

## LGBTQIA+ HEALTHCARE

# Health needs of people with intersex variations

By Morgan Carpenter



### Understanding intersex variations

Intersex is a term for a range of innate variations of sex characteristics that don't fit medical norms for female or male bodies, including genetic, chromosomal, hormonal or genital characteristics. Multiple different terms exist to describe intersex variations including 'disorders or differences of sex development' or 'disorders of sexual differentiation' (DSD), 'innate variations of sex characteristics', and a range of specific diagnostic terms. Relevant diagnoses include androgen insensitivity, congenital adrenal hyperplasia (CAH) with XX or mosaic sex chromosomes, 5 $\alpha$  reductase deficiency, 17 $\beta$  hydroxysteroid dehydrogenase 3 deficiency, gonadal dysgenesis, micropenis, and many sex chromosome variations.

Language in this area is contested and, while some traits such as 47,XXY (Klinefelter syndrome), hypospadias or even XX CAH may sometimes not be regarded as intersex<sup>1,2</sup> people with these traits experience many of the same issues of stigmatisation, isolation and medicalisation as people with commonly recognised traits. Often debates about what makes someone intersex turn on a presumed sense of gender identification, sexual orientation, an experience of sex assignment, or uncertainty about sex<sup>1</sup>. Intersex community organisations challenge both inappropriate and tokenistic uses of nomenclature, but you may encounter these in your practice<sup>3</sup>. Inappropriate associations between intersex and concepts of gender fluidity, gender identity 'confusion', third sex categories, or being transgender are not a product of terminology like the word intersex, but occur also with DSD<sup>4,5,6,7</sup> and



are likely independent of nomenclature preferences, reflecting ideas about the relationships between bodies and identities. Of course, some people with intersex variations grow up to be LGBT, and all LGBT identities are acceptable. It is important to recognise that, irrespective of diagnosis, people with intersex variations are a very diverse population, and do not share any universal experience of sex, gender, or sexual orientation.

Language is also contested because it can presuppose ideas that intersex traits need to be 'fixed' for people with intersex variations to be 'real' or valid women or men. Community organisations, and human rights and parliamentary institutions link the term 'disorders of sex development' to harmful surgical and hormonal interventions that can take place before individuals can personally give informed consent<sup>8,9,10,11</sup>. Stigmatisation



and experiences of normative conceptions of sex and gender are what link intersex and LGBT people.

Treating the term intersex as if it refers to a non-binary sex or gender category carries psychosocial risks. Third or non-binary categories on intake forms are better termed 'non-binary'. It is best practice to align your data collection with the ABS Standard on sex, gender, variations of sex characteristics, and sexual orientation<sup>12</sup>.

Respect for the language choices of patients and their families will contribute to their wellbeing, but clinicians have long had a key role in educating individuals and parents about nomenclature. It is important to allay fears and negative connotations associated with LGBT identities and experiences, counter misconceptions, and facilitate access to affirmative peer support for individuals and their families. It is also essential to respect the human rights and identities of infants, children, adolescents, and adults with intersex variations.

## Medical diagnosis

Intersex traits may be diagnosed at birth or in the perinatal period, or they might be determined prenatally, during puberty or adolescence, or later in life, such as when attempting to conceive a child.

Prenatal diagnosis of some traits, particularly sex chromosome variations, is possible, for example using non-invasive prenatal testing, amniocentesis, or screening during IVF. Some institutions are reporting concern about high rates of pregnancy terminations for some sex chromosome variations, and these are not commensurate with the realities of life with an intersex variation. Prenatal treatment to modify genital appearance in congenital adrenal hyperplasia prioritises appearance over established cognitive development risks<sup>13</sup>. Most intersex traits are not candidates for pre-conception screening because the adverse impacts of having an intersex variations are not intrinsic but are instead associated with stigma and social norms<sup>14</sup>. It is essential not to emphasise unlikely negative outcomes, and to provide referrals to affirmative support. With love and support, people with intersex variations can live happy and fulfilling lives.

Diagnosis in the perinatal period can occur either due to a visible difference that complicates sex assignment, or



due to adrenal insufficiency. Adrenal insufficiency can be fatal if not treated.

Some intersex traits become evident due to physical changes at puberty (such as virilisation or under-virilisation), or an absence of physical changes at puberty (such as amenorrhea or delayed puberty). Other traits, including sex chromosome variations like 47,XXY (Klinefelter syndrome), are known to have relatively low rates of diagnosis.

Cognitive and related developmental issues may be present in some cases (notably with sex chromosome variations), and renal or other issues may also be features (for example, of Mullerian agenesis). Each of these may require referral to specialists.

The times of diagnosis and of disclosure of medical information to an adolescent can be the most challenging times for patients. Open and early disclosure is critical to maximise the choices that individuals have over their bodies, and also reduce the risks of snap decisions. Contact with peers can help individuals and parents to make better informed choices. Support from a psychologist, counsellor or social worker can also be helpful in some cases.

## Surgical and hormonal interventions

Some medical interventions on infants and young children are urgent and necessary for physical health, including on the grounds of evidenced high risks of gonadal tumours, managing an inability to urinate, and treatments to manage salt wasting associated with congenital adrenal hyperplasia. Some traits are also associated with cognitive issues (such as ADHD), developmental delays, or renal issues. Individuals old enough to consent may also need or wish to undergo medical interventions including genital, gonadal and fertility-related interventions. Support is needed to ensure these choices are informed, supported by evidence of efficacy, and in line with their preferences and values.

Infants and children with intersex variations are still routinely subjected to feminising or masculinising surgeries, hormonal treatments, and associated medical examinations or dilation. Despite calls for more research dating back to 1995<sup>15</sup>, global clinical statements report a lack of evidence in support of early 'normalising' medical interventions, and a lack of clinical consensus about timing, necessity and procedures<sup>16, 17</sup>. Consensus, lack of consensus, existing evidence and lack of evidence are each used to justify early surgeries to 'normalise' children's bodies<sup>17</sup>, indicating that such interventions are grounded in the values and beliefs of clinicians<sup>18</sup>. Reports exist from multiple jurisdictions in Australia showing that unnecessary medical interventions are routine, and may take place on the grounds of gender stereotypes, parental distress or other psychosocial rationales<sup>19, 20, 21, 22, 23</sup>.

Clinicians working with adolescent and adult populations have criticised an absence of non-surgical pathways<sup>24</sup>. Clinical reports clearly interpolate social and cultural factors into decision-making<sup>25, 26, 27</sup>. Early surgeries are known to carry risks for cognitive development<sup>28</sup>. Evidence also suggests that parents do not provide fully informed consent on behalf of their children and many may experience regret<sup>29, 30, 31</sup>.

Interventions based on non-urgent rationales have been condemned by community organisations, a Senate inquiry, and human rights institutions<sup>32, 33</sup>. Independent community organisations call for an end to deferrable early medical interventions, along with transparency



and accountability through independent oversight, and lifetime human rights-affirming standards of care<sup>32</sup>.

Clinical reports persist in framing infant surgeries as a means of resolving parental distress<sup>34, 35</sup> or risks of future stigma<sup>21, 19</sup>. The Senate community affairs references committee reported in 2013 that such rationales for surgery are circular and an inappropriate response to stigma and distress. Human rights bodies have drawn attention to misuses of best interests tests in justifying medical interventions grounded in gender stereotypes and social norms, stating that this test should never outweigh a right to personal consent<sup>10</sup>. Internationally, many jurisdictions have begun to legislate in response to a failure to effectively self-regulate<sup>36, 37, 38</sup>.

In response to these concerns and evidence of continuing harm in medical settings, the Australian Human Rights Commission has called for reform of the criminal law to end medical interventions grounded in psychosocial rationales, implement independent oversight and national guidelines and promote better research. ACT and Victoria have made public commitments to reform<sup>11, 39, 27, 40</sup>.

These issues may arise in relation to children in your care if they are proposed to undergo medical interventions to satisfy ideas about the genital or other physical appearance of girls or boys, or ideas that associate functionality with the idea that boys need to be able to stand to urinate. You need to be aware that these are regarded as human rights abuses and institutions may become culpable for such practices.

## Psychosocial context

Like other sexual and gender minorities, people with intersex bodies are stigmatised and individuals can experience high levels of distress. Generally, clinical reports rely on small case studies limited by ascertainment and confirmation bias – for example, a study by clinicians at RCH Melbourne<sup>41</sup> is interpreted as indicating high levels of distress in a systematic review<sup>42</sup> but is still relied upon in 2020 as a justification for early surgical intervention<sup>43</sup>. Psychosocial rationales, including risks of stigmatisation and the distress of parents and family members are commonly cited as rationales for early surgical intervention. The Australian Human Rights Commission has criticised beliefs about psychosocial rationales for treatment in hospital teams responsible for the care of children with intersex variations, noting that specialist bodies in psychology and psychiatry reject surgeries and other treatments for mental health reasons<sup>39</sup>.

Like all children, those with intersex variations most need the unconditional love and support of their parents. People with intersex variations have suffered a history of deliberate non-disclosure of medical histories and diagnostic information, and such approaches still persist in our region with an impact on individuals' ability to manage their health and their engagement with health services<sup>16, 44</sup>.

Negative experiences of medicine, non-disclosure, stigmatisation, and experiences of difference including infertility, all contribute to trauma<sup>29, 45</sup>. These experiences mean that patients might prefer not to be in your clinic. Compassionate, trauma-informed care is essential, ensuring that your patient consents, is engaged, and in control. Affirmative, open, and age-appropriate disclosure can counter risks and experiences of shame and secrecy.

Community connectedness and access to a GP are important protective factors, mitigating risks of suicidal ideation, anxiety and depression<sup>46, 16</sup>. GPs can play a key role in promoting open communication, including in situations where youth may experience communication obstacles in hospital and home settings, an absence of affirmative information in education settings, and suffer the prevalence of popular misconceptions<sup>47</sup>. Referrals can be made to independent community organisations, listed below.

## Peer and family support referrals

The following organisations provide independent affirmative support for individuals, parents, and families.

- **Intersex Human Rights Australia:**  
Providing independent affirmative support for individuals, parents, and families: resources, policy guidance and community development  
<https://ihra.org.au>
- **Intersex Peer Support Australia:**  
The Androgen Insensitivity Syndrome Support Group Australia: provides support for individuals and family members irrespective of diagnosis  
<https://isupport.org.au>

## Resources

- **Intersex Human Rights Australia and Intersex Peer Support Australia:**  
Inclusive Practice  
<https://ihra.org.au/inclusion/>
- **Intersex Peer Support Australia and Intersex Human Rights Australia:**  
Healthcare Pathways  
<https://ihra.org.au/pathways/>
- **Lum S, ed.:**  
YOUth&I Issue 1 (2019)  
<https://darlington.org.au/wp-content/uploads/2019/10/YOUthAndI-Layout-Final-Web.pdf>
- **Lum S. Intersex Human Rights Australia:**  
Youth  
<https://ihra.org.au/youth/>
- **Intersex Human Rights Australia:**  
Intersex for Parents  
<https://ihra.org.au/parents/>
- **ReachOut.com:**  
Supporting an Intersex Teenager  
<https://parents.au.reachout.com/skills-to-build/connecting-and-communicating/things-to-try-supportive-parenting/supporting-an-intersex-teenager>



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