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Review of Victorian government, community and related resources on intersex

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2 About this review

This review has been carried out in June 2021 by Morgan Carpenter, bioethicist and executive director of Intersex Human Rights Australia. It fulfils part of a contract with the Department of Health in Victoria. Morgan can be contacted at morgan.carpenter@ihra.org.au.

Conflict of interest: Morgan declares a conflict of interest in relation to discussion of resources by IHRA and Intersex Peer Support Australia (IPSA).

3 Summary of key issues

3.1 Key issues arising in the resources review

The review identifies pervasive mixed messaging by health and community organisations, in relation to both medical practices affecting people with intersex variations, and the characteristics of the population. These illustrate a contradiction discussed in a book chapter (Carpenter 2018a) and peer-reviewed article (Carpenter 2018b), that different language is associated with radically different values, beliefs and ideas about the nature of the subject population. In particular, people with intersex variations are simultaneously depicted as disordered female and males, and in need of “fixing”, while at the same time are depicted as an other sex category entirely, or even a sexuality or gender identity. The messaging frames people with intersex variations as queer, as disordered, as child subjects for treatment, and as having our health needs met by adult, LGBT-focused services.

Clinical framings presuppose a need for medical intervention, direct parents to inappropriate resources, and omit consideration of established human rights concerns about medical interventions. Diagnosis-specific community/clinical organisations frequently promote normative ideas about children’s future gender identities that disregard the diversity of the population, and promote a need for medical interventions aligned with those identities to make bodies more “normal”.

LGBT(I)QA+ community framings disregard and disrespect the diversity of the population of people with intersex variations, and have lacking or limited awareness of rights to autonomy, self-determination, and bodily integrity. Only IPSA and IHRA demonstrably accept people with a diversity of identities. MRKH Australia stands out for its focus on mental health.

Some resources contain material that may have been partially updated, or with information cut and pasted from different sources; some of this material is internally inconsistent, such as an inclusive practice guide by the Victorian public service.

Interactions between different spaces are evident, for example, AXYS states that the term intersex does not apply to people with sex chromosome variations, and it is certainly the case that the most widespread representations of what it means to be intersex, on the sites of the most highly resourced and LGBT(I)QA+-focused community organisations do not in any way demonstrate comprehension or understanding of people with sex chromosome variations. However, negative evaluations of nomenclature by diagnosis-specific groups rarely consider the work of intersex-specific organisations, and can appear to regard people with their specific diagnosis who have LGBT identities as improbable, irrelevant, or even unacceptable.

At the same time, clinicians may represent that their patients (or more often parents) distance themselves from the word intersex. On the one hand, this could be regarded as a consequence of misuse of the term but, on the other hand, is also a reflection of clinical approaches to the education of parents and children – including the use of terminology – in

ways that are designed to promote compliance (Timmermans et al. 2018; Hegarty et al. 2020; O'Connor 2016; Carpenter 2018a).

Many clinical resources describe surgery in terms that present it as a neutral option, despite decades of contestation, and nearly a decade of criticism by human rights institutions including as forms of experimentation, harmful practices, and inhuman or degrading treatment (for a summary of UN Treaty Body recommendations to Australia, see Intersex Human Rights Australia 2019). Some other resources such as those by the Victorian government, omit material about contested medical practices, failing to address these abuses, failing to prepare parents, and so tacitly accept the continuation of such practices.

In some cases, multiple different resources exist on the same topic, even on the Victorian government website. These typically differ in significant respects, such as the referral destinations given, or even discussion of surgical treatment. It seems likely that different stakeholders might pick and choose between these according to their interests, while some stakeholders might believe that certain resources are shared more widely than they may be.

3.2 A note on changing nomenclature

It should be noted that changes to nomenclature from “intersex variations” in public-facing resources, if proposed, would need careful attention. Proponents of changes to nomenclature need to consider that the existence of intersex variations serves particular purposes to third parties, and changes to nomenclature that do not address those motivations cannot be expected to change the way that bodies with intersex variations are discussed.

Koyama and Weasel twenty years ago found that discussion of intersex serves to underpin discussions about social construction of gender and sex, while ideas about intersex as the “other” are underpinned by concepts that equate sex with biological sex characteristics (Victorian Government 2019). The introduction of “DSD” nomenclature has not prevented such discourses. Specific traits such as XXY chromosomes or CAH can serve as examples of a third sex or the social construction of gender and sex (Colangelo 2017).

Stakeholders are often adept at picking up and citing more up-to-date, careful and precise definitions, but far less adept at addressing issues facing people with intersex variations. LGBT health stakeholders, including those with significant roles in professional healthcare associations, may construct intersex as a sex or a gender identity, and these stakeholders may even define “DSD” in a way that includes “transsexualism” in order to access medical treatment (National Foundation for Australian Women and The University of Melbourne 2016; Wallbank 2015; Carpenter 2018a). Calls for respectful, non-tokenistic inclusion in “LGBTI” settings can be perceived as demands for exclusion or special treatment (Carpenter 2021).

For clinical stakeholders, use of specific diagnostic terms and “disorders” or “differences of sex development” without reference (or with negative reference) to alternative social models of understanding intersex variations can be considered part of a model of practice

designed to educate families and promote compliance with treatment (Carpenter 2021; Hutson et al. 2020). Like LGBT health stakeholders, clinical stakeholders can also frame “DSDs” in ways that contest the identities and sexes of people with intersex variations. For example, “DSD women” are presented as illustrating a “new realm of gender fluidity” in a sports consensus statement co-authored by the director of the Murdoch Children’s Research Institute, Melbourne (Hamilton et al. 2021, 5). Clinical guidelines in sport also promote the idea that women with DSDs who refuse medical intervention should compete in a third sex category of sport (Karkazis and Carpenter 2018).

A better way forward might be for resources to continue to utilise commonly-understood terms (i.e. “intersex variations”), but to also respectfully recognise a range of terms used by community members. At the same time, funders should insist that service providers respect the diversity of the population of people with intersex variations, including in relation to age across the lifespan, and in relation to sex, gender, sexual orientation and gender identity. Funders should insist that stakeholders meaningfully address and service the healthcare and related human rights concerns of the communities they claim to service or represent, including those concerns expressed by the communities of people with intersex variations. Inclusion should be accompanied by representation in senior staffing and/or board positions. This has implications for service funders and public institutions, in addition to service providers.

4 Victorian government

4.1 [Bettersafecare.vic.gov.au](https://www.bettersafecare.vic.gov.au)

Clinically-faced resources are available the site <https://www.bettersafecare.vic.gov.au>. I searched this site for resources using each of the following terms: “intersex”, “CAH”, “DSD”, “disorder of sex development”, plus used prior knowledge about the existence of specific pages.

Congenital Adrenal Hyperplasia (CAH) in neonates

<https://www.bettersafecare.vic.gov.au/clinical-guidance/neonatal/congenital-adrenal-hyperplasia-cah-in-neonates>

- This is likely to be a resource utilised by medical professionals, and shared with parents.
- Normalises human rights abuses: refers to early elective surgery: “Most surgical correction [sic] is now delayed until 6 months of age or later. Opinion currently varies between centres as to surgical management options.”
- Omits consideration of human rights issues relating to treatment of infants.
- May be outdated with inconsistent page dates: “Review by: May 2019.” But also “Page last updated: 17 Feb 2021.”

Ambiguous genitalia in neonates

<https://www.bettersafecare.vic.gov.au/clinical-guidance/neonatal/ambiguous-genitalia-in-neonates>

- This is likely to be a resource utilised by medical professionals, and shared with parents.
- Normalises human rights abuses: reference to opinions from the “surgical teams”.
- Omits consideration of human rights issues relating to treatment of infants.
- Reference to “growth retarded or premature female neonates” – gendered and ableist language.
- Reference to “pseudo-ambiguity”
- Reference to DSD Families, a parent and clinician led group in the UK that is linked to the anti-gender anti-trans ‘gender critical’ movement.¹
- Prioritisation of international resources for “consumers” over local resources.
- Refers to parents as “consumers”.
- Outdated links to Australian resources.
- Links to outdated PDF (immediately below).
- Is likely deployed by hospitals in preference to material that has had VIEAG oversight.
- May be outdated with inconsistent page dates: page last updated 14 May 2021, but “Review by: February 2020”.

Ambiguous genitalia – parent factsheet (on above webpage)

<https://www.bettersafecare.vic.gov.au/sites/default/files/2018-09/Ambiguous%20genitalia.pdf>

- Decent advice on naming the child, though reference could be made to gender-neutral names (a previous version of this resource advised against this recommendation, in line with post-1950s “optimal gender” models for pre-emptive surgical assignment of children with intersex variations).
- Omits consideration of human rights issues relating to treatment of infants and children. No guidance to parents on what kinds of treatment they should seek, consent to, or be offered.
- Reference to DSD Families, a parent and clinician led group in the UK that is linked to the anti-gender anti-trans ‘gender critical’ movement.
- Prioritisation of international resources for parents over local resources.
- No links to Australian community resources.
- Is likely deployed by hospitals in preference to material that has had VIEAG oversight.
- Omits some advice on naming.
- Last updated 2018.

Hypospadias in neonates

<https://www.bettersafecare.vic.gov.au/clinical-guidance/neonatal/hypospadias-in-neonates>

- Relies on appeals to clinical expertise, notably the expertise of surgeons.
- Omits consideration of human rights issues relating to treatment of infants and children.

¹ Morgan has engaged in discussions on this issue with DSD Families trustee Jo Williams.

- Normalises human rights abuses, in the form of unnecessary elective interventions that modify sex characteristics: “all cases” “should be referred to a paediatric surgeon”, routinised surgeries evident in “Occasionally surgery is not required if hypospadias is proximal”; an unsupportable claims “To reduce the psychological impact surgical correction is usually performed in infancy between 6-18 months, if possible as a one-stage procedure but more than one surgery may be required”, and cultural norm about urination while standing expresses as a functional requirement “If a chordee is present surgical correction is required because when standing there will be difficulty with directing urinary stream”.
- Reference also to sexual intercourse, but infants and children do not engage in sexual intercourse.
- Contains an infant genitalia photograph – this is supposed to be recognised as bad and obsolete practice.
- Page date error.
- Attempt to distinguish from intersex and DSD (likely aimed at perpetuating surgical management in a proportion of cases)
- The line drawing of types of hypospadias makes assumptions about penis shape that are typically erroneous as bodies are more diverse the male-typical phallus and scrotum shape (for comparison purposes, consider the penis pictures for hypospadias against scales developed to ascertain AIS and CAH, such as the Quigley scale and Prader scale).
- No community links.
- International/non-local links.
- Obsolete surgical references (all a decade old or earlier).

The health and wellbeing of the lesbian, gay, bisexual, transgender, intersex and queer population in Victoria - Findings from the Victorian Population Health Survey 2017

<https://www.bettersafecare.vic.gov.au/publications/vphs2017-lgbtiq>

- Specific variations not stated in intersex sample n=57.
- Methodology section portrays intersex as a gender identity, see p.96 and 191.
- Equates non-LGBTIQ+ with heterosexual, and LGBTIQ+ with non-LGBTIQ+ throughout – see also methodology section on p.95 that portrays heterosexual intersex people as giving “contradictory responses”.
- Does not acknowledge bodily diversity in section on discrimination, says that intersex people face discrimination on grounds of gender, gender identity, sexual orientation.
- This of course suggests that neonates referred to on the above pages are not heterosexual. At what point is a neonate with CAH, ambiguous genitalia or hypospadias not-heterosexual or holding a so-called intersex gender identity?
- No questions on experiences of early medical interventions or their sequelae.
- No reference to specific comorbidities related to intersex variations.
- Methodologically unsound.

Understanding congenital anomalies in Victoria

<https://www.bettersafecare.vic.gov.au/news-and-media/understanding-congenital-anomalies-in-victoria>

- No directly relevant content, but followed link to PDF, below.

Congenital anomalies in Victoria 2015-2016

https://www.bettersafecare.vic.gov.au/sites/default/files/2018-06/FINAL_Congenital%20Anomalies%20in%20Victoria%202015_2016_WEB.pdf

- Uses consistent diagnostic terminology (ICD-10-AM).
- Reference to obsolete language “indeterminate sex and pseudohermaphroditism” using ICD-10-AM, page 37;
- Reference to “sex chromosome abnormalities” page 39.
- Note that the ICD-11 introduces “DSD” terminology, opposed by a large number of community groups, see <https://ihra.org.au/35299/joint-statement-icd-11/>

4.2 Health.vic.gov.au

Public (including parent and patient)-faced resources are available the site <https://www2.health.vic.gov.au/>. I searched this site for resources using each of the following terms: “intersex”, “CAH”, “DSD”, “disorder of sex development”, plus used prior knowledge about the existence of specific pages.

Community health pride resources

<https://www2.health.vic.gov.au/primary-and-community-health/community-health/pride-lgbtqi-inclusive-practice-resources>

- Lack reference to intersex traits, and intersex peer support organisations.
- Presume that intersex people and our families have an affinity with LGBT populations

Decision-making principles

<https://www2.health.vic.gov.au/about/populations/lgbti-health/rainbow-equality/working-with-specific-groups/infants-children-adolescents-with-intersex-conditions>

- Almost entirely based on clinical principles at Gillam, Lynn, Jacqueline Hewitt, and Garry Warne. 2010. ‘Ethical Principles for the Management of Infants with Disorders of Sex Development’. *Hormone Research in Paediatrics* 74 (6): 412–18. <https://doi.org/10.1159/000316940>.
- These principles have been critiqued by IHRA and others for their elision of concerns about human rights implications of involuntary and coercive treatment, transparency, lack of attention to non-medical forms of understanding intersex bodies, the role of parents as substitute decision-makers for elective procedures, and lack of resourcing for independent peer and family support. See the IHRA critique at <https://ihra.org.au/21944/vic-health-framework-response/>

- The original clinical principles have been widely adopted (perhaps because they sustain existing contentious practices) but they were immediately critiqued at Dreger, Alice, David E. Sandberg, and Ellen K. Feder. 2010. 'From Principles to Process in Disorders of Sex Development Care'. *Hormone Research in Paediatrics* 74 (6): 419–20. <https://doi.org/10.1159/000316943>.
- The 2013 version of the Victorian principles were quietly amended in 2015 to remove reference to the psychosocial risk of “reduced opportunities for marriage” to be considered in relation to medical intervention. The original material is preserved on page 93 of the 2013 Senate report on involuntary or coerced sterilisation (Senate of Australia Community Affairs References Committee 2013, 93). The edit appeared to have been intended at removing an obvious problem with the principles, but was merely a superficial change in disclosure, rather than representing any change to medical thinking in relation to parental consideration of children’s future prospects, and made the residual principles appear more reasonable.

Health and wellbeing paper

<https://www2.health.vic.gov.au:443/about/populations/lgbti-health/health-of-people-with-intersex-variations>

- Critiqued by IHRA and others for its elision of concerns about substitute decision-making by parents and for other reasons, see <https://ihra.org.au/35611/response-to-the-victorian-paper-on-the-health-and-wellbeing-of-people-with-intersex-variations/>

Babies with atypical genitalia: information for families

<https://www2.health.vic.gov.au/Api/downloadmedia/%7B31FA1A70-820D-49AB-BA19-BBE8739CE0DF%7D>

- Contains basic information for parents and carers, including information on referrals to hospitals, community organisations and diagnosis-specific groups (IHRA, IPSA under the name AISSGA, and diagnosis-specific groups).
- Multiple different documents exist for this population with different content and referrals, and it is not clear which document might be provided by medical practitioners.
- Reassurance that most children do not require long term interactions with the healthcare system or cause uncertainty about sex assignment may have unintended effects on parents confronted by those situations.

Sex characteristic variations in babies and children: information for families

<https://www2.health.vic.gov.au/Api/downloadmedia/%7B30FFB31A-C060-4B3D-84EA-BA5B5612431C%7D>

- Contains basic information on variations of sex characteristics for parents and carers, including information on referrals to hospitals, community organisations and diagnosis-specific groups (IHRA, IPSA under the name AISSGA, and diagnosis-specific groups).
- The resource content is substantively duplicated in numerous other hospital, Departmental and community resources, and it is not clear which may be made available to parents and carers.

- Advice on surgery does not address the human rights implications of cosmetic and other unnecessary elective interventions.

4.3 Victorian public service

Inclusive language guide

At <https://www.vic.gov.au/inclusive-language-guide>

Copy at https://res.cloudinary.com/minus18/image/upload/v1585712745/LGBTIQ-Inclusive-Language-Guide_bqdbiv.pdf and elsewhere

- States that “sex refers to a person’s biological sex characteristics”, framing intersex characteristics as outside female and male, while also containing more accurate material on sex characteristics.
- The reference to sex as biological sex characteristics ignores the process of sex assignment or observation at birth, presumes that AIS, ambiguous genitalia, XXY and CAH are sexes, and is generally othering.
- This approach also renders meaningless a reform to the Equal Opportunity Act 2010 (Vic) that is yet to commence but which will provide protections on grounds of sex characteristics.
- The federal style manual at <https://www.stylemanual.gov.au/format-writing-and-structure/inclusive-language/gender-and-sexual-diversity> and the ABS Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables, 2020 at <https://www.abs.gov.au/statistics/standards/standard-sex-gender-variations-sex-characteristics-and-sexual-orientation-variables/latest-release> provide more respectful and accurate models.
- The inclusive practice document also refers to “LGBTIQ” as “only one part of any person or community” when the acronym is an aggregate of multiple concepts of sexual orientation, gender identity and expression, and sex characteristics.

5 Community and support organisations

Organisations are included in this section if they claim a remit relevant to people with innate variations of sex characteristics and they are based in Victoria, or they are a national diagnosis-specific or intersex-specific organisation. These parameters exclude national ‘LGBTI’ organisations and those using similar acronyms containing an ‘I’.

5.1 Australian X & Y Spectrum Support (AXYS)

Website: <https://axys.org.au>

This is not strictly a community organisation as it has a director who is a health practitioner in a “DSD” role at RCH Melbourne.

The website has rapidly expanded in recent years and now contains a bewildering range of resources that are difficult to navigate. An unsorted, text-only list of around 86 resources on “X & Y chromosome variations including Klinefelter syndrome/XXY, XYY, XXX, XYYY, XXXY, XXXXY and other variants” is available at <https://axys.org.au/resource-library/>. Not all resources have been evaluated as part of this review.

Filters are available for some sex chromosome variations, and by resource type (for example, submission, workbook, research paper, brochure, presentation, book) and subject (adults, carer, NDIS, professionals, teachers). Choices of filter are not obvious and do not effectively filter materials. The resource listing does not provide dates of resources.

On this page, it is difficult to distinguish key resources from lower priority resources. For example, a “Myth busters” information sheet is in the same unsorted list of resources as conference presentations, submissions, and prenatal diagnosis information sheets.

- Much of the myth-busters information is helpful. However, it also promotes particular ideas about “normal” bodies, “normal” identities, and medical interventions to promote these concepts of normality. Materials such as a myth-busters information sheet at <https://axys.org.au/wp-content/uploads/2018/12/Myth-Busters-Final.pdf>, a prenatal diagnosis sheet at <https://axys.org.au/wp-content/uploads/2018/12/XXY-Prenatal-Sheet-For-Prenatal-Final.pdf> and a submission to the Australian Human Rights Commission at <https://axys.org.au/wp-content/uploads/2018/12/Submission-to-the-Australian-Human-Rights-Commission-Final.pdf> frequently refer people with XXY sex chromosomes as men, which disregards the diversity of gender identities in the population.
- The myth-busters page states that “Males with XXY are not more likely to be homosexual than the general population”, which lacks citations. This statement is relevant in consideration of materials on the diversity of identities of people with XXY, and to consideration of services by LGBT(I)QA+ community services.
- The submission also references testosterone treatments in infancy and puberty, which are not appropriate for this cohort.
- At the same time, the submission remarks that terminology like “people born with variations in sex characteristics” is inappropriate or not understood. This statement is relevant to consideration of materials published by LGBT(I)QA+ community services.
- A peer-reviewed article on the “psychosocial impact of Klinefelter syndrome and factors influencing quality of life” at <https://axys.org.au/wp-content/uploads/2018/10/Australian-KS-psychosocial-issues-and-quality-of-life-.pdf> [dates from 2011](#) raises many important issues, such learning difficulties that were not treated in persons diagnosed as adolescents or adults, and physical characteristic that may also be related to age of diagnosis. However, the paper is ten years old. In relation to how the materials in the paper cross-reference with issues raised by elsewhere by AXYS and by other types of community organisation, the paper refers to only to men and boys. 11% of 87 study participants were gay or bisexual (described as homosexual or bisexual “sexual preference”), and 84% heterosexual. Large proportions reported “looking” (20%) or “feeling” (30%) “neither masculine

nor feminine” with fewer “looking” (2%) or “feeling” (5%) “feminine” (Herlihy et al. 2011).

Gaps and issues include:

- An absence of recognition of the diversity of the population of people with sex chromosome variations, and how medical treatment impacts upon this.
- An absence of consideration of human rights implications of medical treatments.

5.2 Congenital Adrenal Hyperplasia Support Group Australia Inc.

Website: <https://cah.org.au>

A products and resources section of the website includes a product catalogue, including hard copy book and important products that can help identify and treat people with CAH in emergency contexts.

The “About CAH” page links to a since deleted Victorian government Better Health page on ambiguous genitalia. It contains links to international groups; not all links are active. These issues suggest that the site may not be current or maintained.

5.3 Intersex Human Rights Australia (IHRA)

Website: <https://ihra.org.au>

The IHRA website contains a very large number of pages and resources, however, key resources are all available via a single alphabetised page at <https://ihra.org.au/category/articles/resources/>. The resources are subject-specific and accompanied by images that attempt to convey subject content. These resources are all maintained to ensure their currency and accuracy. Key resources are stated as regularly updated and reviewed by a subcommittee of the board that includes a bioethicist, a lawyer and a medical doctor (the medical doctor, a surgeon, is a woman with lived experience of an intersex variation, and a specialist in abdominal wall reconstruction and hernia repair). This provides expert validation. Users of key resources are provided an opportunity to provide feedback. This approach is necessary as such resources are linked to on the federal Healthdirect.gov.au website.

Resources recognise a range of human rights issues associated with medical interventions. They also recognise a diverse range of terms known and used by community members and families, seeking respect for diverse identities and preferences that is linked to support for individual autonomy.

Resources include those:

- **For specific audiences:** intersex for allies, intersex for parents, youth, forms and data collection, researching intersex populations, media and style guide

- **On specific human rights and health concerns:** bodily integrity, body shaming, COVID-19, discrimination, genetic discrimination and eugenics, clinical guidelines, healthcare pathways, inclusive practice, identification documents, statements by UN Treaty Bodies on intersex human rights in Australia.
- **On specific settings:** workplaces, detention settings, education, domestic and family violence, sport.
- **On principles and theory:** definitions, intersectionality and overlaps with other populations, population figures, the Darlington Statement, the Yogyakarta Principles plus 10.
- **Video resources:** including a debate between bioethicists and paediatric surgeons, an introductory animation, poetry and television programs.

Gaps and omissions include:

- No specific resources on particular intersex variations.
- No specific resources on fertility/infertility.
- Gaps in relation to ageing, dealing with a new diagnosis, accessing healthcare.
- Resources are often highly technical and may be inaccessible to many readers.

IHRA and IPSA collaborate on the Darlington Statement website at <https://darlington.org.au>. This site contains resources including:

- The Darlington Statement, a community declaration.
- Multiple other community statements, developed at events.
- Healthcare pathways resources that identify affirmative healthcare pathways that respect individuals' human rights and choices.
- Inclusive practice resources that promote meaningful and respectful inclusion, including consideration of nomenclature.
- The YOUth&I youth publication, containing diverse personal stories.

5.4 Intersex Peer Support Australia (IPSA)

Website: <https://isupport.org.au>

IPSA (also known as the AIS Support Group Australia) is formerly a diagnosis-specific group now open for people with all kinds of intersex variation.

IPSA have a knowledge hub with links to mostly third-party resources including:

- Diagnosis: mention of different variations, and links to multiple third party resources.
- Specific health issues, such as infertility, HRT, gender and LGBT, intimacy, osteoporosis, the "social model of intersex", surgery and medicalisation.
- Legal issues, including identification documents and human rights advocacy.
- Parents, including disclosure, genetic terminations, and issues affecting infants.
- Support, including art and activism, biographies, and the Darlington Statement.

These resources are curated but of varying quality and accessibility. Some resources are over a decade old. Not all resources have been evaluated as part of this review.

Gaps include:

- Materials developed by IPSA on specific variations and health issues.
- Materials that give third-party resources a context.

IPSA also has a member-only space containing biographies, referral information.

5.5 Minus18

Website: <https://www.minus18.org.au>

A Google search of the site for the term intersex returns about 81 results. Some results were omitted by Google as duplicative of other results. Search results returned are predominantly references to the words that comprise a standardised acronym, such as “LGBTIQ+”. Many of these references refer to people who “identify as” an acronym.

- Minus18 “champions for LGBTQIA+ youth”, and makes reference to “prioritise and forge specific strategies to engage and support” intersex communities in its 2020-2022 strategic plan, but is absent from the VIEAG.
- Reference to intersex is typically a reference to an identity without reference to issues relating to intersex bodies and how bodies are treated or specific healthcare and human rights concerns, for example, on pages about:
 - “how to educate when your child is LGBTQIA+”
<https://www.minus18.org.au/articles/learn:-how-to-educate-when-your-child-is-lgbtqia+>
 - “what to do if you think your child might be LGBTQIA+”
<https://www.minus18.org.au/articles/look:-what-to-do-if-you-think-your-child-might-be-lgbtqia+>
 - “how to support and celebrate your LGBTQIA+ child”
<https://www.minus18.org.au/articles/love:-how-to-support-and-celebrate-your-lgbtqia+-child>
- Advice on “what’s the difference between sexuality and gender” states that “The word **queer** is an umbrella term, basically to mean lesbian, gay, bisexual, trans and intersex (LGBTI) and anyone else who isn’t straight or cisgender” at <https://www.minus18.org.au/articles/what's-the-difference-between-sexuality-and-gender>
- One page offers a role model of someone who is intersex, dating from November 2017: <https://www.minus18.org.au/articles/i'm-intersex:-here's-what-that-means>. The information on this page is largely ok, but contains some errors. For example, including framing someone intersex as outside “‘binary’ sexes”, at the same time as referring to the “typical” female or male bodies, and referring to author as a trans man – making his birth assignment as female incomprehensible. The page refers to the term “hermaphrodite” as a slur, when the reality is more complicated than this.

- The Minus18 page for IDAHOBIT at <https://www.idahobit.org.au> contains a number of free resources containing rainbows and references to LGBTQIA+ people at <https://www.idahobit.org.au/index.php/get-active/resources>. This page. Also contains links to older and third party resources, such as former Safe Schools resources and a link to a Victorian public service inclusive language resource at <https://www.minus18.org.au/resources/lgbtiq+-inclusive-language-guide>
- The site is not accessible to cisgender, heterosexual people with intersex variations. Not relevant for infants, children, adolescents, or family members who share those identities. At the same time, the organisation misrepresents the characteristics of LGBT people with intersex variations.

5.6 MRKH Australia

Website: <https://www.mrkhaustralia.org>

MRKH Australia is a volunteer-run organisation but it is not strictly a community organisation as it has a director who is a health practitioner in a “DSD” role at RCH Melbourne.

MRKH Australia has only recently registered as a charity. It provides some new resources including personal stories and a toolkit resource on mental health.

- The mental health toolkit includes a range of resources and links, including to peer organisations and mainstream mental health services. The contents are generally helpful for any individual seeking mental health support.

The site resources support a diverse range of views and experiences in relation to MRKH. The site contains images of conventionally attractive and typically young women with diverse ethnic backgrounds. It does not demonstrate an acceptance of age and bodily diversity.

Experiences of people with MRKH who use the word intersex – including some of the earliest voices and peer group founders – are omitted. An example is the work of Esther Morris Leidolf (Leidolf 2006).

5.7 Queerspace

Website: <https://www.queerspace.org.au>

A Google search of the site for the term intersex returns about 81 results. Some results were omitted by Google as duplicative of other results. Search results returned are predominantly references to the words that comprise a standardised acronym, such as “LGBTIQ+”. Many of these references refer to people who “identify as” an acronym.

- The Queerspace page on training, professional development and education refers to “We define queer as anyone who identifies in the queer and lesbian, gay, bisexual, trans, intersex, gender diverse spectrum.” This suggests that infants and children with ambiguous genitalia and other traits are queer.
- <https://www.queerspace.org.au/training-education/>
- A letter of 2 February 2021 encourages the Victorian parliament to consider an amendment to protect people with intersex variations in medical settings as part of the then conversion practices bill. <https://www.queerspace.org.au/open-letter-members-victorian-state-parliament/>
- The Queerspace WithRespect intimate partner violence resource for professionals at <https://www.withrespect.org.au/professionals/about/family-violence-lgbtqi-communities> refers to a lack of data on intersex people, and also refers to “LGBTIQ people can experience all the dynamics attributed to heterosexual intimate partner violence”. It also refers to services “Knowing the differences between sex, gender and sexuality and the impact of misgendering someone”, but this construction of intersex as sex can risk misunderstanding the sexes of intersex people, including both cisgender and binary transgender intersex people.
- The site is not accessible to cisgender, heterosexual people with intersex variations. Not relevant for infants, children, adolescents, or family members who share those identities. At the same time, the organisation misrepresents the characteristics of LGBT people with intersex variations.

5.8 Switchboard Victoria and Rainbow Door

Websites: <https://www.switchboard.org.au> and <https://www.rainbowdoor.org.au>

- From a website search, the term intersex is mentioned only within generic statements that name terms in the acronym LGBTIQ+ or LGBTI. The site contains no specific resources, just mention of “LGBTI” people, and people who “identify as” an acronym.
- On the Family Violence Support page at <https://www.rainbowdoor.org.au/family-violence>, the Rainbow Door page uses the term heterosexual as an antonym (opposite) to LGBTIQ+, failing to recognise that many intersex people grow up to be heterosexual. This suggests that the organisation does not provide a safe support environment for heterosexual intersex people.
- The site is not accessible to cisgender, heterosexual people with intersex variations. Not relevant for infants, children, adolescents, or family members who share those identities. At the same time, the organisation misrepresents the characteristics of LGBT people with intersex variations.

5.9 Thorne Harbour Health

Website: <https://thorneharbour.org>

A Google website search for the term intersex returns about 135 results. Some results were omitted by Google as duplicative of other results. Search results returned are predominantly references to the words that comprise a standardised acronym, such as “LGBTIQ”.

- Reference is made on the home page and throughout to “sex, sexuality & gender diverse communities” where sex is supposed to refer to intersex people, as in “Our NDIS services support the needs of our lesbian, gay, bisexual, trans and gender diverse, and intersex communities to ensure that all gender, sex, and sexually diverse individuals” on page <https://thorneharbour.org/lgbti-health/ndis-national-disability-insurance-scheme/>
- All resources and programs are designed around the needs of LGBT populations, with a remit expanded to reference intersex people also. There are no specific resources or programs designed around the needs of intersex people.
- The site makes numerous references to intersex status and “intersex stigma” alongside more frequent statements about homophobia and transphobia.
- A page on cervix screening at <https://thorneharbour.org/news-events/media-releases/public-cervix-announcement-new-campaign-highlights-safe-inclusive-cervical-screening-lgbtiq-people/> refers to screening availability for people with a cervix who have an intersex variation.
- The site is not accessible to cisgender, heterosexual people with intersex variations. Not relevant for infants, children, adolescents, or family members who share those identities. At the same time, the organisation misrepresents the characteristics of LGBT people with intersex variations.

5.10 Turner Syndrome Association of Australia

Website: <https://www.turnersyndrome.org.au>

The website home page describes the association as “for females living with Turner Syndrome and their support networks”.

A resources page provides links to:

- A database of medical professionals
- Clinical guidelines – a peer-reviewed paper on care for girls and women with Turners (Gravholt et al. 2017). Many fertility, lifetime healthcare, and gonadectomy recommendations are supported by very low or low quality evidence.
- A removed link to US clinical practice guidelines (the text for a link is present but there is no clickable link).
- A few international resources.
- Some Victorian and NSW hospital and mental health links.

Gaps and omissions:

- No resources appear to have been developed by this group.
- No reference to any Victorian resources other than one by RCH Melbourne.
- Exclusion of people with Turner syndrome who do not regard themselves as female.

6 Clinical organisations

6.1 Australasian Paediatric Endocrine Group (APEG)

APEG provides a series of patient booklets at <http://apeg.org.au/patient-resources/hormones-me-booklet-series/>

Hormones and me, Turner syndrome

- This resource is dated, having been published in 2012, and based on material first written in 2000.
- The resource contains detailed information on a range of physical health issues associated with Turner syndrome.
- The language is medically focused without attention to mental health, social, ethical and human rights considerations.
- The resource presumes heterosexuality and a cisgender female identity, including in relation to starting puberty with hormone treatment.

Hormones and me, Klinefelter syndrome

- This resource was published in 2011 and is dated affecting language and some medical advice (for example, that relating to fertility).
- It presumes children will grow to express a cisgender male identity, including in relation to starting puberty with hormone treatment. Statements on sexual orientation and identity on page 15 serve to reassure readers of the apparent normality of people with XXY, while disregarding evidence on a range of self-conceptions and sexual and gender identities. Page 25 clarifies that a child with XXY is “a ‘proper’ boy”.
- The resource contains detailed information on a range of physical health issues associated with Klinefelter syndrome, with frequent attention to genital appearance and size.
- The language is medically focused without attention to mental health, ethical and human rights considerations. Some limited attention is given to psychosocial and emotional issues, framed as “psychological behaviour problems in adolescence and adulthood”, which is likely to be unconstructive for readers with XXY. This material is unlikely to facilitate diagnosis with associated psychosocial traits.

Hormones and me, Congenital Adrenal Hyperplasia (CAH)

- The booklet was revised in 2011, and can be expected to be out of step with current clinical guidelines.
- The booklet provides an explanation of the diagnosis, and on adrenal gland functioning.
- Language in relation to CAH is pathologizing, even recognising that the trait can result in significant health issues that may require lifelong management, for example, with hydrocortisone.
- The document states that parents of a child with CAH speak with their doctor “as soon as possible” when thinking of becoming pregnant or early during a pregnancy “so that genetic testing can be done”. This may serve two purposes: in the absence

of neonatal screening, this can ensure that infants are treated before the possibility of an adrenal crisis, and it also serves as a means of preventing the birth of a child with CAH. The latter rationale is implied on page 16.

- Prenatal management using dexamethasone during pregnancy is stated as possible. This treatment has cognitive risks and was the subject of a recommendation of the 2013 Senate inquiry report (Hirvikoski et al. 2012; Dreger, Feder, and Tamar-Mattis 2012; Senate of Australia Community Affairs References Committee 2013). These risks and recommendation are not disclosed.
- Surgery on young girls is described as “Some girls with CAH will have corrective surgery to their genitalia. Surgery is usually performed in infancy”. A potential need for later surgeries is also disclosed. Clitoral surgery is described as “preserving sensation”. On the same page, “a lot of previous reconstructive surgery” is presented as a risk factor in childbirth. A later page identifies that “Any surgical procedure requiring general anaesthetic are likely to require” additional hydrocortisone therapy”. A reference for management of acute stress is provided, and is available on the APEG resources page.
- The clitoris is described as “a small button-like sensitive organ above the opening of the vagina”.
- No human rights or ethical considerations associated with surgery are disclosed.
- A link is provided to a US organisation that closed in 2008.

Hormones and me, Delayed puberty

- This booklet dates from 2011.
- The resource shares some characteristics with other APEG resources.

A word on nomenclature

<https://d192ha6kdpe15x.cloudfront.net/apeg/assets/uploads/2020/11/A-word-on-nomenclature-for-website.pdf>, dated October 2020.

- This resource omits criticisms of DSD nomenclature made by academics and community organisations since at least 2011 (Holmes 2011; Davis 2011; Carpenter 2018a; Intersex Human Rights Australia 2009) and by human rights institutions (Office of the High Commissioner for Human Rights 2019; for example, Inter-American Commission on Human Rights 2015), that the shift in clinical nomenclature to “DSD” entrenched unnecessary pathologisation of intersex traits, and asserts medical authority while disregarding other non-pathological ways of understanding benign intersex features.
- Despite a deliberate clinical shift from intersex to “DSD” in 2006 (Hughes et al. 2006; Houk et al. 2006), the document asserts a definition of intersex. This definition is idiosyncratic and inconsistent with current standardised definition and human rights norms expressed in a UN OHCHR background note (Office of the High Commissioner for Human Rights 2019), while also failing to reference that definition and those norms.
- Claims made about the precision of the term intersex are made while disregarding similar contestation in relation to the term DSD (González and Ludwikowski 2016; Griffiths 2018; Wallbank 2015).

- A claim is made about participation in an meeting, an invite-only meeting, that disregard the marginalisation of the two “patient group representatives” at that meeting (Thomas 2006).

APEG also provides a range of clinical resources at: <https://apeg.org.au/clinical-resources-links/dsd/>. This page mostly contains links to support groups and third party resources. Listing last updated 25 May 2018.

The page include links to DSD Families, a group known to be linked to the UK anti-trans, anti-gender “gender critical” movement. This group may be highly inappropriate or harmful for children with diverse identities.

6.2 RCH Melbourne

Differences of sex development

<https://www.rch.org.au/endo/differences-of-sex-development/>

- This contains a link to DSD Families, a UK parent and clinician run group linked to the anti-gender anti-trans movement.
- Some internal links are obsolete, such as a link to a page on atypical genital.
- Links are provided to peer support groups, hospitals, clinical organisations, and some general services providers such as Headspace, the Domestic Violence Resource Centre Victoria and others. Some names are obsolete. No links are given to LGBTI service providers in Victoria.
- The page is not dated.

Complete androgen insensitivity syndrome

https://www.rch.org.au/endo/cais/Complete_androgen_insensitivity_syndrome/

- This is a version of an longstanding resource first written by Garry Warne. IPSA was consulted on the current text.
- A series of pages that introduce complete AIS to individuals and family members, with a link to Intersex Peer Support Australia. The counselling and support section refers to the old name and website for IPSA.
- The surgery section lacks a date for mention of a “recent review” on gonadal cancer risk. Clinical views vary on this issue, with a 2019 paper making concrete recommendations for gonad preservation (Weidler et al. 2019).
- The document is not dated.

Hypospadias

https://www.rch.org.au/kidsinfo/fact_sheets/Hypospadias/

- Pathologising language from the outset; rationales for this appear to be self-esteem and “urine can come out in the wrong place”, a rationale often described as a “functional” rationale that men have to be able to stand to urinate. There is little evidence to support these beliefs (Carmack, Notini, and Earp 2015).

- Reference is made to “correction” surgery at 6-18 months of age, “More than one operation may be required.” The text states that “benefits of surgery will outweigh the risks”, presupposing a decision favouring surgery.
- Early exposures to general anaesthetic are known to have risks for cognitive development (Schneuer et al. 2018); this risk is not stated.
- A line drawing of a penis appears to show typical male genital appearance, but actual genital appearance is more variable than that shown, and this might have the effect of promoting an aspiration for post-surgical appearance amongst parents.
- These surgeries carry risks of high rates of complications, with some outcomes only becoming evident from adolescence (Carmack, Notini, and Earp 2015; Barbagli et al. 2012). Current medical literature in the journal of the Asia Pacific Association of Paediatric Urologists and other paediatric urology societies still refers to “hypospadias cripples”(Neheman et al. 2020a; Hanna 2020; Neheman et al. 2020b).
- The document is not dated.

Information about genital examinations

https://www.rch.org.au/endo/for_patients_and_families/Information_about_genital_examinations/

- This document provides advice for families on how and when clinicians perform genital examinations.
- Rationales include determining prenatal exposure to testosterone (an ascertainment of virilisation that can impact on sex assignment), and determination of gonad location.
- Reference is made to “an option for having surgery to change the genital anatomy” for “some children”, and so photography may be requested.
- Reference is made to respecting the consent of a child or adolescent, to avoiding “repeated genital examinations of a person” due to an impact on mental health and “sense of self”, and to attention to communication.
- The document contains contemporary language on “variations in sex characteristics” but is not dated.

RCH MRKH information

https://www.rch.org.au/rch_gynaecology/young-women-and-parents-and-carers/RCH_MRKH_information/

- References people with MRKH as women and girls, disregarding other self-conceptions.
- Provides extensive mental health advice and support, in marked contrast to the pages on hypospadias, and also CAIS.
- Links are provided to hospital and selected diagnosis-specific groups.

7 Academic organisations

7.1 Rainbow Health Victoria

Website: <https://www.rainbowhealthvic.org.au/>

Rainbow Health Victoria maintain a list of currently 29 resources at <https://www.rainbowhealthvic.org.au/research-resources?c=resources>

- These resources are either for “LGBTI+” populations, or transgender and diverse populations, with no intersex-specific resources.
- The resources listing does not state the date or age of included documents.
- The resources date, in some cases, to 2009 in relation to a guide to inclusive practice for health and human services, at https://www.rainbowhealthvic.org.au/media/pages/research-resources/well-proud/3712379566-1605661769/wellproud_updated2011.pdf
- The 2009 inclusive practice resource frames intersex as a matter of gender identity, and adds three bullet points on intersex to the end of a section on “sex and gender diverse people”. A bullet point states “permanent treatments are preferably delayed until the child is old enough to consent themselves”.
- The resources section also links to third party resources.

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