



SUPPORTING YOUR INTERSEX CHILD

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This resource was produced by:

Egale Canada Human Rights Trust

Founded in 1995, Egale Canada Human Rights Trust (Egale) is the only national LGBTQI2S organization. Egale works to improve the lives of LGBTQI2S people in Canada and to enhance the global response to LGBTQI2S issues by informing public policy, inspiring cultural change, and promoting human rights and inclusion through research, education, and community engagement. Egale's vision is a Canada, and ultimately a world without homophobia, biphobia, transphobia, and all other forms of oppression so that every person can achieve their full potential, free from hatred and bias.

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Introduction

There is a history of trauma and stigma in relation to intersex variations that stems from coercive, non-consensual surgical and pharmaceutical interventions. The lack of disclosure and autonomy given to intersex people is also a long standing issue. This resource was designed to answer common questions that parents of intersex children often have, while empowering parents and their children to make informed decisions based on current research from intersex activism.

This resource for parents of intersex children includes general guidelines for navigating the healthcare system and navigating conversations with your child, your family, and with schools. Since being intersex is often confused with gender identity, we have included a handy guide to help parents understand this distinction themselves, and more easily explain it to others. A curated resource list is included at the end for further information.

It is important to keep in mind that you and your child are partners embarking on this journey. An important part of your role is to preserve and support your child's autonomy while providing guidance and resources when needed.

Glossary

Disorders of Sex Development (DSD) has been used by medical professionals to refer to intersex bodies. Some intersex people use these terms when referring to themselves. A growing number of intersex people consider DSD terminology to be stigmatizing and pathologizing and prefer to use the term intersex.²

Dyadic refers to a person whose chromosomal, hormonal, or anatomical sex characteristics fall within the conventional classifications of male or female. Using this term, instead of 'normal' female or male helps challenge social stigma by avoiding the implication that people with intersex variations are somehow less normal. Alternatively, some activists are pushing for the use of the term Endosex, which simply means not intersex. This push is to avoid endorsing any binary ideals that the term Dyadic linguistically suggests. While it is important to recognize that the binary is limiting and harmful, we will still be using the term Dyadic in this resource because the medical system, healthcare system, and society at large that you and your child must navigate within still operates between the confines of the binary.

Intersex refers to a person whose chromosomal, hormonal or anatomical sex characteristics fall outside the conventional classifications of male or female. The designation of "intersex" can be experienced as stigmatizing. There is a history of medical practitioners imposing it as a diagnosis requiring correction, often through non-consensual surgery or drug treatments on infants, children and young adults (some people may not be identified as "intersex" until puberty or even later in life). The term is not an identity, but rather an umbrella term that encompasses a range of variations in biological sex differentiations.

Sex/Gender Binary is the notion that there are only two possible sexes (male/female) and genders (man/woman), and that they are opposite, distinct and uniform categories. This view also asserts that gender is determined by sex.

Navigating the healthcare system

If your child's intersex variation is identified at birth, you may be overwhelmed with an abundance of information that is difficult and confusing to understand. Here are some tips and facts that are important to remember and consider:

- Intersex variations occur within 1.7% of the population, similar to the percentage of children born with red hair.¹ While this statistical comparison is centered on North American and Western populations, it still serves to show that you and your child are not alone.
- Medical staff may immediately suggest a 'treatment plan' that includes surgical procedures and/or hormonal treatments. Many of the recommended surgeries are 'normalizing' surgeries that aim to conform your child's body to stereotypical ideas about what bodies look like. Oftentimes they are not medically necessary and in fact can have harmful effects on your child's genitals and reproductive system.
- Unless an intervention is deemed medically necessary and supported with evidence, hold off on consenting to any surgeries or hormonal treatments until your child is old enough to participate in that decision.
- Many intersex people who have been subjected to non-consensual genital surgery as a child or infant come to regard it as a violation of their bodies akin to sexual abuse later in their life.²

Doctors often make and/or recommend decisions about which sex to assign an intersex infant based largely on the ease of surgical intervention. For example, if they determine that an infant's penis is too small, they may suggest amputation and subsequently assign the child as female since it is easier to remove tissue than to add it. As a result of this, infants with ambiguous genitalia are more often assigned female than male.

Navigating the healthcare system

- Your child may need routine examinations and testing. It is important that you advocate for them while respecting their autonomy and their right to privacy as well.
- Ensure that your child knows about their rights as a patient, it is your job as a parent to prevent all potentially invasive or abusive approaches to intersex variations
- Empower your child to say no and allow them to express any experiences they may have felt uncomfortable with.
- There may be a time when your child wants to speak to medical professionals on their own in private - allow them that space.
- Involve your child in conversations about their health and medical decisions.
- Seek out and consult a range of professionals and community members who may have experienced similar medical situations as you and your child.
- Do your own research to learn more about the specific contexts of your child's intersex variation.
- Keep track of your child's medical records for them.

FACT

Under the Canada Health Act, medical institutions have the power to withhold a patient's medical record if they deem it to be in the patient's best interest.⁴ As a result, many intersex people have had trouble accessing their medical records as adults. As a parent, it therefore becomes more important for you to keep track of your child's medical records for them.



Remember your rights!

You and your child have the right to receive compassionate and considerate health care that takes into account your personal beliefs and values, and you and your child have the right to be included in the decision-making process free of coercion and pressure.

You have the right to **informed consent**, which consists of:

- Access to information that is explained carefully and accessibly.
- The complete transparent set of medical information pertaining to your child and their intersex variation.
- An explanation of the risks and benefits of accepting or refusing any treatment or surgical procedure being offered to your child, including the state of research evidence related to the suggested treatment. You also have a right to know why your doctor or medical team thinks that treatment or surgery is justified.
- The right to refuse any treatments or surgical procedures that are not in the best interest of your child.



FACT

In Canada, the Criminal Code [s. 268(3)] allows for parents and medical practitioners to undertake non-consensual, cosmetic surgeries on intersex infants.³As such, there are no criminal repercussions to the pathologization and harm to intersex bodies which is in direct violation of the UN Convention Against Torture. There is currently a call to action to hold Canada accountable to international human rights law.

Remember your rights!

You and your child have the right to **privacy**, which consists of:

- Full confidentiality in any communications of treatment, examinations and testing.
- The right to refuse any unnecessary examinations, and to be able to accompany your child during any necessary ones while being able to limit the presence of anyone not needed in attendance.
- The right to be informed if medical staff is looking into using your child as a participant in medical research. You have the right to decline participation.



Be aware of medical practitioners wanting to take photographs of your child's body. You have the right to know why your child is being photographed and what the photographs are being used for. Photographs are rarely medically necessary, but if they are, you have the right to ensure that the photographs are kept confidential within your child's records.

Navigating conversations with your child

- The prevailing best practice is to be transparent with your child about their intersex variation. Secrecy leads to feelings of shame, isolation, and confusion and often negatively impacts future relationships.
- Teach your child the difference between secrecy and privacy. Privacy is a right and allows you and your child ownership of your personal information so you can assess who to tell what, and how that may benefit you.
- An important concept to instill is that all people and bodies are different and that being intersex is just a way your child's body may be different from other children's, but that this is not a bad thing. Start talking to your child about their body from when they are born instead of waiting for the right time or age. You can use more specific language about bodies and biology as your child gets older, but the conversations should always be happening.
- Allow your child to have the freedom to choose when, how and to whom they want to be open with about being intersex. Support them through each decision by exploring what the possible risks or benefits of each decision could result in.
- Just like any other child, your child's sexual orientation and gender identity should not be assumed. Be open and accepting should they tell you something different than you expect.

Typically, parents will assign a gender to their child. However, as a child learns more about themselves and their body, they may come to identify with a different gender. Be open to this and empower your child to explore their gender identity.

- Have open conversations about the difficulties, bullying and ignorance your child may face. Provide support in navigating those situations and build a foundation of transparent and non-judgmental conversations at home. Instilling confidence about bodies is a formidable task for any child, nevermind a child whose body doesn't look like their classmates'.
- Teach your child about their rights as a patient, student, and human being. Empower your child with the knowledge that they have the ability to give and take away consent.

Navigating conversations with your family

- Being open and transparent about your child's intersex variation with immediate family and community members fosters an early sense of acceptance and a celebration of your child's difference. Your child should be loved because of their differences, not despite them.
- Siblings who are dyadic (non-intersex) may go through socially expected experiences of puberty. Be aware that your child might experience jealousy or a sense of being left out. Create space for them to communicate these feelings with you.
- Teach your child how to respond to questions, bullying and teasing in healthy and positive ways. In addition, teaching your dyadic children these skills empowers them to become powerful allies.
- Knowing that this may be a difficult journey for you, your child and your family, we strongly recommend that you avoid putting the burden of your emotions and processes onto your child. Instead, continue to seek out various resources, peer support and/or therapy.



Early conversations about difference and diversity will foster acceptance for intersex people. It will also allow for the recognition of other non-normative bodies or identities that your child may encounter or even embody in their own development.

Navigating school systems

- School staff should be informed at a basic level if your child needs to take medication or needs accommodations such as gender neutral or private bathrooms and changing rooms.
- As with any other personal information, the amount of disclosure you offer staff should be up to you and your child. Involve your child in this decision making process.
- Remind staff that your child has a right to confidentiality and privacy.
- If your child chooses to be open about being intersex, check in with their teachers about what they know about intersex variations and be prepared to offer some resources for their learning.
- Ask the school about its anti-bullying policy and what protocols are in place should your child be bullied.
- Encourage your child to access peer support groups and spaces both in school and online. This will allow them to feel more in touch with community and experience less isolation. Meeting other intersex people and parents of intersex children will be beneficial to both you and your child.



Teachers are legally and contractually required to learn about, support and advocate for intersex students' needs. Your child's right to confidentiality and privacy are also protected under the human rights code.

Components of identity

GENDER

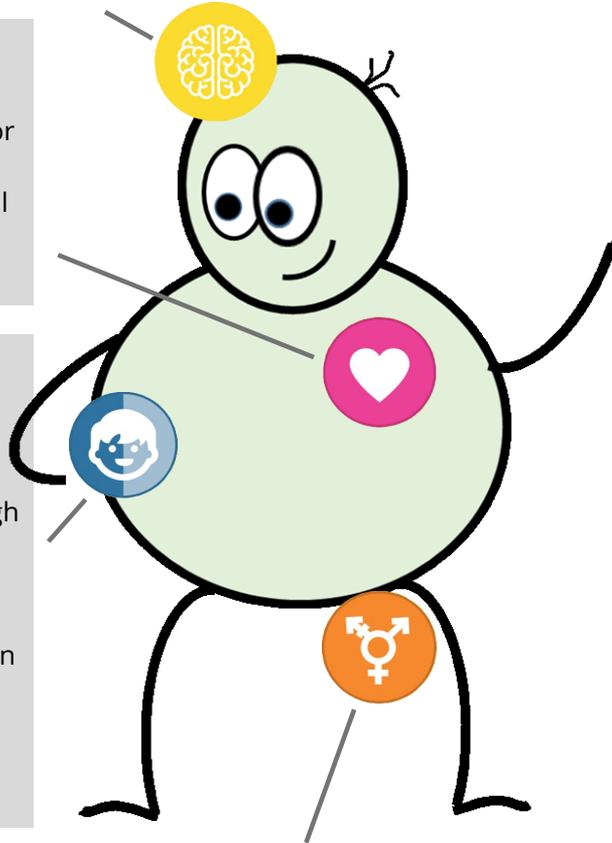
Gender is a person's internal and individual experience of their gender. This could include an internal sense of being a woman, man, both, neither, or another gender.

ATTRACTION

Attraction (or sexual orientation) describes someone's potential for emotional, intellectual, spiritual, intimate, romantic, and/or sexual interest in other people, often based in part on gender.

GENDER EXPRESSION

Gender expression is the way a person presents and communicates gender socially. Gender can be expressed through clothing, speech, body language, hairstyle, voice, and/or the emphasis or de-emphasis of bodily characteristics. The ways in which gender expression is deemed masculine, feminine, or androgynous are personally and culturally specific.



ASSIGNED SEX

Assigned sex is the medical and legal classification of a person as male or female based on biological characteristics at birth. This assignment is usually based on a brief visual examination of external genitals at birth and/or on an ultrasound and does not reflect the range and diversity of biological characteristics that relate to sex, such as chromosomes, hormones, internal reproductive organs, and secondary sex characteristics.

Components of identity

Gender, gender expression, attraction, and assigned sex are all **independent** pieces of identity. It's often assumed that they will exist in specific combinations (e.g. someone assigned male at birth is expected to identify as a man, express them self in conventionally masculine ways, and be attracted to women). A common misconception about intersex people is that they because of their variation, they will identify as non-binary but in fact **any combination of identities can exist!** This is true for everyone, including people with intersex variations. Regardless of what sex a child is assigned at birth or what biological characteristics they have, they may identify with any gender, express gender in any way, and experience any type of attraction. The way that your child relates to or understands their body and identity may be different than dyadic (non-intersex) children, but *it's important not to attribute their gender or attraction to their intersex variation.*

The terms **intersex** and **transgender** are often confused. Intersex is sometimes included as the "I" in the acronym LGBTQI2S (or other variations) and included in discussions of this community. It's important to note that LGBTQ (lesbian, gay, bisexual, trans, and queer) are all labels voluntarily taken on by individuals based on their internal sense of self and felt identity, whereas intersex variations describe the biology someone is born with. Intersex is generally a label or diagnosis placed on someone by doctors and is not a self-determined piece of identity.

Intersex describes someone who is born with a combination or variation of biological sex characteristics that don't fit neatly into the medical definitions of male and female.

Transgender (or trans) describes someone whose gender is different from the gender associated with the sex they were assigned at birth (for example, a woman who was assigned male at birth, or a genderqueer person who was assigned female at birth).

Being intersex is about someone's biology at birth and being trans is about someone's personal sense of identity. Oftentimes, intersex people have to fight against the surgeries they do not want, whereas trans people have to fight for the surgeries they need. If someone with an intersex variation is a gender that doesn't "match" their assigned sex, they may be both intersex and transgender, and **it's important to allow your child to decide which words feel best to describe their identity and experiences.**

Resources

Downloadable Resources

Supporting your intersex child – A parents' toolkit

<https://oiieurope.org/supporting-your-intersex-child-a-parents-toolkit/>
PDF booklet offering advice on navigating decisions and conversations with medical professionals, family members, schools, and your child.

What we wish our parents knew

<http://interactadvocates.org/wp-content/uploads/2015/12/BROCHURE-interACT-Parents-final-web.pdf>
Brochure offering tips and advice to parents on how to work in greater partnership with their child when navigating health, medical and social decisions.

Online Media

Global Map of Intersex Organizations

<https://www.intersexionsproject.eu/en/intersex-map/>

Me, My Sex, and I (40min)

<https://www.youtube.com/watch?v=87XvVdLaWT8>
BBC documentary offering insights from people with an intersex variation, and the medical teams at the forefront of the field, including clinical psychologist Tiger Devore, whose own sex when born was ambiguous.

Resources

How Sex Development Works

<https://pie.med.utoronto.ca/htbw/module.html?module=sex-development>

Online learning website by SickKids that explains how various intersex conditions develop prenatally and/or continue to develop or impact an individual into adulthood.

The Way We Think About Biological Sex is Wrong (14min)

https://www.ted.com/talks/emily_quinn_the_way_we_think_about_biological_sex_is_wrong

Emily Quinn's TED talk featuring first-person account of life as a person living with an intersex variation.

Is Anatomy Destiny? (19min)

https://www.ted.com/talks/alice_dreger_is_anatomy_destiny

Alice Dreger's TED talk exploring the nature of the sex binary and other anatomical distinctions that are not always as clear-cut as we are led to believe, and what this means for us as individuals and as a society.

Websites and Online Support Groups

Axys

<https://genetic.org>

Not-for-profit dedicated to addressing the needs of people affected by one or more extra X and/or Y chromosomes, and to initiating action to help improve lives of individuals and families.

Resources

Canadian Intersex Network

<https://www.facebook.com/androgynycanada/>

Community-based network for people who have an intersex variation.

CARES Foundation

www.caresfoundation.org

Not-for-profit organization committed to improving the lives of families and people affected by Congenital Adrenal Hyperplasia (CAH).

Dsdfamilies

<http://www.dsdfamilies.org/>

Extensive repository of information aimed at parents of children at all ages who have an intersex variation. Includes several first-person educational stories by and for children with an intersex variation.

Interface Project

www.interfaceproject.org

Stories and videos that explore the lived experiences of people who have an intersex variation

Intersex Human Rights Australia - Intersex for Parents

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

Information and links to additional resources for parents who have recently discovered their child has an intersex variation.

Resources

Intersex Society of North America

www.isna.org

Although this organization is no longer active, their website remains online and includes valuable resources and information for parents and people with an intersex variation.

PFLAG

www.pflag.org

Not-for-profit organization supporting parents, families and allies of LGBTQ2S and individuals with an intersex variation.

Citations

1. Office of the United Nations High Commissioner for Human Rights. (2015). *Intersex Fact Sheet* [Ebook] (pp. 1-2).
2. IGLYO, OII Europe, EPA. (2018). *Supporting your intersex child* [Ebook] (pp. 1-40). Netherlands.
3. Egale Canada urges the Federal Government to meet domestic and International Human Rights requirements of Intersex People on International Intersex Awareness Day -. (2019). Retrieved 22 July 2019, from <https://egale.ca/egale-canada-urges-the-federal-government-to-meet-domestic-and-international-human-rights-requirements-of-intersex-people-on-international-intersex-awareness-day/>
4. Rainbow Health Ontario. (2015). *RHO Fact Sheet: Intersex Health Fact Sheet*. [Ebook] (pp. 1-5). Toronto.



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