Continuing Intersex awareness

Webinar 1: Understanding Intersex  
Presenter: Bonnie Hart

Webinar 2: Intersex Human rights  
Presenter: Morgan Carpenter

Any questions throughout webinar, email charlie.willbridge@lgbtihealth.org.au

www.lgbtihealth.org.au/hub
Morgan Carpenter  morgancarpenter.com
Organisation Intersex International Australia  oii.org.au
Intersex Day project  intersexday.org
Global Action for Trans Equality  transactivists.org

Acknowledgement of country and elders
UN definition
Australian demographics (quick recap from Bonnie’s webinar)
Medicalisation
Human rights developments
Pinkwashing
Goals and barriers

Note: contains descriptions of human rights violations and abuse, including in medical settings.

“Intersex people are born with sex characteristics that don’t fit typical definitions of male and female”
Available from: http://www.unfe.org/intersex-awareness

"Because their bodies don’t comply with typical definitions of male or female, intersex children and adults are frequently subjected to forced sterilisation and irreversible surgery, and suffer discrimination in schools, workplaces and other settings."
United Nations High Commissioner for Human Rights
Zeid Raad Al Hussein

Like and share if you agree
visit www.unfe.org/intersex-awareness for more information
Who are we?

Demographic data from first national study of people born with atypical sex characteristics in Australia:

- 272 individuals born with atypical sex characteristics.
- Age 16-85+ with >35 variations.
- Independent, led by Dr Tiffany Jones of University of New England, with sole responsibility for analysis and reporting.
- Reference group: Morgan Carpenter (OII Aus), Bonnie Hart (AISSGA), Dr Gávi Ansara (National LGBTI Health Alliance).

Note: multiple choices possible

Complexities of asking about birth assignment:
“I was christened male, but reassigned female at day 5, and then realigned back to my male self at age 29.”
### Sexual orientations

<table>
<thead>
<tr>
<th>Orientation</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>Heterosexual</td>
<td>48%</td>
</tr>
<tr>
<td>Bisexual</td>
<td>22%</td>
</tr>
<tr>
<td>Gay</td>
<td>6%</td>
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<tr>
<td>Lesbian</td>
<td>12%</td>
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<tr>
<td>Queer</td>
<td>15%</td>
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<tr>
<td>Questioning</td>
<td>11%</td>
</tr>
<tr>
<td>Pansexual</td>
<td>10%</td>
</tr>
<tr>
<td>Asexual</td>
<td>10%</td>
</tr>
<tr>
<td>Prefer no label</td>
<td>10%</td>
</tr>
<tr>
<td>Another label</td>
<td>4%</td>
</tr>
</tbody>
</table>

Multiple choices possible; note response rate. n=176

### Sex characteristics

More than 35 different variations, including 5-alpha-reductase deficiency, complete and partial androgen insensitivity syndrome (AIS), bladder extrophy, clitoromegaly, congenital adrenal hyperplasia (CAH), cryptorchidism, De la Chapelle (XX male) syndrome, epispadias, Fraser syndrome, gonadal dysgenesis, hyperandrogenism, hypospadias, Kallmann syndrome, Klinefelter syndrome/XY, leydig cell hypoplasia, Mayer-Rokitansky-Küster-Hauser syndrome (MRKH, mullerian agenesis, vaginal agenesis), micropenis, mosaicism involving sex chromosomes, mullerian (duct) aplasia, ovotestes, progestin induced virilisation, Swyer syndrome, Turner’s syndrome/X0 (TS), Triple-X syndrome (XXX).
Sex characteristics

“intersex”: 60%

Note: multiple choices possible

Educational attainment

n=251
“I had a hard time as I looked different and was called names from primary to high school. I was called retard or downs' syndrome, lots of nasty names. I was physically less mature and that became so tough in high school. I wanted more help from staff than I got, definitely”
(female with Turners syndrome, 30 years)

“I nearly died of septicaemia as a teenager, due to my genital surgery, I missed so much school I actually had to drop out entirely. It changed my whole life. Immense emotional impact to this day”
(woman with intersex condition, PAIS, 44 years)
“My school principal, teacher and counsellor made it hard for me to get the time off school I needed... My classmates either thought I was a freak or did not understand what was going on and saw me as a bludger trying to get out of class (I was bleeding like a stream from my vagina for god’s sake, it is not something you want to say is happening or go to school with).”

(woman with intersex variation Mayer-Rokitansky-Küster-Hauser syndrome, 27 years)

- 63% earn under $41,000 per year; 41% earn less than $20,000
- For comparison, Australian median full time income: $80,000; all employees average income: $59,576
Medical interventions

“strong evidence suggesting a pattern of institutionalised shaming and coercive treatment”

60% received treatments on basis of sex characteristics, half at under 18 years of age.

Majority experienced at least one negative impact from treatment.

44% reported counselling/ training/ pressure from institutional practitioners (doctors, psychologists etc.) on gendered behaviour; 43% from parents.

60% had thought about suicide, 19% had attempted it (Australian average <3%).

“[Gonadectomy]...exists in my memory as some type of clinical rape; 10 student doctors standing around staring up my vagina as the doctor put his fingers in me and spoke about me like I wasn't there. Everyone was complicit in this, my parents, extended family, the doctors, the state as far as I knew, the whole world.”

(intersex female, CAIS, 37 years)
“I was forced on Testosterone at 15yrs. They tried to correct my body and my behaviour. Now I’m embracing it.”
(intercsex woman with 47,XXY, 24 years)

“[I had surgery] that left me with little to no control over my penis during sex. [I was given inadequate information about risks and issues with pain and sensation] ... I wish I had been able to meet other people like me first to know what to do ... But they said there were no groups, which I now know is a lie from the internet and this study.”

(man with intersex variations PAIS and Hypospadias, 24 years)
“I laughed when the doctor proposed it. So I am a little different, so he hasn’t seen genitals like mine before... so? I lived over twenty years without feeling broken, why should I be fixed?... Whose genitals don’t look a little bit funny? ... Nobody looks like the ideal, we’re all a bit hairy, a bit pokey; at least I can enjoy what I have.”

(intersex female with PAIS, 32 years)

How did we get here?

“Because it is simpler to construct a vagina than a satisfactory penis, only the infant with a phallus of adequate size should be considered for a male gender assignment”

“Not one has complained of loss of sensation, even when the entire clitoris was removed.”


“Such clinical advice, concerned primarily with surgical potentials, is relatively standard in medical texts, and reflects the current thinking of many pediatricians.

“This management philosophy is based on two pediatric beliefs held strongly enough that they might be considered postulates: 1) individuals are psychosexually neutral at birth, and 2) healthy psychosexual development is dependent upon the appearance of the genitals. These ideas arise most strongly from the original work of Money and colleagues.”

“factors [contributing to] improved results since 1975 are the earlier timing of diagnosis and operative intervention, and newer improved operative techniques.”


Boston demonstration, 26 October 1996: origin of Intersex Awareness Day
“Appearance-altering surgery is not urgent...
“Rationale for early reconstruction includes beneficial effects of estrogen on infant tissues, avoiding complications from anatomic anomalies, satisfactory outcomes, minimizing family concern and distress, and mitigating the risks of stigmatization and gender-identity confusion of atypical genital appearance.”


“consensus statements ... describe recommended indications for genital and gonadal surgery
“surgery 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.
“...for functional reasons such as to allow a male individual to urinate while standing, and for psychosocial reasons such as to allow the child to develop without the psychosocial stigma or distress which is associated with having genitalia incongruous with the sex of rearing”

“limited evidence reporting long-term outcomes of early surgical management for reasons of appearance ... with particular concern regarding sexual function and sensation.”
“Current international guidelines recommend long-term follow-up of children with DSD who have early surgery. This does not occur in Australia”


“increased medical knowledge and better surgical techniques
“...we acknowledge that outcomes related to current approaches remain to be established.”

Royal Children's Hospital Melbourne. Submission to the Senate Inquiry Into the Involuntary or Coerced Sterilization of People with Disabilities in Australia: Regarding the Management of Children with Disorders of Sex Development; 2013.
“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 ...

“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”


“The [2006 Chicago] statement recommended caution on surgical treatment, but nevertheless facilitates such interventions. A 2016 follow-up statement does the same.

“The authoritativeness and “consensus” in the Chicago statement lies not in comprehensive clinician input or meaningful community input, but in its utility to justify any and all forms of clinical intervention. Clinical practices have not been impacted by the statement; they have been validated.”

Parents

“Parents may not realise that they are de facto opting for experimental surgery on their children. Furthermore, their emotional states during decision making may not be optimal. Research suggests that medicalised presentations of genital difference have undue influence on parental decisions and that parental regret can be high.”

“an additional, non-surgical care protocol is required to enable parents to cope with what may feel like insurmountable pressure to appear normal”


“sex, gender, and sexual orientation, these concepts are actually intertwined on many levels. Parental choice against intersex may thus conceal biases against same-sex attractedness and gender nonconformity”

“The prenatal hormone theory of sexual orientation is derived from research on lower mammals, and draws limited corroboration from human research on endocrinological abnormalities associated with physical manifestations of intersexuality. Its application to the more common forms of homosexuality has led to conflicting findings and major controversy. The scientific groundwork is insufficient to support the introduction of prenatal hormone screening or treatment for the prevention of homosexuality.”


“Without prenatal therapy, masculinization of external genitalia in females is potentially devastating. It carries the risk of wrong sex assignment at birth, difficult reconstructive surgery, and subsequent long-term effects on quality of life. Gender-related behaviors, namely childhood play, peer association, career and leisure time preferences in adolescence and adulthood, maternalism, aggression, and sexual orientation become masculinized in 46,XX girls and women with 21OHD deficiency ...

“We anticipate that prenatal dexamethasone therapy will reduce the well-documented behavioral masculinization and difficulties related to reconstructive surgeries.”

“One to two per cent of live births are intersex, which can result in psychological trauma, infertility, lifelong endocrine care, multiple surgeries and increased risk of conditions like gonadal cancer”

Hudson Institute of Medical Research. Hudson researchers identify new syndrome leading to intersex. 2015.

Goals
Self-determination (the key goal of the intersex movement)
Bodily autonomy, physical integrity
Informed, personal consent
Access to peer support (autonomy is relational)
Protection from harmful practices, ending mutilations
Human rights-based clinical pathways
Reparations and justice
Recognition of diversity
Ending shame, secrecy, stigma
Same rights as peers

Human rights timeline
1996: first demonstration, at a Boston paediatric conference
2005: South African law; San Francisco Human Rights Commission
2006: Yogyakarta Principles (18B); Chicago statement
2008: first successful legal case, by Christiane Völling (Germany)
2012: Swiss biomedical ethics report
2013: report of UN Special Rapporteur on torture; Third Intersex Forum; Australian anti-discrimination protection and Senate report
2014: WHO interagency paper; joint submission on ICD reform
2015: Malta prohibits coercive “normalisation”, Chile suspends; UN expert meeting; Council of Europe and IACHR reports
2016: Asia Pacific Forum of NHRIs report; UN for Intersex Awareness
“77. Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, “in an attempt to fix their sex”, leaving them with permanent, irreversible infertility and causing severe mental suffering.”

“88. ... repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, unethical experimentation, medical display, “reparative therapies” or “conversion therapies” ... outlaw forced or coerced sterilization in all circumstances and provide special protection”

Méndez J. Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, A.HRC.22.53. Feb 2013.

“there is no medical consensus around the conduct of normalising surgery
“Normalising appearance goes hand in hand with the stigmatisation of difference.
“There is frequent reference to 'psychosocial' reasons to conduct normalising surgery. To the extent that this refers to facilitating parental acceptance and bonding, the child's avoidance of harassment or teasing, and the child's body self-image, there is great danger of this being a circular argument that avoids the central issues.”

“guidelines should favour deferral of normalising treatment until the person can give fully informed consent”

Australian Senate, Community Affairs References Committee. Involuntary or coerced sterilisation of intersex people in Australia. Canberra; 2013.
“end medically unnecessary “normalising” treatment of intersex persons, including irreversible genital surgery and sterilisation, when it is enforced or administered without the free and fully informed consent of the person concerned.

“Sex assignment treatment should be available to intersex individuals at an age when they can express their free and fully informed consent.

“Intersex persons’ right not to undergo sex assignment treatment must be respected.

“medical classifications which pathologise variations in sex characteristics should be reviewed”


“the right to ... bodily integrity and physical autonomy...

“It shall be unlawful for medical practitioners or other professionals to conduct any sex assignment treatment and/or surgical intervention on the sex characteristics of a minor which treatment and/or intervention can be deferred until the person to be treated can provide informed consent...

“medical intervention which is driven by social factors without the consent of the minor, will be in violation of this Act.”

Malta. Gender Identity, Gender Expression and Sex Characteristics Act. 2015.
“All human beings are born equal in dignity and rights. Those foundational, bedrock principles of universality and equality mean that all of us, without exception, and regardless of our sex characteristics, are equally entitled to the protections of international human rights law.”


“States must, as a matter of urgency, prohibit medically unnecessary surgery and procedures on intersex children. They must uphold the autonomy of intersex adults and children and their rights to health, to physical and mental integrity, to live free from violence and harmful practices and to be free from torture and ill-treatment. Intersex children and their parents should be provided with support and counselling, including from peers.

“States should investigate human rights violations against intersex people, hold those found guilty of perpetrating such violations accountable and provide intersex people subjected to abuse with redress and compensation.”

“Recognition before the law means having legal personhood and the legal protections that flow from that ... neither primarily nor solely about amending birth registrations or other official documents. Firstly, it is about intersex people who have been issued a male or a female birth certificate being able to enjoy the same legal rights as other men and women ... “Secondly, some intersex people seek to amend their sex or gender details on official documents ...

“Finally, it is ... not about creating a third, separate category for the registration of people born with an intersex trait”


Pinkwashing

“Disjunctions are evident between social and medical policy and, in both domains, between rhetoric and reality. This disjunction differentiates between the medical treatment of “individuals with DSDs” and social policy advances for the intersex or broader LGBTI communities.”

“The Victorian Government values and celebrates diversity. It affirms the right to equality, fairness and decency for Lesbian, Gay, Bisexual, Trans and Gender Diverse, and Intersex (LGBTI) Victorians and is committed to removing discrimination from Victorian laws, services and society...

“Inclusion is about recognising and valuing diversity, including a diversity of sexualities, gender identities and intersex variations ... ensuring that services are delivered in ways that are non-discriminatory and LGBTI inclusive and welcoming ”


“Ambiguous genitalia in neonates ... is rarely anticipated and can be a source of great distress for parents, delivery room and nursery staff ... a medical emergency ...”

“Corrective surgery is usually undertaken within the first year of life ... Very early surgery at under six months of age is less commonly performed than in the past”

“require surgery to restore[sic] the genital appearance to normal”

“Minimise psychosocial risk to child
“risk of social or cultural disadvantage to the child, for example, reduced opportunities for marriage or intimate relationships”


* note: “marriage” has been removed from the current online version, which retains the date February 2013, but the previous wording is cited in chapter 5, paragraph 5.4 of the 2013 Senate report on involuntary or coerced sterilisation.

“The availability of the third marker for children will also reduce the risk that parents will force their child to conform to a particular gender or subject them to gender assignment surgery or other medical procedure to match the child’s physical characteristics to the chosen sex.”

Letter from the Chief/Health minister in ACT regarding new birth sex classifications. April 2014
“Currently in the ACT, in the event of a birth of a baby with a disorder of sex development (DSD), clinicians follow a standard investigation and management practice that is consistent with a national approach from the Australasian Paediatric Endocrine Group and international consensus statements from key disciplines such as paediatric endocrinology, surgery... it is recognised that surgery of this sort is best performed in centres of excellence. For this reason children with a DSD are normally referred to either Melbourne or Sydney.”

Letter from the Chief/Health minister in ACT regarding the Senate inquiry into involuntary or coerced sterilisation. January 2014

“Intersex people have suffered from feelings of exclusion from society because in part their status is not properly recognised on documents and ID cards. One person wrote to me saying, 'Every time I have to show my ID at a pub or a university, I feel deeply humiliated.'”

Tackling barriers

We need your help to tackle:

Barriers to familial and self-understanding, and barriers to the social connectedness that can help individuals overcome stigma.


Rhetoric of inclusion that limits our self-determination, and fails to acknowledge our diversity. Including government, media, and institutional framing of intersex as a gender diversity issue.

Continuing Intersex awareness

morgan carpenter.com

charlie.willbridge@lgbtihealth.org.au

www.lgbtihealth.org.au/hub