unfortunate.[9]

IMPACT

There is little research on long term outcomes, and on mental health, typically with a disconnect between childhood and adolescent treatment, and care for adults; in many cases, doctors are even unaware of good referrals for teenagers leaving their care.

Nevertheless, it is clear that legacies of secrecy and shame, and unnecessary display, persist today. Conway reports on women with Androgen Insensitivity Syndrome at an adult clinic in London:

the group of women often over that age of 25 for whom paediatric care might not have been transparent in terms of accurate diagnostic information, may have a legacy [of] psychological issues that hinder engagement with medical services.[46]

A mental health study looked at 37 patients, where 36 had coincidentally undergone surgical interventions:

The prevalence rates of self-harming behavior and suicidal tendencies in the sample of persons with DSD were twice as high as in a community based

comparison group of non-traumatized women, with rates comparable to traumatized women with a history of physical or sexual abuse.[54]

Sterilization creates a requirement for lifelong hormone treatment, and low levels of sex hormones are associated with depression and poor mental health. Schützmann's research appeared to show that outcomes for people affected by sterilizations were independently markedly worse:

Within the total sample, the subgroup of persons with gonadectomy was significantly more distressed, with depression being particularly increased.[54]

SOCIAL JUSTICE

Theories of both intersectionality and structural violence speak of the importance of social justice. What might social justice for people with intersex variations look like?

Venhola says “Why operate on the child's body if the problem is in the minds of the adults?”.[55]

While the Australasian Paediatric Endocrine Group persist in portraying the ethical debate as a matter of surgical timing, and degrees of ambiguity and “severity”[10], Dreger, Sandberg and Feder seek a focus on psychosocial support, rather than psychosocial rationales for surgery:

Many have now recognized that the central challenge in DSD care is not centered on the surgeries per se, but rather finding a way to help families (and healthcare professionals) overcome the shame and anxious secrecy that may shape minds and force hands in ways that ultimately harm all involved...[56]

Children have an enormous capacity to get used to anything. We argue that honesty and openness are the best gifts for children and their families. Secrecy creates shame and leads to poor mental and physical health outcomes. We encourage parents to try to make sure that early choices are ones that they can be honest about when their child is older, including when they are old enough to become sexually active.

Presenting children with age-appropriate facts about their body in a matter-of-fact manner will help them to see those differences in the same light – and peer support is essential to help overcome the weight of stigma and social pressure.

For adults, experiences of trauma, secrecy and stigmatization mean that engagement levels with clinicians are low, and disclosure is much less likely than for same sex attracted and transgender individuals. Nevertheless, we need recognition, an apology, reparation, and counseling and support to overcome the legacies of shame and secrecy.

That recognition includes a transfer of agency. Intersex voices need to be heard. Conway states, “In a world where individuals attending an adult DSD service are often highly informed experts in the field, the role of medical care is often to guide on safety aspects and accept that the evidence base from which conventional practice has developed is questionable”.[46]

It is also necessary for intersex to be understood as a human rights and social justice issue, and not a medical issue. In Australia, we need the implementation of the 2013 Senate committee report on the “Involuntary or coerced sterilisation of intersex people in Australia”. Everywhere, above all, we need to know that our bodies are ok as they are, and that it is ok to be intersex.

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