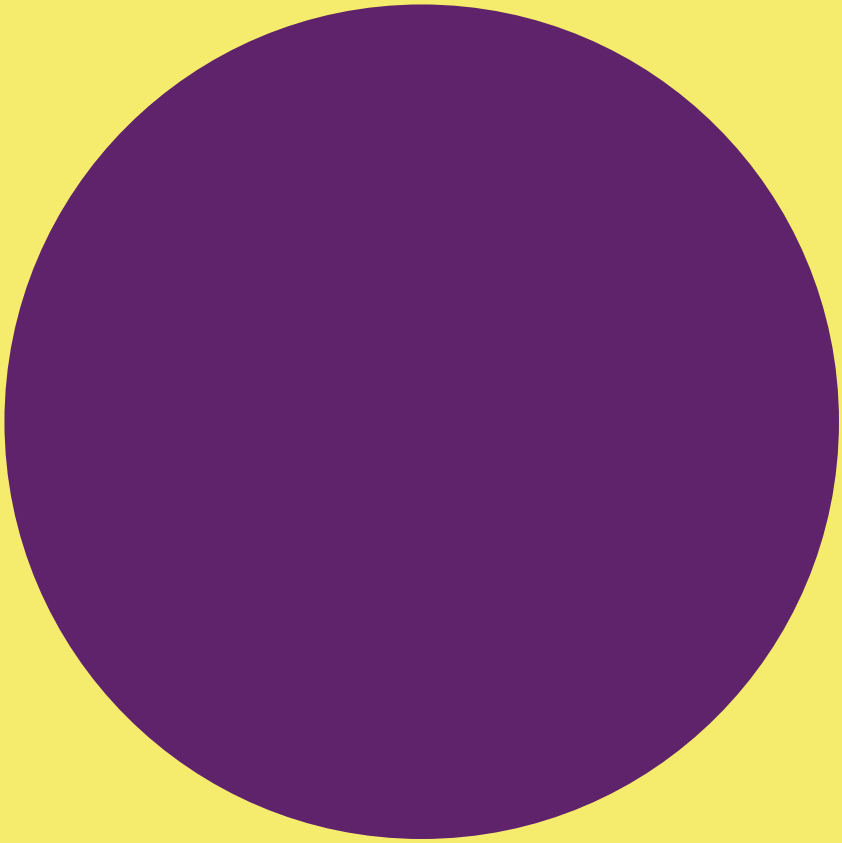
UNDERSTANDING INTERSEX EXPERIENCES



CONSEIL QUÉBÉCOIS LGBT

a Guide for Healthcare Professionals and Social Workers

Understanding Intersex Experiences: a Guide for Healthcare and Social Workers

A project by the Conseil québécois LGBT with financial support from the Programme de lutte contre l'homophobie et la transphobie of the Ministre de la Justice du Québec

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Table of contents

Intro-duction

HOW TO USE THIS GUIDE

This guide is designed to help you find the information you need.

At the end of the guide, you will find a toolkit that includes best practices for psychosocial intervention, a glossary, a list of common diagnoses that fall under the intersex umbrella, and recommendations for further reading.

Underlined words are defined in the glossary.

Throughout the guide, boxes provide more details on topics that are highlighted **in bold** in the text.

A list of best practices can be found at the end of each section. These therapeutic recommendations are also listed in the "Best practices" section of the toolkit.

WHY THIS GUIDE?

This guide aims to demystify intersex people's experiences, especially with medical institutions, in Quebec. It provides essential tools for adequate psychosocial intervention practices that do not pathologize intersex, and respect the human rights of intersex people. This guide questions long-held assumptions about intersex people that the medical field still takes for granted.

The history of medicine is riddled with discrimination, especially toward Black people, Indigenous peoples, people of color, women, trans people, and intersex people. So, as you read along, we invite you to reflect on your own conscious or **unconscious biases** toward intersex people.

We also encourage you to question the effects of positivity bias toward medical institutions, which can perpetuate discrimination that occurs in society in general.

Unconscious biases are unquestioned ideas, such as prejudice or stereotypes, that we learn throughout our lives (for example, through the education we receive) and that affect the way we see others and society. These beliefs are learned and held involuntarily. They reflect our social status, our privileges, our background, our life choices, etc. Unconscious biases affect everyone, even if their nature differs from one person to the next.

It is important to question such biases, especially when working with marginalized communities, in order to create the conditions for trust, understanding, and therapeutic alliance[1].

1. To learn more about white people's unconscious bias toward Black people, see: https://www.medicalnewstoday.com/articles/gender-bias-in-medical-diagnosis. To learn how unconscious bias affects LGBTQIA+ communities, see: https://www.lgbtqiahealtheducation.org/publication/learning-to-address-implicit-bias-towards-lgbtq-patients-case-scenarios/

BACKGROUND

Intersex people face several forms of discrimination in society, the health care system, and social services. Although it is difficult to determine the exact prevalence of intersex, an estimated 1.7% of the population is born intersex. This means that there could be as many intersex people as there are redheads! Access to adequate resources and support is key to intersex people's health and well being.

In Quebec, doctors still perform irreversible and non-essential surgeries on intersex children who do not consent to these procedures. The results of a recent study published by Les 3 sex* shows that between January 1, 2015 and January 31, 2020, more than 1385 surgeries were performed on intersex children between 2 and 14 years-old[2].

2. https://les3sex.com/fr/news/2014/enquete-les-enfants-intersexes-sous-le-bistouri

Defining intersex

The United Nations (UN) uses the following definition, which acknowledges and respects the human rights of intersex[3] people. Most intersex advocacy groups accept this definition.

> *Intersex people are born with sex characteristics (including genitals, gonads and chromosome patterns) that do not fit typical binary notions of male or female bodies.*
>
> *Intersex is an umbrella term used to describe a wide range of natural bodily variations. In some cases, intersex traits are visible at birth while in others, they are not apparent until puberty. Some chromosomal intersex variations may not be physically apparent at all. (...) Being intersex relates to biological sex characteristics, and is distinct from a person's sexual orientation or gender identity[4].*

In this guide, we use "intersex" because its use is common in intersex communities.

However, not all people born with such variations refer to themselves as "intersex". It is important to pay attention to and respect the terms a person uses. The term "intersex" (as a noun or an adjective) should never be imposed on anyone.

Today, international intersex advocacy focuses on putting an end to non-consensual medical interventions on intersex people. In Canada, advocacy groups' claims include the removal of a paragraph in the Canadian Criminal Code that allows non-consensual surgical interventions on intersex children, and the creation of support structures that meet intersex people's needs.

3. Other terms used to refer to intersex people are "intersexuality" or "intersexualism." These are dated terms that were used to refer to bodily variations under the umbrella of intersex. Just like older terms related to "hermaphroditism," they are outdated.
4. unfe.org. For a detailed definition, see: www.unfe.org/wp-content/uploads/2017/05/UNFE-Intersex.pdf

MEDICAL DEFINITION

In the medical community, pathologizing language that evokes disease or abnormality is still used to describe intersex people. The official diagnostic definition of intersex is "Disorder of Sex Development" or DSD[5]. Many doctors also use specific and often dehumanizing diagnostic language to refer to intersex people and their bodies. Choosing to use that terminology contributes to the justification of non-consensual medical interventions.

APPROPRIATE LANGUAGE

The best terminology is that which an intersex person uses in reference to themselves. Certain medical terms should be avoided because they trigger memories of very negative experiences in most intersex people. Pathologizing language can revive trauma from past medical experiences. Healthcare professionals who use that language can appear to condone or minimize these experiences, which may be detrimental to the therapeutic alliance and increase intersex people's feelings of **isolation**.

5. Other terms often encountered in the medical community are "differences in sex development" and "disorders of sexual differentiation."

Intersex people experience a lot of isolation. Surgeries may cause intersex children to miss school often. The scarcity of support and community resources, and the fact that intersex experiences often remain invisible, can contribute to social isolation. While fighting social isolation is very difficult for white intersex people, Indigenous and racialized intersex people are all the more likely to be isolated and vulnerable, as advocacy and support groups are mostly white spaces.

As with homophobia and transphobia, the treatments that intersex people undergo are rooted in heterosexist assumptions. Therefore, some people consider that alliances between 2LGBTQI+ and intersex communities can be useful. Other intersex individuals report that they feel excluded or invisible in 2LGBTQI+ communities. Moreover, not all intersex people want to be included in 2LGBTQI+ communities because intersex does not determine a person's gender identity and sexual orientation. For instance, publicly identifying as intersex can have negative consequences in situations where sexual diversity and gender diversity are not welcomed.

The exclusive use of medical terms further isolates intersex people, as it complicates the search for non medical information on intersex, and limits access to diverse, non pathologizing perspectives.

Intersex is NOT

- another word for trans experiences or nonbinary genders
- a gender identity
- a gender expression
- a sexual orientation
- a type of sexual activity or sexual behaviour
- a disease, an "anomaly" or a "disorder"
- a mental illness

Best practices

- Describe people's bodies and experiences in the words that they use.
- Avoid medical terminology and pathologizing language.
- Respect people's experiences ; do not minimize the violence they have faced.
- Support individuals as they develop a non-pathologizing relationship with their body and experiences.
- Do not impose "intersex" as an identity term.

Medical Inter-ventions

This section seeks to raise awareness about the interventions performed and imposed on intersex people.

It includes :

- A brief history of the medicalization of intersex
- A list of the most common medical interventions
- An overview of medical interventions and their effects

A BRIEF HISTORY OF MEDICALIZATION

1955-2006

In the 1950s, Johns-Hopkins Hospital (United States) promoted the medicalization of intersex through the "optimum gender of rearing" approach. This approach assumes that it is possible to "shape" a child's gender through:

1. Body modifications to make the child conform to the assigned gender (girl or boy)
2. Constant **gender socialization** that rewards or discourages behaviour according to the assigned gender (girl or boy).

Gender socialization consists in educating a child differently depending on the gender they are assigned. This includes teaching gender stereotypes, such as boys' interest in cars, and girls' interest in dolls. Based on assumptions about the child's gender, specific behaviours are either encouraged or discouraged. For instance, boys are more often encouraged to express anger and act impulsively, whereas empathy and sensitivity are more valued in girls.

Giving urgency as a pretext, this approach subjects intersex children to medical interventions that are non-consensual, irreversible, and unnecessary for their health. This sense of "urgency" may result from the belief that children become aware of their gender before they reach two years of age, and that identity formation cannot happen unless their body conforms to masculine or feminine norms. Gender socialization is then enforced to make sure the child develops in line with the gender they are assigned and their (often modified) body. Medical interventions performed on children younger than two years-old are also said to be less traumatic. However, the accounts of individuals who went through these interventions confirm that traumas develop regardless of age.

The gender of the child is chosen based on surgical and hormonal options to construct genitals that would enable heteronormative sexual activity (penetration of the penis into the vagina). If the intersex child is assigned male, whether they would be able to stand to pee is also considered.

At the time, parents were also advised not to disclose to their child that they were intersex, fueling the **culture of secrecy**, which impact is felt today.

The **culture of secrecy** was an important aspect of the initial approach to intersex case management. Doctors went as far as hiding information from parents or encouraging parents to hide information from their child about their intersex status and surgeries performed on their body. Although the paradigm of secrecy is losing ground, some practices inherited from this concealment-centered model of care remain.

According to a 2018 study of intersex people's quality of life in the United States, the median age at which intersex individuals discover they are intersex is 20.6 years. To this day, some individuals have been and still are subjected to this culture of secrecy; they do not have a full understanding of the medical interventions that they underwent, and some do not even know that they are intersex.

2006-today

In 2006, the model of care was updated, especially to address growing criticism. The new model of care rejects the claim that a child's gender may be shaped by other people, relying instead on the claim that everyone has a "real sex." As a result of this stance, doctors now assign the sex of an intersex child based on the gender they think the child will be most likely to identify with later on in their life. This did not put an end to medical interventions, which are still believed to be both necessary and time-sensitive. The medical community still insists on performing these interventions shortly after birth, ideally before the child is two years old. Most doctors are still convinced that an intersex child who has not undergone surgical or hormonal "corrections" will be discriminated against and will be incapable of developing a stable gender identity.

In 2022, medical interventions on intersex children are still legal in Quebec, even if they are performed less frequently. The culture of secrecy has gradually lost ground but it has not disappeared. Medical professionals claim that surgical and hormonal interventions are rarely advised today and that this decision is the parents' to make. Yet, accounts from intersex people and their families reveal significant gaps between medical institutions' official stance and the experiences of intersex people and their parents in medical care settings. This suggests that doctors and medical institutions seek to play down their responsibility for the medical violence that is still inflicted on intersex people.

CURRENT MEDICAL APPROACH

Despite the 2006 reform, the principles that inform medical care have changed very little since the 1950s. Even if the professionals who perform medical interventions claim to put intersex people's wellbeing first, the latter are seldom able to consent to these interventions.

Moreover, these interventions are still rooted in heterosexual norms, that is to say that their goal is still to make sure that the person's genitals meet the medical and social standards that define penetrative sex and, when possible, reproductive sex.

As they rely on genital "normalization", current practices place little emphasis on the potential impacts and side effects of intervention, especially in the long term. Several United Nations bodies[6] and human rights organizations condemn the current approach to intersex care. They consider non consensual interventions to be a violation of human rights that should be abolished.

TYPES OF MEDICAL INTERVENTION

Surgical interventions

Surgical interventions modify the body—oftentimes, the internal and external reproductive organs—to produce normative anatomical configurations, in line with the assigned gender. Surgeries can be performed shortly after birth, in childhood, in adolescence, or in adulthood. Repeat procedures may be required to fix initial "unsatisfactory" results, or to make "corrections."

Hormonal Interventions

Hormone replacement therapy aims to stimulate the development of secondary sexual characteristics associated with the gender of assignment or gender of rearing (female or male). They can be prescribed to children as well as adults. Treatment plans and dosage may vary, depending on the intersex variation. Though hormone replacement therapy may be essential in some situations, it is most often prescribed to further "normalize" the body.

Because it is less spectacular than surgery, hormonal interventions are often considered to be more acceptable. They are non consensual interventions nonetheless, which trigger significant and often irreversible physical changes.

6. The United Nations' Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment is available here: https://www.ohchr.org/sites/default/files/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

Summary of Medical Interventions

So-called Feminizing	So-called Masculinizing	Type of Intervention
Clitorectomy, clitoral reduction or recession, clitoroplasty	Hypospadias "repair" (repositioning or reconstruction of urethral tube and opening)	**Surgical**
Vaginoplasty	Surgeries on the chest	
Gonadectomy	Gonadectomy	
Labiaplasty	Scrotoplasty	
Removal of testes	Testicular prosthesis	
Vaginal dilation	Surgical testicular descent (orchiopexy)	
Blocking voice changes, hair growth, muscular and bone development that are seen as masculine	Blocking breast growth and body fat distribution (hips, etc.) that is considered feminine	**Hormonal**
Inducing so-called feminine voice changes, fat distribution, muscle and bone mass, hair growth, and breast growth	Inducing so-called masculine hair growth, voice changes, fat distribution, bone and muscle development	

On top of these surgical and hormonal interventions, intersex people often experience potentially negative and coercive dynamics, such as frequent gynaecological exams in their youth, hospitalizations following surgical interventions, or having photos taken of their genitals without informed consent.

Moreover, since intersex people are often an object of curiosity in the medical community, it is not uncommon for them to have to endure visits from interns, trainees, and external specialists during their hospital stays. As a result, a routine gynaecological exam may be a (re)traumatizing experience.

Medical interventions can be performed on the fetus during pregnancy (dexamethasone, medical abortion), shortly after birth, throughout childhood, after the onset of puberty or in the absence of puberty, and during adulthood.

Today, some intersex variations can be detected during pregnancy, such as, atypical chromosome markers (XXX, XXY, X0/XY, etc.) and congenital adrenal hyperplasia. The interventions that may be recommended following detection seek to reduce the likelihood of intersex traits during foetal development, rather than protect the health of the child. When intersex variations are detected, some medical professionals may also suggest medical abortion.

The impact of medical interven-tion

Medical interventions have multiple effects, which are not only physical, but also psychological and social, and may also overlap. For instance, physical and social effects have repercussions on mental health. It is known that chronic pain has a tremendous influence on mental health: this pain is all the more severe when it results from non-consensual interventions.

While reproductive capacity and genital "normalization" are emphasized, little attention is given to potential negative outcomes and side effects of medical interventions, especially in the long term. Even if medical discourse highlights advances in surgical techniques that allow for less destructive interventions, predicting the actual, long-term impacts of rapidly evolving techniques remains impossible.

Some scientific publications state that the psychosocial effects of medical violence inflicted on intersex people are similar to the impacts of sexual and physical abuse in children and adult survivors[7].

7. For more information on these comparisons, visit: https://isna.org/articles/analog/

Effects of medical interventions

Impacts on everyday life		Impacts on sexuality
Unwanted or unexpected sexual arousal	Depression	Difficulty making sexual or romantic connections
Mandatory vaginal dilations	Anxiety	Trust issues with partners
Painful scarring, neoplasty	Eating disorders	Body shame
Chronic urinary tract infections	Behavioral disorders	Scar tissue pain
High blood pressure	Agression	Anorgasmia
Follow-up «corrective» or «touch up» surgeries	Self-harm	Loss of genital sensitivity
Chronic pain	Trust issues	Vaginal stenosis
Fibromyalgia	Interpersonal difficulties in the family	Chronic pain
Arthritis	Body shame	Uterine prolapse
Hormone replacement therapy-induced weight gain	Challenges linked to chronic pain	Anxiety and fear of showing one's body

Impacts on everyday life		Impacts on sexuality
Incontinence	Difficultés à aller chercher de l'aide médicale	Difficultés à exprimer un consentement sexuel
Blood clots	Difficulty seeking psychosocial support	Higher risk of being a victim of assault or sexual violence
Complex post-traumatic stress disorder or (C)PTSD	Substance abuse	Difficulty setting personal boundaries
Higher risk of complications with general anaesthesia, especially in children under three years-old	Experiences of discrimination and stereotyping in medical settings	Unwanted increase or decrease of libido (caused by hormone replacement therapy)
Missed school days for medical appointments	Invisibility of intersex because of surgical or hormonal "elimination" of intersex traits	Decreased sexual arousal or lack thereof
Early menopause	Postoperative infections	Complex post-traumatic stress disorder or (C)PTSD
Changes to appearance of genitals as a result of surgery or scarring	Feeling bound to explain one's appearance to sexual partners	Sexual anxiety

The impact of social stigma

In addition to the effects of medical interventions, societal perceptions of intersex cause psychological challenges.

Intersex people are discriminated against, their experiences are erased and tokenized. Besides, their bodies are often **fetishized**.

These factors fuel **minority stress**. Together with the lack of specialized resources and services, they increase social isolation and feelings of loneliness in intersex people.

Fetishization is a marked sexual interest in an object or distinctive feature that is not necessarily sexual. Morbid curiosity about intersex individuals' genitals is often behind the fetishization of intersex people. Such curiosity is dehumanizing and puts intersex people at risk of sexual violence. To protect themselves, many avoid disclosing that they are intersex and do not want to come out to their partner. Fetishization reinforces prejudice and stereotypes about intersex people.

Best practices

- Learn about approaches to intervention with people with chronic pain.
- Never minimize someone's pain or anxiety.

Minority stress is a theoretical model that provides a framework for understanding experiences of stress in minority groups. Intersex people are a minority group. Such groups are said to experience social stress factors (such as stigma, discrimination, intersexphobia, etc.) that are direct results of their minority status in society. This stress is constant as it relates to identity or distinctive traits, and it is specific to the individual, who cannot be anyone but themselves. Internalizing this chronic state of stress can lead to low self-esteem and negative psychological outcomes. This theoretical model also allows for an intersectional perspective, as one may belong to several minority groups. For example, compared to a white intersex person, a Black intersex individual will experience additional stress factors. Individuals affected by minority stress may dread situations in which the risk of discrimination is heightened, and develop defence mechanisms. For example, they may stop seeking medical help.

Diverse expe-riences

TRANS INTERSEX PEOPLE

Estimates say that somewhere between 8 and 15% of intersex people transition. The intersection of trans and intersex experiences makes for unique experiences and specific health care needs.

While some may believe otherwise, intersex does not cause transness, nor does it shield individuals from transphobia in medical institutions and society. Rather, intersex individuals are more likely to experience transphobic violence[8]. Intersex people who transition may be subjected to increased medical scrutiny, especially if transness manifests in childhood. Acting on the belief that it is both possible and desirable to "undo" transness, medical professionals may push for surgical interventions and impose further gender socialization. Intersex individuals who were born between 1955 and 2006, when the "optimum gender of rearing" approach was the norm, may have suffered the most from this emphasis on socialization. Though gender socialization has become less prevalent since 2006, it remains common in practice, according to intersex people's testimonies.

In addition to increased medical oversight, trans intersex people who need access to gender affirming surgeries can find that medical procedures that they underwent, and which they did not consent to, during their childhood get in the way of their medical transition. For instance, scar tissue may be too extensive to operate again.

Best practice

Adopt a trans-inclusive[9] approach and support questioning individuals in their gender exploration.

8. Some believe that intersex people have an easier time transitioning because they are intersex. On the contrary, intersex people can face additional obstacles during their social or social transition. On trans experiences and transition, see: https:// www.conseil-lgbt.ca/wp-content/uploads/2020/11/Guide-mieux-comprendre-enjeux-trans_CQLGBT.pdf

9. For more information on trans-inclusive approaches, see: Pullen Sansfaçon, Annie and Denise Medico. 2020. Jeunes trans et non binaires. De l'accompagnement à l'affirmation, Montréal: Remue-ménage.

AGING & ELDERLY INTERSEX PEOPLE

Aging and elderly intersex individuals face several challenges. They have to cope with the effects of the culture of secrecy, recurring and humiliating medical examinations, and non-consensual surgeries that were often much more invasive until the 1970s, when it was not uncommon to undergo clitorectomy or vaginoplasty in childhood.

Sometimes, aging and elderly intersex people only have access to incomplete or misleading medical records, which makes it difficult to find answers to their questions. The psychological support some received, blamed their discomfort and trauma on imaginary ills or a lack of cooperation on their part. Today, healthcare professionals invalidate aging and elderly intersex people's distress when they expect them to be grateful for the way they were treated, or when they discourage them from sharing their own experience or public criticism of the medicalization of intersex.

Because of the assumption that medical interventions during childhood could erase and thus "fix" intersex, doctors have shown little interest in the effects of non-consensual procedures and the needs of the aging and elderly intersex population. Grassroots research initiatives in intersex communities are still emerging, for want of adequate resources. We do know that aging and elderly intersex individuals struggle to find adequate medical care, as doctors who specialize in intersex care are usually pediatricians.

Aging and elderly intersex individuals fear that past experiences of prejudice and discrimination may resurface in long term care and assisted living facilities. Interactions with the staff members who are responsible for their hygiene can make them very vulnerable. Essentially, because of their past experiences of medical violence, aging and elderly intersex people may not trust health care professionals, including those who offer psychosocial support.

Best practices

- Learn about systemic inequities in access to care, and the specific challenges that aging and elderly intersex individuals face.
- Keep in mind that some aging and elderly individuals do not know that they are intersex, or what medical interventions they underwent (concealment model of care).
- Help people recover as much of their medical record as possible.

BLACK, INDIGENOUS AND RACIALIZED INTERSEX PEOPLE

Though there is little literature Black, Indigenous or racialized intersex people's experiences, they face many additional difficulties that are specific to their communities.

For example, since Black, Indigenous, and racialized individuals are more likely to be criminalized, they may fear having to come out as intersex upon being arrested or strip-searched. This is an additional stress factor in their lives. The criminal justice system is split according to binary sex, and those who do not easily fit into either category (male or female) can find themselves further stigmatized and discriminated against. This creates additional risks of physical and psychological violence, compounded by racist discrimination in the judiciary.

The treatment of Black, Indigenous, and racialized people in the history of medicine has caused distrust of the healthcare system – consider, for example, that "advances" in the field of gynecology were made at the expense of enslaved Black women. Prejudice and discriminatory views that manifest in medical settings further prevent access to care. Negative experiences can discourage some from seeking medical attention, for fear of even more violence.

Besides, intersex community groups are mostly white spaces that lack both resources and support. Thus, it is difficult for them to develop a more intersectional approach and actively include Black, Indigenous and racialized intersex experiences. This explains why Black, Indigenous, and racialized intersex people are more isolated, why their experiences remain unacknowledged, and why they have a harder time accessing adequate support and connecting with individuals with similar experiences.

Best practices

- Keep in mind that individuals may have intergenerational trauma.
- Be aware of the challenges Black, Indigenous, and racialized intersex people face in medical settings.
- Seek training in intersectional intervention strategies.
- Adopt a critical outlook on policing, especially on the policing of Indigenous and Black communities.
- Learn about the different types of oppression and discrimination that racialized communities face, and actively work against them.

PARENTS OF INTERSEX CHILDREN

The experiences of the parents of intersex children matter because parents are the ones who consent to most medical interventions on their children. Current medical discourse claims that medical interventions are requested by parents, or that these interventions are performed for the sake of the child's psychological well being. Parents can experience various challenges with decision-making and medical care that impact the mental health of their intersex child.

Before 2006, parents were routinely discouraged from revealing the truth to their intersex child. Today, the official guideline is to discuss it in an open and age appropriate way. However, recent research shows that parents find it difficult to address it. Incomplete information from health care professionals, pathologizing medical jargon, the persistence of gendered socialization, and the fear of social repercussions still discourage parents from telling their child that they are intersex. Moreover, there are few non-pathologizing resources for parents: their grasp on the issue is often wanting, which makes it even harder to discuss it openly.

Meanwhile, the fear of making or having made the wrong decision also fosters parents' feelings of guilt. Resentment may also build if the child did not have a say in medical decisions that parents made. Guilt, conflict, and resentment have a negative impact on family dynamics and undermine intersex individuals' wellbeing.

Finally, children can develop an unhealthy relationship with their body or experience feelings of body shame if information about intersex is kept from them or if they lack access to information about body diversity.

Best practices

- Make resources available to parents that focus on positive representations of body diversity
- Work with parents toward age appropriate ways to address intersex with their child
- Inform parents about intersex peoples' rights to access their medical records

Social and psy-chological support needs

Intersex folks' needs depend on the challenges they face, where they are at in their healing journey, and what their family background looks like. When it comes to therapy and intervention, learning about intersex, listening to intersex individuals' needs, and adopting a sensitive approach are important steps to ensure that intersex people's human rights are respected.

Common issues to consider are isolation, chronic pain, trust issues, and trauma from non-consensual medical interventions. The individual's body autonomy and their capacity for sexual intimacy are particularly challenged. Parallels can be drawn with other intervention approaches to sexual violence, obstetric violence, and family violence. Anti-oppressive, harm reduction, trauma-informed and intergenerational trauma-informed[10] approaches are also recommended, as well as therapeutic approaches that prioritize individuals' empowerment and autonomy. They foster a therapeutic alliance that embraces intersex people's diverse experiences. Remember that regardless of the therapeutic approach, psychosocial counseling always puts the person who is seeking help in a vulnerable position.

10. For more information on trauma-informed therapy: https://ncsacw.acf.hhs.gov/userfiles/files/ SAMHSA_ Trauma.pdf

TRAUMA-INFORMED INTERVENTION

Considering that intersex individuals have often had traumatizing experiences in medical institutions and social services, interpersonal skills are essential to successful care practices. Sharing personal information about their identity, their sexuality, their medical history, or their feelings of loneliness and isolation can make intersex people emotionally vulnerable.

Even though you have not experienced what is being shared with you, you must make conscious efforts to communicate that you understand it. Active listening with minimal interruptions can help you understand the person's unique experiences.

While the therapeutic relationship must revolve around the person's own experience first and foremost, it remains crucial that you learn about intersex issues in your own time, so that they feel comfortable confiding in you without having to educate you.

Explaining intersex can be a burden, involving a considerable amount of emotional labor. This can discourage intersex individuals from opening up.

INCLUSIVE WORK SPACES AND PRACTICES

Your first interaction is incredibly important. In order to encourage trust, your workspace should be as inclusive as possible. Whenever possible, use intake forms that do not include sex markers and invite people to share their chosen names and pronouns. Using forms and worksheets that use gender-neutral language is also good practice. These are just a few examples of practices that prioritize the person's comfort and encourage the therapeutic alliance.

TOOLKIT

Best practices

This toolkit includes the best practices outlined throughout the guide, as well as additional advice.

PRIORITIZING SENSITIVE APPROACHES

While there is no universal therapeutic approach, the following emphasize agency and inclusion:

- Anti-oppressive practice
- Trauma-informed approaches to childhood sexual abuse
- Trauma-informed approaches to family violence
- Harm-reduction approach
- Interpersonal and intergenerational trauma-informed practices
- Chronic pain management approach
- Trans-inclusive healthcare

GENERAL RECOMMANDATIONS

Sensitivity and professionalism

- Use the terminology that the person uses to describe their body and experiences
- Do not impose "intersex" on anyone
- Understand that everyone is the expert on their own body
- Practice active listening to respect the individual's experiences ; validate their experience of violence and their pain
- Avoid arguing in defense of the medical system or seeking to justify medical acts
- Make sure to regularly ask for consent and mention that the person has a right of refusal
- Remember that many people may not know about their own medical history or that they fall under the umbrella of intersex
- Do not ask about the appearance of someone's genitals or anatomy unless they mention it first
- Recognize that intersex people's experiences go beyond intersex ; do not assume that their motivations for seeking therapy are connected to their intersex status

Providing information and de-pathologizing care

- Support individuals in de-pathologizing their relationship to their body and their medical history
- Be proactive in seeking information about intersex so that you do not rely on intersex people to educate you
- Prioritize educational resources that celebrate body diversity
- Inform parents and intersex people about their rights, such as accessing their medical record and refusing medical interventions
- Inform and support parents so that they feel comfortable initiating age-appropriate conversations about intersex with their child.

Understanding social injustice and the diversity of experiences

- Learn about inequalities in access to care and marginalized groups' specific challenges, and actively work to reduce them (racism, transphobia, ageism, etc.)
- Keep the possibility of intergenerational trauma in mind in your practice
- Seek training to adopt intersectional care practices
- Adopt a critical outlook on policing, especially within Indigenous and Black communities
- Learn about and actively work against racist oppression and discrimination
- Learn about and actively work against ongoing colonial and anti-Indigenous oppression
- Address your own unconscious biases and actively work to deconstruct them

TOOLKIT

Glossary

Assigned or assumed gender: gender marker assigned on the basis of sex assignation by doctors at birth or shortly thereafter, based on assumptions about the gender identity the child may develop.

Chromosomal patterns, chromosome markers: Everyone has chromosome markers (a combination of X and Y markers). Generally, people who are assigned female at birth have XX chromosomes, people who are assigned male at birth have XY chromosomes. There are many possible combinations of chromosome markers and anatomical aspects.

Criminalization: the process of judicialization, from surveillance to incarceration.

Dexamethasone: corticosteroid medication that can be used upon detection of congenital adrenal hyperplasia during pregnancy.

Gender affirming surgery: elective surgery on primary or secondary sexual characteristics that supports the expression of one's affirmed gender.

Gender expression: the way someone expresses their gender in social settings (clothing and hairstyle, body language, voice tone and pitch, etc.)

Gender identity: a person's own experience of gender and the way they define it on their own terms, be it man, woman, non-binary, agender, or some other possibility.

Heteronormativity: refers to the idea that heterosexuality is the "default" sexual orientation dictating social norms. Heterosexism reinforces these norms.

Heterosexism: refers to the belief that heterosexuality is superior and preferable to all other romantic or sexual models, and practices that enforce heteronormative social norms.

Intersexphobia or Interphobia: discrimination against intersex people based on their being intersex.

Medical violence: experiences that take place in medical settings and cause harm and trauma to patients and their families. Non-urgent and non consensual medical interventions (surgical or hormonal) are a form of medical violence.

Pathologization and pathologizing: the process of describing something as a disease (sometimes unnecessarily).

Primary sexual characteristic: physical feature that is generally observed at birth (ex: gonads, internal and external genitalia).

Secondary sexual characteristic: physical feature that generally develops at puberty, as hormone levels rise (testosterone and estrogens), such as hair growth, muscle growth, voice changes, etc.

Stereotyping: adopting a biased view on a community or a person based on unquestioned notions and narratives.

Trans: umbrella term that refers to people who do not identify with the sex or gender they were assigned at birth and who choose to identify as such. Trans people can identify as women, men, nonbinary, agender, bigender, etc. Not all nonbinary and genderfluid people identify as trans.

For more information on key terms, see the Translation Bureau of Canada's online glossary: https://www.btb.termiumplus.gc.ca/publications/diversite-diversity-eng.html

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Common Diagnoses

- Klinefelter syndrome
- Turner syndrome
- Congenital adrenal hyperplasia
- Hypospadias
- Disorders of sex development/ Differences in sex development/ Diverse sex development/Variations in sex characteristics
- Ambiguous genitalia
- XY gonadal dysgenesis/Swyer syndrome
- Androgen insensitivity syndrome (mild, partial or complete)
- Polycystic ovary syndrome
- 5-alpha reductase deficiency
- Penile agenesis

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Resources

www.cia-oiifrance.org

www.intersexemontreal.wixsite.com/groupe

www.interligne.co/espace-intersexe

www.egale.ca/awareness/soutenir-votre-enfant-intersexe

www.inter-action-suisse.ch

www.interactadvocates.org

www.hrc.org/resources/understanding-the-intersex-community

www.unfe.org/fr/intersex-awareness

www.amnesty.org/fr/latest/campaigns/2017/05/intersex-rights

www.isna.org

www.oiiinternational.com

www.oiifrancophonie.org

Ouvrage : A comprehensive guide to intersex par Kyle J. Peterson (Jessica Kingsley Publishers.)

Blog francophone : www.temoignagesetsavoirsintersexes.wordpress.com

The National LGBTQIA+ Health Education Center, associé au Fenway Institute (États-Unis) offre plusieurs outils et formations créditées portant sur les enjeux de la DSPG en contexte de soins, incluant les personnes intersexes : www.lgbtqiahealtheducation.org

Leur guide sur les soins pour les personnes intersexes est disponible ici : www.lgbtqiahealtheducation.org/wp-content/uploads/2020/08/Affirming-Primary-Care-for-Intersex-People-2020.pdf

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