

Health in Focus

Intersex Health

An evidence review and practical guide designed
for healthcare providers and researchers



rainbow health ontario
santé arc-en-ciel ontario

SHERBOURNE HEALTH

Rainbow Health Ontario
rainbowhealthontario.ca

Rainbow Health Ontario

333 Sherbourne St

Toronto, ON M5A 2S5

rainbowhealthontario.ca

PURPOSE

This *Health in Focus* educational resource was created to highlight the healthcare needs of intersex people. This document will help you identify the issues facing intersex people in healthcare and social services, while grounding you in an understanding of experiences faced by intersex people throughout their lives within the healthcare sector.

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KEYWORDS

Intersex, variations in sex characteristics, disorders of sex development, intersex health care, non-consensual genital surgery, childhood medical intervention, bodily autonomy, informed consent, healthcare discrimination, mental health outcomes, medical trauma, sterilization risk, human rights law, self-determination, binary sex model, pathologization of intersex bodies, intersex research gaps, clinical ethics, health policy and legislation, patient-centered intersex care

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SUMMARY

“Intersex” is an umbrella term to describe an array of variations to physical sex that may not be considered typically male or female, or part of the binary understanding for human sexual development. Those who are intersex have a difference to or mixture of sex characteristics, such as sex chromosomes, reproductive organs, external and internal genitalia, hormones, and/or secondary features that develop during puberty. Intersex traits can be apparent at birth or may not become evident until puberty, when trying to conceive, or later. For a variety of reasons, many people can go their entire lives without knowing they were born with an intersex variation (McGill University, 2025).

Intersex characteristics occur in one out of every 1,500 births (Intersex Society of North America, 2006). That means that, on average, an intersex child is born every two days in Canada, and five intersex children are born

each day in the U.S.A. Globally, intersex people represent approximately 1.7 per cent of the world’s population (Intersex Society of North America, 2006).

Within some medical circles, the term “Disorder of Sex Development” (DSD) has replaced earlier terms such as sex reversal, hermaphrodite or pseudohermaphrodite (Intersex Society of North America, 2006). However, there has been a shift in language due in part to the stigmatization and pathologization of intersex bodies and the notion of calling a variation a “disorder”. These terms include “Intersex Condition(s)”, using the name of their specific condition i.e., Androgen Insensitivity Syndrome (AIS), “Variations in Sex Characteristics” (VSC), or using the term intersex as an umbrella to describe their condition(s) (Intersex Society of North America, 2006). When meeting with patients, it is important to ask about their preferred terminology, as variation exists on an individual level.

UNDERSTANDING THE TERMINOLOGY

The following terms appear in this resource. For additional definitions please see Rainbow Health Ontario’s Glossary: <https://www.rainbowhealthontario.ca/2slgbtq-health/glossary/>

- **Intersex** - An umbrella term for people born with variations in sex characteristics such as reproductive systems, chromosomes or hormones that do not fit typical binary notions of male or female bodies. Intersex is about bodily diversity, not gender identity, though some intersex people may also identify as trans or non-binary.
- **Disorder of Sex Development (DSD)** - A clinical term that replaced older terms such as hermaphrodite or pseudohermaphrodite.
- **AIAB** - An acronym for assigned intersex at birth, similar to AFAB/AMAB. It refers to the sex assigned to a person at the time of birth.
- **Ultersex** - An identity label for “trans intersex” individuals. It refers to intersex individuals who do not identify with the sex assigned to them at birth.

HISTORICAL DISCRIMINATION

Since the 1950's, doctors have routinely used surgery and hormone treatments to make intersex babies more closely resemble the sex they were assigned by the attending physicians. These decisions are often made in consultation with families who know very little about intersex conditions. It is estimated that 30-80 per cent of intersex children undergo more than one surgery, with some having as many as five surgeries (Fausto-Sterling, 2000). Often, these surgeries are not medically necessary, but rather aesthetic in nature to make an intersex body adhere to the binary understanding of sex.

In the 1990's, intersex adults began to speak out against surgery and hormone treatment on children, and the secrecy surrounding it. They argued that such interventions caused trauma and physical harm (Gay and Lesbian Medical Association, 2010). Several medical professionals soon joined them in opposing cosmetic genital surgeries for children.

CURRENT PROTECTIONS & BARRIERS

Canadian federal and provincial initiatives aimed at advancing 2SLGBTQ+ rights and inclusion continue to fall short when it comes to intersex rights (EGALE Canada, 2018). Non-consensual genital surgeries on intersex infants and children are still performed in Canada, reflecting a broader failure to safeguard and support intersex individuals. This failure is evident in three key areas:

1. Canada's permissive policies and legislation that allow non-consensual intersex genital surgeries.

2. The absence of protective laws, supportive infrastructure, dedicated research, and resources for intersex people within Canada.
3. Canada's silence and lack of advocacy for intersex individuals' right to self-determination at the international level.

At present, intersex people in Canada lack formal recognition of their rights under both federal and provincial law. While Section 3(1) and Idem 3.1 of the Canadian Human Rights Act prohibit discrimination on the basis of "sex, sexual orientation, gender identity and expression," and similar protections are echoed across provincial and territorial human rights legislation, none explicitly address discrimination based on variations in sex characteristics. This omission leaves intersex individuals vulnerable to lifelong experiences of violence, harassment and stigma, and perpetuates the practice of non-consensual medical interventions at birth or during early childhood.

DISTINGUISHING INTERSEX FROM 2SLGBTQ+

Being part of the 2SLGBTQ+ community is distinctly different from being intersex. Intersex is about congenital physical differences in sex characteristics. The majority of intersex individuals identify as heterosexual (Migeon, et al., 2002). However, according to studies, a higher percentage of intersex individuals identify as being part of the 2SLGBTQ+ community than their endosex counterparts (Jones, et al., 2016).

Although some intersex people may share issues in common with transgender, non-binary and/or gender non-conforming people, it is inaccurate to describe them

as such. Transgender, non-binary and/or gender non-conforming people are not born with atypical sexual and reproductive systems and do not have the same history of surgical intervention during their childhood as intersex people. There are, however, intersex individuals who do not identify with their sex assigned at birth (including when assigned intersex at birth aka AIAB), who may refer to themselves as Ultersex, which is a sex label for “trans intersex” individuals (LGBTQIA+ Wiki, 2025), or another term that they feel best describes their experiences.

For example, individuals with 5-alpha reductase deficiency aka 5ARD may be assigned female at birth due to their external genitalia appearing female. However, when they experience a typical male puberty, they may feel more comfortable living as a man and identify with a male gender identity. Typically, intersex individuals with such experiences do not consider themselves transgender, as their journey with their body and gender identity are distinctly different (Intersex Canada, 2024).

PHYSICAL & MENTAL HEALTH OF INTERSEX PEOPLE

Intersex rights advocates from diverse research fields argue that medical and surgical interventions on intersex children result in profound trauma and mental health challenges (Ghatta, 2019)—impacts that are frequently overlooked and left unacknowledged by medical professionals.

Bodily trauma arises directly from non-consensual genital surgeries performed on intersex infants. These procedures are carried out solely because the infants’ bodies do not

conform to normative definitions of male or female. The intent of such interventions is to surgically alter existing genitalia to more closely resemble one of the two genital forms deemed acceptable by medical practitioners.

Intersex genital surgeries are typically irreversible and often have lasting negative effects on young people’s health and well-being (Jones, Intersex Studies: A Systematic Review of International Health Literature, 2018). These procedures can lead to sterilization (Carpenter, 2016), incontinence and scarring (Cresti, Nave, & Lala, 2018), while also diminishing an individual’s capacity for sexual pleasure (Kismodi, Corona, Maticka-Tyndale, Rubio-Aurioles, & Coleman, 2017) or complicating intimate relationships in other ways. Despite these serious consequences, many medical practitioners continue to justify such interventions as an acceptable trade-off to prevent bodies from existing outside the normative male/female sex and gender binary.

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In addition to the physical trauma that intersex people endure when they are subjected to non-consensual genital surgeries, intersex people experience undue hardship and shame as a direct result of these interventions. Among other difficulties, these experiences often result in depression (Cresti, Nave, & Lala, 2018) and potential lack of trust in medical systems, among other difficulties. Further, the medical interventions that people with intersex variations are subject to results

in the erasure of intersexuality throughout policy and across legal cultural spheres (Monro, Crocetti, & Yeadon-Lee, 2019).

Medical interventions on intersex people erase intersexuality across policy and law.

In light of the limited knowledge surrounding intersex conditions, it is essential that clinicians actively pursue their own research to better serve their patients. Families and individuals rely on clinicians for guidance across all aspects of medical care, including consultations with parents of newborns. To provide accurate and supportive advice, clinicians must develop a thorough understanding of the complexities and nuances of intersex conditions.

IMPLICATIONS FOR HEALTHCARE PROVIDERS

Because intersex variations are relatively common, clinicians should ask patients directly about their sex and gender identities instead of relying on assumptions based on appearance. While some intersex individuals identify outside the male/female binary, the majority identify as either male or female.

GAPS IN RESEARCH

Because intersex people represent a minority population and their diagnoses have historically been shrouded in secrecy, statistically representative data remains scarce. More research is needed to understand the lived experiences of intersex individuals — both those who underwent multiple childhood

RECOMMENDED RESOURCES

Here is a list of other possible resources and/or websites to explore:

- Intersex Canada website: <https://intersexcanada.org/>
- Hilary Ball “The Push for Intersex Rights Recognitions in Canada” resource: <https://mjlh.mcgill.ca/2022/02/28/the-push-for-intersex-rights-recognitions-in-canada/>
- EGALE Canada Intersex Resource Hub: <https://egale.ca/awareness/intersexhub/>
- McGill University “Towards Affirmative Intersex Health Communication in Canada” guide: <https://www.genomicsandpolicy.org/Ressources/36.pdf>
- MRKH Intersex Organization website: <https://mrkh.org/>
- Interconnect website: <https://interconnect.support/>
- interACT Advocates for Intersex Youth website: <https://interactadvocates.org/>
- Soutien Intersexe - Montréal: <https://intersexemontreal.wixsite.com/groupe>
- Intersex Society of North America website: <https://isna.org/> (Note: This organization is no longer active, but their website is archived online and contains valuable resources)

surgeries and those who did not — in order to distinguish the physical and social effects of the conditions themselves from those caused by medical interventions. In addition, there is a notable absence of long-term, longitudinal studies examining the psychological and physical outcomes of different treatment models. Consequently, many doctors, parents, and intersex individuals are forced to make healthcare decisions without the support of robust, evidence-based data.

surgeries, lack of information about any specific cancer risks and/or significant barriers to accessing appropriate care (Cancer Council NSW, 2023; Tamar-Mattis, 2017; Ussher, et al., 2024). To move forward, more studies are needed to develop patient-centered models of intersex health care. Without such evidence-based frameworks, physicians are likely to continue relying on pathologizing approaches to treatment.

Institutional barriers and research gaps significantly hinder progress on intersex health care.

Institutional barriers and research gaps in the medical field significantly hinder progress on intersex health care. Researchers often face administrative obstacles when attempting to access patient data, and many report difficulties stemming from medical doctors' reluctance to collaborate with intersex rights advocates. These challenges are compounded by the stigma, erasure and inconsistent terminology used to describe intersex traits in patient records. The erasure of intersexuality is further reflected in the absence of large-scale, population-based health data on intersex individuals.

Because medical research typically relies on a male/female binary classification, intersex people are often excluded from studies that could directly address their health need. This gap is especially damaging in cancer research, wherein the exclusion of intersex bodies from studies leads to misrepresentation of causal links to justify non-consensual

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