Handle with Care: Assessing Canadian Medical Policy for Children with Intersex Variations

by

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Spring 2019

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Ethics Statement

The author, whose name appears on the title page of this work, has obtained, for the research described in this work, either:

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or

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Abstract

It is estimated that 1 in 2000 babies are born with atypical genitalia, also known as an intersex variation. In Canada, parents can consent to elective surgery to make the genitalia appear more typically female or male, but there is a growing recognition of the physical and psychological harms associated with these surgeries being performed on children too young to consent. The ability of parents to provide informed consent is hindered for reasons including a lack of information about the child’s wishes and potential framing bias by doctors. To minimize exposure to the significant risks associated with such procedures, it is recommended that Canada conduct a consultation process and a commission of inquiry to investigate current practices associated with elective genital surgeries on infants and young children. Based on those processes, minimum standards for psychological support should be established, and restrictions on early surgeries should be considered.

Keywords: intersex variation; DSD; atypical genitalia; health policy; surgery; Canada
As one person trying to get it right, sometimes the best you can do – the most you can do – is point to the sky, turn to the guy next to you and ask, “Are you seeing what I’m seeing?”

- Alice Dreger, Galileo’s Middle Finger
Acknowledgements

People with intersex variations have historically and continue to experience harm, and systemic barriers to supportive and safe health care. The issue of non-consensual elective surgery is one of a number of pressing research questions currently under focus in intersex research. There is also a great need to better understand issues related to quality of life and healthcare throughout the life cycle.

Thank you to the interview participants, whose insights were vital to the project. I am very grateful for having had the opportunity to speak with every person who was willing. Thank you to those who answered questions informally by phone, email, and over coffee. Many people helped me to network, explore ideas, and fill knowledge gaps.

Thank you to my supervisor, Josh Gordon, for supporting this idea when I first brought it up, and thank you to Marina Adshade for asking so many thoughtful questions during the defence. Thank you to the other professors, and to my family and friends who provided encouragement and support along the way.

Thank you to my Mom and Dad for all the love and good advice, for teaching me to trust my intuition, and for encouraging me to follow my heart, in work and in life.
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<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
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<td>DSD</td>
<td>Difference of Sexual Development</td>
</tr>
<tr>
<td>CAH</td>
<td>Congenital Adrenal Hyperplasia</td>
</tr>
<tr>
<td>MGD</td>
<td>Mixed Gonadal Dysgenesis</td>
</tr>
<tr>
<td>PAIS</td>
<td>Partial Androgen Insensitivity Syndrome</td>
</tr>
</tbody>
</table>
### Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Atypical genitalia</td>
<td>Genitalia that do not meet strict typical conceptions of male or female.</td>
</tr>
<tr>
<td>Differences of sexual development (DSD)</td>
<td>An alternative term to replace ‘Disorders of Sexual Development’ which is seen as less stigmatizing and more supportive to many with conditions in this category.</td>
</tr>
<tr>
<td>Disorders of Sexual Development (DSD)</td>
<td>A term introduced in the 2006 as part of a new nomenclature for intersex variations. While some embrace this term, it is considered offensive and overly medicalizing.</td>
</tr>
<tr>
<td>Gonad</td>
<td>Reproductive gland that produces eggs (ovary) or sperm (testis) and hormones. An ovotestis is a rare type that contains both ovarian and testicular tissue.</td>
</tr>
<tr>
<td>Intersex</td>
<td>The condition of having genital, gonadal, or chromosomal characteristics that are not strictly female or male. <em>Also refers to a gender identity.</em></td>
</tr>
<tr>
<td>Intersex Variation</td>
<td>A physical trait that is associated with one or more atypical sex characteristics. <em>(Synonym: intersex trait)</em></td>
</tr>
<tr>
<td>Karyotype</td>
<td>Chromosomal configuration (ex: XY, XX, 45X/46XY, etc.)*</td>
</tr>
<tr>
<td>Phenotype</td>
<td>The physical expression of genetic characteristics.</td>
</tr>
</tbody>
</table>
Executive Summary

People with intersex variations or differences of sex development (DSD) have physical characteristics that do not meet strict notions of male or female bodies. These differences can be on the level of chromosomes, hormones, reproductive organs or genitalia. Individuals can go through their entire lives without knowing about their sex difference, some discover the difference around puberty, and some are identified at birth as a result of atypical genitalia. In Canada, infants and children with atypical genitalia may undergo surgery to create a more typical feminine or masculine appearance, and/or function. These surgeries are done with more caution today than in the past, but there continue to be serious psychological and physical risks associated with elective genital surgeries performed in infancy and early childhood.

A literature review was conducted to develop an understanding of key issues, and guided the approach to the interview process. The review focused heavily on medical and academic literature pertaining to surgical guidelines, outcomes, and decision-making processes. Three conditions commonly associated with atypical genitalia are examined in detail: Congenital Adrenal Hyperplasia, Partial Androgen Insensitivity Syndrome and Mixed Gonadal Dysgenesis. Interviews were conducted with experts from health care, academia, research, and advocacy. The interviews supported research from the literature review, including the finding that it is unclear how consistently mental health professionals are integrated in multidisciplinary teams and decision-making processes. Interview results suggest that resources are lacking, and that parents may not receive adequate support.

The analysis section is divided into two parts. First, an overview of key risks associated with early surgery is presented and analyzed based on data quality. The second piece of the analysis section discusses criteria related to health, stakeholder acceptance, and implementation complexity. Policy options considered include maintaining the status quo, initiating a consultation process, strengthening psychological and social support resources for families, implementing a moratorium on early elective surgeries in Partial Androgen Insensitivity Syndrome, and implementing a moratorium on early elective surgeries in all DSD.
Due to a lack of long-term data regarding surgical outcomes, it is impossible to definitively predict the psychological and physical impacts associated with various policy approaches. The final recommendations of this report include consultation and a public commission of inquiry to investigate current practices and impacts associated with elective genital surgeries on infants and young children. Following the commission, it is expected that restrictions will be recommended, including at minimum, a moratorium on early elective surgeries for children with Partial Androgen Insensitivity Syndrome.
Chapter 1.

Introduction

People with intersex variations have sex characteristics that are not strictly male or female. Sex differences can be on the level of chromosomes, hormones, reproductive organs (e.g. uterus, ovaries and testes) and genitalia. Intersex variations are sometimes obvious at birth when a baby is born with atypical genitalia, some only become apparent when a child reaches puberty, and in other cases, individuals can go through their entire lives without knowing.

In Canada, infants and children born with atypical genitalia are at risk of psychological and physical harm as a result of elective genital surgeries performed in infancy and early childhood. Surgeries to feminize or masculinize atypical genitalia became common practice in the 1960s, and continue today, though doctors in Canada and internationally have expressed a greater degree of caution towards performing them in early childhood.¹ Surgeries are most often promoted on the premise of supporting the child’s psychological well-being. However, human rights groups and medical experts have increasingly called these surgeries into question across the world, arguing that these surgeries are primarily, if not exclusively cosmetic, and involve irreversible physical and psychological risks including loss of sexual tissue and sexual sensation, loss of fertility, pain, incontinence, mental suffering, and wrong gender assignment.²

This study focuses on the medical practice of performing elective genital surgeries on children with intersex variations in infancy and early childhood. This report reviews existing medical practices gleaned through the literature and interviews with health professionals, as well as academics and representatives from relevant stakeholder and advocacy groups. A jurisdictional scan including the United States, Australia, and Malta is used to examine international practices and emerging trends in care. Examination of three conditions commonly associated with atypical genitalia is

used to illustrate the realities of decision-making related to care—Congenital Adrenal Hyperplasia, Partial Androgen Insensitivity Syndrome and Mixed Gonadal Dysgenesis.

Elective genital surgeries can be described as being feminizing or masculinizing, falling into two categories: (1) strictly changing the cosmetic appearance and (2) reconstruction to alter function. In the context of this study, cosmetic most often refers to the surgical reduction of a large clitoris or phallus, and reconstruction refers to procedures such as vaginoplasty and proximal hypospadias repair, which are promoted to support penetrative intercourse and unassisted fertility. This study takes the perspective that any procedures that are not motivated by medical need are elective. Surgeries that are reconstructive in nature, such as vaginoplasty or proximal hypospadias repair do not guarantee function, and are accompanied by rates of complication at or above fifty percent, which further challenges their purported necessity.

Before parents can consent to surgery, they are provided information related to the condition and treatment risks and alternatives. Research suggests that doctors may underestimate their own biases when speaking with parents and that parents are “forced to make choices about treatment for their children on the basis of inadequate information.” Some participants in this study stressed the need for the presence of mental health experts to help balance potential biases towards surgical intervention. A recent U.S. study found that some parents did not feel they had sufficient understanding about the child’s condition and information received from doctors about surgical outcomes was recalled as being oversimplified. Another study involving medical students acting as parents found that those spoken to by a psychologist were forty-three percent less likely to opt for surgery compared to those spoken to by an endocrinologist. In this case, the psychologist used less medical terminology and framing than the endocrinologist and focused on a more holistic concept of well-being.

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4 Katrina Karkasiz, Fixing Sex: Intersex, Medical Authority and Lived Experience, 215.
5 Interview #7; Interview #6
Experts stress the need for psychosocial care from mental health staff with expertise in differences of sex development. It is important to be able to assess a parent’s level of stress, and ability to cope, and to ensure they have support and someone they can talk to about concerns they may have. The child’s quality of life “and adaptation of the family...depend on the extent to which healthcare providers attend to psychosocial aspects of the condition.” Current practices in Canada involve consultation between parents, physicians, and a multidisciplinary team of specialists that is designed to include multiple mental health professionals, but evidence from the research interviews and Canadian scholars suggests that psychological support is underfunded. It is not clear how comprehensively or consistently mental health professionals are integrated in multidisciplinary teams and decision-making processes.

Reports of satisfaction among people who have had early surgery vary. There are people who express deep gratitude for having not received surgery. There are some who feel that it was the right choice for them. And there are those for whom early surgery was a painful, traumatizing mistake. One of the most highly referenced studies indicates that eighty-five percent of participants were mainly satisfied and fifteen percent were dissatisfied with their gender assignment. The same study notes an even division of people who think surgery should happen when the child is an infant (47%) versus those that think it should not happen before adolescence (24%) or adulthood (22%).

Research shows that most people with intersex variations identify as male or female, but there is a significant proportion who identify as intersex. It is important to note that people with intersex variations are more likely than the general population to identify with a different gender than the one they were assigned at birth. Some variations are associated with a five percent, twenty-five percent, and sixty percent chance of being assigned the wrong gender at birth. International guidelines for clinical care have

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11 Mary Bartram, “Making the most of the federal investment of $5 billion for mental health,” *CMAJ* 6, no. 189 (2017):1360-1363; Interview #4
13 Ibid.
become more focused on the potential of delaying surgeries until children are able to decide for themselves, but lack of long-term research is a barrier for acceptance in the broad medical community.

The analysis section is divided into two parts; first, an overview of key risks associated with early surgery is presented and analyzed based on data quality. The second piece of the analysis section discusses criteria related to health, stakeholder acceptance, and implementation complexity. Policy options considered include maintaining the status quo, initiating a consultation process, strengthening psychological and social support resources for families, implementing a moratorium on early elective surgeries in Partial Androgen Insensitivity Syndrome, and implementing a moratorium on early elective surgeries in all DSD.

Due to a lack of long-term data regarding the impacts of surgical outcomes, it is impossible to definitively predict the psychological and physical impacts associated with various policy approaches. The final recommendations of this study include consultation and a public commission of inquiry to investigate current practices and impacts associated with elective genital surgeries on infants and young children. Following the commission, it is expected that restrictions will be recommended, including at minimum, a moratorium on early elective genital surgeries for children with Partial Androgen Insensitivity Syndrome.
Chapter 2.

Background

2.1. What are Intersex Variations?

Intersex variations refer to chromosomal, hormonal, and/or reproductive anatomical differences that do not satisfy typical notions of male or female bodies.\(^{14}\) Intersex variations are sometimes detected in utero or are visible at birth if the child has atypical genitalia. Other times, individuals will discover their difference at puberty; it is also possible that individuals live their entire lives without knowing. More than forty different intersex variations have been identified,\(^{15}\) and they can be caused by a variety of factors including inherited genetics, prenatal maternal over- and under-exposure to androgens (male hormones), endocrine-disrupting chemicals, and missing enzymes. Research suggests that hormone disruptors in the environment may be responsible for increasing rates of intersex variation.\(^{16}\)

In the medical field, intersex variations are referred to as disorders of sex development (DSD), a term which was introduced in 2006.\(^{17}\) This study recognizes that “DSD” continues to be a stigmatizing and pejorative term to many.\(^{18}\) Where DSD is used in this report, this project refers to the alternate term differences of sexual development, which is done in an attempt to de-pathologize the meaning of DSD.\(^{19}\)

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\(^{17}\) Lee et al., “Consensus Statement on Management of Intersex Disorders.”


2.2. Prevalence in the General Population

It is estimated that the frequency of intersex characteristics is 1.7% among the general population.\textsuperscript{20} It is important to note that the majority of this figure comprises individuals who do not have atypical genitalia that would be subject to evaluation for normalizing surgery. Internationally recognized estimates say that about one in two thousand babies is born with atypical genitalia that results in the sex being called into question, though this can range from 1:2000 to 1:5000 as seen in Table 1. Applying this rate to Canada’s live birth rate,\textsuperscript{21} it is estimated that around two hundred babies are evaluated annually, and may receive some form of feminizing or masculinizing elective genital surgery.

It is estimated that annually in Canada, there are twenty-nine babies born with Congenital Adrenal Hyperplasia, three born with Partial Androgen Insensitivity Syndrome, and nineteen born with Mixed Gonadal Dysgenesis. These are among the most common conditions associated with atypical genitalia.

<table>
<thead>
<tr>
<th>DSD/Intersex Variation</th>
<th>Prevalence Rate</th>
<th>Estimated number of births per year*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congenital Adrenal Hyperplasia</td>
<td>1:15,000\textsuperscript{22}</td>
<td>25-30</td>
</tr>
<tr>
<td>Mixed Gonadal Dysgenesis</td>
<td>1:20,000\textsuperscript{23}</td>
<td>19</td>
</tr>
<tr>
<td>Partial Androgen Insensitivity Syndrome</td>
<td>1:130,000\textsuperscript{24}</td>
<td>3</td>
</tr>
<tr>
<td>All DSD: Number of babies born annually with atypical genitalia</td>
<td>1:5000\textsuperscript{25} - 1:2000</td>
<td>75 - 188</td>
</tr>
</tbody>
</table>

* Equal to prevalence rate multiplied by 2017 birth rate

\textsuperscript{20} “UN Free & Equal: Intersex Awareness.” UN Human Rights Office of the High Commissioner.
\textsuperscript{23} Ibid.
\textsuperscript{25} Lee et al., “Global DSD Update since 2006,” 159.
Babies in Canada are routinely screened at birth for the variant of CAH that leads to adrenal crisis if left untreated. Otherwise, diagnostic tests are usually triggered by visible genital variance at birth or the absence of menstruation in a girl with androgen insensitivity. The most accurate approach is confirming the patient’s genetic condition; however, this is only estimated to occur in twenty percent of cases of DSD. We are only presently able to do clinical testing for a limited number of DSD and it is assumed that many have yet to be identified genetically. Other definitive diagnoses are often based on examination of gonadal and internal reproductive anatomy. A German study found that half of infants did not have a definitive diagnosis by six months of age but that this was not a prerequisite for surgery.

Some research has been done to look at the most likely gender identity in specific variations. These studies are imperfect for multiple reasons, but they are indicative of trends (Table 2). Patients with atypical genitalia caused by CAH have XX chromosomes and are estimated to identify as female around ninety-five percent of the time. In Partial Androgen Insensitivity Syndrome, gender identity is highly unpredictable, and Mixed Gonadal Dysgenesis is also considered difficult to predict.

Table 2. Research on Predicted Gender Identity and Fertility in Selected DSD

<table>
<thead>
<tr>
<th>Condition</th>
<th>Typical Gender Identity</th>
<th>Fertility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congenital Adrenal Hyperplasia (CAH)</td>
<td>90-95% identify as female</td>
<td>Ovaries and uterus</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Fertility varies (0-50%)</td>
</tr>
<tr>
<td>Partial Androgen Insensitivity Syndrome (PAIS)</td>
<td>Gender assignment wrong 25% of the time</td>
<td>Testes (abdominal or scrotal) Fertility possible in some cases with IVF</td>
</tr>
<tr>
<td>Mixed Gonadal Dysgenesis (MGD)</td>
<td>Unknown*</td>
<td>1 dysgenetic gonad and 1 testis or ovary May have a hemi-uterus. Generally considered infertile; 1 reported birth via IVF</td>
</tr>
</tbody>
</table>

*Systematic review concluded that gender dysphoria affects 8.5-20% of people with DSD.

26 Lee et al., “Consensus Statement on Management of Intersex Disorders.”
27 Lee et al., “Global DSD Update since 2006.”
29 Thyen et al., “Epidemiology and Initial Management of Ambiguous Genitalia at Birth in Germany.”
32 Lee et al., “Global DSD Update since 2006;”
33 Krishna et al., “Pragmatic approach to intersex, including genital ambiguity, in the newborn.”
2.3. Institutional Context

2.3.1. Canada

At present, the Government of Canada has no public position on the treatment of people with intersex variations. In 2018, Global Affairs Canada affirmed that it would focus efforts on promoting the rights of intersex people in Canada. In 2018, the Canadian Center for Gender and Sexual Diversity and EGALE Human Rights launched campaigns to ban early surgeries, and Canada’s first national intersex conference was held. Each organization has called on the government to amend Section 268 of the Criminal Code of Canada, which currently allows surgery for the purposes of creating “normal sexual appearance or function.”

None of the major medical associations in Canada have policy statements pertaining to treatment for people with intersex variations, and practices can vary across hospitals. Current practice standards state that there is a lack of consensus between doctors on “indications, timing, procedure and evaluation of outcome” with surgeries. A Consensus Statement published in 2006, and a 2016 update loosely guide current practices. Surgical decisions are based on the views of the parents, “diagnosis, genital appearance, surgical options…potential for fertility…and, sometimes, circumstances relating to cultural practices.”

Standard practices involve using multidisciplinary teams with a variety of different specialists to (1) make determinations about the child’s diagnosis and (2) support the family through decision-making processes. The multidisciplinary team framework is designed to include two mental health professionals, a social worker and a psychologist or psychiatrist. Healthcare professionals interviewed indicated that social workers are

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36 Government of Canada. “Aggravated Assault (Section 268) of the Criminal Code of Canada.”
38 Lee et al., "Global DSD Update since 2006."
39 Ibid; Lee et al., “Consensus Statement on Management of Intersex Disorders.”
40 Lee et al., “Consensus Statement on Management of Intersex Disorders,” e491.
typically present at multidisciplinary meetings, but additional support from a psychologist would typically need to be requested from another clinic or external organization. Given persistent unmet need of psychological support resources in general across Canada, it is not surprising that multiple interviewees expressed concern about underfunding in this area. The 2017-2018 federal budget committed five billion dollars over five years to improve mental health services, but on an annual basis, it is estimated that mental health remains underfunded by 2.6 billion dollars.41

Parents are likely to make different decisions about surgery depending on how the child’s DSD and treatment options are discussed. This can be impacted by the extent to which a behavioural health professional is involved.42 In a recent study with medical students acting as parents, it was found that sixty-six percent of those who spoke to an endocrinologist said they would choose early surgery for their child, whereas among those who talked to a psychologist, only twenty-three percent of participants supported early surgery.43 Interestingly, this study showed that people believed their decision was based on their own values and opinions, suggesting that the psychologist and endocrinologist tap into different values of parents.

41 Mary Bartram, “Making the most of the federal investment of $5 billion for mental health,” CMAJ 6, no. 189. (2017); E1360-1363.
42 Streuli et al. “Shaping Parents.”
43 Ibid.
Table 3. Specialties Involved in the DSD Multidisciplinary Team

<table>
<thead>
<tr>
<th>Multidisciplinary Team Member</th>
<th>Canadian Context</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Psychologist/Psychiatrist</td>
<td>• Involved upon request</td>
</tr>
<tr>
<td>Geneticist and Genetic Counselor</td>
<td>• Involved</td>
</tr>
<tr>
<td>Gynecologist</td>
<td>• Involved</td>
</tr>
<tr>
<td>Pediatric Endocrinologist</td>
<td>• Involved</td>
</tr>
<tr>
<td>Pediatric Urologist</td>
<td>• Involved</td>
</tr>
<tr>
<td>Nurse</td>
<td>• Involved</td>
</tr>
<tr>
<td>Social Worker</td>
<td>• Involved; Possibly underfunded</td>
</tr>
<tr>
<td>Medical Ethicist</td>
<td>• Unknown</td>
</tr>
</tbody>
</table>

2.3.2. International

 Internationally, there have been a growing number of calls to ban medically unnecessary surgeries on children’s genitalia without their informed consent. In 2009, the UN began investigating non-consensual gender confirming surgeries in response to calls from advocacy groups, and in 2013, a special investigator for the UN urged governments to ban unnecessary surgeries on children with intersex variations. Other organizations that recognize these surgeries as human rights violations include the Office of the High Commissioner for Human Rights, Human Rights Watch, Amnesty

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44 Lee et al. “Consensus Statement on Management of Intersex Disorders.”
45 Elders et al., “Re-Thinking Genital Surgeries on Intersex Infants.” Palm Center: Blueprints for Sound Public Policy.
International, and at least half a dozen UN agencies.\textsuperscript{47,48} The World Health Organization has recognized these surgeries as human rights violations\textsuperscript{49} but continues to promote surgical management through the International Classification of Diseases (ICD), which is a set of international standards for health management.

In February 2019, the European Parliament passed a resolution calling on member states to take steps to improve the lives of intersex people, including improved mental health and education for parents and individuals, and banning surgery without the child’s consent.\textsuperscript{50} In January 2019, the United Kingdom announced a call for evidence for information from intersex people as well as others such as parents and care providers with a goal to improve the government’s understanding of the experiences and needs of this population.\textsuperscript{51} Alongside the call for evidence is a technical paper that reviews key background information and current scientific evidence. In 2015, Malta became the first country to ban medically unnecessary genital surgeries on children without informed consent. Since then, Malta has also introduced new education policy for trans, gender variant and intersex kids which aims to improve inclusivity in schools, including guidelines for protecting children’s privacy, and counseling resources.\textsuperscript{52}

In 2018, California passed a resolution to condemn genital normalizing surgeries and is currently in the process of considering legislation. In 2017, three former US Surgeon Generals jointly published a paper urging a moratorium based on the significant psychological and physical risks associated, and a lack of evidence that growing up with atypical genitalia leads to psychosocial distress or that individuals are better off if they

undergo early surgery. Other groups calling for an end to early elective surgeries include the American Medical Association board of trustees, Physicians for Human Rights, and the American Medical Student Association, which represents approximately sixty-eight thousand medical students in the US and Canada.

2.4. Gender Identity Varies in the Intersex/DSD Population

The majority of individuals with intersex variations or DSD identify as male or female. Some identify as intersex. Not everyone with an intersex variation embraces that label, and people can embrace it in different ways. Some health professionals commented that some patients they have seen prefer to think of their variation as strictly a medical condition, and not related to their sense of gender.

Research has been conducted to understand the relationship between certain specific variations and future gender identity. Current research indicates that there is no definitive “evidence linking specific sex characteristics with…gender identity…” While some relationships have been identified, there is no way to predict with certainty. A review of studies looking at gender dysphoria in various DSD showed rates of dysphoria between eight and a half and twenty percent across a number of conditions.

2.5. Capacity to Provide Consent

Informed consent states that the patient (represented by the parent) must have “an appreciation of the nature, extent, and probable consequence of the conduct consented to.” The merits of the existing consent process are questioned on the basis that new parents may be highly distressed, have little or no knowledge of the condition, and are reliant on experts in the hospital setting to help with decision-making who may provide oversimplified information. Parents are encouraged to pursue surgery in the first one to two years of life as many surgeons cite their greater level of experience doing

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53 Elders et al. “Re-Thinking Genital Surgeries on Intersex Infants.”
54 Interview #2; Interview #7
56 Furtado et al., “Gender dysphoria associated with DSD.”
58 Crissman at al., “Children with DSD: A Qualitative Study of Early Parental Experience.”
surgery at this age, and emphasize the child’s lack of awareness as an advantage. Lastly, the argument is made that parents simply do not know their child well enough yet to make a judgement about genital reconstruction.

**Children’s Ability to Provide Consent**

There is no clear consensus on the minimum age a child should be to consent to surgery. A recent article about proposed legislation in California highlights the issue that “there is a fine line between ensuring a minor is old enough to make the decision without pressure from their parents, doctors or peers and not forcing all kids to wait until after puberty.”\(^{59}\) Literature on children’s ability to participate in medical decisions supports the notion that most children can actively participate in decision-making by age eight or nine, and typically have established decision-making competency by age twelve.\(^{60}\) This being said, there is agreement that age of capacity to consent varies by child. The Supreme Court of Canada has said that the capacity to provide consent “requires the cognitive ability to process, retain and understand the relevant information,” and that the patient “be able to weigh the foreseeable risks and benefits of a decision or lack thereof.”\(^{61}\)

The provinces and territories have different standards for the minimum age of consent for medical treatment. In the majority, there is an assumption that at the age of sixteen, individuals are able to provide consent directives.\(^{62}\) In Quebec, the minimum age is fourteen. For nine of the provinces and territories, it is stated that those younger than consent-related cutoffs are potentially able to consent, based on judgment of capacity by health care providers.\(^{63}\)

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63 Ibid.
2.6. Overview of Selected Intersex Variations

This study focuses on three of the most commonly identified intersex variations associated with atypical genitalia which have been identified as having "some evidence base."\textsuperscript{64} By and far, Congenital Adrenal Hyperplasia has the largest evidence base.

2.6.1. Congenital Adrenal Hyperplasia

Congenital Adrenal Hyperplasia is the most common variation associated with atypical genitalia.\textsuperscript{65} It is an inherited genetic condition where the absence of particular enzymes leads to overproduction of male hormones and causes virilisation (masculinization) of genitals in children with XX chromosomes. The most common type is salt-wasting CAH, which is a life-threatening adrenal condition that requires management with medication.

Virilisation of the genitalia varies, falling somewhere between a typical female phenotype and typical male phenotype. The penis and clitoris develop from the same physical structure—the genital tubercle—around the third month in utero. The Prader scale is a zero to five stage scale showing progressive levels of genital masculinization ranging from a typical female (stage 0) to a typical male phenotype (stage 5). A 2006 consensus statement indicates that surgery to reduce the size of the clitoris should only be considered for Prader stages three, four, and five. The 2016 update to that statement does not revisit this issue, but indicates that male gender assignment should be considered in children classified as Prader stage four and five "when social and cultural environment are supportive."\textsuperscript{66}

One doctor indicated that surgery to reduce an enlarged clitoris is no longer a default recommendation, and that most families can wait for the child to make the decision, but surgery is sometimes done at the parent’s request.\textsuperscript{67} Another indicated that early clitoral reduction surgery tended to be a more common decision among parents of girls whose clitorises are at the more virilized end of the spectrum.\textsuperscript{68}

\textsuperscript{64} Lee et al. “Consensus Statement on Management of Intersex Disorders,” e493.
\textsuperscript{65} Karkasiz, \textit{Fixing Sex}.
\textsuperscript{66} Lee et al., "Global DSD Update since 2006," 169.
\textsuperscript{67} Interview #2
\textsuperscript{68} Interview #4
Partial Androgen Insensitivity Syndrome (PAIS) is an inherited genetic condition that occurs in individuals with XY chromosomes and is characterized by partial insensitivity to testosterone. Presentation of the genitalia in individuals with PAIS varies. A person can have anywhere from a vagina and a slightly enlarged clitoris to a penis with hypospadias. PAIS is described as being the most difficult DSD to diagnose. Children are often “loosely labelled as ‘PAIS’ when no conclusive biochemical or genetic abnormalities are identified...”

With respect to gender, PAIS is not consistently associated with one gender identity. Literature indicates that a quarter of the time, individuals are dissatisfied with their gender assignment. Others suggest the odds may higher:

[Cases of PAIS] are the ones that have always bothered us the most, because…they’re very difficult to predict how they’re going to turn out as people, and back when we had to be more binary about things, you know you sort of picked a number out of a hat and fifty percent of the time you’re right, fifty percent of the time you’re wrong, and now we just try to like, delay stuff like that as much as we can...

Standard practice is to generally to remove testes from individuals with PAIS as soon as a diagnosis is made due to the estimated fifteen to fifty percent risk of tumor development. Children with PAIS may also undergo other feminizing or masculinizing surgeries such as hypospadias repair or vaginoplasty, although one physician specified that vaginoplasty is not done in PAIS patients until after puberty.

Hypospadias is a condition where the urethra comes out somewhere along the underside of the penis. It is a common condition that occurs at a rate of around one in

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72 Krishna et al., “Pragmatic approach to intersex, including genital ambiguity, in the newborn.”
73 Interview #2
74 Commonwealth of Australia, “Community Affairs References Committee: Involuntary or coerced sterilisation of intersex people in Australia.”
75 Interview #4.
two hundred and fifty male births. Surgery involves moving the urethra to the tip of the penis primarily to enable urination while standing. Promoting fertility is a rationale in the less common proximal hypospadias, where the urethra opens near the base of the penis.

2.6.3. Mixed Gonadal Dysgenesis

Mixed Gonadal Dysgenesis (MGD) occurs in people with XY chromosomes, or people with sex-chromosome mosaicism (45,X/46,XY). It is cited as the second most common cause of atypical genitalia, and characteristically involves the presence of one dysgenetic or “streak” gonad (which does not function) and one testis or ovary. Genital development ranges from appearing somewhere along the spectrum of typically female to typically male, often falling at one end or the other of a phenotype. Some have “asymmetrical genitalia: On one side a scrotum…on the other side a labia majora…” Surgery could be masculinizing or feminizing; one interviewee noted that the most common surgery in this group is for hypospadias. Gonadectomy is generally recommended for children with MGD to mitigate risk of cancer development in the gonads, which is estimated to be between fifteen to thirty-five percent in dysgenetic gonads. The remaining gonad may be retained depending on the gender of rearing. A child being raised female will usually have the remaining gonad removed to prevent development of male sex characteristics at puberty.

76 Lee et al., “Global DSD Update since 2006.”
79 Interview #2
81 Interview #2
82 Commonwealth of Australia, "Involuntary or coerced sterilisation of intersex people in Australia."
Chapter 3.

Methodology

This project reviews the physical and psychological impacts of different approaches to care for children born with atypical genitalia as a result of an intersex variation or difference of sex development (DSD). A literature review serves as the primary methodology and guided the interview process. Expert interviews provided insights about the Canadian context and confirmed findings from the literature review. An assessment of key risks based on quality of research data outlines tradeoffs associated with different pathways for patient care. The status quo and a moratorium on early elective surgeries are evaluated in consideration of psychological and physical health, implementation complexity, and stakeholder acceptance.

Literature review

A literature review included academic articles, news content and grey literature representing stakeholder groups. Academic and medical literature is used to illustrate treatment standards for children with atypical genitalia in Canada, as well as health outcomes associated with different clinical management practices. The jurisdictional scan identified recent trends in policy and activism, as well as medical and legal policies that pertain to treatment of people with atypical genitalia in Canada, the United States, Australia, and various European countries.

To help facilitate discussion and narrow scope, three conditions associated with atypical genitalia are examined in detail: Congenital Adrenal Hyperplasia (CAH), Mixed Gonadal Dysgenesis (MGD) and Partial Androgen Insensitivity Syndrome (PAIS). These conditions are included due to the presence of some evidence base in each, though outcome data from women with CAH is heavily relied upon due to its much more established research base. While emphasis on CAH outcomes can limit generalizability, the data remains relevant in key areas, including feminizing surgical outcomes and psychological well-being.
Interviews

Interviews were used to help provide an understanding of current practices in Canada, gather opinions on clinical care and gauge perspectives on potential policy options. Interviews reflect the perspectives and experiences of eight experts and stakeholders representing health care professionals, intersex rights advocacy, and academic researchers. Participants were identified through publicly available contact information through the literature review, or referred by personal or professional contacts of interviewees/prospective interviewees.

The following Interviewees all have some relation to or experience with intersex, medical, or gender policy in Canada or internationally:

- **Christine Allen**, Registered Midwife, Manager, Policy and Communications, Ontario Association of Midwives, Toronto
- **Rodney Hunt**, Lecturer, Interim Aboriginal University Preparation Program, Faculty of Health Sciences, Simon Fraser University, Vancouver
- **Daniel Metzger**, Pediatric endocrinologist, BC Children’s Hospital, Vancouver
- **Pediatric Psychologist** (Confidential)
- **PhD Philosopher** (Confidential)
- **Alexander Pershai**, Gender and Development Specialist, Facilitator of Trans Newcomers Resource Hub, MOSAIC, Vancouver
- **Mel Thompson**, Intersex Coordinator, Canadian Centre for Gender and Sexual Diversity, Ottawa
- **Diane Wherett**, Pediatric endocrinologist, SickKids Hospital, Toronto

The research results presented in this report are limited by the following:

- Lack of quality longitudinal evidence on surgical outcomes
- Absence of data about trends in Canadian medical practices
- Absence of data about incidence rates
- Limited contact with affected community and no contact with parents
- No recorded contact with Canadian surgeons and social workers

Lack of quality longitudinal evidence on surgical outcomes is arguably the greatest
barrier to movement in the debates about early elective genital surgeries. The shortcomings of existing evidence are discussed in Section 8.1.1. Nonetheless, the available outcome data serves as an important baseline of information.

Parents and individuals with intersex variations were not specifically solicited as research participants in order to minimize the risk of emotional harm. Based on the small size and short timeframe of the study, it was not realistic to obtain a representative sample of affected individuals and parents, and it is thought that the process of working with a small number could impose a high research burden associated with the potential sensitivity of the interview content. Perspectives of parents and affected communities are drawn from literature on lived experiences of parents and people with intersex variations, through personal accounts, letters, past research interviews and academic research. Many interviewees discussed the reactions and concerns of parents surrounding diagnosis and decision-making.

Despite efforts to speak with surgical experts, no surgeons were interviewed as part of this study, which constrains the ability of this study to make determinations about current surgical practices in Canada. However, two endocrinologists were interviewed who have been working in this area for twenty years or more, and were able to speak about surgical decision-making practices in major children’s hospitals, with presumably high traffic of such patients compared to elsewhere in Canada.

One pediatric psychologist was interviewed who provided valuable insights into the mental health and wellness concerns in DSD care, but no Canadian behavioural health professionals were interviewed, despite efforts to connect with social workers and other relevant professionals. The lack of Canadian representation—and the fact that many indicated they were too busy to speak—may indicate a lack of capacity in this area. This shortcoming limits this report’s understanding of their role and function; however, this is mitigated to some extent by information provided by other experts.
Chapter 4.

Interview Themes

4.1. Parents Need Psychological Support

Healthcare providers and other interview participants described the importance of early and sustained emotional support resources for parents from appropriate specialists in mental and behavioural health, as well as peers. Support should include education about the specific condition, and concepts related to sex and gender identity. Parents can be stressed by many factors, including complex medical information, long diagnostic processes, and strains on social relationships where stigma is a concern. Disclosure of information to others is highlighted as a particularly stressful experience. One health provider talked about the feeling of loss parents can experience after finding out a child has an intersex variation associated with infertility, stressing that parents need to be encouraged to actively process their feelings.

Our goal as providers is to help parents early on wrap their mind around what has happened, to understand this is not a freakish event...we have a remarkable amount of knowledge of how these things occur. It’s a complicated process, sex development...just because we do not hear about it does not mean that there are not many people affected, that there’s a future for their child—somebody will love them, you know, there is no foreclosure of options...

It is crucial that children with atypical genitalia be supported with messages that they are acceptable and loveable. Almost all interviewees talked about the importance of parent’s attitudes towards children’s differences for promoting their well-being; this is especially important to help mitigate potential feelings of shame and isolation. Multiple interviewees also emphasized the role of peer support for supporting parents and children from others who have gone through the same or a similar experience.

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83 Interview #4; Interview #7
84 Sandberg et al., “Psychological Aspects of the Treatment of Patients with DSD.”
86 Crissman et al., “Children with DSD: A Qualitative Study of Early Parental Experience.”
87 Interview #7
88 Ibid.
Access to other parents is almost always mentioned as one of the most important things, right, not feeling like you’re alone, not feeling like your kids are alone...

Some interviewees talked about a lack of resources generally available in the context of DSD-related healthcare. One health provider noted that a psychologist and psychiatrist used to be part of the healthcare team, but were never replaced after they retired.

[Support] is becoming increasingly hard to get…we’ve had hospital budget cutbacks every year and one of the first things that gets cut back is social work…

One of the greatest challenges for the health team is communicating to parents “whatever decision is taken, including no decision, the outcome is likely to be unsatisfactory.” Mental health professionals are trained to assess and support family coping skills, and are essential health providers to include in processes that may involve high levels of stress and anxiety for families. Furthermore, behavioural health professionals are uniquely positioned on health care teams due to their specialized training in facilitating group communication processes.

4.2. Some Parents Insist on Surgery

It appears that the greatest determinant for whether or not a child receives early surgery in Canada is the personal views of parents and the family. The experience of growing up with atypical genitalia is culturally situated in that the social environment shapes the meaning and experience of having atypical genitalia.

It kind of depends on the social environment. It might be that nobody cares, that…the family’s comfortable, that the extended family, if they’re changing diapers…for the baby, is comfortable, babysitters, daycare, you know, childcare, and then as the kid gets older, you know, it may be a big issue, but the child is gonna grow up with genitals that look entirely different, and so…it depends on how they handle that. Some kids…and families will handle it and others will be a lot of shame and secrecy…

89 Interview #6
90 Interview #4
92 Sandberg et al., “Psychological Aspects of the Treatment of Patients with DSD.”
93 Interview #4
Some interviewees referenced parents who had insisted on early surgery. One physician noted a general tendency to delay surgery when possible, but indicated that surgery had been performed at the request of parents, even after attempts to steer them away from surgery.

[W]hen you have a family that is sort of open to...a gender that we may not be able to figure out for a little while, that works, but some people come from backgrounds where that doesn’t work and then we just kind of have to bite the bullet and go with the flow...sometimes there’s sort of a social, cultural, religious thing that we have to negotiate as well...[sometimes] it doesn’t work to be not binary, so sometimes those kids are more likely to get some kind of a surgery that we might not do otherwise...94

This finding points to a potential research focus for improving emotional support for families: identifying those parents who are most likely to request early surgery in order to better respond to their concerns.

4.3. Parents Need Balanced Advice from Experts

Interviewees referenced the advisory role that is performed by hospital physicians, and how parents look to their children’s doctors for advice. Some commented on an unequal power relationship between parents and doctors based on a lack of medical expertise among parents. Doctors are seen to have an authoritative ability “to define the situation through scientific…language…which is seen as objective and straightforward.”95 One health care provider talked about the conversations that occur between doctors and parents, and indicated factors that doctors might discuss to promote early surgical intervention, including the child’s lack of awareness, and surgeons’ greater level of experience and outcomes associated with early surgery. This participant also emphasized that surgical decision-making is challenging at any age, and children early in adolescence are not necessarily “in a position to make decisions.”96

Parents need to be educated and counselled after they are made aware of a child’s intersex variation in order to mitigate anxiety and confusion, and the pediatric

94 Interview #2
95 Karkasiz, Fixing Sex, 213.
96 Interview #4
doctor or surgeon may not be the best person to serve that role. A social worker or psychologist can be used to inform parents about the implications of the child’s variation, and about practical aspects of raising a child with an intersex variation, such as how to educate and talk to others. Doctors often need to explain concepts related to sexual anatomy and gender identity in order to communicate the impacts of various treatment options. While current standards and interview findings indicate that the ‘no surgery’ option is offered to parents, there is some question as to how it is presented as an option; a PhD philosopher talked about the issue of framing bias.

If the [doctor] isn’t being forceful about the importance of surgical intervention, there are still ways that, you know, doctors aren’t transparent to themselves about their own biases…Most parents will find the prospect of ‘doing nothing’ unappealing. As parents you want to do everything for your child, that’s how we think about parenting, so, if a doctor thinks doing nothing is the right thing, if you’re putting it as doing nothing…if you’re a vulnerable parent and you want support and…you’re wanting to do right by your kid, you’re going to want to involve, you know, the experts, right? And these are the terms on which experts are involved.

if you don’t opt for medical intervention of any kind, then who do you turn to?

One participant argued that in addition to full disclosure of surgical risks, parents should be educated about the human rights perspective on early elective surgeries to improve transparency and fairness of the information disclosure process. The same interviewee suggested a peer or patient advocacy representative could be made available to attend medical meetings with parents.

4.4. Children Should Be Able to Decide

Seven of eight interviewees explicitly acknowledged the importance of children with DSD being able to make decisions related to elective procedures. There was a strong theme in many of the interviews that children should be able to make choices that can carry traumatic and lifelong impacts. One physician said “surgery may affect sexual

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98 Ibid. 256.
99 Interview #6
100 Ibid.
101 Interview #9
sensation and...you want a person old enough to understand the implications of that to make a decision about whether they want surgery that could do that.”

Another health provider talked about surgery for hypospadias, which is sometimes defined as a DSD, but in isolation is generally not treated as an intersex variation per se by the medical community “because it is rarely accompanied by atypical development of the reproductive or endocrine system and thus raises little question regarding gender assignment.” It occurs at a high rate in the general population (estimated 1:250 male births), and in various intersex conditions.

[T]he bulk of what pediatric urologists do in Canada and the US—minor hypospadias repair of the urethra, which is on the distal shaft, okay, these are the most common cases, and they’re done very, very frequently and they will tell you, if they’re open, that this is not a functional issue...I think that the risks are high enough that this should be deferred until the patient is old enough to make their own decision...

Doctors are not always certain about whether or not pursuing surgery was the right thing for the patient, and that in some cases, the need for corrective re-operations is extraordinarily high.

I’ve also seen surgeons who are not ready to take responsibility...you do a clitoral reduction and you nick the blood supply and the clitoris...is gone...and it’s sort of like “well, it’s a complication, they knew it was a complication”, but it didn’t have to be done in the first place and I think with proximal hypospadias–these are complicated surgeries, lots of complications, at the best hospitals, do you know, 60-65% complication rate. It’s not unusual for kids with....severe forms to have six, seven procedures, or more and the thought is, there’s no attention to the fact that each time you do a surgery like this, as a patient getting older, you’re not only operating on their genitals, you are operating on their self-perceptions, on their body image, and they are getting messed up."

The process of undergoing multiple genital surgeries can send children the message that they are not normal. Surgeries intended to improve body image can take a physical and psychological toll on children and, when done early, have been described by advocates and human rights organizations as institutionalized sexual abuse, and

102 Interview #4
103 Karkasiz, Fixing Sex, 143.
104 Interview #7
105 Ibid.
106 Karkasiz, Fixing Sex.
genital exams have been described as traumatizing by some people with intersex variations.

4.5. Public Awareness is Needed

A number of participants made reference to social awkwardness around discussing genitalia in general. An essential step in the journey to reducing shame and stigma for children and parents is acknowledging that intersex variations occur naturally and they do not need to be associated with shame. Many interviewees stressed the need for public conversations and education.

[Public discussion about intersex issues, without blaming anyone... informing people about different variations in terms of biological development...allowing people to kind of, see intersex as something completely normal, something that happens... it is [also] very important to have parents of intersex children who decided not to go for surgery just to share their experiences.

Stakeholders involved in a variety of areas can play a role to play in supporting affected children and families. An interviewee from the Association of Ontario Midwives explained that one of their goals is to educate parents about gender inclusivity. Other groups that might be engaged are teachers and church groups. In the same way that that many schools and churches have become more supportive of LGBT individuals, these same groups could be engaged to learn about intersex variations. Intersex has appeared in some Canadian elementary school curriculums, but in both BC and Ontario, teachers have autonomy with respect to what all they cover in the class. It appears that in each of these jurisdictions, intersex falls into a discretionary category, leaving coverage up to individual teachers.

One confidential interviewee pointed out an issue with having truly honest public discussion about such a contentious issue: it may be difficult for some experts to speak openly about their perspectives. This participant said “there’s no question that if I spoke

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107 Interview #6; Interview #3
108 Interview #7
109 Interview #3
110 Caroline Alphonso and Jeff Gray, “Teachers free to use own judgment for sex ed, Ontario court rules as it dismisses legal challenge of curriculum.”
111 Erik Rolfsen, “Sex education and gender identity in schools rife with controversy.”

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openly about these things, it would be the end of my academic career.”\textsuperscript{112} Another participant said that a “risk in having these conversations is resistance from people who went and had [surgery] done thinking they were doing right by their children...[people who]...don’t want to believe that they have harmed their children.”\textsuperscript{113}

\textsuperscript{112} Interview #7
\textsuperscript{113} Interview #6
Chapter 5.

Summary of Key Research Findings

The literature review and expert interview process led to the development of key research findings, which inform the structure and analysis of the policy options considered in Chapter 6.

- Very little is known about how surgical outcomes fare physically and psychologically over the long term.
- Isolation and shame are salient experiences for children and parents.
- Rationales for surgery often center on promoting sexual confidence and function and minimizing stress in public changerooms and swimming pools.
- Parents sometimes insist on surgical intervention, despite doctors recommending deferral of surgery until the child is older.
- It is not clear how consistently mental health professionals are integrated in multidisciplinary teams and decision-making processes. Interview results suggest that resources are lacking, and that parents may not receive adequate support.
- Peer support can be a valuable resource for parents and children.
- People with intersex variations face systemic barriers in accessing appropriate health care services, for example, in search of a knowledgeable family physician.

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115 Cools et al., “Caring for individuals with a difference of sex development (DSD): a Consensus Statement.” *Nature Clinical Practice Endocrinology & Metabolism* 14 (2018): 415-29; Interview #1
Chapter 6.

Policy Options

6.1. Status Quo

The primary policy statements that guide Canadian practices are the 2006 Consensus Statement on Management of Intersex Disorders and the 2016 update. The 2006 statement affirms the importance of having a multidisciplinary team of experts to guide families through education and decision-making processes, including multiple experts in behavioural health. Furthermore, the consensus specifies that a specialist with “appropriate communication skills” should be in charge of discussing matters related to care decisions.\textsuperscript{116} At present, surgeons are understood to be the most likely candidate to talk about consent with the parents. It is not clear whether or not psychologists are consistently involved in multidisciplinary team meetings and it is not clear how involved social workers/other behavioural health experts are in conversations to educate parents and discuss care options.

It is unclear how frequently early elective surgeries occur in Canada. Conversations about the risks of surgery and delaying decision-making are more common today than in the past\textsuperscript{117} and there appears to be more caution among health providers when discussing surgeries. Experts indicated that in girls with CAH, surgery is more likely to occur in those with more highly virilised genitalia. These findings describe the perspectives of two doctors, which cannot be generalized to the Canadian context.

A lack of integration of behavioural health support in patient care and decision-making processes can increase the risk of framing bias through a lack of sufficiently comprehensive information provided to parents and children. It also means that parents’ distress is more likely to be witnessed and responded to by a specialist without training in psychology and the skills that go along with that. While parents can request counselling referrals through the hospital physician, such supports for families may be inadequate where resources are underfunded.

\textsuperscript{116} Lee et al. “Consensus Statement on Management of Intersex Disorders,” e490.
\textsuperscript{117} Interview #4
6.2. Call for Evidence + Psychological Support Guidelines

A Call For Evidence from Canadians with intersex variations and others would form the basis of a consultation process. The goal would be to collect information about the social and health needs of the population, identify research and policy priorities, and develop a statement of facts about what is known about current decision-making processes and practices. Simultaneously, a commission of inquiry would investigate current practices. It is essential that people with intersex variations be meaningfully involved in the design of research and policy. The final results of these processes would be used to develop new psychological support guidelines and shared publicly.

The psychological support guidelines would set out clear requirements for incorporating individuals trained in behavioural healthcare (such as a social worker or psychologist) into the education and decision-making processes for parents. International guidelines recognize the importance of such experts but in practice, their role appears to be minimized due to a lack of dedicated funding and/or perceived need. Best practices emphasize the need for a holistic approach,\(^\text{118}\) which “considers the needs of family members…” as well as “the physical, emotional, social, economic and spiritual needs of the patient.”\(^\text{119}\) It is an important, and challenging task for health providers to ensure that education and decision-making processes are grounded by balanced information.\(^\text{120}\) The guidelines would establish minimum standards related to the content and conduct of parental education, counseling, and conversations about providing consent. The guidelines should also consider ways to integrate resources such as trained peer support and patient advocates.

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\(^{119}\) Cools et al., “Caring for individuals with a DSD,” 418.

\(^{120}\) Sandberg et al., “Psychological Aspects of the Treatment of Patients with DSD.”
6.3. Moratorium on Elective Surgery in Partial Androgen Insensitivity Syndrome

A partial moratorium would eliminate parents’ ability to consent to early elective surgery on behalf of their children in cases where the child has been diagnosed with Partial Androgen Insensitivity Syndrome (PAIS), or where the diagnosis of PAIS cannot be ruled out. The rationale for this policy option is based on the evidence that shows gender identity is relatively impossible to predict with confidence in PAIS. The most conservative estimates say a quarter of the time, gender assignment will be wrong. One interviewee noted that surgery in PAIS would not typically occur before puberty, so it may be that these surgeries are routinely avoided in early childhood, but there is no additional evidence to support that conclusion. It is important that the psychological support guidelines be implemented with this option to ensure availability of resources to parents and children.

6.4. Moratorium on Elective Surgery for All DSD

A complete moratorium would eliminate parents’ ability to consent on behalf of their children to early elective procedures. This policy is based on the evidence that shows early elective surgeries are associated with severe physical and psychological risks, and the lack of compelling evidence that shows early surgeries yield better results over the long-term. This policy is further supported on the fact that a significant proportion of people with DSD will not identify with the gender assigned to them; depending on the type, that number may range from five to sixty percent.  

Amending Section 268(a) of the Criminal Code of Canada, which protects the use of genital surgery to create normal sexual appearance, is another approach that could be pursued to implement a moratorium. This is in line with calls from human rights organizations in Canada, however, this avenue is not recommended, as this approach is more likely to face categorical resistance from the medical community.

121 Furtado et al., “Gender dysphoria associated with DSD.”
Responsibility for implementing a moratorium would fall on individual provinces and territories. Each province or territory would need to mandate this change to the Colleges, which are the regulatory authorities that govern physician accreditation and clinical practices. A moratorium implemented this way would be less rigid than one implemented through the Criminal Code. In theory, the provinces could establish an independent review panel for exceptional circumstances. It would be important to set parameters if this is utilized, including a minimum waiting period before surgery can be performed, and mandatory annual independent review of the review board’s decisions.

There would be some concern if certain provinces adopt a moratorium and others do not, creating incentive for people to go out-of-province for surgery, however a provincial moratorium would provide a valuable signal to parents and the public that the safety of surgery is in question, and they would presumably be less likely to pursue it in infancy/early childhood. Nonetheless, a moratorium policy presents the potential risk that some parents will seek early surgery outside of Canada, or through an underground market within Canada. Undocumented, non-sanctioned surgeries present two key risks: first, that surgery will be performed by someone with less experience, and results will be worse, and second, if surgery is performed outside of the Canadian health system, the child will likely have no record of the procedure, and may suffer on account of that.
Chapter 7.

Ethical Principles

The question of whether or not to perform elective genital surgery on an infant or young child raises questions around individual rights and consent. Research in the area of health ethics recognizes that “health professionals are often forced to make both explicit and implicit choices that extend beyond the objective and practical and into the contested and ethical.” Utilitarian and rights-based ethics approaches are used to help clarify conflicting perspectives towards early surgical intervention.

7.1. Utilitarian Argument

A utilitarian argument supports the path that leads to the greatest good for the greatest number. This framework can be helpful to illustrate a potential perspective behind the current policy environment. Utilitarianism compares costs and benefits and urges the selection of the option that maximizes benefits relative to costs. In this perspective, if the benefits of parental choice, in relation to early surgery outweigh potential costs, parents should be allowed to decide.

Whether or not the potential risks outweigh the potential benefits of early surgery depends on the way we assign value to these risks and benefits. How do we quantify the distress associated with the various risks a child with atypical genitalia might face? How do we place value on someone being able to keep the enlarged clitoris or penis that they were born with? If the five percent likelihood of wrong gender assignment turns into ten percent, how does our perspective change? What about twenty-five percent? Some will say that five percent odds are low enough of a risk to accept, and others will disagree based on their valuation of the human cost associated with wrong gender assignment.

Utilitarianism has the advantage of taking a macro-level perspective and pursuing the option with the greatest net benefit across the population. In general, this

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perspective stands up well to scrutiny in the domain of public policy in its goal to maximize efficiency. It also aligns itself with the concept of public health, which seeks to promote wide-scale health benefits in the population. However, both a utilitarian and a public health perspective may be criticized for promoting the benefit of the majority and sidelining the welfare of (certain) individuals. This study acknowledges the merits of utilitarianism in healthcare, but is concerned by the fact that this approach may have a predisposition towards de-prioritization of minority rights. In the case of early intersex surgeries, it is very difficult to quantify the human costs and benefits, and it is not clear to what extent these costs and benefits truly occur, making a robust accounting process practically impossible.

### 7.2. Rights-based Argument

A rights framework supports the path that leads to the greatest respect for human dignity. One of the key challenges of this approach is finding a fair balance of rights between competing groups, as a human rights perspective prioritizes the rights of one group over others who may face a cost. The principle of human rights asserts that governments have an “obligation to respect, protect, and fulfill human rights…” which includes ensuring that government does not interfere either directly or indirectly with enjoyment of those rights, and that third parties are prevented from interfering with people’s rights. Duty-based ethics states that people should treat others as ends in and of themselves, “and cannot merely be treated as a means to the end of others’ good.” The concept of health equity is important, and “seeks to reduce inequalities and to increase access to opportunities and conditions conducive to health for all.”

Intersectionality is a concept that relates to the idea of social justice. It refers to the study of social categorizations such as race, class, and gender and how they create "overlapping and interdependent systems of discrimination or disadvantage."

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124 Schröder-Bäck et al., “Teaching seven principles.”
Intersectionality-Based Policy Analysis tries to determine “what inequities and privileges are created by current policy responses” and helps identify policy options that target structural change to reduce inequities.\textsuperscript{129}

**Reasonable Limitations to Rights**

Human rights and autonomy may be limited in some instances, but in order to be justifiable, it needs to pass a test of proportionality—a question of whether or not the interference in an individual’s life is too severe for what is being accomplished. The legal principle of reasonable limitations to human rights says that the burden of proof for infringing rights “needs always to lie with those advocating restriction.”\textsuperscript{130} International and human rights legal precedent shows that limits are assessed on:

1. “whether there were other less restrictive ways to achieve the same aim;
2. whether there are effective safeguards or controls over the measures, including provision of due process rights and access to independent review; and
3. the extent of the interference with human rights—the greater the interference the less likely it will be considered proportionate.”\textsuperscript{131}

It is not clear that adequate justification for surgery has been provided in the case of children with intersex variations. Effective safeguards are not in place to monitor outcomes, and the interference with individual rights is disproportionately great, risking severe mental distress from general loss of physical autonomy, loss of sexual function, and wrong gender assignment. An Australian report looking into the issue of early surgeries wrote that: “A model that confers rights on third parties, through substitute decision making, before it guarantees the rights of the child, is likely to be a disproportionate limitation of the child’s right to autonomy/self-determination.”\textsuperscript{132}

\textsuperscript{129} Hankivsky, Olena (Ed.) *An Intersectionality-Based Policy Analysis Framework*. Vancouver, BC: Institute for Intersectionality Research and Policy, Simon Fraser University. 2012: 34.

\textsuperscript{130} Schröder-Bäck et al., “Teaching seven principles.”


\textsuperscript{132} Ibid.
Chapter 8.

Analysis

Section 8.1 provides a general risk assessment of various clinical pathways, and Section 8.2 considers potential policy options using selected criteria.

8.1. Risk Assessment

Risk assessment involves evaluating the probability and the magnitude of impacts associated with risk scenarios. Once these are outlined, an assessment must be made about the quality, or confidence level of the data used to describe probability and impacts. A scale provided by Public Safety Canada (Table 4) ranks data quality from A to E, where A is the highest level of confidence. When an assessment of the data confidence level is deemed to be low or very low, decision makers are encouraged to exercise caution in interpretation.133

Table 4. Confidence Level of Data Quality

<table>
<thead>
<tr>
<th>Confidence Level</th>
<th>Quantification</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Very High confidence in the judgement based on a thorough knowledge of the issue, the very large quantity and quality of the relevant data and totally consistent relevant assessments.</td>
</tr>
<tr>
<td>B</td>
<td>High confidence in the judgement based on a very large body of knowledge on the issue, the large quantity and quality of the relevant data and very consistent relevant assessments.</td>
</tr>
<tr>
<td>C</td>
<td>Moderate confidence in the judgement based on a considerable body of knowledge on the issue, the considerable quantity and quality of relevant data and consistent relevant assessments.</td>
</tr>
<tr>
<td>D</td>
<td>Low confidence in the judgement based on a relatively small body of knowledge on the issue, the relatively small quantity and quality of relevant data and somewhat consistent relevant assessments.</td>
</tr>
<tr>
<td>E</td>
<td>Very Low confidence in the judgement based on small to insignificant body of knowledge on the issue, quantity and quality of relevant data and/or inconsistent relevant assessments.</td>
</tr>
</tbody>
</table>

Source: Public Safety Canada, "All Hazards Risk Assessment Methodology Guidelines 2012-2013."

8.1.1. Quality of Available Data

Collection of patient data is difficult for many reasons, including variation in phenotypes, rarity of conditions, the long waiting period between surgery and follow-up and patients “lost to follow up,” which refers to patients who were previously involved with the study but stopped participating. Available data is mainly from individual cases, small hospital-based study groups, and first person or narrative accounts. One exception to a generally limited evidence base is CAH, for which there is a growing body of research. The psychological implications of growing up with an intersex variation are uncharted territory in terms of large-scale research studies. The most recent clinical statement used to inform practise in Canada states:

There is no evidence regarding the impact of surgically treated or non-treated DSD during childhood for the individual, the parents, society or the risk of stigmatization…

Other quality issues of existing data include:

- **Data is not always representative of current surgical practices**
  To some extent, we are bound to look at outdated practices. However, nerve-sparing clitoral reduction surgery became standard practice in the 1980s, and we have information about these outcomes, as well as those from the 1990s.

- **Outcome studies overemphasize short-to-medium term subjective cosmetic results** and fail to include quality of life indicators

- **Comparison of surgical outcomes between data sets is difficult due to difference in assessment criteria**

- **Studying sexual function is challenging for many reasons**
  We want long-term results but typically get outcome data from people under the age of thirty; many young women have reported being unsure of whether or not they have actually experienced an orgasm; and, most tests used are subjective questionnaires.

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134 Cools et al., “Caring for individuals with a DSD.”
136 Lee et al., “Global DSD Update since 2006.”
137 Ling Lean et al., 2005: One study describes successful cosmetic outcomes as two or fewer abnormalities and the “unlikelihood to be judged abnormal by a non-medically trained person…”
138 Meyer-Bahlburg, “Gender Assignment and Reassignment in Intersexuality.”
139 See Appendix F: Sample of Surgical Outcomes.
8.1.2. Identifying Risks by Scenario

An evaluation of high-level risks associated with various clinical pathways is presented in Table 5. Two generic scenarios are used to identify specific rationale(s), risks, and to examine the quality and quantity of evidence available to support the presence of key risks. This assessment is limited by a lack of quantitative data available to estimate the probability of certain risks occurring, and the fact that the magnitude, or impacts of various surgical risks, including wrong sex assignment have not been quantified with large-scale long-term controlled studies.\textsuperscript{140}

<table>
<thead>
<tr>
<th>Pathway</th>
<th>Key Rationale(s)</th>
<th>Key Risks Associated with this Pathway</th>
<th>Data Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Early Surgery</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subgroup</td>
<td>• Not medically necessary</td>
<td>Child may experience psychological distress from atypical genitalia</td>
<td>D-E</td>
</tr>
<tr>
<td>No early surgery + surgery when older</td>
<td>• Individual should be able to decide</td>
<td>Surgeons may be less capable if child wants surgery when older</td>
<td>D</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Individual may experience greater distress from having surgery when older</td>
<td>D</td>
</tr>
<tr>
<td>Early Surgery</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subgroup</td>
<td>• Promote psychological health</td>
<td>Child may be surgically assigned wrong sex</td>
<td>C-D</td>
</tr>
<tr>
<td>Elective surgery + medically necessary surgery</td>
<td>• Minimize distress from social stigma (public pools, bathrooms, etc.)</td>
<td>Loss of healthy sexual tissue</td>
<td>A</td>
</tr>
<tr>
<td></td>
<td>Subgroup → Minimize total procedures to:</td>
<td>Possibly impaired sexual function</td>
<td>D</td>
</tr>
<tr>
<td></td>
<td>o Minimize psychological distress</td>
<td>Child may experience distress from poor surgical results or complications</td>
<td>C-D</td>
</tr>
<tr>
<td></td>
<td>o Minimize scar tissue</td>
<td>Psychological distress if reoperations needed as child matures</td>
<td>D</td>
</tr>
</tbody>
</table>

Note: Gonadectomy has been excluded from this table to narrow analysis. See Appendix B for information about gonadectomies.

## 8.1.3. Assessed Confidence of Data Quality

### Table 6. Assessment of data quality for key risks identified

<table>
<thead>
<tr>
<th>Key Risks</th>
<th>Probability-related data</th>
<th>Data Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>No Early Surgery</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child may experience psychological distress from atypical genitalia</td>
<td>● No long-term studies on untreated atypical genitalia</td>
<td>D-E</td>
</tr>
<tr>
<td></td>
<td>● Difficult to separate impacts of atypical genitalia and surgery¹⁴¹</td>
<td></td>
</tr>
<tr>
<td>Surgeons may be less capable if child wants surgery when older</td>
<td>● No controlled data looking at surgery in infancy vs. older¹⁴²</td>
<td>D</td>
</tr>
<tr>
<td></td>
<td>● Most done &lt;2 years; a significant group have had surgery &gt;9 years</td>
<td></td>
</tr>
<tr>
<td>May experience more distress from undergoing surgery when older</td>
<td>● Limited relevant data; No controlled data</td>
<td>D</td>
</tr>
<tr>
<td></td>
<td>● Single-center study; 46% of respondents with a DSD said surgery should not happen before adolescence</td>
<td></td>
</tr>
<tr>
<td><strong>Early Surgery</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wrong sex assignment</td>
<td>● 5% risk (CAH) 25% risk (PAIS)</td>
<td>C-D</td>
</tr>
<tr>
<td></td>
<td>● Unclear; Systematic review: 8.5-20% across DSD</td>
<td></td>
</tr>
<tr>
<td>Loss of healthy sexual tissue</td>
<td>● Guaranteed in clitoral/phallic reduction procedures</td>
<td>A</td>
</tr>
<tr>
<td>Impaired sexual function</td>
<td>● Inconsistent research on surgery/sexual quality of life¹⁴³</td>
<td>D</td>
</tr>
<tr>
<td></td>
<td>● Qualitative research from surgeries in 1970s-1990s</td>
<td></td>
</tr>
<tr>
<td>Poor surgical results or complications¹⁴⁴</td>
<td>● Some case-controlled studies; narrative evidence</td>
<td>C-D</td>
</tr>
<tr>
<td></td>
<td>● Significant dissatisfaction with appearance/function of results (10%+)¹⁴⁵</td>
<td></td>
</tr>
<tr>
<td></td>
<td>● Reoperation rates estimates include: Vaginoplasty: 50%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hypospadias (Distal): 25-28%¹⁴⁶,¹⁴⁷</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hypospadias (Proximal): 28-50%¹⁴⁸,¹⁴⁹</td>
<td></td>
</tr>
<tr>
<td>Psychological distress if reoperations are needed</td>
<td>● Narrative evidence and medical literature show negative experiences and stress associated with repeat surgeries</td>
<td>D</td>
</tr>
<tr>
<td></td>
<td>● Unclear how often children undergo multiple reoperations</td>
<td></td>
</tr>
</tbody>
</table>

¹⁴¹ Lee et al., “Global DSD Update since 2006,” 167.
¹⁴² Lee et al., “Consensus Statement on Management of Intersex Disorders”
¹⁴⁴ Supported by literature review and data found in Appendix F.
¹⁴⁸ Ibid.
8.1.4. Summary

The most significant risks associated with early elective genital surgeries include wrong gender assignment, loss of healthy sexual tissue, impaired sexual function, and distress from poor surgical results or complications. The most significant risks associated with delaying surgical decisions include psychological distress from atypical genitalia, possible increased distress from greater awareness of experience if child undergoes surgery when older and potentially worse outcomes if surgeons are less capable at working with older children.

At present it is impossible to compare the level of distress that may be generated by the risks associated with pursuing or delaying elective surgeries. Assessment of the data quality presented in Table 6 highlights research areas that suffer from a lack of consistent and quality evidence. In order to improve our ability to evaluate the threat of the key risks associated with early versus late surgeries, two key research areas are identified as being highly important for supporting decision-making:

- Psychological distress associated with surgical and non-surgical pathways
- Physical and sexual outcomes associated with surgical management

8.2. Analysis Criteria

1. Psychological well-being of children
2. Physical health and safety of children
3. Projected support among people with intersex variations, parents and physicians
4. Ease of implementation

For the purpose of this analysis, psychological well-being is considered the most important criteria, and its score is double-weighted to reflect this valuation. Impacts to psychological well-being are estimated using qualitative factors related to exposure to emotional distress and rankings are given a range to reflect flexibility in how impacts may be assessed. Physical health and safety is reflected using rates of complication requiring reoperation, and ease of implementation is based on the estimated difficulty of policy implementation and maintenance. Stakeholder acceptance is explored in a
qualitative fashion, and provides a score of one (Low), two (Moderate), three (High) based on how many of the three stakeholder groups are expected to provide moderate or high support (See Appendix E for complete framework).

### 8.2.1. Using Best and Worst-case Scenarios to Compare Policies

In light of an inability to quantify the current uptake and outcomes of surgeries in Canadian hospitals, this analysis describes best and worst-case scenarios to consider how the status quo and a moratorium on early elective surgeries comparatively contribute to potential psychological distress. The key measure of physical risk (complication rates) is held constant in all scenarios. Congenital Adrenal Hyperplasia is used as a specific condition to focus on because it has the largest evidence base.

**Three key risk areas differentiate between best and worst case scenarios:**

- Whether or not additional operations are required to address complications
- Whether the individual is satisfied with the cosmetic and functional results
- Whether the individual feels they were assigned the right gender

On an individual basis, severe dissatisfaction with any of these factors could be classified as a type of worst-case scenario. In the hypothetical best and worst-case scenarios used here, we assume that in all cases five percent of children will be surgically assigned the wrong gender, and that complication rates will remain constant regardless of when surgery is performed. In terms of physical safety, we assume that those who undergo clitoral surgery will have an estimated ten percent risk of a need for reoperation and those who receive vaginoplasty will have a fifty percent risk of a need for reoperation. The key differentiator between the two groups is the volume of repeat surgeries and general satisfaction with surgical results.

**Best-case Scenario:** In a best-case scenario, those who do undergo reoperations will have as few as possible (one or two), and the majority will be satisfied with cosmetic and functional results of surgery.

**Worst-case Scenario:** In a worst-case scenario, those who undergo reoperations will be more likely to need additional surgeries in the future and the individual will be more likely
to be dissatisfied with the cosmetic and/or functional results. There are many types of worst-case scenarios: (1) individual has impaired sexual function and/or sexually related pain, (2) complications necessitate numerous follow-up surgeries in childhood, and (3) the individual is distressed by the loss of healthy sexual tissue and/or assigned the wrong gender.

The analysis matrices presented on the following page reflect simplified estimations of what best and worst-case scenarios might look like. They are useful for considering the relative merits of different policy avenues but do not categorically indicate one best option. If reality is more closely aligned to the best-case scenario, the status quo may perform as well as a moratorium or slightly better in terms of how much psychological distress is generated. If reality is more closely aligned to the worst-case scenario, it is expected that a moratorium may perform better than the status quo.

In reality, it is expected that most experiences in Canada fall somewhere between the best and worst cases. Without knowing more about current practices, we cannot definitively say what the long-term physical and psychological outcomes associated with a moratorium or continued maintenance of the status quo would be.
## Analysis Matrix: Best-Case Scenario

<table>
<thead>
<tr>
<th>Objective</th>
<th>Status Quo</th>
<th>Moratorium</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological well-being</td>
<td>MODERATE/HIGH (4.5)</td>
<td>MODERATE (4)</td>
</tr>
<tr>
<td></td>
<td>(Range: 4-5)</td>
<td>(Range: 3-5)</td>
</tr>
<tr>
<td>Physical Safety</td>
<td>LOW (1)</td>
<td>LOW (1)</td>
</tr>
<tr>
<td>Stakeholder Acceptance</td>
<td>MODERATE (2)</td>
<td>LOW (1)</td>
</tr>
<tr>
<td>Ease of Implementation</td>
<td>HIGH (3)</td>
<td>MODERATE/HIGH (2.5)</td>
</tr>
<tr>
<td>Total</td>
<td>10.5</td>
<td>8.5</td>
</tr>
</tbody>
</table>

## Analysis Matrix: Worst-Case Scenario

<table>
<thead>
<tr>
<th>Objective</th>
<th>Status Quo</th>
<th>Moratorium</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological well-being</td>
<td>LOW/MODERATE (3)</td>
<td>MODERATE/HIGH (5)</td>
</tr>
<tr>
<td></td>
<td>(Range: 2-4)</td>
<td>(Range: 4-6)</td>
</tr>
<tr>
<td>Physical Safety</td>
<td>LOW (1)</td>
<td>LOW (1)</td>
</tr>
<tr>
<td>Stakeholder Acceptance</td>
<td>MODERATE (2)</td>
<td>LOW (1)</td>
</tr>
<tr>
<td>Ease of Implementation</td>
<td>HIGH (3)</td>
<td>MODERATE/HIGH (2.5)</td>
</tr>
<tr>
<td>Total</td>
<td>9</td>
<td>9.5</td>
</tr>
</tbody>
</table>

### 8.2.2. Psychological well-being of children

The most common rationale for surgery is promoting psychological well-being through positive body image and reduced social stigma, but research does not show that early surgery yields better outcomes for individuals over the long term. For those who would ultimately request surgery as a teen or adult, it is unclear what the implications of ‘having to wait’ for surgery are. To reflect potential variability in the estimations used in the analysis, a score range is included in the analysis matrix, and the average score of that range is used.
In a best-case scenario, the **status quo** is expected to generate *moderate to high* overall psychological well-being. Proponents argue that for some children, surgery done early can shield them from distress around the surgical event itself, and reduce potential distress associated with atypical genitalia during childhood. Given the assumption that some would continue to receive surgery that they would not otherwise choose, the best-case score for the status quo is expected to fall at the lower end of the range. In a worst-case scenario, the status quo is expected to rank as *low to moderate* due to higher rates of surgeries to address complications, and higher rates of dissatisfaction with surgical results.

In a best-case scenario, a **moratorium** is expected to generate *moderate* overall psychological well-being. In a worst-case scenario, it is expected to generate *moderate to high* overall psychological well-being. It is generally expected that a moratorium performs better than the status quo due to its ability to lower the risk of wrong gender assignment, which is considered to be among the worst possible scenarios due to irreversibility and severity of impact. Furthermore, a moratorium reduces risks to sexual function for individuals who would not elect to have surgery.

**Table 7. Excerpts from criteria analysis, overall psychological well-being**

<table>
<thead>
<tr>
<th>Early Surgery: Worst Case</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Objective</td>
<td>Status Quo</td>
</tr>
<tr>
<td>Psychological well-being</td>
<td>LOW-MODERATE (3)</td>
<td>MODERATE-HIGH (5)</td>
</tr>
<tr>
<td></td>
<td>(Range: 2-4)</td>
<td>(Range: 4-6)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Early Surgery: Best Case</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Objective</td>
<td>Status Quo</td>
</tr>
<tr>
<td>Psychological well-being</td>
<td>MODERATE-HIGH (4.5)</td>
<td>MODERATE (4)</td>
</tr>
<tr>
<td></td>
<td>(Range: 4-5)</td>
<td>(Range: 3-5)</td>
</tr>
</tbody>
</table>

Researchers say that the majority of women with atypical genitalia will want surgery before they engage in sexual activity, but there is "little evidence to support any
benefits of such surgery during childhood."150 Delaying irreversible decisions about reconstructive surgery can prevent the child from experiencing surgical complications in childhood, and incorporating patient consent means that individuals can consider tradeoffs for themselves.151 The extent to which genital surgery impacts sexual function and emotional well-being depends on the personal feelings of the individual, surgical results, and social environment/support.

Surgically enforcing a feminine or masculine genital configuration can lead children to experience distress and resentment when they realize their gender was imposed.152 Genital surgery has been linked to depression and other mental health challenges.153 On top of an increased risk of suicide, research has found that people with intersex variations most commonly report mental health diagnoses of depression, anxiety and PTSD.154 The process of genital examinations is described in literature as particularly distressing for people with atypical genitalia, and despite the fact that they seem to be minimized as much as possible these days,155 increased surgeries at a young age and potential complications necessitate an increased need for genital exams.

Research reflecting surgeries done during the 1980s and 1990s (Table 8) show significant levels of dissatisfaction across the board, with those assigned female having particularly high levels of dissatisfaction with functional results (47%) and cosmetic results (15%). Some women who have undergone feminizing surgeries worry about whether or not partners can tell,156 and a common fear among feminized XY women is getting hurt during sex (56-70%).157

151 ibid.
152 Morgan Holmes. Intersex: A Perilous Difference. (Susquehanna University Press. 2008.)
155 Interview #4
156 Krege et al., "Long-term Follow-up of Female Patients with Congenital Adrenal Hyperplasia from 21-hydroxylase Deficiency, with Special Emphasis on the Results of Vaginoplasty." BJU International 86, no. 3 (2000): 253-8.
157 Köhler et al., “Satisfaction with Genital Surgery and Sexual Life of Adults with XY DSD."
Table 8. Satisfaction with cosmetic and functional surgical result (XY adults)

<table>
<thead>
<tr>
<th></th>
<th>Assigned Female</th>
<th>Assigned Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cosmetic</td>
<td>Good/very good</td>
<td>Dissatisfied/very dissatisfied</td>
</tr>
<tr>
<td></td>
<td>50</td>
<td>70</td>
</tr>
<tr>
<td></td>
<td>35</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>15</td>
<td>20</td>
</tr>
<tr>
<td>Functional</td>
<td>Moderate</td>
<td>Dissatisfied/very dissatisfied</td>
</tr>
<tr>
<td></td>
<td>29.4</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td>23.5</td>
<td>40</td>
</tr>
<tr>
<td>Cosmetic</td>
<td>Dissatisfied/very dissatisfied</td>
<td></td>
</tr>
<tr>
<td></td>
<td>47.1</td>
<td>20</td>
</tr>
<tr>
<td>Functional</td>
<td>Moderate</td>
<td>Dissatisfied/very dissatisfied</td>
</tr>
<tr>
<td></td>
<td>40</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>40</td>
<td>10</td>
</tr>
</tbody>
</table>

Source: Köhler et al. (2012)

It is important to acknowledge that data showing dissatisfaction with surgical outcomes does not necessarily indicate that individuals regret that surgery was done, nor can it show how these individuals would have assessed satisfaction with their genitalia if they had not had surgery. It is expected that no single approach to surgical decision-making will lead to satisfaction across all individuals. There will be some individuals who express dissatisfaction with surgical outcomes, and while some do indicate regret that surgery was done, it is also possible that some who express dissatisfaction with their results may still believe that early surgery was the right decision for them. On the other hand, some who are satisfied with surgical results may feel that early surgery was not the best choice for them and/or that they would have been happy with their natural genitalia.

It is often assumed that because an estimated ninety-five percent of children with CAH identify as female, surgically assigning the wrong gender is at risk of happening five percent of the time. It can be argued that this number is too low, if we consider the
fact that genetic females are more likely to get surgery if they are more heavily virilized, and that current guidelines recommend raising such children as boys when possible and suggest a higher likelihood of male gender identity in such children. If more heavily virilized children are less likely to identify as female and more likely to undergo feminizing surgery, it is logical to suggest that risks of assigning the wrong gender are higher than five percent when surgery does actually happen.

A moratorium that targets Partial Androgen Insensitivity Syndrome (PAIS) would only limit elective surgery for a very small portion of the affected population (estimated 3.5%). It is expected that this would have positive psychological impacts for those affected, but given the small size of the group and lack of clarity around current practices, it is difficult to estimate what actual impact would occur from this policy change. It may be that the spirit of this policy is informally in place and that this policy would be redundant, as it was indicated by one physician that surgeries for PAIS children are not done before puberty.

Implementing New Psychological Supports

Parents experience high levels of distress due to uncertainty around surgery and how to maintain privacy around a child’s DSD – these concerns are ideally attended to by a behavioural health professional. Increased psychological support and enhanced education is expected to improve parental coping skills and have some ability to support parents’ willingness to delay surgery. The rationale is that if parents are better able to cope with the realities of their child’s DSD, they will be more able to accept the idea of waiting until the child is older. Each of these outcomes has the potential to support the child’s long-term psychological well-being.

Literature on suicidality among gender minorities shows the importance of positive social environments and social support networks in promoting well-being and mitigating suicidality. In general, gender minorities are two to three times more likely to experience suicidality. Data from the largest Canadian study looking at social determinants of health among at the trans population found that sixty-seven percent had

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158 Lee et al., “Global DSD Update since 2006.”
159 Crissman et al., “Children with DSD: A Qualitative Study of Early Parental Experience.”
161 Ibid.
attempted suicide by the age of nineteen; the most obvious mitigating factor for those surveyed was the presence of a parent or parents who were very supportive. 

8.2.3. Physical health and safety of children

The key physical risk that drives parents to pursue early surgery is the concern that surgical outcomes may not be as good when the child is older, either because surgeons do not have as much experience, or the fact that infant's tissue is particularly good at healing. Others suggest that certain outcomes, such as vaginoplasty, may be better once the child and genitalia has more fully grown. We do not definitively know the timing when physical outcomes of surgeries are optimal. This analysis does not judge earlier or later timing to be ideal, and both best and worst-case scenarios use the same estimates of surgical complication. Given the high rates of reoperation for vaginoplasty (which is part of the constructed scenario) both the status quo and a moratorium are ranked as low on physical health and safety in all scenarios.

Even if some surgeries have slightly better surgical outcomes in early life, we expect in all scenarios that some individuals would not choose surgery in the first place, and would experience increased physical safety as a result of a moratorium compared to the status quo. These considerations have not been factored into the physical health and safety assessment due to lack of data.

Research has shown that ninety percent of cosmetic surgeries are feminizing and surgical guidelines state that women are phenotypically easier to create than men. For this reason, this study focuses on these procedures as they reflect the largest evidence base of relevant surgical outcomes. Table 9 outlines the physical risks and benefits of three of the most commonly discussed feminizing procedures.

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164 Holmes, *Intersex: A Perilous Difference.*
<table>
<thead>
<tr>
<th>Procedure</th>
<th>Risks</th>
<th>Benefits</th>
<th>DSD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clitoroplasty</td>
<td>- Loss of sexual sensation/function</td>
<td>- No physical advantages</td>
<td>CAH PAIS MGD &amp; others</td>
</tr>
<tr>
<td>Removal of clitoral tissue to reduce size</td>
<td>- Scarring, pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Loss of healthy sexual tissue</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Cosmetic outcomes may change over time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vaginoplasty</td>
<td>- Vaginal stenosis (50%+ of time)</td>
<td>- May provide ability to have penetrative intercourse</td>
<td>CAH PAIS MGD &amp; others</td>
</tr>
<tr>
<td>Surgery on the vagina; usually to lengthen and/or widen</td>
<td>- Possible block of menstrual flow, necessitating surgery</td>
<td>- May facilitate natural fertility</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Incontinence</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Dilation usually required for maintenance, which requires readiness/motivation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gonadectomy</td>
<td>- Loss of self-produced hormones; need to take lifelong supplement</td>
<td>- Prevent masculinizing puberty</td>
<td>PAIS MGD &amp; others</td>
</tr>
<tr>
<td>Removal of internal or external gonads (testes, ovotestes, ovaries)</td>
<td>- Loss of potential fertility via assisted reproductive technology</td>
<td>- Eliminates risk of malignancy in gonads Risk varies: 175 o 15-50% risk in PAIS o 15-35% risk in MGD o &lt;3% risk in other DSD</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Possible increased risk of osteoporosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Some women have reported lower libido</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

There is evidence that women who have had genital surgery are more likely to struggle with sexual function compared to those who have not. Repeated surgeries are associated with higher levels of complication and limit the success of future surgeries by creating scar tissue. Revision surgery to address vaginal stenosis is

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166 Michala and Creighton, “Complications of female genital surgery and DSD I.”
167 Karkasiz, Fixing Sex, 173.
168 Ibid.
169 Ibid.
170 Ibid.
174 Ibid.
175 Lee et al., “Consensus Statement on Management of Intersex Disorders.”
176 Krecev et al., “Long-term Follow-up of Female Patients with Congenital Adrenal Hyperplasia.”
178 Michala and Creighton, “Complications of female genital surgery and DSD I.”
necessary in the majority of children who undergo early vaginoplasty. Repeated stenosis, which is a narrowing and/or loss of flexibility in the vagina, and impaired sensation of the clitoris are both correlated with lower levels of sexual satisfaction. For a sample of relevant surgical outcome data, see Appendix F. Research has shown that people who have undergone early feminizing surgery are approximately half as likely to be satisfied with their overall sex life compared to controls without DSD, however, this finding is weakened by the absence of a non-surgical DSD control group, as one may expect certain DSD to be associated with decreased sexual satisfaction.

8.2.4. Acceptance Among Stakeholders

People with intersex variations

People with intersex variations are expected to be in support of the Call for Evidence, which is designed to facilitate a consultation process and increased transparency of practices in Canada. A similar positive reaction is expected in response to a commission of inquiry into current practices associated with early surgeries. Each of these actions provides recognition of the intersex community by the government, and signals openness to providing further support. In order to ensure a certain level of accountability and stakeholder representation, it is essential that people with intersex variations be meaningfully involved in the Call for Evidence process and the commission of inquiry from the outset. The change of management strategy for education and surgical decision-making increases support for families and is expected to improve overall sharing of information. This being said, it is expected that a significant number of people with DSD or who identify as intersex will feel that this option does not go far enough in terms of protecting children’s health.

A partial moratorium may be viewed in different ways. It may be seen as a failure for only limiting surgeries on a very small portion of the target population; it may also be viewed positively, as this option would promote awareness and give some legislative precedent to intersex rights in Canada. It is expected that a full moratorium would bring mixed reaction, but that a significant proportion would strongly support a full moratorium. Internationally and in Canada, the intersex advocacy community has made clear its goal

178 Ibid.
179 Ibid.
180 Köhler et al., “Satisfaction with Genital Surgery and Sexual Life of Adults with XY DSD”
to see a moratorium implemented. While is difficult to judge the representativeness of research that shows some are for and others are against early surgery, one of the most highly referenced studies shows that among a group who had received surgery forty-seven percent thought surgery should happen in infancy versus twenty-four percent that thought it should not happen before adolescence and twenty-two percent said it should not happen before adulthood.182

Parents

The role of parents in shaping the child’s life is paramount. As a result, it is essential to consider the impacts on, and experiences of parents in DSD management. Research shows that parents find it highly stressful to manage uncertainty around the child’s diagnosis and optimal management, and disclosure of the child’s difference to others.183 Parents may also worry about managing medication.184 Some may feel guilty about the child’s condition, fearing that they caused it, and some may worry that they will struggle to accept and love their child as they are, though there is scant evidence to prove the latter point.185 In fact, research has shown that multiple surgeries, genital exams and complications can negatively impact the parent-child relationship.187

One author writes that “combined pressures…often meld sadness, phobia, shame, worry, frustration, anger, and fear, create unique stressors for parents…”188 Some parents have reported marital stress and divorce as a result of the DSD diagnosis and some have indicated that surgery provided psychological relief.189 In literature and interviews conducted for this study, clinicians have noted that some parents do not think they can handle delaying surgery until the child can be involved. In a study that looked at parent’s experiences, one mother said:

183 Crissman et al., "Children with DSD: A Qualitative Study of Early Parental Experience"
185 Karkasiz, Fixing Sex, 180.
186 Lee et al., “Consensus Statement on Management of Intersex Disorders.”
187 Feder, Making Sense of Intersex.
188 Karkasiz, Fixing Sex, 180.
189 Ibid.
190 Interview #2; Interview #4
'You reach a point where you think...Let’s just get this over with for all of us.' I could wait, but I will admit I thought, ‘My gosh, that’s years of worry for me, of thinking, “What if?” ’ Two to four o’clock in the morning are the longest hours of the day; you worry about ridiculous things in those hours: ‘What if she goes on a field trip and she falls and they somehow see her genitals? Are they going to know?’191

Narrative studies have been conducted among parents and children with intersex variations to understand their experiences around decision-making.192 There are parents who stand by their decision to consent to surgery, there are some who are glad they said no, and there are some who have expressed profound regret due to harm caused by the surgery.193 Among parents of children who underwent surgery for hypospadias, one study found that 8.6% of parents had strong regret, and forty-one percent of parents said they had mild regret (somewhere between 1-25% out of 100%).194 Regret is correlated with physical complications, but also can occur in their absence.195

It is expected that the vast majority of parents would support an enhanced education and decision-making model. Parents would still speak to the hospital specialists, but would now be required to at the very least, have a mental health professional present when being told and educated about the diagnosis. This change is expected to increase parents’ understanding of treatment implications, and would be naturally supportive of parents who are unsure and considering delaying surgery.

It is expected that many parents (not just parents of children with DSD) will be highly resistant to limits to medical options, and will oppose a full moratorium. However, not all parents support early surgery.196 Some see delaying surgical decisions as preserving the child’s options. As human rights for gender-diverse people become more diffused globally, it is possible that parents will become more likely to delay surgical decisions. While parents are expected to resist any limits to their parental rights, it is

191 Karkasiz, Fixing Sex, 204.
195 Streuli et al., “Shaping Parents.”
196 Karkasiz, Fixing Sex, 206.
possible that some proportion may be relieved to not have to make such a major
decision so early in their child’s life. It is believed that the majority of parents would
support a moratorium on early surgeries in PAIS, based on the high risk of wrong gender
assignment, and the fact that PAIS surgeries are already more likely to be delayed until
after puberty.197

**Physicians** This group refers to the doctors in the hospital setting who typically provide
care for parents and children (endocrinologists, urologists, etc.)

It is expected that a majority of physicians will be in support of the introduction of
a new education and support guidelines, as they will increase support for families, add
strength to the decision-making process, and likely lighten the pressure on doctors to
provide certainty to parents. However, there will likely be some opposition, for example,
as a result of conflict with the new approach, or perceived loss of authority.

Physicians will oppose a complete surgical moratorium.198 A moratorium is seen
as excessively limiting current practices and would introduce the threat of criminal or
other charges. The threat of legal or regulatory sanction is strong enough that physicians
will be deterred from performing surgery, and may have the unintended consequence of
creating reluctance among some doctors to work with DSD for fear of litigation following
surgery. Urologists opposing a proposed surgery ban in California indicated concern
about potential litigation, specifically because a minor’s ability to consent is often
dependent on a doctor’s interpretation.199 One doctor commented on surgeries that
some might say fall in a grey area between elective and medically necessary:

[S]omebody can say ‘okay well that’s illegal’...when we’re for instance,
relieving a little kid from having urinary infections over and over and it
becomes a bit of a fine line. Is this really more about cosmetics, is this
really more about letting them pee without getting infection all the
time...you’re always worried if something’s illegal that you can never ever
do it...200

This statement points to the need for consultation with experts in setting restrictions on
early surgery. As another interviewee pointed out, surgical success varies by procedure

197 Interview #4
198 Interview #2
199 Gutierrez, “Calif. Considers ban on genital surgery on intersex children.”
200 Interview #2
and whether or not a surgery is allowed should be based on the risks involved, and how good the surgical outcomes are.\textsuperscript{201}

A group of thirty-two surgeons surveyed in the most recent international consensus statement on DSD patient care did not generally agree on protocols related to timing, procedure or outcome evaluation for DSD.\textsuperscript{202} Furthermore, a 2016 systematic review of health research for people with DSD/intersex variations found that forty-four percent of the articles viewed early surgeries as being potentially problematic and thirty-one percent viewed intervention as unproblematic,\textsuperscript{203} suggesting that there may be growing willingness to adopt restrictions around early elective surgeries. In particular, it is expected that a high number of physicians would support a moratorium on early surgery in PAIS due to the narrow scope and rationale. With respect to a full moratorium for all DSD, it is expected that a small portion of physicians will be in support, but may not openly share that opinion. Some have publicly opposed early surgeries internationally,\textsuperscript{204} and it is possible that there are physicians in Canada against early surgery but fear the risk of professional repercussions of speaking out.

### 8.2.5. Implementation Complexity

A Call for Evidence and an investigative commission of inquiry would be administered at the federal level. The results of the Call for Evidence would be used to inform new psychological support guidelines for care and potential future restrictions on elective surgeries. Guidelines should be finalized at the national level, but given that they would be implemented at the provincial and territorial level, it is appropriate for jurisdictions to make appropriate adjustments, such as how many staff to train initially.

A key implementation challenge is training workers to provide specialized behavioural health support to families and children with intersex variations. It is essential that social workers, psychologists, or other behavioural health providers working with families are highly trained and knowledgeable about DSD. Given the small number of children who are born annually with intersex variations, the workforce can be modest.

\textsuperscript{201} Interview #6
\textsuperscript{202} Lee et al., “Global DSD Update since 2006.”
\textsuperscript{203} Tiffany Jones, "Intersex Studies: A Systematic Review of International Health Literature." \textit{SAGE Open} 8, no 2. (May 2018).
\textsuperscript{204} Elders et al., “Re-Thinking Genital Surgeries on Intersex Infants.”
Training two specialists in each province or territory could have a significant impact. Over time, the goal would be to expand the number of specialized workers. Given the increased workload introduced by initial training requirements and general increased support for families, it may be necessary to hire one or two additional workers per province/territory.

It is recommended that implementation of a moratorium be done using option (1) below, but there are ultimately two avenues that could be pursued:

(1) The provincial and territorial governments could implement a moratorium by mandating a change in practice to the regulatory authority in that jurisdiction. In the provinces, it is the Royal Colleges of Physicians and Surgeons. In Nunavut and the Northwest Territories, it is the Department of Health/Social Services, and the Medical Council in Yukon. Implementation is likely to be met with strong resistance from the medical community but implementation at the provincial and territorial level will allow for increased flexibility and negotiation of a moratorium framework.

(2) The federal government could amend Section 268(a) of the Criminal Code to ban early elective surgeries. Administratively, this would be the easiest option to implement, but is expected to face even stronger resistance from the medical community and the public due to the threat of criminalization.

Discussion: Political Feasibility of a Moratorium

Two stakeholder groups are expected to voice strong resistance to a moratorium policy: pediatric surgeons and parents. In addition to parents of children with intersex variations, it is likely that a contingency within the general public, including other parents, and potential parents will argue for the parental right to consent to early surgeries. Given the fact that many parents continue to insist on surgery despite encouragement to delay, it is clear that many feel that they should have the right to decide on surgery. On the same note, parents and physicians may be concerned that restrictions on surgery in DSD would set legal precedent to limit parents’ rights in other healthcare decisions.

If early genital surgeries were banned, it would be difficult to avoid similar debates about parental ability to consent to male circumcision, which continues to be a
common practice in Canada despite some concern from the medical community about risks. However, male circumcision and surgeries done to feminize or masculinize the genitalia are not analogous comparisons. Circumcision is markedly less invasive than surgery that a child with an intersex variation would undergo. While both can be described as irreversible procedures and have been associated with reduced sexual sensation, circumcision involves the removal of foreskin, whereas the least invasive surgeries for children with DSD involve relocation of the urethra (distal hypospadias repair), and removal of erectile tissue (clitoral reduction). While it is possible that a moratorium could face insurmountable resistance from parents and doctors, it is anticipated that a moratorium implemented at the provincial and territorial level may be politically feasible given the unique nature of, and risks associated with early surgeries among children with intersex variations.

Chapter 9.

Recommendations

*These recommendations are provided as a starting point for policymakers, and should only be implemented following comprehensive consultation with affected communities.*

**Step 1: Implement Call for Evidence and Commission of Inquiry**

The first step Canada should take is a consultation process intended primarily to clarify existing practices across the country, and solicit feedback from Canadians with lived experience. This action would seek to identify problem areas and improve health resources for this population, it would support network building, and it would contribute to raising awareness. At the same time, the government should launch a commission of inquiry with respect to current practices in Canada associated with early elective genital surgeries. Both actions should prioritize inclusion of those with lived experience throughout the process, and once finalized, summary reports should be shared publicly.

**Step 2: Introduce Psychological Guidelines and Moratorium on Early Elective Surgeries in Children with Partial Androgen Insensitivity Syndrome**

There is no question that parents of children with atypical genitalia often face distress and find decision-making difficult; understandably so, as some of the best evidence states that we do not have good long-term data on which to base decisions. This lack of evidence gives rise to a need for strategies to promote informed decision-making. Introducing psychological support guidelines would promote more comprehensive and holistic discussions of the implications of different treatment options.

Following the commission of inquiry, it is recommended that a moratorium on early genital surgeries for PAIS be introduced at the provincial/territorial level. It is expected that introducing limitations on medical practices will face opposition from physician groups and some parents. Delaying implementation for up to two years during the commission process provides time for the provincial regulatory authorities to adapt to the moratorium mandate. Depending on the findings of the commission, it is expected that additional restrictions on early surgeries will be considered.

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206 Sandberg et al., “Decision Making in DSD.”
Chapter 10.

Conclusion

In the early 1990s, the international intersex movement began to speak out against the practice of normalizing genital surgeries. First-hand accounts and studies started to surface showing long-term physical and emotional harm, and by the late 1990s, multidisciplinary teams of specialists were appearing in Canadian hospitals to improve the standard of care for children with DSD. Two decades later, it is unclear how well multidisciplinary teams in Canada are working. Specialists with training in behavioural health support are often deemed essential to these teams in the literature and by health professionals, but in practice it is not clear that these experts are consistently integrated into multidisciplinary teams and decision-making processes.

A decision of whether or not to do early elective surgery is influenced by information provided by the healthcare team and the views of the parents. Healthcare providers are responsible for providing adequate education about the condition and discussing clinical management options. Many parents look to medical providers for certainty in the face of something they likely have not heard of before and have difficulty understanding. In some cases, parents insist on surgical intervention despite recommendations to defer decision-making until the child is older. The prospect of “doing nothing” and waiting can be challenging for parents who worry that their decision will make the child’s life harder as they age.

Medical policies pertaining to transgender Canadians dictate that before anyone undergoes surgery, that person must undergo one, if not multiple psychological evaluations in order to determine their readiness to make such an important decision. These rules are designed as protections against risk, and to provide better outcomes. This same principle has reasonable applicability to children with intersex variations. While parents may have multiple meetings with doctors before making a surgical decision, evaluation by a behavioural health professional is not an explicit requirement.

At present, there is an absence of literature specific to the medical management of intersex variations in the Canadian context. This study contributes to the literature in
this area by providing insights from a variety of individuals with relevant expertise, including Canadian healthcare providers, academics, and the Canadian advocacy community. The analysis exercises presented in this Chapter 8 have generated useful discussion tools, including a summary assessment of key risks associated with surgical and non-surgical treatment pathways. The use of best and worst-case scenarios may be helpful for fostering discussion among policymakers, but does not serve as a comprehensive assessment of the status quo or a moratorium.

Two key areas for future research were identified by this project. First, there is a need to better understand the healthcare needs of people with intersex variations throughout their lives, including improving our understanding of the implications of growing up with unaltered intersex variations. Second, there is a need to better understand the long-term psychological and physical impacts of elective surgeries in infancy and early childhood.

The precautionary principle states that where there are risks of serious or irreversible threats to human health, “scientific uncertainty should not be used as a reason to postpone preventive measures.” The psychological needs of parents and children with intersex variations have often been neglected on the assumption that surgical treatment will address emotional and socially related issues the family might face. In light of evidentiary uncertainty and the serious risks posed by early genital surgeries, there is a clear need to take action to improve our understanding of and support for the health needs of Canadians with intersex variations.

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References


Commonwealth of Australia, “Community Affairs References Committee: Involuntary or coerced sterilisation of intersex people in Australia,” Canberra: Community Affairs References Committee; 2013.


Dreger, Alice. “Intersex Rights.” Published online April 2017: https://aeon.co/essays/people-born-intersex-have-a-right-to-genital-integrity.


Appendix A.

Selection of Interview Questions

General themes

- Background and current policies in Canada
- Filling gaps in research
- Characteristics of successful health interventions for children identified with atypical genitalia at birth
- Views on suggested policy options

Questions

1. Can you describe the extent and variety of your experience working with/supporting people with intersex variations?

2. What is your understanding of standard medical practice when caring for infants and children in Canada who are identified with atypical genitalia?

3. What is your perspective on how infants with atypical genitalia should be treated?

4. Are you aware of any Canada-wide efforts to disseminate best practices for treating intersex infants born with atypical genitalia?

5. In what instances should parents be able to and/or not be able to consent to surgery on behalf of their children?

6. Under the Criminal Code of Canada, genital “normalizing” surgery is exempted from the definition of aggravated sexual assault (S. 268.3.a) – what do you think of efforts to repeal this exception in the criminal code, seen by some advocates as a protection for those in the intersex community?
Appendix B.

Common Feminizing Surgeries

**Vaginoplasty** involves the surgical creation, or reshaping of a vagina. Research emphasizes the crucial importance of having an expert surgeon in order to get better outcomes and minimize the need for repeat surgeries.\(^{208}\) Timing of these surgeries in children is particularly controversial.\(^ {209}\) Some doctors and researchers argue against vaginoplasty for children before puberty on the basis of a complication rate above fifty percent when done in young children,\(^ {210}\) frequent needed follow-up surgery, and the typical need to perform self-dilation to maintain shape. Others make the case that existing teams have greater levels of experience and outcomes may be worse if children wait and get a surgeon who is not as good.\(^ {211}\) If the child receives surgery for something else, (e.g. a cosmetic issue or a urinary issue) doctors may recommend doing procedures together, or within a close timeframe. Some doctors who generally believe vaginoplasty should be postponed until after puberty believe that complication risks are worth taking earlier in childhood when the child has atypical genitalia.\(^ {212}\)

**Clitoral reduction** involves the surgical removal of parts of the clitoris or micropenis. The only known purpose of the clitoris is sexual pleasure.\(^ {213}\) There are still things we do not know about how different parts of it contribute to a person’s sexual sensitivity, ability to get aroused and orgasm.\(^ {214}\) A study of women with CAH who had undergone feminizing surgery in the 1980s found decreased clitoral and vaginal sensitivity among women who had undergone feminizing surgery in childhood compared with controls;\(^ {215}\) those who had not undergone surgery had sensitivity results similar to controls.

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\(^ {209}\) Krege et al., “Long-term Follow-up of Female Patients with Congenital Adrenal Hyperplasia.”

\(^ {210}\) Michala and Creighton, “Complications of female genital surgery and DSD I”

\(^ {211}\) Ling Lean et al., “Cosmetic and anatomic outcomes after feminizing surgery.”


\(^ {214}\) Minto et al., “The effect of clitoral surgery on sexual outcome.”

Gonadectomy involves removal of internal gonads – usually testes, but can refer to streak gonads, ovaries, or ovotestes. Health professionals interviewed indicated that decisions around removal are mainly based on whether or not there is a high risk of malignancy, though specific thresholds were not indicated. Gonadectomy is also done in order to avoid development of certain sex characteristics at puberty depending on the gender of rearing. Risk of cancer in internal gonads for many DSD is under three percent.216

Gonadectomy is described as standard practice in patients with PAIS, given that malignancy rates are estimated to be as high as fifty percent.217 This is clearly a risk to the patient, but may not categorically mean that a diagnosed child’s gonads should be removed immediately. Malignancy risk varies by case and it may be possible that a child can be monitored for cancer, and may wish to retain the gonads for some period of time in order to allow for a natural puberty, or other personal reasons. Whether or not this surgery should occur should depend on the cancer risk, and options to delay surgery and monitor the gonads should always be offered to the parents and patient when possible/when surgery is not needed with urgency.

216 Lee et al., “Consensus Statement on Management of Intersex Disorders.”
217 Ibid.
Appendix D.

Jurisdictional Scan

Australia

Australia uses a parental consent model in line with the Canadian approach. Australian medical practice embraces the same clinical guidelines that are used in Canada and the United States.\textsuperscript{218} It is not clear, however, how often surgeries are carried out. A distinguishing factor noted in the Australian context is the fact that the Family Court system have been involved in the approval of a small number of intersex surgeries. It is not entirely clear what the threshold is for the court to be involved, but surgery that will sterilize a child that is not done to address disease or malfunction is one indicator.\textsuperscript{219}

In 2013, an Australian Senate committee published a first-ever parliamentary report on the Involuntary or coerced sterilization of intersex people in the country. In the same year, federal anti-discrimination laws were amended to include intersex individuals as a protected identity. Despite recommendations from the committee to delay early surgery until the individual can provide informed consent, no obvious substantive policy changes have been enacted.

Australia appears to have a highly developed intersex support and advocacy community relative to Canada, which has been in existence since the late 1980s. In response to calls from the well-established advocacy community in Australia, the United Nations has asked the Australian medical community to report on the frequency of such surgeries nationally.\textsuperscript{220} Academic research from Australia has established some of the most comprehensive knowledge on the intersex community anywhere in the world. For example, a 2016 publication represents the most in-depth national-level study found

\begin{footnotesize}
\begin{itemize}
\item \textsuperscript{218} Namely, the 2006 Consensus Statement by Lee et al.; Confirmed by Commonwealth of Australia. “Involuntary or coerced sterilisation of intersex people in Australia.”
\item \textsuperscript{220} Alice Dreger, “Intersex Rights,” published online April 2017. https://aeon.co/essays/people-born-intersex-have-a-right-to-genital-integrity.
\end{itemize}
\end{footnotesize}
throughout the research process. \(^{221}\)

**Malta**

Malta is currently the only country in the world where early elective surgeries are banned (in force as of 2015). The underlying rationale of the policy is that elective procedures should only be done at the request of the affected individual when they have the cognitive capacity to consent, though no specific age threshold is specified for when a child is able to decide. Under the same Act, Malta began to allow people eighteen years of age or older who are transgender to change their gender marker without state or medical intervention. \(^{222}\)

Within a year of criminalizing early surgeries, Malta also introduced new education policy for trans, gender variant and intersex kids. A policy document outlines measures to improve inclusivity in schools, including guidelines for protecting of children's privacy, and counseling resources. \(^{223}\) A procedures document “addresses how schools should respond when a trans, gender variant or intersex student comes out or transitions and asks schools to implement detailed school support management and student transition management plans.” \(^{224}\) An additional policy measure for inmates in correctional facilities provides accommodations for trans inmates to reside in separate facilities, access gender affirming procedures and various supportive health services. \(^{225}\)

**United States**

The United States broadly embraces the same policy guidelines \(^{226}\) used in Canada and Australia, which endorse a parental-consent approach for early surgeries. The US does not systematically collect information about the frequency of intersex surgeries, and it is


\(^{223}\) Cassar, “Malta and LGBTQ equality, one year on.”

\(^{224}\) Ibid.

\(^{225}\) Ibid.

\(^{226}\) Lee et al., “Consensus Statement on Management of Intersex Disorders.”
not clear how often such procedures are done. In 2018, the state of California passed a resolution to condemn genital normalizing surgeries and is as of the time of this publication (April 2019) is in the process of considering legislation. In terms of gender diversity recognition, only eleven states currently recognize a third gender category on identification (with most of these recognitions occurring since 2017). While this is indicative of a more socially conservative climate compared to Canada and Australia who recognize a third gender at the federal level, it is impossible to say with certainty if surgeries happen more often in the U.S. A 2017 court case involving a five-year old boy who was surgically assigned female at birth and had his gonads removed has set precedent after being awarded nearly half a million dollars for failing to obtain informed consent.

In 2017, three former US Surgeon Generals published a paper urging a moratorium based on the significant psychological and physical risks associated, and a lack of evidence that growing up with atypical genitalia leads to psychosocial distress or that individuals are better off if they undergo early surgery. Other US-based groups calling for an end to early elective surgeries include the American Medical Association board of trustees, Physicians for Human Rights, and the American Medical Student Association, which represents approximately 68,000 medical students in the US and Canada. A strong advocacy community has been based out of the US, including InterACT a legal advocacy organization and the now-closed Intersex Society of North America – which was the first North American intersex support and advocacy group.

227 Human Rights Watch, "I want to be like nature made me."
229 M.C. Crawford vs. Aaronson
230 Elders et al. “Re-Thinking Genital Surgeries on Intersex Infants.”
## Appendix E.

### Criteria and Measures Weighting Framework

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Weight</th>
<th>Measure</th>
<th>Measurement scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological well-being</td>
<td>2</td>
<td>Estimated level of overall well-being</td>
<td>High = (3) Moderate = (2) Low = (1)</td>
</tr>
<tr>
<td>Physical health and safety</td>
<td>1</td>
<td>Complication rates (vary by procedure; 10-50%)</td>
<td>&lt;15% = High (3) 15-30% = Moderate (2) &gt;30% = Low (1)</td>
</tr>
<tr>
<td>Support from people with intersex variations</td>
<td>1</td>
<td>The extent to which people with intersex variations, parents and physicians support the option</td>
<td>General support among: All stakeholders = High (3) 2/3 stakeholders = Moderate (2) 1/3 stakeholders = Low (1)</td>
</tr>
<tr>
<td>Support from Parents</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support from Physicians</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ease of Implementation</td>
<td>1</td>
<td>Minimization of administrative burden</td>
<td>High = (3) Moderate = (2) Low = (1)</td>
</tr>
</tbody>
</table>
Appendix F.

Sample of Surgical Outcomes, Feminizing Genitoplasty

<table>
<thead>
<tr>
<th>Author</th>
<th>N=</th>
<th>Mean age at first surgery</th>
<th>Age range: first surgery</th>
<th>Complication rate requiring re-operation</th>
<th>Total surgeries when re-operation needed</th>
<th>Study age range</th>
<th>Mean age</th>
<th>Surgical years</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fagerholm et al.</td>
<td>24</td>
<td>4.5</td>
<td>0.4 to 19.2</td>
<td>43%</td>
<td>3.2</td>
<td>15-36</td>
<td>25</td>
<td>1980-2008</td>
<td>Various vaginal</td>
</tr>
<tr>
<td></td>
<td>19</td>
<td>3.8</td>
<td>0.4-14.3</td>
<td>37%</td>
<td>2.9</td>
<td>15-36</td>
<td>25</td>
<td>1980-2008</td>
<td>Clitoral</td>
</tr>
<tr>
<td>Minto et al.</td>
<td>28</td>
<td>3.5</td>
<td>0.1-42</td>
<td>14%</td>
<td>2.5</td>
<td>18-70</td>
<td>31</td>
<td>1970s-1980s</td>
<td>Clitoral</td>
</tr>
<tr>
<td></td>
<td>18</td>
<td>9.2</td>
<td>1-28</td>
<td>39%</td>
<td>2.3</td>
<td>18-70</td>
<td>31</td>
<td>1970s-1980s</td>
<td>Vaginoplasty</td>
</tr>
<tr>
<td>Krege et al.</td>
<td>27</td>
<td>3.6</td>
<td>1yr-9yrs</td>
<td>N/A</td>
<td>N/A</td>
<td>12-30</td>
<td>N/A</td>
<td>1972-1988</td>
<td>Vaginoplasty</td>
</tr>
<tr>
<td>Ling Lean et al.</td>
<td>32</td>
<td>(N=16) &lt; 2 yrs old</td>
<td>(N=16) &gt; 2 yrs old</td>
<td>38%</td>
<td>N/A</td>
<td>13-33</td>
<td>18.4</td>
<td>Born 1970-1991</td>
<td>Vaginoplasty; Clitoral</td>
</tr>
<tr>
<td>Crouch et al.</td>
<td>15</td>
<td>(13) &lt; 4 years (1) 9 yrs</td>
<td>(1) 16 yrs</td>
<td>73%</td>
<td>2.36</td>
<td>17-39</td>
<td>25.4</td>
<td>~1980s</td>
<td>Clitoral</td>
</tr>
</tbody>
</table>

1 Median age

2 No significant difference found in surgical outcomes between two age sub-groups.
Appendix G.

Concealment vs. Patient-Centred Care

The concealment approach to patient care centers on the idea that atypical genitalia represent a psychosocial emergency that creates distress for children and their families. This model became regular practice in the 1960s, and supports genital surgery in infancy or early childhood to create a more feminine or masculine appearance. Concealment also recommends that patients be told as little as possible about their conditions to minimize distress and gender confusion. One of the most common arguments for elective surgery is that the long-term consequences of growing up with atypical genitalia are not known, and there is a lack of evidence to support the notion that delaying genital surgery will yield better long-term outcomes for the child.

The patient-centered model views intersex conditions as natural variations that do not necessarily need to be altered. It rests on the premise that patients and families should be involved and engaged as members of the healthcare team in decision-making. Patient-centered implies that individuals themselves are fully involved in decisions related to their medical care. Any risks to maintaining highest possible quality of physical health must be consented to by the individual when the risks are not being pursued for a clear medical purpose.

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234 Dreger, “Shifting the Paradigm of Intersex Treatment.
Appendix H.

Interview Schedule

Interview #1: January 19, 2019
Interview #2: January 25, 2019
Interview #3: January 30, 2019
Interview #4: February 7, 2019
Interview #5: February 9, 2019
Interview #6: February 11, 2019
Interview #7: February 28, 2019
Interview #8: March 8, 2019
Interview #9: March 13, 2019