



Perspective

# From Harmful Practices and Instrumentalisation, towards Legislative Protections and Community-Owned Healthcare Services: The Context and Goals of the Intersex Movement in Australia

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**Abstract:** People with innate variations of sex characteristics (also known as intersex traits or disorders or differences of sex development) have any of a wide range of innate physical traits that differ from medical and social norms for female and male bodies. Responses to these physical differences create experiences and risks of stigmatisation, discrimination, violence, and harmful medical practices intended to promote social and familial integration and conformity with gender stereotypes. As is evident globally, the Australian policy response to the existence and needs of people with innate variations of sex characteristics has been largely incoherent, variously framing the population as having disordered sex development in need of “fixing”, and a third sex/gender identity group in need of recognition, with only recent engagement by intersex community-controlled civil society organisations. This paper presents an overview of the context and goals of the intersex human rights movement in Australia. Australian intersex community organisations have sought to apply human rights norms and develop new infrastructure to address key health and human rights issues, and necessitating new ways of resolving policy incoherence. Together with human rights, mental health, and public health institutions, they have called for significant changes to medical models of care and reform to research and classification systems. Intersex community organising and resourcing have made a tangible difference. The Australian Capital Territory is the first jurisdiction in the country to move ahead with reforms to clinical practice, including a legislative prohibition of certain practices without personal informed consent, oversight of clinical decision-making, and investment in psychosocial support. A national community-controlled psychosocial support service has also commenced.

**Keywords:** intersex; disorders of sex development; LGBT; human rights; social policy; health policy



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## 1. Introduction

People with innate variations of sex characteristics, or intersex traits, have any of a wide range of innate physical traits that differ from medical and social norms for female and male bodies. Responses to these perceptions of difference create experiences and risks of stigmatisation, discrimination, violence, and harmful medical practices intended to promote social and familial integration and conformity with gender stereotypes.

Like all stigmatised populations, a range of different language is used to describe intersex traits, but many individuals with these traits lack access to words that can help them understand themselves. Dominant ideological frameworks treat people with intersex traits as disordered and in need of “fixing”, or elimination from the gene pool, and as an “other” third category of sex, in need of recognition. Each framework is reflected in different data, including disease and procedure classifications, and sex/gender classifications. Neither approach respects the diversity of the population and differing personal values

and preferences. Both approaches contribute to widespread experiences of stigma and shame, including in social, intimate, and clinical settings.

This context provides a challenging landscape where different institutions have developed distinct and incommensurate policies and practices that treat the population in different ways. Policy and public incomprehension and incoherence also mean that the goals and work of the intersex movement are often poorly recognised or understood.

While multiple analyses of the early intersex movement in the United States and Canada exist (an early insider perspective can be read in (Chase 1998)), and recent legal attention has focused on advocacy within the international human rights system (Bauer et al. 2019; Lum 2021; Zelayandia-Gonzalez 2023), fewer studies have considered the goals and work of the contemporary intersex movement outside of North America, and no comparable peer-reviewed analysis has yet been published on intersex advocacy in Australia. The intention of this paper is to present a coherent overview and analysis of community responses to policy and public incoherence. The paper presents a comprehensive overview of the history and context for community development, advocacy and service delivery, and the work of community organisations to construct and seek reform. The paper begins by summarising contested definitions of the population, and outlining health issues and medical treatment practices. The paper then considers the historical context, recent developments in advocacy and service delivery, and community goals for the future.

## 2. Defining the Population

The population is known using a range of different terms, each associated with distinct values and contested borders. The term intersex has a medical origin and was appropriated or adopted by the first self-organised groups of intersex people in the 1990s. Up until 2006, the term intersex coexisted with pejorative traditional terms such as “hermaphrodite”, and the clinical term “pseudo-hermaphrodite”.

In 2005, an invite-only clinical meeting and subsequent “consensus statement on management of intersex disorders” introduced a new clinical umbrella term of “disorders of sex development” (DSD) (Hughes et al. 2006; Houk et al. 2006), sometimes referred to by similar terms such as “disorders of sexual differentiation” (Medicare Benefits Schedule Review Taskforce 2020) and “differences of sex development” (Kalfa et al. 2024). While these terms have been implemented within medicine, globally, they have never been accepted or adopted by community and patient organisations in Australia.

Individuals also use specific diagnostic terminology, with more than 40 distinct entities such as:

- Chromosomal variations: such as 47,XXY (Klinefelter syndrome), 45,X0 (Turner syndrome), mosaicism, mixed gonadal dysgenesis.
- Androgen production or action in people with XY chromosomes: androgen insensitivity (AIS), 5 alpha reductase deficiency, 17 beta hydroxysteroid dehydrogenase 3 deficiency.
- Androgen production in people with XX chromosomes: congenital adrenal hyperplasia, maternal androgen excess, aromatase deficiency.
- Structural variations affecting gonad or genital development: micropenis, anorchia (no testes), ovotestes, hypospadias, cloacal and bladder exstrophies, vaginal agenesis (MURCS/MRKH), gonadal dysgenesis, familial hypogonadism.

Diagnostic terminology is undergoing rapid change, from terminology using eponyms and language based on terms using the word hermaphroditism, towards descriptive terms and terms arising from genetics research.

Many Australian institutions persist in framing intersex variously as a sexual orientation (“LGBTI or heterosexual”) or a gender identity; a sex, indeterminate sex, third sex category, and “sex diverse”; or a population constructed as both adults with a marginalised identity and babies subjected to surgery. For example, some national sporting, scientific, and mental health organisations have framed intersex as a form of gender diversity (Australian Sports Commission and CSIRO 2022; Headspace 2020).

Adults with innate variations of sex characteristics have higher rates of sexuality and gender diversity or discomfort with gender roles than the general population (T. Jones 2016; Furtado et al. 2012; Nimkarn and New 2010). These factors and the possibility of so-called “natural experiments” mean that clinical work aimed at establishing the genetic or environmental origins of sexuality and gender identity has taken place on people with intersex variations (see, for example, Meyer-Bahlburg 1990). However, people with intersex variations can grow up to be heterosexual or not and cisgender women or men or not, while infants and children lack the age and agency to express any identity.

The high prevalence of misconceptions means that it is common for the word intersex to be included in descriptions of LGBTI or related population groupings without comprehending or attending to the specific needs and circumstances of the population. A national mental health organisation, for example, presents mental health considerations as relating to respect for pronouns and avoidance of heteronormative language (Headspace 2020). The diverse lifelong or chosen legal or social statuses of individuals with innate variations of sex characteristics are frequently disregarded or not comprehended (Carpenter 2020). This should be understood to directly impact service utilisation, disclosure, engagement, and nomenclature preferences by people with lived experience, irrespective of their actual identities.

A neutral language of innate “variations of sex characteristics” (VSCs or IVSCs) was introduced by community organisations in Australia and Aotearoa New Zealand from 2017 (AIS Support Group Australia et al. 2017). This terminology aims to avoid many misconceptions that impact the population, and it has utility in both legal protections from harmful practices and discrimination (Australian Capital Territory 2023), and in data collection (Australian Bureau of Statistics 2021).

The boundaries of all definitions are to some extent subjective, reflecting shifts in social and clinical constructions of boundaries between “normal” and “abnormal” bodies, as well as the role of subjective judgements by clinical individuals and groups in problematising bodies that are different. Nevertheless, Australian intersex community-controlled organisations exist for all people who risk or experience stigma and discrimination because of their innate sex characteristics or sex development, and their families.

Many people do not have a language to describe themselves. Up until 2006, with variable change since that date, many people have not been told their diagnosis, nor the facts about their medical treatment (Lee et al. 2016; Office of the Privacy Commissioner 2018; Carpenter 2024). This was thought to protect individuals from stigma but also to promote conformity with social expectations. For example, women with complete androgen insensitivity (and XY chromosomes and testes) have been told they had hysterectomies when they never had a uterus (Carpenter 2024). Disclosure of long-term consequences of surgeries has also been limited, and individuals informed of their diagnosis have been encouraged not to disclose their traits to others (Intersex Peer Support Australia 2023).

### 3. Health Issues

Individuals with some traits experience specific risks, including for mental health issues arising from experiences of trauma, stigmatisation, and shame, including experiences arising in medical settings. Some traits are sometimes associated with specific health issues, frequently including innate or iatrogenic infertility. Some traits need urgent treatment or may be fatal if not treated (such as salt wasting congenital adrenal hyperplasia or bladder exstrophy). Newborn bloodspot screening has been introduced to identify risks associated with salt wasting. Some traits are associated with cancer risks in gonads such as testes, ovotestes, or streak gonads. Gonadal cancer risks have an unhelpful history of exaggeration and intertwining with “psychosocial” rationales for treatment (Senate 2013; Carpenter and Intersex Human Rights Australia 2022). Psychosocial rationales are aimed at eliminating risks of stigmatisation through surgery and hormonal treatment, facilitating “social or familial integration”, and mitigating parental distress. Some traits are associated with cardiovascular, skeletal, renal, neurodevelopmental, and other issues.

Diagnosis can occur prenatally, at birth, during childhood or adolescence, and later in life—for example, due to diagnosis of an intersex trait in a relative of a prospective parent, genital appearance at birth, a failure to menstruate in an adolescent girl, atypical pubertal development, or infertility. Medical responses aim to make bodies appear or function more typically in line with sex observed or assigned at birth. Depending on age of diagnosis, this can lead to medical treatments that an individual would not choose for themselves. Genetics research is contributing to the prenatal elimination of human tissues with intersex traits (Eggers et al. 2016; Amor 2020)—for example, as part of “risk estimation” in “reproductive planning for the family” (O’Connell et al. 2021; Amor 2020), despite concerns about the ethical basis for their elimination (Kirk et al. 2020; Carpenter and Intersex Human Rights Australia 2020).

Many people with innate variations of sex characteristics have significant health issues arising from medical treatment. This particularly includes experiences of trauma, loss of sensation and sexual function from unnecessary early medical interventions; limited or absent disclosure of health information, and a lack of ability to make informed decisions about treatment, including lack of access to resourced peer support; and distress from infertility or limited fertility (Office of the High Commissioner for Human Rights 2019; Australian Human Rights Commission 2021; Carpenter 2024).

It remains the norm for children with intersex variations who have a diagnosis to be subjected to surgical and/or hormonal interventions early in life (see, for example, Adikari et al. 2019). These interventions are intended to make children’s bodies appear or function in ways that are more typical for observed/assigned sex and gender. For example, Australia’s paediatric endocrine group has described “surgical management” as indicated “for the purpose of appearance including reduction of an enlarged clitoris or repair or construction of a urinary outlet to the end of the penis”, despite “particular concern” regarding post-surgical “sexual function and sensation” (Australasian Paediatric Endocrine Group et al. 2013). “Normalising” surgeries and hormonal interventions are frequently grounded in gender stereotypes or psychosocial rationales for treatment.

Clear demonstrations of underlying gender stereotypes can be found in clinical propositions that girls with intersex variations need surgery to “enhance” genital appearance, while boys need surgery to ensure a “functional” norm of standing to urinate (Carpenter 2024; Family Court of Australia 2016; Australasian Paediatric Endocrine Group et al. 2013). Instead of mitigating risks of discrimination and stigmatisation, the Senate Community Affairs References Committee and community, public health, and human rights institutions regard these interventions as examples of discriminatory treatment, associated with the stigmatisation of bodies that are different (Senate 2013; Australian Human Rights Commission 2021; Public Health Association of Australia 2021).

These interventions can deliberately pre-empt choices made by individuals and assume future values and preferences. In addition, there is no evidence that surgeries are capable of addressing risks of stigmatisation (Lee et al. 2016; Australian Human Rights Commission 2021; Liao 2022). Medical examinations and experiences, ignorance, and shame exacerbate experiences of stigmatisation, with an impact on mental health (Liao 2022; Hegarty 2023; Hart and Shakespeare-Finch 2021; Schützmann et al. 2009) as well as sexual function and sensation.

Contested by intersex community organisations since the 1990s, the pre-emptive treatment model has been perpetuated by lack of disclosure and awareness of medical practices and by the marginalisation and exclusion of both people with lived experience and psychosocial professionals (Carpenter 2024). Medical practices are set out in invite-only expert “consensus statements” due to a lack of supporting evidence and even a lack of clinical consensus regarding surgical timing, indications, and evaluation of outcome (Lee et al. 2016). The lack of evidence and clinical consensus, as well as evidence of lack of clinical adherence to clinical guidelines, mean that guidelines are unlikely to change medical practice without the external imposition of new parameters for clinical decision-making via legislative reform (Intersex Human Rights Australia 2020).

Multidisciplinary teams evaluating treatment may consider only a subset of patients posing ethical or diagnostic “dilemmas” (Vora et al. 2016) and are led by surgeons or endocrinologists. Psychosocial care for families and individuals is often poorly understood and regarded as relevant only after surgical or hormonal treatment (Carpenter 2024). Community organisations are absent (Gramc et al. 2021; Liao 2022). The mere existence of multidisciplinary teams has been proposed as a way of improving care and sidestepping legal oversight (Vora et al. 2016), but “medically unnecessary surgical procedures that carry significant risk of harm continue to be presented as legitimate options” (Human Rights Watch 2017). At the same time, Australian clinical reports have persistently misrepresented community and institutional calls for oversight and an end to unnecessary or deferable procedures as if they are a call to end all medical treatment for children, including uncontentious and non-deferable treatment (Carpenter 2024; O’Connor 2016, p. 531; Vora et al. 2021, p. 5; Australian Human Rights Commission 2021, p. 131).

#### 4. The Historical Context in Australia

As biological variations, intersex traits have always existed in humans, other mammals, and other species. Traditional Christian and Islamic law and common law had places for “hermaphrodites” or “al-khunthā”, to be treated as female or male, with different legal rights depending on predominant characteristics or method of urination. The term hermaphrodite has since taken on specific meanings in biology; these traditional terms are now often understood to be pejorative, and their long legal history has largely been erased. Historical First Nations approaches in these lands are not well understood; for example, the views of Tiwi subjects of scarce early Australian medical journal reports are difficult to distinguish from the medical gaze (Ford 1941; Walker et al. 1970).

Medicalisation of people with innate variations of sex characteristics occurred alongside medicalisation of sexuality and gender diverse populations, arising from moral panics about people who break social, legal, and religious expectations for women and men, girls and boys (Reis 2009). As recently as a national inquiry into religious freedoms in 2018, no evidence was found of religious motivations to discriminate against intersex people (Ruddock et al. 2018). However, moral panics about transgender people, biological-only definitions of sex that cannot account for actual observed or assigned sex, and continued associations between intersex and LGBT populations mean that conservative religious bodies are beginning to reinterpret traditional understandings to, for example, discuss “disorders of sexual development” in the same manner as transgender populations (Intersex Human Rights Australia and GATE 2019; Synod of the Diocese of Tasmania 2023).

Early surgical, hormonal, and associated interventions on infants and children arose in the 1930s and became widespread in the 1950s (Hampson et al. 1956; Reis 2009), reaching Australia by at least the 1960s (Fraser et al. 1966) and still remaining routine today (Adikari et al. 2019; Hutson et al. 2020).

The Family Court has adjudicated “special medical procedures” involving medical interventions with sterilising effects, at least since passage of the Family Law Act 1975 (Commonwealth). The Court appears to have approved every relevant case involving children with innate variations of sex characteristics, approving surgical and/or hormonal treatment in line with clinical affidavits. For example, the sterilisation of a child was authorised in the judgement of a 2016 Family Court case where the judge referred to a history of feminising surgeries on an infant as surgeries that “enhanced the appearance of her female genitalia”; that surgical history had not been the subject of court oversight (Family Court of Australia 2016; Kelly and Smith 2017; M. Jones 2018; Overington 2016). Brennan J. in the High Court of Australia, has asserted that surgeries aimed at ameliorating “cosmetic deformities” and “pathological conditions” are “therapeutic” while questioning the ability to distinguish between therapeutic and non-therapeutic treatment (High Court of Australia 1992). Australian clinicians have asserted that the review of “challenging DSD cases” or ethical or diagnostic “dilemmas” by multidisciplinary teams provides a viable alternative to court oversight (Vora et al. 2016).

The United Nations Office of the High Commissioner for Human Rights has expressed concern that “Loose conceptions of medical necessity or therapeutic treatment may facilitate social and cultural rationales, and other rationales that lack evidence of urgent need” (Office of the High Commissioner for Human Rights 2019). Nevertheless, the Australian government asserted in 2021 that “Court authorisation is required for any surgical or sterilisation procedure that is not medically necessary for children with intersex characteristics” (Working Group on the Universal Periodic Review 2021). This statement is not borne out in evidence from the 2016 Family Court case regarding surgical interventions that “enhanced the appearance” of female genitalia prior to the court case, nor subsequent clinical reports (for example, note the matter of fact disclosure of feminising surgery on infants disclosed in Adikari et al. 2019; Carpenter 2024).

Constructions of intersex people as a third sex, neither female nor male, have been evident in court decisions dating back to 1979; these adversely impact men and women with intersex variations and make their lived experiences incomprehensible. In 1979, a man, assigned male at birth with XX sex chromosomes, was described as a “true hermaphrodite” in a Family Court decision to annul his marriage (Family Court of Australia 1979). Legal discussion of his case described him as a “true trans-sexual” “assigned” by “sex change surgery” (Bailey 1979), despite his being registered male at birth, with no evidence of any attempt to change that sex registration. While criticised as creating a precedent out of step with historical norms (Finlay 1980), the decision has since remained cited as a case of a man’s “mistaken identity”—that he was not really a man (Family Court of Australia 2018). Contrarily, a first passport with an “X” sex marker was issued in 2002, to a West Australian with 47,XXY chromosomes who sought this option (Butler 2003; Meyer-Bahlburg et al. 2004). Reporting of this passport decision plausibly contributed to a change in clinical nomenclature in 2006 (Hughes et al. 2006).

A public, policy, and academic focus on matters of identity has remained pervasive since (see, for example, Fenton-Glynn 2018), despite community calls to better respect the plurality of identities, lived experiences, and preferences within the population of people with innate variations of sex characteristics. For example, the “X” sex marker on passports remains associated with intersex bodies today, despite longstanding attempts to address the underlying national guidelines (National LGBTI Health Alliance et al. 2015).

The first waves of legislation referring to the population occurred in the 1990s and early 2000s, largely predating or unresponsive to intersex community development work:

- In a wave of legislation introducing anti-discrimination protections for transgender people, where definitions of transgender or gender identity included reference to “people of indeterminate sex” (Carpenter 2022). This is still evident in New South Wales anti-discrimination legislation introduced in 1996 (New South Wales 1996) and has been replaced in most jurisdictions by protections on grounds of “sex characteristics”.
- In a wave of legislation (all but Western Australia between 1994 and 2000) to prohibit female genital mutilation, containing exceptions permitting surgery on children with “ambivalent sex”. This is still evident in the criminal codes of most States and Territories (Attorney General’s Department 2013).
- An overlapping wave of legislation regulated the recognition of transgender people, where “reassignment surgery” has been defined to include surgery to resolve or eliminate “ambiguities” in children’s sex characteristics (Carpenter 2023). This remains evident in the Western Australian criminal code and gender recognition legislation (Western Australia 2000, 2004).

It seems likely that some of these developments occurred due to advocacy by transgender people, possibly informed by the 1979 Family Court decision. While these can be expected to be well intentioned, they arise out of a different set of interests and have contributed to incomprehension and harm. Some of the beliefs underlying this advocacy include a belief that association of “transsexualism” with unambiguously biological causes would ameliorate stigma and facilitate access to surgical interventions experienced by intersex people (Wallbank 2015; critiqued in Carpenter 2018).

The first Australian community organisation (Intersex Peer Support Australia or IPSA, then known as the Androgen Insensitivity Syndrome Support Group Australia), became peer-led in 1996 and registered in 2001. Originally only for people with androgen insensitivity, it was established alongside a small number of other diagnosis-specific groups. IPSA now supports all people who experience or risk stigmatisation and harm because of their innate sex characteristics and their families, and it is still run by volunteers. Intersex Human Rights Australia (IHRA) was established in 2009 and registered in 2010 to focus on health and human rights policy; funded by foreign philanthropy, its first staff were appointed at the end of 2016. IHRA began offering psychosocial support services for individuals and family members through the InterLink program in 2023, with pilot funding from the federal Department of Social Services. While still limited, resourcing has made a critical difference to the ability of IHRA to promote reform and deliver community services.

The first government reports referring to a “GLBTI” population were published over two decades ago in Victoria and addressed intersex health issues ([Ministerial Advisory Committee on Gay and Lesbian Health 2002](#)). In contrast to contemporaneous legal developments where opposition to association of intersex traits with the attribute of gender identity in anti-discrimination law was unsuccessful, this positive development was influenced by early intersex advocates and provides an indication of a longstanding community focus on health policy. Misconceptions remain pervasive in policy and LGBTQ+ community settings. With recent and important exceptions, there has been limited attention to the specific needs and circumstances of people with innate variations of sex characteristics, evidenced by a lack of widespread understanding of those needs and circumstances, and a preoccupation with identity-based protections and recognition ([Carpenter 2021](#)).

## 5. Recent Developments

With a growth in Australian intersex organising and resourcing over the last decade, new anti-discrimination protections have been implemented: opportunistically on grounds of intersex status in the Commonwealth in 2013, then in Tasmania and South Australia, and then on grounds of sex characteristics (Australian Capital Territory, Northern Territory, Queensland, Victoria, and Tasmania, with commitments made in the Commonwealth Parliament ([Burke 2022](#)), in Western Australia, and with a proposal before the New South Wales Parliament).

Advocacy by IHRA and disability organisations led to the explicit inclusion of intersex people in a Senate Community Affairs References Committee inquiry into involuntary or coerced sterilisation ([Senate 2013](#)). This was likely the first parliamentary inquiry into intersex health issues anywhere in the world. Reporting in October 2013, it called for significant reform to clinical practice, including establishment of human rights affirming guidelines for treatment that favour deferral of non-urgent treatment until people are old enough to make their own decisions. It also called for independent oversight of clinical decisions and resourcing for psychosocial support for individuals and families. No recommendations were implemented.

In 2017, community organisations and advocates gathered at an event in Darlington, Sydney, and developed a common platform known as the Darlington Statement ([AIS Support Group Australia et al. 2017](#)). It calls for protections from discrimination and harm, including through the criminalisation of deferrable medical interventions, independent oversight of clinical practices, resourcing for psychosocial support for individuals and families, and more.

In 2017, the Australian Human Rights Commission established an inquiry into medical practices. This followed advocacy by IHRA and also reporting of a 2016 Family Court case. Following a process supported by a reference group including community, legal, human rights, and clinical experts, it reported in 2021 ([Australian Human Rights Commission 2021](#)). In considering rationales for contested medical interventions, the Commission found that:

*Psychosocial rationales do not rise to the standard of medical necessity to avoid serious harm, given that less intrusive options exist that should be preferred, and that psycho-*

*logical and psychiatric experts do not believe that there is any robust scientific evidence to support the assertion that interventions in the circumstances are in the individual's best interests. (Australian Human Rights Commission 2021)*

In considering the case for binding legislation and regulation in place of non-binding clinical guidance, it found that:

*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)*

The Commission called for the criminalisation of unnecessary medical interventions, with legislation and regulation to be “guided by a human rights framework based on the following principles”:

- “Bodily integrity principle”, recognising that all “people have the right to autonomy and bodily integrity”.
- “Children’s agency principle”, recognising the evolving capacity of children to express their views and have their views taken into account as they get older.
- “Precautionary principle”, where medical interventions should be deferred until a child can express their own views regarding treatment, “where safe to do so”.
- “Medical necessity principle”, recognising that some interventions on children are necessary if “required urgently to avoid serious harm to the child”.
- “Independent oversight principle”, where decisions about medical necessity are subject to “effective independent oversight” due to the impact and “risk of making a wrong decision” (Australian Human Rights Commission 2021).

Following a formal commitment in 2019, the Australian Capital Territory (ACT) government undertook a process of reform to clinical practices. This led, in 2023, to the introduction and passing of legislation to protect the rights of people with innate variations of sex characteristics in medical settings, alongside significant investment in psychosocial support. The legislation provides for a criminal prohibition of certain interventions, and oversight for interventions on individuals with certain variations if they are unable to personally consent (Australian Capital Territory 2023; Carpenter 2023). Provisions ensuring transparency and reporting of medical interventions, and the establishment of a Restricted Medical Treatment Assessment Board and Variations in Sex Characteristics Psychosocial Support Service, are internationally significant (Carpenter 2023). Biomedical organisations have opposed legislation. However, mental health and public health organisations have supported the reforms by the ACT government (Public Health Association of Australia 2022, 2023; Chief Minister, Treasury and Economic Development Directorate 2021). The State of Victoria has made similar commitments to reform (Department of Health 2021), with legislation anticipated to be introduced during 2024 (Department of Health 2023).

Community organisations have also begun to develop models of care and offer psychosocial support services to individuals and caregivers (Queensland Council for LGBTI Health, Intersex Human Rights Australia, and Intersex Peer Support Australia 2020a, 2020b, 2020c, 2020d), as well as critiquing existing Australian bioethical frameworks (Carpenter 2024). In 2023, the InterLink service was rolled out nationally to provide one-on-one support and group support for individuals and caregivers.

Positive developments in some jurisdictions of the Australian federation—those aligned with community demands—may be explained by the existence in those jurisdictions of governmental structures supporting community engagement, population size, community organising, and resourcing. Underpinning this, community development and networking has contributed to the development of better tools, platforms, and concepts to promote coherent understandings of the population.

## 6. Research and Data

Clinical practices in Australia are poorly documented in clinical reports (an exception being a brief summary of practices at a Queensland clinic in [Adikari et al. 2019](#)), but significant evidence has been constructed in clinical literature, legal cases, and engagement with national and State/Territory inquiries. As is the case elsewhere, Australian clinical studies predominantly comprise paediatric surgeons and endocrinologists studying surgical outcomes in their own paediatric patients, subject to confirmation bias, ascertainment bias, lack of standardised protocols, and other methodological concerns ([Carpenter et al. 2024](#)), often with the intention of justifying unnecessary surgical practices.

Clinical research has, for example, compared people with intersex variations against the experiences of children with a serious bowel disorder to assert that early feminising and masculinising surgeries are justified on children on the basis of satisfactory outcomes, despite lower likelihoods of experiences of orgasm and greater frequencies of pain during intercourse, and despite significant levels of distress in the population ([Warne et al. 2005](#); [Schützmann et al. 2009](#)). Clinicians in a Victorian hospital have reported more recently on findings from studies of their own patients subjected to feminising surgeries in infancy for congenital adrenal hyperplasia; despite low response rates, reports detail outcomes of post-surgical clitoral sensitivity testing (“vibration” tests) in participating adolescents and adults, respondents’ views, and (reported separately) increased probabilities of incontinence and other urinary issues ([Bogdanska et al. 2015](#); [Villegas et al. 2015](#); [Bogdanska et al. 2018](#); [Preston et al. 2024](#)). Early masculinising surgeries at the same institution lack long-term follow up, with limited clinical research examining outcomes in adolescent boys, who are too young to establish long-term outcomes ([Carpenter 2022](#); [Hutson 2020](#)). Surgeon expertise and techniques are framed as a contributing factor to improved outcomes ([Hutson et al. 2020](#)), evading arguments about the necessity or timing of surgery ([Carpenter 2024](#)). Outcomes elsewhere in Australia are not documented.

Recent international studies have explicitly sought to justify early medical interventions; these reports clearly show a lack of consensus amongst people with lived experience about the necessity and timing of surgery, identifying both significant adverse anatomical and psychosocial outcomes, as well as significant differences between patient-reported and clinician-reported evaluations of outcomes ([Kalfa et al. 2024](#); [van de Griff et al. 2022](#)). Community organisations argue that research aimed at justifying practices that violate individuals’ human rights is unethical ([Carpenter 2022](#)).

Significant Australian public research funds have been invested for more than twenty years in establishing genetic aetiologies for intersex traits. This research has been justified in part by experiences of trauma and distress in parents and people with innate variations, and conducted using human genetic samples and genetically-engineered animal models ([Koyama 2003](#); [University of Queensland n.d.](#); [Hudson Institute of Medical Research 2020](#)). A 2020 summary states that DSDs “are surprisingly common, and can result in genital abnormalities, gender mis-assignment, infertility and psychological trauma” ([Hudson Institute of Medical Research 2020](#)). The use of psychosocial rationales in genetics research is particularly striking given the role of harmful practices in producing poor mental health outcomes and the absence of resourcing for community-based and clinical psychosocial support services prior to the establishment of the InterLink program and ACT’s hospital psychosocial support service in 2023. Further, the research is used not merely to improve diagnosis, but also to facilitate “family planning”, i.e., the elimination of intersex traits from the gene pool on the basis of their undesirability ([Carpenter and Intersex Human Rights Australia 2020](#); [Kirk et al. 2020](#); [O’Connell et al. 2021](#)).

Data on clinical practices are available in disease classifications and Medicare Benefits Schedule (MBS) procedure classifications. Procedure codes include the paediatric-only “Congenital disorder of sexual differentiation with urogenital sinus, external genitoplasty with endoscopy and vaginoplasty” (37,848) and also “Hypospadias, examination under anaesthesia with erection test, on a person under 10 years of age” (37,816). In a process that lacked community engagement, language in the MBS associated with

some paediatric surgeries was updated to “congenital disorders of sexual differentiation” as part of a review concluded in 2020 ([Medicare Benefits Schedule Review Taskforce 2020](#)). A 2019 Taskforce report stated that “Patients with DSD remain free to choose their social identity”, while the availability and utilisation of these paediatric-only codes indicates that patients are not free to choose their own treatment or its timing ([Medicare Benefits Schedule Review Taskforce 2019](#)).

MBS procedure reimbursement numbers are not a good fit with known data on practices in individual hospitals; for example, the number of feminising surgeries at a single Victorian hospital reported in 2013 exceeds the national number of relevant reimbursements in contemporaneous MBS data cubes ([Carpenter 2018, 2022](#)). Given a lack of clarity about the number of procedures on children with innate variations of sex characteristics, the Victorian state government has sought to ascertain procedure volumes in that jurisdiction, but without clear conclusions. The ACT government has also sought to establish accurate numbers on procedures in its jurisdiction and has made reporting on procedures a key component of 2023 legislative reforms ([Australian Capital Territory 2023](#)). It is currently expected that this will require the development of new standards during an initial legislative implementation period.

Despite work by some leading researchers to ensure meaningful inclusion of people with intersex variations ([Amos et al. 2022](#)), “LGBTI” studies are predominantly focused on the experiences of adults with marginalised identities, and/or have had goals or preconceptions that make it difficult for people with innate variations of sex characteristics to see our needs reflected. Misconceptions remain pervasive, such as framings of intersex as a third sex, a gender, a sexual orientation, or an identity in need of recognition. These reflect a profound lack of comprehension of the population and lack of engagement with the literature, adversely impacting engagement and participation rates. Due to safeguarding and reputational risks, IHRA is unable to share most surveys but seeks to influence better practices.

An Australian pilot sociological study in 2015 on people “born with atypical sex characteristics” with 272 respondents found significant concerns, including adverse outcomes arising from medical interventions without personal consent and the impact of stigma and social, familial, and clinical attitudes; high rates of disability and poverty; and variable completion of schooling and other educational stages ([T. Jones et al. 2016](#)). While the study’s descriptive title facilitated questions about nomenclature preferences, the study is a convenience sample with its own methodological limitations. It is possible to argue that no research on people with innate variations of sex characteristics has yet been truly representative, and such a study may be implausible due to the legacy of non-disclosure and partial disclosure ([Carpenter 2022, 2024](#)).

In what some researchers have termed a transition from “paediatric emergencies to a sense of abandonment” ([Crocetti et al. 2023](#)), a lack of clinical attention to the outcomes and experiences of adults with innate variations of sex characteristics contributes to a lack of structured research available on adult health and well-being. Recent US research has found a relationship between early surgeries without personal consent and later avoidance of healthcare, including both preventative and emergency healthcare ([Wang et al. 2023](#)), while Australian qualitative research has identified benefits from social and community connection ([Hart and Shakespeare-Finch 2021](#)).

The Australian Bureau of Statistics Standard on Sex, Gender, Variations of Sex Characteristics, and Sexual Orientation seeks to facilitate consistent, coherent data collection practices that respect the diversity of the population, particularly diversity in preferences for sex and gender classifications ([Australian Bureau of Statistics 2021](#); [Carpenter and Intersex Human Rights Australia 2019](#)). It achieves this by defining sex initially in relation to legal registration at birth, where registration is typically based on sex characteristics observed at birth. The Standard is as yet unevenly implemented ([Australian Bureau of Statistics 2022](#)), but it forms the basis for new general practice guidelines ([Royal Australian College of General Practitioners 2021](#)) and a draft national statement on sex, gender, varia-

tions in sex characteristics, and sexual orientation in health and medical research ([National Health and Medical Research Council and Department of Health and Aged Care 2023](#)).

## 7. Community Perspectives Looking towards the Future

People with innate variations of sex characteristics are faced with a challenging set of radically different ideas about who we are and how we should live, and these limit individuals' agency to freely express values, preferences, and choices.

These different ideas include a medical model that seeks to "fix" intersex bodies, engaging multiple human rights issues, including the rights to security, bodily and mental integrity, health, sexual and reproductive rights, privacy, legal capacity, and non-discrimination ([Office of the High Commissioner for Human Rights 2019](#)). Current and historic practices also violate rights to freedom from harmful practices, ill-treatment, and violence ([Office of the High Commissioner for Human Rights 2019](#)). Additionally, people with innate variations of sex characteristics can have health needs that need attention, including some risks that can result in harm if not addressed.

At the same time, legal and social constructions of intersex reflect novel and simplistic ways of classifying and recognising people with innate variations of sex characteristics that fail to respect the diversity of individuals' lived experiences, values, and preferences.

These issues mean that intersex health and human rights advocacy is driven by simple propositions grounded in respect for the diversity of the population and its plurality in values and preferences, such that:

- To the maximum extent possible, everyone should be able to make their own decisions about their own bodies.
- Individuals should be able to access safe, appropriate, and timely medical treatment in line with actual needs and sex characteristics, including treatments that are necessary for health and well-being and treatments that affirm their values and preferences ([AIS Support Group Australia et al. 2017](#)).
- Social and community connection to other people with lived experience is essential for good health outcomes, informed decision-making, and the constructive amelioration of stigma, shame, and trauma ([Hart and Shakespeare-Finch 2021](#)).
- To the maximum extent possible, everyone should be able to make their own decisions about their identities and expression.
- A novel biologically-defined legal sex category termed "intersex" fails to respect the diversity of the population and the rights of individuals to self-determination ([AIS Support Group Australia et al. 2017](#)) and so is not supported.
- Even where considered inconvenient, birth-registered sex should always be respected unless an individual indicates otherwise ([Carpenter 2020](#)).
- It is necessary to address misinformation, disinformation, and a lack of interdisciplinary engagement across silos in order to implement effective, coherent reforms to legislation, regulation, policy, and practice.

Intersex community responses to challenging clinical, legal, and social environments have taken the form of community and capacity building, research and documentation, engagement with clinicians, legal and human rights institutions and policymakers, and the provision of trauma-informed psychosocial and peer support services. Key components of this work include attempts to create engagement across institutional silos, promoting coherent policy development that respects the plurality of individual preferences and values.

Working with other stakeholders, intersex community organisations seek to transform models of care from narrow biomedical approaches that "manage" atypical bodies through surgical and endocrinological interventions, to approaches that centre the role of psychological support in co-ordinating care, supporting caregivers, addressing stigma, and helping individuals to understand and express their own values and preferences for treatment ([Carpenter 2023](#)). As has occurred in the ACT, legislative reform appears to be a prerequisite to other forms of reform to clinical practice, such as investment in clinical and

community-based psychosocial support. Intersex community organisations seek nationally consistent reforms in line with these developments.

Intersex community organisations also seek to implement and evaluate best practice healthcare pathways and develop new bioethical frameworks that centre psychosocial support and respond to community, mental health, public health, and human rights perspectives (Carpenter 2024). These include a toolkit of healthcare pathways resources developed by Bonnie Hart that present a set of best practice indicators matched to industry accreditations standards, detailing the role of peer support and advocacy services in helping individuals and families navigate healthcare services across the lifespan (Queensland Council for LGBTI Health, Intersex Human Rights Australia, and Intersex Peer Support Australia 2020a, 2020b, 2020c, 2020d). Over the next decade, community goals include the provision of intersex community-controlled healthcare services, including psychosocial support, GP services, genetic counselling, and allied health services.

In relation to MBS procedure codes, community organisations seek to eliminate paediatric-only reimbursement codes for unnecessary early surgeries and improve safe access to healthcare by adolescents and adults. Community organisations also seek to improve safe access to appropriate healthcare through the Pharmaceutical Benefits Scheme, screening programs, and adult sexual and reproductive health services, including access to fertility-related services, and call on governments to also consider how to meaningfully respond to calls for redress for people subjected to interventions without personal informed consent—for example, through access to subsidised care plans (Intersex Human Rights Australia 2022).

Reform to promote coherent data collection needs to encompass classifications of demographic data and procedure data. Reform of sex, gender, and variations of sex characteristics classifications in hospitals and other settings should align with the Australian Bureau of Statistics Standard. Data on procedures do not currently adequately capture information on numbers and rationales for medical interventions on children with innate variations of sex characteristics. It appears that reform will also be necessary to ensure adequate reporting to new legislative oversight bodies, and jurisdictions enacting legislative reforms must consider how to ensure national consistency in reporting arrangements. Consideration should be given to ways of extending the preservation of medical records. In relation to research, community organisations aim to secure resources for community-based participatory research, addressing community priorities and pervasive data gaps, while also working to ensure that medical and health research funds are not used to justify human rights violations.

In relation to education, Australian researchers report a “lack of a systematic” and affirmative approach to messaging in school curricula and support services, including in puberty and consent education (Brömdal et al. 2020; Zavros-Orr 2021). Similarly, recent international research shows best-selling psychology textbooks provide an uneven representation of the population that can lack engagement with lived experience and even “obscure genuine healthcare concerns” (Hegarty and Vaughan 2024). Improvements to better engage with lived experience and healthcare needs can promote a better understanding of the population and mitigate risks of stigmatisation and shame.

## 8. Conclusions

Unique features of developments in Australia include a history of incommensurate and disjointed legal and clinical policy, as well as a poorly recognised history of regulation of certain surgeries on children; nationwide policy attempts to address “LGBTI” human rights concerns; and the growth of intersex community organising to promote human rights and health, engage in community development, research, and advocacy, and develop a common community platform.

Intersex community organising and resourcing has made a difference, evidenced through significant developments in policy attention and direction, legislative reform, and service delivery. Australian intersex community organisations have sought to apply

human rights norms, construct new ways of resolving policy incoherence, and develop new infrastructure to address community-identified health and human rights issues.

Consistent with calls made in the community consensus platform and by the Australian Human Rights Commission, the Australian Capital Territory is the first jurisdiction to move ahead with reforms to clinical practice, including a legislative prohibition of certain practices without personal informed consent, oversight of clinical decision-making, and investment in psychosocial support. A community psychosocial support service has also commenced. Additionally, recent developments have opened up a significant fracture within medicine, where positions on the regulation of medical practices expressed by mental health practitioners and some other national health and medical organisations are now aligned with the community platform. Together with human rights institutions and institutions of mental health and public health practitioners, community organisations have called for significant changes to medical models of care and reform to research and classification systems.

Activities to respect, protect, and fulfil the human rights of people with innate variations of sex characteristics remain a work in progress, but they can now build on significant progress, including the community platform, national inquiries, law reform, new models for resourced psychosocial support, and the development of new statistical standards.

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