



# **Ambivalent attention and indeterminate outcomes: constructing intersex and DSD in Australian data**

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## Introduction

As yet, there is no coherent understanding of intersex people in Australian law, policy and data. This paper presents multiple different and incommensurate models that represent the intersex population in different ways, including in Australian data, and in policy and practice. These reflect different values and beliefs about the population.

A dominant clinical model regards people with intersex variations as female or male with ‘disorders of sex development’ that need to be ‘fixed’ to ensure familial and social integration. Data frameworks associated with this model include disease and procedure classifications. Diagnoses are enumerated in the International Classification of Diseases (ICD). Procedures are enumerated in Medicare Benefits Schedule item codes. Clinicians have focused on studies of their paediatric surgery outcomes, and on genetics research.

A dominant socio-legal model regards people with intersex variations as ‘sex diverse’, ‘indeterminate sex’, neither female nor male, and needing to be represented through legal frameworks and data models recognising a third sex. Further, public policies and statements frequently imply that actions on grounds of sexual orientation or gender identity address matters of concern to people with intersex variations. Data frameworks associated with this model include categories of sex and gender in guidelines on recognition of sex and gender, birth registrations, gender recognition and anti-discrimination laws. Research on LGBT(I) populations has typically focused on the needs and circumstances of adults and adolescents with particular marginalised identities.

These two models interact in sometimes unexpected ways, including in ABS data on stillbirths that, until November 2021, included ‘indeterminate sex’ as both an International Classification of Diseases (ICD-10) category and a sex category. While the data present cases in each category, there were no intersecting cases.

Neither the clinical model nor the socio-legal model respect the diversity of the population nor human rights to health and bodily integrity. Both models reflect the dominance of non-intersex interests, with little (albeit recently increasing) account taken of community perspectives. Intersex-led community organisations are few, relatively new, and impoverished. The needs and circumstances of people with intersex variations are frequently misrepresented and poorly reflected in available data. There is a lack of data on adult health and welfare, ageing, and intersections with Indigeneity and disability.

## Defining the population and key issues

The UN Office of the High Commissioner for Human Rights defines intersex as follows:

Intersex is an umbrella term used to describe a wide range of innate bodily variations in sex characteristics. Intersex people are born with physical sex characteristics (such as sexual anatomy, reproductive organs, hormonal patterns and/or chromosomal patterns) that do not fit typical definitions for male or female bodies (Office of the High Commissioner for Human Rights 2019)

This definition has been widely adopted, including by Australian intersex-led organisations.<sup>1</sup> The population is extremely diverse: there is no single, common experience of sex determination, sex registration, sexual orientation or gender identity. However, experiences of stigmatisation, discrimination and harm due to physical differences, including risks or experiences of medical interventions without personal, informed consent, are widely shared. The population crosses all age groups. Intersex traits are increasingly determined prenatally, and attention is now shifting to preconception screening. Many traits are genetic; some may cluster in families, with a higher frequency in some populations (for example, see Shetty et al. 2012). *De novo* genetic changes also occur.

Indigenous and other intersectional experiences are poorly reported. In one historical clinical account of an Indigenous extended family in 1941, the social and cultural circumstances of an extended family in the Tiwi islands are difficult to distinguish from the clinical gaze (Ford 1941). People with intersex variations are commonly associated with LGBT populations, but those old enough to freely express an identity may be LGBT or may be heterosexual and cisgender.<sup>2</sup> An Australian 2015 sociological study found that 52% of respondents born with atypical sex characteristics were women, while 23% were men and 25% understood themselves in other ways, such as using non-binary descriptors (T. Jones et al. 2016). The population shares common risks and experiences with people with disabilities, arising from both social stigma and a treatment of intersex people as having medical disorders, with some evidence of higher rates of disability (T. Jones et al. 2016).

There have been many studies of the health and wellbeing of people with intersex variations, but it is likely that no study to date has been based on a representative sample of the population. While there is widespread broad agreement about the fundamental characteristics of the population, there is contention about where to draw lines in relation to diagnostic groups to include within the population cohort, and also significant differences in values and beliefs about the meaning of intersex characteristics. Intersex variations are variously construed as diseases to be 'fixed' in females and males, as markers of a third sex, and as signs of being gender diverse or sexuality diverse. The current situation exemplifies a situation where people with intersex variations are simultaneously 'fixed' by medicine as females or males with 'disorders of sex development', and 'othered' by social and legal policy (Carpenter 2018b). This creates gaps in social understanding where endosex (non-intersex) understandings of people with intersex variations inhibit personal understanding and community connectedness by people with intersex variations (Fricker 2007).

Fricker conceives of epistemic injustice as an injustice in knowing. It takes the form of testimonial and hermeneutical injustices. Hermeneutical injustice occurs when a structural prejudice leads to a lack of collective and personal understanding of a meaningful experience. For people with intersex variations, this arises in two common ways. The first is due to an ongoing lack of disclosure of a diagnosis to individuals or their parents (Lee et al. 2016, 170; Office of the Privacy Commissioner 2018), or of a disclosure motivated to

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<sup>1</sup> This human rights definition has also given rise to new synonyms for intersex variations including 'born with variations of sex characteristics', or 'innate variations of sex characteristics'.

<sup>2</sup> Cisgender is a term used to describe people who are not transgender or gender diverse. It is not possible to predict with certainty in any instance if a child with an intersex variation will grow up to be cisgender or transgender, heterosexual or same sex attracted.

produce compliance with treatment (Timmermans et al. 2018). Secondly, it arises in the pervasiveness of radically different conceptions of the population – evident in policy, data capture and reporting – that individuals are frequently unable to reconcile with their lived experience. These injustices also provoke responses such as ‘code switching’ where individuals choose their words to suit different social contexts, to feel more comfortable, or to mitigate risks of stigmatisation or incomprehension. For example, they may use words other than intersex, particularly where this term has become associated with misconceptions. In the 2015 Australian sociological study, 60% of respondents used the term intersex in some form to describe their sex characteristics; 3% used the term ‘disorders of sex development’, rising to 21% when accessing medical services (T. Jones et al. 2016).

Testimonial injustice arises where clinical bodies and policy-makers fail to pay due attention to concerns expressed by community representatives and organisations. This has been occurring for more than twenty-five years. That period has seen an unscientific dismissal of dissenting voices by clinical bodies (examples can be observed in Warne 2013; J. Hutson et al. 2020) and a privileging of narratives that fit the demands of larger, more visible intersecting populations. This includes reporting on Medicare procedure nomenclature that attends to clinician perspectives but not community perspectives, constructions of intersex as a third sex category in legislation and guidelines, and an attention to demands for improved access to legal gender recognition as if these satisfy the demands of the intersex movement (for example, AAP 2019). Some analysis erroneously and imprecisely constructs intersex as both a form of ‘gender diversity’ and a ‘biological sex assigned at birth’ (Saxby 2022) while other reports suggest that people with innate variations of sex characteristics do not feel connected to an LGBTQ+ community (for example see Morgan 2021). It is vital to acknowledge the impact of misconceptions about intersex in LGBTQ+ and policy spaces, and a widespread ignorance of distinctly different community characteristics and demands.

## **Community demands and key reports**

The main Australian intersex-led organisations are the charities Intersex Human Rights Australia (IHRA) and Intersex Peer Support Australia (IPSA). IPSA, also known as the Androgen Insensitivity Syndrome (AIS) Support Group Australia, became an incorporated peer led organisation in 2001, and it remains volunteer-led. IHRA was founded as Organisation Intersex International Australia in 2009 and registered as a not-for-profit company in 2010. It appointed its first part-time staff from December 2016, funded by foreign philanthropy. A handful of other volunteer-run organisations exist, including diagnosis-specific organisations such as MRKH Australia. A Gender Agenda, a trans-led group in the Australian Capital Territory (ACT), has funded a part-time intersex peer support position since 2017. A small number of new partnerships are now established between IHRA, IPSA and other organisations, such as a partnership between Queensland Council for LGBTI Health and IPSA on a peer and family support program commencing in 2022.

In our region, community demands are articulated in the Darlington Statement. The product of a community development process, the Statement calls for legal protections from deferrable medical interventions, resourcing for peer and family support, effective independent oversight and human rights-affirming standards of care for clinical practice, access to appropriate healthcare, redress, and respect for the diversity of the population

which requires an end to characterisation of intersex people as a third sex (AIS Support Group Australia et al. 2017).

Key national reports include a 2013 Senate inquiry report on the 'Involuntary or coerced sterilisation of intersex people in Australia' (Senate of Australia Community Affairs References Committee 2013), multiple calls by UN Treaty Bodies for Australian governments to harmful practices in medical settings and protect bodily integrity (a summary can be found in Intersex Human Rights Australia 2019b; Australian Human Rights Commission 2021), and a 2021 report by the Australian Human Rights Commission (AHRC) on 'Ensuring health and bodily integrity' of people born with variations of sex characteristics (Australian Human Rights Commission 2021). The Senate and AHRC reports recommend significant reform to clinical practices, including effective independent oversight, and to resourcing for peer and family support. Both sets of recommendations seek to ensure that the human rights of people with innate variations of sex characteristics are respected in medical settings. These recommendations aim to distinguish medical interventions necessary for physical health and wellbeing from interventions deemed necessary due to gender stereotypes and social and cultural norms, where the latter should be available only on the basis of personal informed consent. Some traits are associated with particular health issues, including infertility and, more rarely, renal, neurodevelopmental and cardiac issues. The Commission report supports community calls for criminalisation of unnecessary medical interventions. The ACT and Victorian governments have made commitments to reform. Implementation in at least one jurisdiction is imminent at time of publication.

## Clinical understandings

A 2006 invite-only clinical ‘consensus’ statement defines ‘disorders of sex development’ (DSD) as ‘congenital conditions in which development of chromosomal, gonadal, or anatomical sex is atypical (Hughes et al. 2006).<sup>3</sup> DSD is sometimes written as ‘disorders of sexual differentiation’ or ameliorated to ‘differences of sex development’. Despite widespread community opposition to ‘disorders of sex development’ nomenclature and its introduction into the ICD-11 (Carpenter 2018a; Johnson et al. 2017; Delimata et al. 2018; Intersex Human Rights Australia 2019a), DSD has replaced previous pejorative terms that include ‘indeterminate sex’ and ‘pseudo-hermaphroditism’ in the ICD-10 (Carpenter 2018a). The term ‘congenital disorders of sexual differentiation’ has also been incorporated into the Medicare Benefits Schedule as part of a review concluded in 2020 (Medicare Benefits Schedule Review Taskforce 2020). Community organisations have formally submitted proposals for alternative nomenclature to the World Health Organization, including ‘congenital variations of sex characteristics’ (Carpenter 2018a; Carpenter and Cabral 2017).

## Diagnosis and sex determination

The medicalisation of intersex traits begins with diagnosis. Examples of diagnoses include 17 $\beta$  hydroxysteroid dehydrogenase 3 deficiency, androgen insensitivity, and Klinefelter syndrome. A list of relevant ICD-11 codes can be found in Appendix 1. Diagnosis of intersex traits or DSDs can be made prenatally, at birth, during puberty or adolescence, or during adulthood, such as when attempting to conceive a child. Where diagnosis occurs at or prior to birth, diagnosis is taken into account when determining sex, or diagnosis may complicate determination of sex.

Even recent papers have described an inability to quickly determine sex at birth as a ‘medical emergency’, ‘rarely anticipated and [...] a source of great distress for parents, delivery room and nursery staff’ (Department of Health and Human Services 2015). The statement about distress is an unfortunate indication of stigma and a lack of education afforded to staff and parents. The statement about medical emergency is often justified by reference to salt wasting congenital adrenal hyperplasia. This trait is associated with genital difference and can be fatal if not treated; testing for this is being rolled out nationally as part of the new-born bloodspot screening program (Department of Health 2020). In cases where sex determination is in doubt, Vora and Srinivasan state in the Australian Journal of General Practice that:

assignment is a dilemma in a small percentage of patients with DSD and requires an individualised approach taking into consideration prenatal androgen exposure, fertility potential, quality of sexual function, surgical options, gonadal pathology/malignancy risk and potential adult gender identity (Vora and Srinivasan 2020, 418).

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<sup>3</sup> For more on this ‘consensus’ statement and the marginalisation of community voices, see Carpenter (2018b) and Dreger (2018).



These statements are not unusual, but instead comprise longstanding clinical practice. Taking a broader look at the entire population of children with variations of sex characteristics, Ahmed and Ali state in a current endocrinology textbook that:

Factors that influence sex assignment include the diagnosis, genital appearance, surgical options, need for lifelong replacement therapy, the potential for fertility, views of the family and sometimes, circumstances relating to cultural practices (Ahmed and Ali 2022, 31)

Many of these factors seek to predict a more likely future gender identity and sexual role, reflecting an attempt to construct future cisgender, heterosexual adults.<sup>4</sup> The reference to 'surgical options' is a clear indication of the persistence of early medical interventions to modify sex characteristics that are predetermined at the moment of sex registration. In line with statements on 17 $\beta$  hydroxysteroid dehydrogenase 3 deficiency in the World Health Organization Foundation for the International Classification of Diseases:

If the diagnosis is made at birth, gender assignment must be discussed, depending on the expected results of masculinizing genitoplasty. If female assignment is selected, feminizing genitoplasty and gonadectomy must be performed. Prenatal diagnosis is available for the kindred of affected patients if causal mutations have been characterized (World Health Organization 2020)

This trait is 'often misdiagnosed in infancy and detected at puberty in genetic males who have been either raised as females and develop hirsutism and primary amenorrhoea, or raised as males and have gynecomastia and incomplete male genital development' (World Health Organization 2020). This indicates that risks or experiences of early surgeries and hormonal interventions due to gender stereotypes are not limited to situations where sex determination is considered to be challenging.

## **Clinical evidence for cosmetic medical interventions**

Clinical data sources include case study reports, summaries of cases taken to interdisciplinary teams that evaluate 'dilemmas', and data on Medicare item codes and diagnoses in the International Classification of Diseases.

Clinical studies are scarce, lack replication, and rely on small samples and case studies that are subject to ascertainment bias and confirmation bias, for example, where staff at a paediatric hospital study their own patients in line with their values and preferences. This literature focuses on justification of early surgical intervention, which offers an explanation for an absence of systemic, longitudinal research on health, wellbeing and ageing.

Appeals for more clinical research date back to at least 1995 (Sandberg 1995; Carpenter 2018b). A lack of 'systematic evidence' for early cosmetic medical interventions (Hughes et al. 2006, 557) has motivated appeals to clinical eminence, including through a 2006 clinical

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<sup>4</sup> I wrote to a co-author of the paper by Vora and Srinivasan in September 2021 in an attempt to ascertain the meaning of 'quality of sexual function' and query three other concerns with materials in the article.

consensus statement. This statement established agreed approaches to early surgeries on the basis that they might mitigate risks of 'gender-identity confusion', parental distress and stigmatisation, and on the basis of limited evidence of cancer risks (Houk et al. 2006, 755).

Australian evidence supporting current medical practices relies on a small single-centre study of 'long-term psychological, sexual and social outcomes' by clinicians at the Murdoch Children's Research Institute and Royal Children's Hospital of 50 of their patients (Warne et al. 2005). There is no evidence (or community knowledge) of community input into study design. The study appears intended to justify the centre's treatment model, with the clinicians reporting:

Most patients with intersex had positive psychosocial and psychosexual outcomes, although some problems were reported with sexual activity. These results overall suggest that a model of care including early genital surgery carried out at a centre of excellence with a multidisciplinary team can minimize long-term complication rates (Warne et al. 2005).

Fifteen years later, this same study is still relied upon as a justification for early surgery:

As all the participants in this follow-up study had genital reconstructive surgery in infancy or early childhood, the results did not support a change in this practice (J. Hutson 2020).

Writing in 2020, the clinicians also note significant concerns:

The DSD patients were less likely to experience orgasm and tended to experience more pain during intercourse, and they also had more difficulties with penetration than the combined control groups. In addition, they were also more likely to have less frequent sexual activity than the control groups (J. Hutson 2020).

Respondents 'reported lower self-esteem and higher anxiety traits' than controls, but had a 'generally positive psychosocial and psychosexual outcome which is in contrast to many other studies' (J. Hutson 2020). The report on this study appealed to surgical expertise at the centre as a factor in explaining outcomes perceived as good and supportive of surgical practices. However, a systemic review by an independent team at an institute for psychiatry in Hamburg, Germany reported on the same study differently:

In the study by Warne et al. (2005), the persons with DSD were similarly as distressed as a comparison group of chronic somatically ill persons. Even though the rates of psychological distress are not directly comparable to our measures, the results similarly indicate markedly increased distress in persons with DSD. (For comparison, German prevalence rates of significant psychological distress in chronically somatic ill persons range from 43% to 50%, see Harter, 2000). (Schützmann et al. 2009).

In relation to the German team's overall findings, the authors comment: 'Our results suggest that adults with DSD are markedly psychologically distressed with rates of suicidal

tendencies and self-harming behavior on a level comparable to non-DSD women with a history of physical or sexual abuse' (Schützmann et al. 2009).

Clinicians at Royal Children's Hospital Melbourne have also reported on outcomes of their early masculinising surgeries at that hospital. Hutson asserts improved psychological well-being in boys after early surgery as the primary rationale for early surgical intervention – 'no serious psychological disturbance and no memory of the intervention' (J. Hutson 2020, 311) – accompanied by a claim of surgical expertise (J. Hutson 2020). The evidence supporting these assertions was a survey of 55 minors aged 13-15 with a low response rate (B. Jones et al. 2009). The study population was too young to be able to ascertain outcomes. Significant long-term consequences of early surgeries such as urethral strictures (a narrowing of the urethra) may not be evident until adulthood. In relation to these surgeries, Katrina Roen notes 'questionable decision-making and consent processes (Roen & Hegarty, 2018) and surgical outcomes that urologists themselves find questionable (Long & Canning, 2016; Long et al., 2017)' (Roen 2019). Non-surgical pathways are lacking (Liao, Wood, and Creighton 2015; Roen 2019).

Despite the existence of these small-scale Australian studies, a 2016 global clinical update found that evidence is still lacking:

There is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery. The levels of evidence of responses given by the experts are low (B and C), while most are supported by team expertise [...] Timing, choice of the individual and irreversibility of surgical procedures are sources of concerns. There is no evidence regarding the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization (Lee et al. 2016, 176)

Continuing lack of widely-accepted evidence, coupled with claims that more evidence is needed before changing clinical practices, act to justify existing practices:

Consensus, lack of consensus, existing evidence and lack of evidence are each used to justify early surgeries to 'normalise' children's bodies, indicating that such interventions are grounded in the values and beliefs of clinicians (Carpenter 2021, 3).

Negative outcomes may be seldom reported in the literature due to publication bias, specifically a bias against reporting negative findings (Earp 2017). In the case of both feminising surgeries and masculinising surgeries, claims of increasing quality of surgical outcomes fail to address more profound considerations regarding the necessity of surgery and the lack of evidence to support their rationales.

## **The Family Court and the Australian Human Rights Commission**

Largely arising out of concern for litigation by Brisbane hospitals (Warne 2013), the Family Court has adjudicated a small number of precedent-setting cases authorising 'special medical procedures', mostly involving sterilisations (Australian Human Rights Commission 2021). A 2011 meeting of the clinical Australasian Paediatric Endocrine Group and the

Family Court sought to take decision-making instead to hospital ethics committees (Warne 2013; Thomsett and Warne 2021). A 2016 audit of decisions made in such settings in Melbourne and Sydney asserted that meetings offered a place to present 'dilemmas' or 'ethical issues', and that they 'provide a viable alternative to involvement of the Family Court' (Vora et al. 2016).

The 2016 Family Court case *Re Carla (Medical procedure)*, adjudicated in Brisbane, may have been instrumental in instigating an inquiry on protecting the human rights of people born with variations of sex characteristics in medical settings by the AHRC. The case involved a pre-school child with 17 $\beta$  hydroxysteroid dehydrogenase 3 deficiency, described by the judge as a 'sexual development disorder'. The judge stated that the child had already had surgeries that 'enhanced the appearance of her female genitalia', without recourse to the court but indicating a prior investment in a particular future appearance and identity (Family Court of Australia 2016, para. 2; Carpenter 2018a; Australian Human Rights Commission 2021). The case was taken to remove the child's gonads, and the judge determined that parents could authorise this treatment. The judgement made reference to obsolete data on cancer risks that recommended monitoring gonads rather than excising them. That reference to obsolete data has since been superseded by gendered approaches to sterilisation, where sterilisation only occurs in children with this trait who are raised female (Family Court of Australia 2016, para. 19; Carpenter 2018a; Australian Human Rights Commission 2021).

The sterilisation was justified through an extensive discussion of the pre-school child's gender identity that was justified by third party reports and gender stereotypes: 'a range of interests/toys and colours, all of which were stereotypically female, for example, having pink curtains, a Barbie bedspread and campervan, necklaces, lip gloss'; 'She happily wore a floral skirt and shirt with glittery sandals and Minnie Mouse underwear and had her long blond hair tied in braids; and [...] never tries to stand while urinating' (Family Court of Australia 2016, para. 15). The child was too young to have agency, and this was deliberately and explicitly pre-empted: the judge commented that surgery would 'be less psychologically traumatic for Carla if it is performed before she is able to understand the nature of the procedure' (Family Court of Australia 2016, para. 30). As is the case with all individuals subjected to sterilising surgeries, the child has been left with a lifelong need for hormone replacement therapy.

The 2017 Darlington Statement community declaration remarked that the Family Court has 'failed' people with innate variations of sex characteristics and noted 'long-term physical and psychological implications of harmful and continuing medical practices, and limited access to support and peers' (AIS Support Group Australia et al. 2017). The Australian Human Rights Commission's report supports these observations:

While individuals' experiences varied widely, there were common themes. These included ongoing distress at physical and psychological consequences, stigma, lack of social and personal support, and challenging interactions with the health system (Australian Human Rights Commission 2021, 34)

‘Normalising’ interventions have been understood by both people born with variations in sex characteristics and those around them as meaning that their bodies are undesirable or problematic. This can fuel stigma and shame (Australian Human Rights Commission 2021, 84)

One individual was administered vaginal dilation from the age of 13 years, and described the experience as a ‘painful, bloody and completely unsupervised practice aimed at allowing me to successfully accommodate a future fictitious husband and hence make me a more normal female’. Other physical consequences related to loss of fertility from interventions, and urinary tract issues, including incontinence, arising from interventions. Some people reported loss or diminution of sexual function, sensitivity and/or capacity to experience sexual pleasure (Australian Human Rights Commission 2021, 38).

In its 2021 report on ensuring health and bodily integrity of people with innate variations of sex characteristics, the Australian Human Rights Commission commented that:

Some clinicians from outside the fields of psychology and psychiatry considered psychosocial rationales to be relevant to determining whether a proposed intervention is justified [...] Some clinicians from outside the fields of psychology and psychiatry and some parents considered that interventions should be allowed to occur where genitalia depart from the medical, binary notions of typical genital appearance [to] promote and support a child’s integration in family, community and culture [and] pre-empt potential bullying or stigmatisation, thus promoting their overall wellbeing.

Clinical experts from specialist bodies in psychiatry and psychology rejected the notion that it is necessary to ‘normalise’ sex characteristics for mental health reasons (Australian Human Rights Commission 2021, 81)

These rationales are also rejected by community organisations. Furthermore, professional bodies for psychiatrists and psychologists identified concerns regarding mental health issues arising from imposed medical interventions, and suggested that medical decisions should focus on individual wellbeing and not ‘a concern for social integration which often means normalisation’ (Australian Human Rights Commission 2021, 81). The College of Psychiatrists states that ‘claims that sex assignment therapies are “necessary” or “therapeutic” are dubious’ and supported deferral of non-urgent decisions with irreversible consequences (Australian Human Rights Commission 2021, 81–82; Royal Australian and New Zealand College of Psychiatrists 2018). Clinical psychologists have also expressed concern at the subordination of psychologists and allied health in hospital multi-disciplinary teams to the interests of surgeons and other non-psychology specialists (Liao and Roen 2019; Liao and Simmonds 2013). Community organisations and the AHRC favour peer support, counselling and education as alternative ways to address potential harms (AIS Support Group Australia et al. 2017; Australian Human Rights Commission 2021, 85).

In supporting a criminal prohibition of deferrable medical interventions without urgent necessity, the AHRC stated that: ‘These medical interventions do cause some people devastating and lifelong harm – and are in conflict with the principle of bodily integrity’:

there is a real risk that medical interventions, other than on grounds of medical necessity, may be undertaken in the future. This position is informed by the views of a range of clinicians that psychosocial factors are justifiable considerations for medical interventions, with such justifications given weight in leading international guidance documents. Therefore, overall cultural change would be unlikely in the absence of binding directions (Australian Human Rights Commission 2021, 131).

The Commission also felt it necessary to address a straw man argument in claims made to it by the Australasian paediatric endocrine association suggesting that other stakeholders want to end all medical interventions ‘in all circumstances’, when ‘neither the Commission nor any stakeholders have advocated such a blanket prohibition’ (Australian Human Rights Commission 2021, 131). This same misrepresentation also appears in recent Australian clinical literature (Vora and Srinivasan 2020, 420; Vora et al. 2021, 5).

### **Procedures: numbers, prevalence and item codes**

Numbers of early medical interventions are difficult to ascertain with any accuracy, despite the existence of multiple data sources. In a media report on feminising surgeries in 2013, the Royal Children’s Hospital Melbourne is reported to perform ‘10-15 genital reconstruction operations a year often on girls under the age of two’, described as ‘gender assignment or genital enhancement operations’ (Bock 2013). In the same year, the hospital reported to the Senate an ‘opinion’ favouring early surgeries (Royal Children’s Hospital Melbourne 2013, 7).

There appears to be no clear correlation between these surgery numbers at a single hospital and contemporaneous data on numbers of relevant surgeries appearing in Medicare data cubes, nor a federal Department of Health review of vulvoplasties that refers to ‘congenital malformations’ associated with intersex-specific ICD codes (Carpenter 2018b, 468–74).

Similarly, information on surgeries in cases of the ‘clinical dilemmas’ and ‘complex cases’ taken to multidisciplinary teams in Sydney, Melbourne and Brisbane provides evidence of routine surgical interventions in some centres, but does not provide accurate data on surgery numbers (Vora et al. 2016; Adikari et al. 2019). The available evidence is troubling. Adikari and others published a review of 24 adolescents treated at a Brisbane Paediatric and Adolescent Gynaecology Service where, likely following age of diagnosis, ‘In CAIS, bilateral gonadectomies were most often done at infancy’; all individuals with PAIS were also subjected to gonadectomies (Adikari et al. 2019). It identifies how:

The most common reasons for referral were primary amenorrhea, hormone replacement, and vaginal dilation and the average age initial review 17 years, 3 months. 5 adolescents were unaware of their diagnosis prior to referral and assessment, with 13 diagnosed in infancy with ambiguous genitalia [sic] or hernia. (Adikari et al. 2019)

The adolescents had frequently been subjected to sterilisations:

Gonadectomy was performed in all cases, except in the Turner's variant. In CAIS, bilateral gonadectomies were most often done at infancy. (Adikari et al. 2019)

The review gives case descriptions for 18 persons, showing a high prevalence of genitoplasties, for example:

Gonadectomy and feminizing genitoplasty 1 year age. Vaginal dilatation. [PAIS]

Gonadectomy and genitoplasmy [sic] as infant. Pubertal induction and HRT. Vaginal Dilatation. [Mixed gonadal dysgenesis]

Gonadectomy and reconstructive surgery as infant. Pubertal induction and HRT. Vaginal dilatation. [PAIS]

Gonadectomy and surgical creation neovagina in adolescence. Pubertal induction and HRT. Vaginal dilators. [5 alpha reductase deficiency – age of surgery in adolescence and the person providing consent are not disclosed]

Gonadectomy and surgical creation neovagina as child. Pubertal induction and HRT. Vaginal dilators. [PAIS]

Gonadectomy and feminizing surgery age 2yo. Pubertal induction and HRT. Vaginal dilatation. [PAIS]

Bilateral orchidectomy and hernia repair aged 12. Pubertal induction and HRT. Vaginal dilatation. [17β-HSD3]

Bilateral gonadectomy. Pubertal induction and HRT. Vaginal dilatation. [PAIS] (Adikari et al. 2019)

These data sources also omit most or all masculinising surgeries from analysis.

The Medicare Benefits Schedule sets out national reimbursement rates for medical procedures. In parallel to the Commission's inquiry, clinical bodies participated in a review of Medicare Benefits Schedule codes and rates. In 2019, changes to item codes for paediatric vaginoplasties and genitoplasties were recommended, to change wording from 'ambiguous genitalia' and named traits to 'congenital disorder of sexual differentiation' (Medicare Benefits Schedule Review Taskforce 2019, 14–15 and 30; Department of Health 2021). These changes have been implemented. The Urology Taskforce noted 'these procedures are mostly performed on pre-pubertal children' (Medicare Benefits Schedule Review Taskforce 2018, 117). Details of item codes and procedure numbers in financial year 2016/7 are given in Appendix 2.

Citing the 2006 clinical 'consensus statement', the Taskforce framed this change as a 'modernisation' where previous 'language used does not reflect contemporary community attitudes' and commented that 'medical and representative organisations were concerned that the language might be influencing non-evidence based treatment for patients'; the new terminology might 'promote a more evidence-based approach to medical/surgical decisions' (Medicare Benefits Schedule Review Taskforce 2019, 15 and 30). However, the statement regarding 'contemporary community attitudes' in relation to nomenclature disregarded and misrepresents community attitudes towards that nomenclature. Further, it chooses to disregard long-stated community and human rights institutions' concerns regarding inadequate evidence, lack of consensus regarding necessity, and inappropriate rationales for surgery and hormone treatments (Senate of Australia Community Affairs References

Committee 2013; Carpenter 2018a; Office of the High Commissioner for Human Rights 2019, 19). As a process this is troubling: clinicians in the field participated in the expert reference group for the AHRC inquiry, as did the author of this paper. The outcomes are disturbing. No directly comparable item codes exist for non-paediatric populations, while a single adult code exists for 'reconstruction' (Department of Health 2021a). The codes exist to facilitate surgeries on individuals too young to personally consent but limit access to support in adulthood. 'Patients with DSD remain free to choose their social identity', the report states (Medicare Benefits Schedule Review Taskforce 2019, 15), but not their own treatment or its timing.

The taskforce review of masculinising surgeries lists at least 15 different codes relating to hypospadias, many applicable to persons under age 10, and where fees are higher on codes relating to that younger population. Medicare items include the disturbing 'hypospadias, examination under anaesthesia with erection test, on a person under 10 years of age'. The review recommended removal of the words 'post-operative' from 'repair of post-operative urethral fistula' and 'repair of post-operative urethral fistula, on a person under 10 years of age' as the meaning of 'post-operative' was considered overly limiting, referring to only the 'immediate post-operative period' (Medicare Benefits Schedule Review Taskforce 2018, 74 and 114–15). These changes have been implemented. Codes for masculinising surgeries indicate a common need for multiple surgeries. General anaesthesia in young children is known to have consequences for child development and school performance (Schneuer et al. 2018). Details of item codes and procedure numbers in 2016/7 are given in Appendix 2.

The Commission made two recommendations in relation to research. The Commission supported a databank to better ascertain actual practices, and it also supported resourcing for collaborative research, co-designed by the community, aimed at helping people with intersex variations to flourish. The databank is likely to raise significant privacy and ethical concerns in the community, due in part to a perceived risk (grounded in prior experience) that it will be used to further the elimination of embryos and fetuses with intersex traits. Research on socio-economic factors, education, employment and ageing are all significant areas of concern, in addition to human rights affirming medical, psychological, health and wellbeing research across the full lifespan (Australian Human Rights Commission 2021, 15).

## **Prenatal interventions**

A 2016 Australian study reported an increase in the percentage of individuals with intersex variations receiving a genetic diagnosis from 13% to 35% (Eggers et al. 2016). Some chromosomal variations can be identified through screening for trisomy. Other variations have mostly been screened through testing of siblings and other relatives of people diagnosed with those variations. The increasing availability of genetic screening is changing this situation.

Multi-million dollar public research grants have been invested in the determination of genetic causes of intersex traits, some of it justified on the basis of 'psychological trauma' (University of Queensland Undated). National Health and Medical Research Council guidelines on the use of assisted reproduction technologies treat intersex variations in the same way as other traits considered to be genetic disorders: permitting elimination only



when a 'genetic condition, disease or abnormality' would 'severely limit the quality of life of the person who would be born' (National Health and Medical Research Council 2017).

The gene review committee of Mackenzie's Mission preconception screening program has determined which genetic traits should be included in a pilot screening program in Australia. Following an invited submission by the author, the committee determined that:

Adverse impacts associated with DSD tend to draw on societal norms rather than intrinsic clinical features. This includes the experience of stigma, discrimination and other harms arising from a person's body not conforming to norms of gender or biological sex. In particular, concerns were raised about the use of medical intervention to "fix" children born intersex without sound clinical rationale. There was also discussion of the message that inclusion of DSD in an [sic] carrier screening panel is premature, not least because of ongoing ethical debate regarding selecting against DSD. Thus, DSD that occurs in the absence of other serious clinical features did not meet our criteria for inclusion (Kirk et al. 2020).

However, in relation to prenatal screening, the situation in Victoria is illustrative. David Amor (2012, 2020) at the Royal Children's Hospital Melbourne discusses the possibility of parents having a child with a 'DSD' primarily as a matter of 'risk estimation', including 'risk of transmission from an affected parent to a child' or of having an 'affected child'. Amor omits any discussion of quality of life, and presents deselection as a value-neutral option where diagnosis of a child with a 'DSD' presents parents with 'difficult choices about future pregnancies' (Amor 2012, 2020). This framing is highly prejudicial.

Prenatal treatment for congenital adrenal hyperplasia is troubling due to the possibility of risks to neurodevelopment arising from treatments aimed at modifying genital development (Hirvikoski et al. 2012; Dreger, Feder, and Tamar-Mattis 2012). The rationales for this treatment reflect those of postnatal surgical treatment. A 2013 Senate inquiry called for their abandonment outside clinical studies (Senate of Australia Community Affairs References Committee 2013), but their current status is undocumented.

## Socio-legal understandings

In contrast to medical conceptions of intersex traits that result in registration as female or male and risks or experiences of forced or coercive medical interventions, socio-legal conceptions frequently regard people with intersex variations as neither female nor male, and in need of recognition through a third sex/gender category. 2013 guidelines on sex/gender, passport application guidelines, and legislation and regulation in a number of jurisdictions suppose that intersex is an appropriate name for a third sex category.

Constructions of intersex as a third sex are explicitly opposed by the Darlington Statement community declaration (AIS Support Group Australia et al. 2017) for failing to respect the diversity of the intersex population, including both cisgender and gender diverse women and men with intersex variations. Those constructions of intersex as a third category have a history far older than the existence of intersex community organisations.

### The Family Court, and ‘sexual reassignment’

In 1979, Family Court of Australia annulled the marriage of a man with an intersex variation on the basis that he was a ‘true hermaphrodite’ (Family Court of Australia 1979). The man was ‘born a male and had been reared as a male’ (Family Court of Australia 1979, 526), and later chose to undergo surgeries aligned with that status (Fraser, O’Reilly, and Rintoul 1966). Nevertheless, he was described in a case report as a ‘true transsexual’ who underwent ‘sex-change surgery’ (Bailey 1979). In annulling the marriage, the judgement broke with a historical model in Western countries of treating ‘hermaphrodites’ as female or male depending on predominant sex characteristics (Finlay 1980; Carpenter 2022a). The decision in this case has been criticised and not followed (Family Court of Australia 2003, paras 205 and 231, 2018, para. 54) but the judgement drew upon a section of the *Matrimonial Causes Act 1959* referring to a situation where the ‘wife’s consent to the marriage was not a true consent because she was mistaken as to the identity of the husband at the time of the marriage’. This argument, which appears to presuppose that a particular kind of identity was available or inherent, was cited by the Family Court in 2018 (2018, paras 53–55). Other than male, any identity seems difficult to justify on the available evidence.

In South Australia, the *Sexual Reassignment Act 1988* allowed for the legal recognition of the identities of transgender people. The Act also defined a ‘reassignment procedure’ that facilitated surgical interventions on children with intersex variations:

***reassignment procedure*** means a medical or surgical procedure (or a combination of such procedures) to alter the genitals and other sexual characteristics of a person, identified by birth certificate as male or female, so that the person will be identified as a person of the opposite sex and includes, in relation to a child, any such procedure (or combination of procedures) to correct or eliminate ambiguities in the child's sexual characteristics

Substantively the same definition still exists in Western Australian law (Carpenter and Intersex Human Rights Australia 2021). These provisions give government imprimatur for harmful practices in medical settings. In South Australia, and as if to recognise the existence

of a third sex, the reference to a ‘person of the opposite sex’ was amended to ‘person of a different sex’ in the *Statutes Amendment (Gender Identity and Equity) Act 2016*. The *Sexual Reassignment Act* was repealed in 2017, at a time when South Australia created a third category of birth registration termed intersex, and legal protections from discrimination on grounds of ‘intersex status’. Intersex organisations had instead recommended action to end unnecessary medical interventions, enact protections on grounds of ‘sex characteristics’ and ensure that any third sex/gender category would be named in a way that would not associate it with intersex people (Intersex Human Rights Australia 2017).

## **Anti-discrimination law**

From the 1990s, Australian States and Territories began enacting references to people of ‘indeterminate sex’ within attributes intended to protect transgender people in anti-discrimination law. In 1996, for example, New South Wales added reference to a ‘transgender person’, ‘who, being of indeterminate sex, identifies as a member of a particular sex by living as a member of that sex’ (New South Wales 1996). This and similar provisions remain the law in New South Wales, Queensland and Western Australia, while legislation in other jurisdictions has since changed. These early attempts at intersex inclusion are associated with gender recognition for transgender people, and some key figures appear to have held positions that consider ‘transsexualism’ to be an intersex trait (Gurney 2004; Wallbank 2015; National Foundation for Australian Women and The University of Melbourne 2016). These protections appear to have little practical value to people with intersex variations because they lack cognisance of actual processes of sex determination and sex registration, and they lack a basis in lived experience or community. They were opposed at the time by the AIS Support Group Australia (now known as IPSA).<sup>5</sup>

In parallel, legislation prohibiting female genital mutilation was enacted from the mid 1990s, typically containing exemptions permitting surgeries on people with ‘ambivalent sex’ (Attorney General’s Department 2013b). In 2004, for example, the Criminal Code Amendment Act 2004 of Western Australia exempts ‘reassignment procedures’ including including ‘in relation to a child, any such procedure (or combination of procedures) to correct or eliminate ambiguities in the child’s gender characteristics’ from a prohibition of female genital mutilation (Western Australia 2004)

The *Sex Discrimination Act 2013* (‘SDA’) marked a shift from earlier forms of inclusion in anti-discrimination law, defining ‘intersex status’ as:

‘the status of having physical, hormonal or genetic features that are: (a) neither wholly female nor wholly male or (b) a combination of female and male or (c) neither female nor male’ (Commonwealth of Australia 2013).

This definition successfully extracted intersex from a proposed attribute of gender identity that made reference to ‘the identification, on a genuine basis, by a person of indeterminate

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<sup>5</sup> For a discussion of opposition in 2002 to inclusion of ‘indeterminate sex’ within an attribute of ‘gender identity’, in Queensland legislation, see Carpenter and Intersex Human Rights Australia (2022), and in ACT legislation see AIS Support Group Australia and Briffa (2003)

sex as a member of a particular sex' (Carpenter and Organisation Intersex International Australia 2012, 6). This new attribute was, as noted in the amending bill's explanatory memorandum, not intended to construct a third sex category (House of Representatives 2013, 12) but the definition has been imputed to refer to an identity category. Indeed, the SDA is sometimes associated with contemporaneous sex and gender recognition guidelines that simultaneously recognise that intersex people have diverse sex and gender markers, and include intersex within a definition of a third 'X' sex/gender marker (Attorney General's Department 2013a; Australian Bureau of Statistics 2021a).

Following enactment of the SDA, many jurisdictions have changed legislated references to sex, as described earlier in the *Statutes Amendment (Gender Identity and Equity) Act 2016 (SA)*. These changes aligned with a review of State and Territory legislation undertaken for a small consortium of not-for-profit organisations in 2013/5. Unfortunately, while IHRA raised objections about misconceptions and omissions, and declined an invitation to endorse the analysis, reforms implemented because of the review merely give the appearance of inclusive practice, while leaving harmful systems intact.

Beyond imputation of matters of identity, the SDA definition of 'intersex status' has other flaws. It is based on model of deficit (i.e. on what intersex people lack), and it lacks any reference to the innate character of intersex variations and so has a meaning far broader than more accurate definitions of the word intersex. While anyone who can benefit from protections should be able to do so, community organisations promote an alternative attribute, 'sex characteristics', that is more precise and cannot be imputed to mean an identity (AIS Support Group Australia et al. 2017).<sup>6</sup> 'Sex characteristics' is defined in the Yogyakarta Principles plus 10 as:

each person's physical features relating to sex, including genitalia and other sexual and reproductive anatomy, chromosomes, hormones, and secondary physical features emerging from puberty (Yogyakarta Principles 2017)

Since 2019, the governments of ACT (Australian Capital Territory 2020), Victoria (Victorian Equal Opportunity and Human Rights Commission 2021b) and Tasmania (Tasmania 2019) have enacted protections from discrimination on this basis. In each case, they replace protections on grounds of intersex status, or earlier enacted protections on grounds of 'indeterminate sex' within an attribute of 'gender identity'.

## **Sex, gender, sexuality, and sex characteristics**

Many different methods of collecting data on sex and gender currently exist around Australia, and many of them include intersex as a category of sex or gender, despite community opposition. The situation is very challenging with a wide range of methods, often unrelated to any norms, standards or consultation process.

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<sup>6</sup> The Victorian Equal Opportunity and Human Rights Commission has nevertheless associated intersex sex characteristics with non-binary identity in a case study, 'Hamish', explaining new protections (2021a).

Institutions and frameworks for people with diverse sexual orientation and gender identity have expanded their remit to encompass intersex people since at least 2002 (Ministerial Advisory Committee on Gay and Lesbian Health 2002). This is usually motivated by a welcome desire for inclusiveness and allyship. Despite welcome exceptions, there has however been remarkably little evidence of action or independent expertise within LGBT spaces on issues identified by intersex community organisations.<sup>7</sup> Research on LGBTI populations, including people with intersex variations, has suffered from a presumption of non-heterosexual, non-cisgender identification, and an inattentiveness to the specific characteristics and needs of people with intersex variations. Too many papers on the health of LGBTI+ populations lack comprehension of the populations they profess to address and simply extrapolate from research on same sex attracted or gender diverse people (for a recent example see Saxby 2021). Unfortunately, some parties have also instrumentalised intersex in order to ‘mess with the system’ (critiqued in Organisation Intersex International Australia Limited 2011), or to access medical interventions imposed on people with ‘DSDs’ in a way that assuages the perceived stigma associated with a mental health diagnosis (National Foundation for Australian Women and The University of Melbourne 2016).

For many people, these circumstances have called into question the value of such aggregations. Engagement in LGBTI research by people with intersex variations has been low, likely as a result. Nevertheless, LGBTI spaces are the only spaces that provide avenues to provide policy input and potential (and as yet unrealised) resourcing, or make the population intelligible to policy-makers. This invitation for this paper provides an example of the way that aggregation of ‘LGBTI’ populations can create an opportunity for analysis and discussion. Systemic exclusion of intersex might lead to systemic adverse consequences.

Participation by people with variations of sex characteristics in population-specific research has been more successful than participation in LGBTI studies. A 2015 Australian sociological study attempted to obtain a representative sample of people ‘born with atypical sex characteristics’. With 272 respondents to an online survey, it provides the largest Australian sample to date (T. Jones et al. 2016). It provides helpful demographic data, and identified new concerns in relation to health and education. The research study was the first of its kind and provided many learnings for future research, but it remains a one-off. Further collaborative community-based research so far lacks funding.

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<sup>7</sup> Notable exceptions by a handful of allied organisations include paid part-time peer support staff, and engagement by Equality Australia on detailed, collaborative law reform work.

## Some interactions between medical and socio-legal models

The intersections of clinical and socio-legal understandings of intersex people play out in idiosyncratic ways. IHRA is unaware of any instances in Australia of children with intersex variations having sex classified at birth as ‘indeterminate sex’ or ‘intersex’, or other terms for a third sex category. Indeed, IHRA opposed construction of a third sex category using these terms in ACT legislation in 2014 because of what appeared to be a failure to understand the population. The Chief and Health Minister had proposed that a third sex category would satisfy a parental right and reduce the risk of medical interventions on children with intersex variations, but the Minister also wrote in relation to the 2013 Senate report to say that children with ‘DSDs’ were subject to routine medical procedures including surgeries (Carpenter 2018b). In 2019, the ACT government made a commitment to end such practices (ACT Government 2019).

The term ‘indeterminate sex’ used in legislation since the 1990s appears likely to have originated in the International Classification of Diseases version 10, and was later translated into the National Data Dictionary, where it was defined in relation to stillbirths (see, for example, Australian Institute of Health and Welfare 1998, 31). In October 2021, the author of this paper reviewed ABS data on stillbirths by International Classification of Diseases version 10 code and by sex (Australian Bureau of Statistics 2021b). This research ascertained that both sex and ICD-10 codes used the term ‘indeterminate sex’. There were no instances where a stillbirth with a diagnosis of ‘indeterminate sex’ received a sex of ‘indeterminate sex’. Cases where sex was described as ‘indeterminate sex’ involved either residual categories, such as ‘other congenital malformations’, or cases involving delayed growth or renal agenesis. In looking at selected specific diagnoses, just one case was reported between 2016 and 2020 of a stillbirth with ICD-10 code Q56, ‘indeterminate sex and pseudohermaphroditism’. This case was in 2016 with sex reported as ‘male’. Following discussions with the ABS in October and November 2021, sex is no longer reported as ‘indeterminate sex’; it is instead more accurately described as ‘sex not specified’ (Australian Bureau of Statistics 2021c). The methodology and analysis are detailed in Appendix 3. The same issues are likely to be evident in other Commonwealth and State and Territory data, including data published by the AIHW.

It is possible that policy-makers who understand people with intersex variations to be a sex, or people of ‘diverse sex’, believe that prohibitions of sex selection in use of assisted reproductive technologies afford protections to all ‘sexes’. The *Assisted Reproductive Treatment Act 2008 (Vic)*, for example, prohibits sex selection for ‘a purpose of producing or attempting to produce a child of a particular sex’. However, an alternative view might utilise an exemption in the same provisions that permits selection where necessary ‘to avoid the risk of transmission of a genetic abnormality or a genetic disease’, and such a view would align with national guidelines on use of IVF (National Health and Medical Research Council 2017). A 2021 amendment affords protection on grounds of sex characteristics in access to reproductive technologies, but not in their application (Victoria 2021).

A reinterpretation of the meaning of intersex people through analysis of policy in relation to LGBT people can be observed in many settings, including in materials shared by the Australian Institute of Family Studies on intimate partner violence (Campo and Tayton

2015), and also in sport, where the director of Murdoch Children’s Research Institute in Melbourne has co-authored a position paper on participation in sport by cisgender women with intersex variations that makes the surprising, erroneous and politicised proposition that ‘DSD women’ illustrate ‘the new realm of gender fluidity’ (Hamilton et al. 2021: 5).

Finally, the federal government funds a national ‘LGBTIQ+’ helpline and support service known as QLife, established in 2013. QLife is delivered by a consortium of generalist LGBTIQ community organisations, and represents itself as providing ‘Australia-wide anonymous, LGBTI peer support and referral’ for ‘LGBTI individuals, their friends and families, and health professionals’ (QLife 2021). However, the needs of people with intersex variations and family members are not met, and additional resourcing to develop a specific service is considered impossible under current circumstances. The 2021 AHRC report identified a need for support services, and found it necessary to call for provision of public funding for ‘improved access to peer support and health services, including online and by telephone’ (Australian Human Rights Commission 2021, 138–39).

## **ABS Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables**

In an attempt to construct an alternative to data models that frame intersex as a third category, community organisations in our region recommend that intersex people be counted via a separate question on innate ‘variations of sex characteristics’, while also including ‘non-binary’ options in questions on sex and gender to count people who understand themselves outside binary ideas of sex and gender (Carpenter 2019). The ABS ‘Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables, 2020’ outlines a data model that better reflects the real world. It distinguishes innate variations of sex characteristics from sex and gender and recognises actual sex registrations, including the sex registrations of individuals with intersex variations (Australian Bureau of Statistics 2021a).<sup>8</sup> Like other methods of defining intersex populations, this approach needs careful explanation, to ensure community members feel safe to participate, and to gender diverse people who may consider the new terminology to be relevant to them (Navarro 2021). It is likely that this model will need further refinement over time, but it provides a respectful alternative to previous models.

The ABS Standard provides a data model that that is compatible with the accurate recording of health information. In developing the data model, Intersex Human Rights Australia notes that, for health and medical research, additional information about specific diagnostic classifications, or the words individuals use to describe their variation, are likely to be essential, and sensitive, data (Carpenter 2019). Its implementation is illustrated by the Royal Australian College of General Practitioners, which has incorporated the ABS Standard into its Standards for General Practices (5th Edition), noting that:

If patients advise that they have a variation of sex characteristics, then they are likely to have any of a range of specific diagnoses (eg androgen insensitivity or a sex chromosome variation). They may have a surgical history, and may require targeted forms of support (eg hormone treatment). If they select ‘don’t know’, they may have clinical signs or symptoms that can be reviewed (Royal Australian College of General Practitioners 2021).

The data model adopted in the ABS Standard has since been adopted in New Zealand (Stats NZ 2021), with a substantively similar approach also recommended by the US National Academies of Sciences, Engineering and Medicine (2022).

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<sup>8</sup> For a discussion about the relationship between sex as a category and sex characteristics, see Carpenter (2022b).



## Conclusions and recommendations

The current situation is challenging. Public services and other stakeholders have adopted incommensurate and incoherent approaches to the existence and needs of people with intersex variations. In many cases, these respond to proposals by stakeholders with specific values and preferences that do not coincide with the interests of community groups or conform to human rights norms. Distinct and incommensurate ideologies about who intersex people are supposed to be are expressed in siloed systems that, on the one hand, seek to justify, codify and price paediatric surgeries with lifelong deleterious consequences and, on the other hand, define and categorise sex and gender in ways that are not capable of respecting the diversity and lived realities of people with innate variations of sex characteristics.

Some examples of these approaches are disturbing. Recent clinical reports in Australia have explicitly misrepresented community expectations and demands in support of reforms to the Medicare Benefits Schedule, and in support of the status quo in relation to medical treatments. 'Disorders of Sexual Differentiation' nomenclature should not have been introduced into the Medicare Benefits Schedule. 'Disorders of Sex Development' nomenclature should not have been introduced into the ICD-11. No stakeholder believes that all medical interventions affecting sex characteristics should cease, but community organisations and human rights institutions recommend legislation and regulation to ensure that any interventions meet human rights norms.

'LGBTI' research papers and proposals that do not comprehend or address the actual needs and circumstances of each of the populations they claim to address are inherently flawed. The impacts in misrepresenting inadequately resourced and stigmatised populations cannot be overestimated, with consequences for social understanding, policy development and engagement in research by people with stigmatised and misunderstood characteristics. Legislation has repeatedly been amended to refer to multiple sexes or eliminate discrimination in access to treatment, without attending to deeper concerns with unwanted or stigmatising medical treatment.

These circumstances are the product of testimonial injustices. Policy-makers and research institutions have valued and privileged endosex (non-intersex) voices, especially clinical and LGBT voices. Policy developments have typically taken place in silos, with inadequate attention in each silo to developments elsewhere. While most waves of legislation have predated community organising, good practice remains scarce and recent. Community organisations hold expertise and perspectives that are cognisant of lived experience and that attempt to grapple with complexity, but they have also been impoverished and disregarded. They give rise to hermeneutical injustices in that individuals with intersex variations can be unable to reconcile incommensurate beliefs about who intersex people are supposed to be with their lived experience. Hermeneutical and testimonial injustices both separate people with intersex variations from their communities because they see misconceptions and stereotypes, and not people with similar lived experience, and similar identities.

## **Legislative reform**

For any actions on intersex health and welfare to have legitimacy they must attend, as a priority, to the human rights implications of historical and current medical practice. Actions to promote lifelong health and wellbeing of people with intersex variations are a longstanding priority. A longstanding inability of medicine to self-regulate or transparently address human rights concerns regarding treatment, and a lack of evidence to underpin guidelines, require attention to demands for legislative reform. Legislative reform needs to ensure oversight. Legislative reform needs to be accompanied by the resourcing of psychological support, community services, and trauma-informed access to healthcare when in line with personal values and preferences and urgent necessity. The recommendations of the Australian Human Rights Commission regarding legislative protections, oversight, resourcing for peer and family support, and education comprise an integrated package of measures that can significantly advance the human rights, health and welfare of people with intersex variations.

## **Research and data**

While no call for more data should prevent action to address these longstanding community priorities, new research, and improvements to research methods and data models that build on the 2020 ABS Standard are also essential. AIHW, ABS and other Commonwealth and State and Territory data should be reviewed to ensure it meets this new Standard.

## **Diagnostic and procedure classifications**

All Medicare item codes and benefits schedules, and the policies behind them, should be reviewed to ensure that elective feminising or masculinising procedures do not take place on individuals too young to personally consent, and to ensure that relevant procedures are accessible when individuals are able to decide upon any treatment.

Medicare Benefits Schedule item codes 37845, 37848 and 37851 for external feminising genitoplasties and vaginoplasties on minors, should be adjusted to take account of omitted evidence. The current reference to 'congenital disorders of sexual differentiation' in paediatric surgery codes appears to perform multiple functions:

- Access is limited to surgery to minors. This is incompatible with human rights norms and should be rejected as a matter of course, to ensure that individuals are always able to consent to their own treatment, when they have the age and agency to do so. A prohibition on use of the code for surgery on infants and children unable to freely give informed consent is consistent with human rights norms. Access to treatment when able to freely give informed consent is consistent with human rights norms.
- The adoption of 'DSD' nomenclature reinforces clinical authority over necessarily disordered intersex bodies and disregards community concerns. At a minimum, it should be replaced by neutral terminology, but terminology limiting access may not be necessary at all.

- Access is limited to surgery on people with innate variations. This excludes access by, for example, gender diverse people. This seems difficult to justify on any ground other than budgetary considerations and should be reviewed in line with community expectations.

The Medicare Benefits Schedule item code 35565 for feminising surgery, available to adults, appears more limited in scope to ‘vaginal reconstruction’ in certain circumstances.

This review of Medicare codes should include removal of access to item codes for unnecessary treatments on children aged under 10, including 37816 for ‘hypospadias, examination under anaesthesia with erection test, on a person under 10 years of age’.

ICD-11 implementation begins in 2022. Reforms to ICD-11 nomenclature and descriptions should be supported before local or widespread implementation, to help ensure that classifications are not associated with human rights abuses (Carpenter 2018a). Ideally, ‘DSD’ nomenclature should be replaced with ‘congenital variations of sex characteristics’.

Reform to item codes does not obviate a need for systemic reform, as it simply removes access to reimbursement for some costs associated with procedures. It does not, in and of itself, end medical practices that are incompatible with human rights norms.

### **Population data and research**

The population of people with innate variations of sex characteristics is hard to reach, due to a legacy of non-disclosure and partial disclosure, and experiences of misconceptions. The narrow and siloed research foci of clinical and LGBTI research have failed to address the lifetime health and welfare needs of the population. Gaps and omissions in data remain the norm, not the exception.

As a principle, the diversity of sex and gender of people with innate variations of sex characteristics needs to be respected, including respect for cisgender women and men with intersex variations, and gender diverse people with intersex variations. Endosex non-binary people also need to be able to identify themselves. The 2020 ABS Standard provides a current best practice model that is suitable for adoption in most settings, including in surveys on physical and mental health and wellbeing. It is likely that this model will need explanation and, over time, refinement.

Within resourcing constraints, community organisations such as IHRA are engaging with Commonwealth and State and Territory jurisdictions with the aim of addressing inappropriate definitions and understandings of intersex in legislation and regulation.

### **Clinical research**

Medical research has a difficult history, including references to trauma as a justification for genetics research that facilitates elimination of embryos and fetuses with intersex traits, and clinical research aimed at justifying existing medical practices. There is no ethical justification for current and historic medical practices, and no ethical justification for

research to justify such practices. In this context, a databank is unlikely to have community support. Community needs are more mundane, and better served by resourcing for collaborative co-designed research to address lifetime health and wellbeing needs.

### **LGBTI research**

‘LGBTI’ research has frequently failed to meaningfully represent the needs and circumstances of people with intersex variations. The 2021 AHRC report calls for data disaggregation in all research intersex people along with sexual and gender minorities, along with attention to the specific needs and characteristics of the intersex population. This attends to a lack of meaningful data on intersex populations, but take-up is likely to be remain limited, including being limited to people with intersex variations who are LGBTQ. Specific research focusing on the needs and characteristics of people with innate variations of sex characteristics is the only approach that has so far generated useful survey numbers.

### **Eliminating stigma and distress**

Education is necessary to help end stigma, and distress associated with new diagnosis. This should include attention to medical education and potentially the retirement of clinicians wedded to old methods, integration of affirmative content into school curricula, and promotion of public awareness.

### **Community engagement**

Action to address health and welfare must involve and resource community organisations. Community organisations like IHRA and IPSA can advise on policy, and develop and implement peer and family support programs. Resourcing for peer and family support should include a helpline for individuals with variations, and parents and prospective parents. A helpline could be achieved in partnership with other stakeholders, but with a distinct identity. Resourcing is also necessary to fund respectful collaborative research that can help people with innate variations of sex characteristics to flourish.

## Appendix 1: Selected ICD-11 codes

This appendix lists selected relevant ICD-11 codes as structured in the ICD-11 for Mortality and Morbidity Statistics, as on 21 November 2021.<sup>9</sup> For a summary of concerns with the ICD-11 see Carpenter (2018a), and for a submission on selected codes see Carpenter and Cabral (2017).

### 05 Endocrine, nutritional or metabolic diseases

Disorders of the adrenal glands or adrenal hormone system

5A71 Adrenogenital disorders

5A71.0 46,XX disorders of sex development induced by androgens of fetal origin

(omitted code)

5A71.01 Congenital adrenal hyperplasia

5A71.1 46,XX disorders of sex development induced by androgens of maternal origin

Disorders of the gonadal hormone system

5A80 Ovarian dysfunction

5A80.0 Clinical hyperandrogenism

(omitted codes)

5A81 Testicular dysfunction or testosterone-related disorders

### 20 Developmental anomalies

**Structural developmental anomalies primarily affecting one body system**

**Structural developmental anomalies of the female genital system**

(additional codes omitted)

LB41 Structural developmental anomalies of clitoris

LB41.0 Agenesis of clitoris

LB41.1 Duplication of clitoris

LB41.2 Clitoromegaly

LB41.Y Other specified structural developmental anomalies of clitoris

LB41.Z Structural developmental anomalies of clitoris, unspecified

LB42 Structural developmental anomalies of vagina

LB42.0 Absence of vagina

(additional codes omitted)

LB42.Y Other specified structural developmental anomalies of vagina

LB42.Z Structural developmental anomalies of vagina, unspecified

(additional codes omitted)

LB44 Structural developmental anomalies of uterus, except cervix

LB44.0 Agenesis or aplasia of uterine body

LB44.1 Hypoplasia of uterus

(additional codes omitted)

LB44.6 Uterovaginal malformation due to diethylstilbestrol syndrome

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<sup>9</sup> Available online at <https://icd.who.int/browse11/l-m/en> with a development version at <https://icd.who.int/dev11/f/en>

- LB44.Y Other specified structural developmental anomalies of uterus, except cervix
- LB44.Z Structural developmental anomalies of uterus, except cervix, unspecified
- LB45 Structural developmental anomalies of ovaries, fallopian tubes or broad ligaments
  - LB45.0 Congenital absence of ovary
  - LB45.1 46,XX gonadal dysgenesis (additional codes omitted)
  - LB45.Y Other specified structural developmental anomalies of ovaries, fallopian tubes or broad ligaments
  - LB45.Z Structural developmental anomalies of ovaries, fallopian tubes or broad ligaments, unspecified

### **Structural developmental anomalies of the male genital system**

- LB50 Micropenis or penis agenesis
- LB51 Anorchia or microorchidia
  - LD2A.2 Testicular agenesis
- LB52 Cryptorchidism (\*where associated with other characteristics)
- LB53 Hypospadias
  - LB53.0 Hypospadias, balanic
    - LB53.0 Hypospadias, coronal
    - LB53.1 Hypospadias, glandular
    - LB53.0Y Other specified hypospadias, balanic
    - LB53.0Z Hypospadias, balanic, unspecified
  - LB53.1 Hypospadias, penile
  - LB53.2 Hypospadias, penoscrotal
  - LB53.3 Hypospadias, scrotal
  - LB53.4 Hypospadias, perineal
  - LB53.Y Other specified hypospadias
  - LB53.Z Hypospadias, unspecified
- (code omitted)
- LB55 Epispadias
- LB56 Bifid scrotum (codes omitted)
- LB59 Hypoplasia of testis or scrotum
- LB5Y Other specified structural developmental anomalies of the male genital system
- LB5Z Structural developmental anomalies of the male genital system, unspecified

### **Multiple developmental anomalies or syndromes**

- (codes omitted)
- LD2A Malformative disorders of sex development
  - LD2A.0 Ovotesticular disorder of sex development
  - LD2A.1 46,XY gonadal dysgenesis
  - LD2A.2 Testicular agenesis
  - LD2A.3 46,XY disorder of sex development due to a defect in testosterone metabolism

- LD2A.4 46,XY disorder of sex development due to androgen resistance
- LD56 Chimaera 46, XX, 46, XY
- LD2A.Y Other specified malformative disorders of sex development
- LD2A.Z Malformative disorders of sex development, unspecified
- LD2F Syndromes with multiple structural anomalies, without predominant body system involvement
  - LD2F.1 Syndromes with multiple structural anomalies, not of environmental origin  
(codes omitted)
  - LD2F.14 MURCS association
  - LD2F.15 Noonan syndrome
  - LD2H.0 Fraser syndrome

### **Sex chromosome anomalies**

- LD50 Number anomalies of chromosome X
  - LD50.0 Turner syndrome
    - LD50.00 Karyotype 45, X
    - LD50.01 Karyotype 46, X iso Xq
    - LD50.02 Karyotype 46, X with abnormal sex chromosome, except iso Xq
    - LD50.03 Mosaicism, 45, X, 46, XX or XY
    - LD50.04 Mosaicism, 45, X or other cell line with abnormal sex chromosome
  - LD50.1 Karyotype 47,XXX \*
  - LD50.2 Mosaicism, lines with various numbers of X chromosomes
  - LD50.3 Klinefelter syndrome
    - LD50.30 Klinefelter syndrome with karyotype 47,XXY, regular
    - LD50.31 Klinefelter syndrome, male with more than two X chromosomes
    - LD50.3Y Other specified Klinefelter syndrome
  - LD50.Y Other specified number anomalies of chromosome X
  - LD50.Z Number anomalies of chromosome X, unspecified
- LD51 Structural anomalies of chromosome X, excluding Turner syndrome
- LD52 Number anomalies of chromosome Y
  - LD52.0 Male with 46,XX karyotype
  - LD52.1 Male with double or multiple Y
  - LD52.Y Other specified number anomalies of chromosome Y
  - LD52.Z Number anomalies of chromosome Y, unspecified
- LD53 Structural anomalies of chromosome Y
- LD54 Male with sex chromosome mosaicism  
(additional code omitted)
- LD56 Chimaera 46, XX, 46, XY
- LD5Y Other specified sex chromosome anomalies
- LD5Z Sex chromosome anomalies, unspecified
- LD56 Chimaera 46, XX, 46, XY

## Appendix 2: Selected MBS item codes

The following table itemises Medicare Benefits Schedule item codes, with the number of procedures in FY2016/17 stated if available from the Taskforce reports. These tables are non-exhaustive and, given the scope of this paper, primarily only from information in the MBS Taskforce review reports on paediatric surgery and urology. Additional procedures may also be relevant, particularly those related to gonadectomies, exstrophies, and additional surgical procedures affecting genitals.

### Feminising surgeries

Item codes for paediatric surgeries:

37845	Congenital disorder of sexual differentiation with urogenital sinus, external genitoplasty with or without endoscopy (previously 'Ambiguous genitalia with urogenital sinus, reduction clitoroplasty, with or without endoscopy') (Anaes.) (Assist.)	3
37848	Congenital disorder of sexual differentiation with urogenital sinus, external genitoplasty with endoscopy and vaginoplasty (previously 'Ambiguous genitalia with urogenital sinus, reduction clitoroplasty, with endoscopy and vaginoplasty') (Anaes.) (Assist.)	4
37851	Congenital disorder of sexual differentiation, vaginoplasty for, with or without endoscopy (previously 'Congenital adrenal hyperplasia, mixed gonadal dysgenesis or similar condition, vaginoplasty for, with or without endoscopy') (Anaes.) (Assist.)	9

The following non-paediatric code is drawn from the Medicare Benefits schedule:

35565 Vaginal reconstruction for congenital absence, gynatresia or urogenital sinus

The following codes may also be relevant in some cases, in some cases they may be associated with or consequential to other feminising (or masculinising) surgeries (Medicare Benefits Schedule Review Taskforce 2018, 2020, 43):

30641	Orchidectomy, simple or subcapsular, unilateral with or without insertion of testicular prosthesis (Anaes.) (Assist.) (this excludes oncology services which are included in item 30642)	321
30643	Exploration of spermatic cord, inguinal approach, with or without testicular biopsy and with or without excision of spermatic cord and testis on a person under 10 years of age	22
30644	Exploration of spermatic cord, inguinal approach, with or without testicular biopsy and with or without excision of spermatic cord and testis (Anaes.) (Assist.)	1,545
30390	Laparoscopy, diagnostic, with or without aspiration of fluid, on a patient 10 years of age or over, if no other intra-abdominal procedure is performed (H)	



- 35638 Complicated operative laparoscopy, including use of laser when required, for one or more of the following procedures:
- (a) oophorectomy;
  - (b) ovarian cystectomy;
  - (c) myomectomy;
  - (d) salpingectomy;
  - (e) salpingostomy;
  - (f) ablation of moderate or severe endometriosis requiring more than 1 hour's operating time;
  - (g) division of utero-sacral ligaments for significant dysmenorrhoea; other than a service associated with another intraperitoneal or retroperitoneal procedure except item 30724 (H)

## Masculinising surgeries

Selected procedures (Medicare Benefits Schedule Review Taskforce 2018):

37354	Hypospadias, meatotomy and hemi-circumcision (Anaes.) (Assist.)	46
37815	Hypospadias, examination under anaesthesia with erection test (Anaes.)	12
37816	Hypospadias, examination under anaesthesia with erection test, on a person under 10 years of age	143
37818	Hypospadias, glanuloplasty incorporating meatal advancement (Anaes.) (Assist.)	12
37819	Hypospadias, glanuloplasty incorporating meatal advancement, on a person under 10 years of age	75
37821	Hypospadias, distal, 1 stage repair (Anaes.) (Assist.)	11
37822	Hypospadias, distal, 1 stage repair, on a person under 10 years of age	175
37824	Hypospadias, proximal, 1 stage repair (Anaes.) (Assist.)	<6
37825	Hypospadias, proximal, 1 stage repair, on a person under 10 years of age	62
37827	Hypospadias, staged repair, first stage (Anaes.) (Assist.)	<6
37828	Hypospadias, staged repair, first stage, on a person, 10 years of age or over	13
37830	Hypospadias, staged repair, second stage (Anaes.) (Assist.)	<6
37831	Hypospadias, staged repair, second stage, on a person under 10 years of age. (Anaes.) (Assist.)	16
37833	Hypospadias, repair of urethral fistula (Anaes.) (Assist.)	27
37834	Hypospadias, repair of urethral fistula, on a person under 10 years of age	73

The following codes (Medicare Benefits Schedule Review Taskforce 2018) may also be relevant in some cases, particularly where associated with or consequential to other masculinising surgeries:

37300	Urethral sounds, passage of, as an independent procedure (Anaes.)	679
37303	Urethral stricture, dilatation of (Anaes.)	2,131
37306	Urethra, repair of rupture of distal section (Anaes.) (Assist.)	18
37327	Urethrotomy, optical, for urethral stricture (Anaes.) (Assist.)	3119

37309	Urethra, repair of rupture of prostatic or membranous segment (Anaes.) (Assist.)	10
37372	Urethral diverticulum, excision of (Anaes.) (Assist.)	62
37408	Penis, repair of laceration of cavernous tissue, or fracture involving cavernous tissue (Anaes.) (Assist.)	26
37411	Penis, repair of avulsion (Anaes.)	<6
37417	Penis, correction of chordee by plication techniques including Nesbit's corporoplasty (previously 'Penis, correction of chordee, with or without excision of fibrous plaque or plaques and with or without grafting') (Anaes.) (Assist.)	505
37418	Penis, correction of chordee with incision/excision of fibrous plaque or plaques, with or without mobilisation of the neuro-vascular bundle and/or the urethra (previously 'Penis, correction of chordee, with or without excision of fibrous plaque or plaques and with or without grafting, involving mobilization of the urethra') (Anaes.) (Assist.)	116

### **Surgery for 'intersex problems'**

Surprisingly, given use of 'DSD' terminology' in relation to some feminising surgeries, the MBS Taskforce report on paediatric surgery also refers to a perceived lack of MBS item codes for 'Surgery for intersex problems i.e. biopsies, excision of gonads':

There are no MBS items specifically referring to intersex. Given the wide spectrum of clinical presentations, likely to be some intersex scenarios that could potentially be accommodated by a range of existing items. For example 35638 can be used for laparoscopic excision of ovaries in the context of intersex and diagnostic laparoscopy (30390) can be used if uncertainty around gender. (Medicare Benefits Schedule Review Taskforce 2020, 43)

The Taskforce advised the Department:

No further immediate action. If ANZAPS want to pursue the inclusion of specific procedures for intersex scenarios not covered by existing items then further discussion is needed to identify gaps in terms of existing items, what new items (and associated Fees) need to be created and whether this is pursued in a process that is separate to this Review. (Medicare Benefits Schedule Review Taskforce 2020, 43)

## Appendix 3: Stillbirths reported 2016-2020

In October 2021, I analysed data on stillbirths during the period 2016-2020 in ABS tables on causes of foetal death (Australian Bureau of Statistics 2021b) in order to identify the characteristics of fetuses described as having 'indeterminate sex' and their relationship to fetuses with intersex-related diagnoses.

**Methodology:** I disaggregated the data on 'indeterminate sex' from data on males, females and total figures, where the total figures included cases of 'indeterminate sex'. I looked at the data on 2020 in more detail to find out causes of death, and I looked at some specific diagnoses associated with intersex variations in order to ascertain the sex reported in those cases.

**Findings:** Around 1% of reported cases each year from 2016-2020 were reported as 'indeterminate sex'. In 2020 there were 19 cases. When I disaggregated those data in 2020 to find out the cause of death, 16 of the 19 cases were listed in residual categories such as:

- 'fetal death of unspecified cause' (ICD-10 code P95) with 8 of 19 cases in 2020.
- 'other conditions originating in the perinatal period' (ICD-10 code P96) with 3 of 19 cases in 2020.
- 'other congenital malformations, not elsewhere classified' (ICD-10 code Q89) with 3 of 19 cases in 2020.
- 'other conditions of integument specific to fetus and newborn' (ICD-10 code P83) with 1 of 19 cases.
- 'Disorders related to short gestation and low birth weight, not elsewhere classified' (ICD-10 code P07) with 1 of 19 cases.

Just 3 cases were not reported in a residual category:

- 'Slow fetal growth and fetal malnutrition' (ICD-10 code P05) with 2/19 cases.
- 'Renal agenesis and other reduction defects of kidney' (ICD-10 code Q60) 1/19 cases.

In looking at selected specific diagnoses relating to innate variations of sex characteristics:

- 'indeterminate sex and pseudohermaphroditism' (ICD-10 code Q56), with just 1 case reported in 2016 with sex reported as male.
- this case appeared in the category 'congenital malformations of genital organs' and there were no other cases in this category during the period 2016-2020.
- stillbirths with Turner syndrome and other sex chromosome variations were all reported as female or male.

**Concluding remarks:** As a result of this analysis and subsequent discussion with ABS staff, the ABS amended their description of the residual sex category at the start of November 2021, and it is now described as 'sex not specified'.

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