



Restoring Epistemic Justice to a Dismissed Population:

A Qualitative Needs Assessment by and for Intersexualized Adults in Canada

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This study was carried out during COVID-19 measures to use remote technologies, working from my office on the Halidimand Tract, traditional territories of the Neutral, Anishinaabe, Haudenosaunee peoples. My participants spoke to me from regions across different traditional territories and unceded lands across “Canada”. I am grateful to be able to do my work in a position of relative security on these lands and hope for my work to promote greater security of the body for others here and elsewhere.

Glossary

To encourage consistent understandings and developing nuance, this glossary shares and elaborates on the glossary of terms in the [Intersex Rights in Canada: Literature Review](#) (Egale, 2020).

Assigned sex: Sex/assigned sex is the classification of a person as male, female, or intersex based on biological characteristics, including chromosomes, hormones, external genitalia, and reproductive organs. The reason we say assigned sex versus biological sex is to acknowledge that sex is often a value determined by medical professionals and is commonly assigned to newborns based on visual assessment of external genitalia. Inclusion here of the recognized category of “intersex,” frequently overlooked in discussions of sex, serves as a reminder that even at the level of biology, sex is not a binary system.

Complete Androgen Insensitivity Syndrome and Partial Androgen Insensitivity Syndrome (CAIS/ PAIS): CAIS and PAIS belong to a class of intersexualized types in which a person with an XY chromosome profile also expresses a genetically caused interference with the synthesis and metabolization of testosterone. The interference stops the further production of features associated with a male appearance. Persons with complete insensitivity typically receive a female assignment at birth and those with partial insensitivity may end up with a male or a female assignment, depending on where they are born, and what the biases/preferences of the medical team involved are. AIS is one of the easiest forms of “intersex” to diagnose prenatally; as a consequence, it is subject to termination for the elimination of “disorders” in an embryo.

Congenital Adrenal Hyperplasia (CAH): CAH is an umbrella term to describe the bodily expression that can result from a class of distinct enzyme deficiencies that alter metabolic hormone production. As a compensatory effort, the adrenal glands produce more androgens than typical, and in an XX infant/ child there can be an appearance that medicine considers to be “masculinized”. The range of alterations in anatomical appearance is vast, but this group is among the most frequently subjected to “corrective” surgery to produce a more “feminine”

appearance. Such surgeries intended to alter appearance without altering function include but are not limited to reduction of clitoral size, reduction of labia size, and separation of partially fused labia. Like AIS, CAH is easy to diagnose prenatally and is also subject to interventions that range from the use of prenatal dexamethasone to termination for the elimination of “disorders” in an embryo.

Disorders of Sexual Development (DSD): This language is a medicalized term used to describe intersex traits. The term was first found in the Clinician Consensus Statement at the Chicago Consensus Conference (2005), a gathering of international intersex activists and medical professionals and understood as a “milestone of intersex political history.” Intersex activists, advocates, and social researchers reject this term, arguing both that this language was created without the meaningful consultation and inclusion of intersex activists at the consensus events, and further, because framing intersex traits as disorder creates a harmful pathology for intersex people. Pathological categorization is used to justify the normalizing of intersex bodies, leading to further stigma, and medical and social discrimination for intersex people. For a full discussion of the stakes involved in the adoption of DSD language, please refer to Holmes (2011) in the Works Cited.

Evidence-based medicine (EBM): Refers to the implementation research evidence, usually drawn from random control trials, to inform medical decision making by clinicians. Sackett et al. set the foundational definition in 1996 as “the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients”. The term is rather loosely employed and can refer to anything from conducting a statistical meta-analysis of accumulated research, promoting randomized clinical trials, or supporting uniform reporting styles for research to a personal orientation toward critical self-evaluation. Initially, EBM was defined in opposition to clinical experience, but later definitions emphasized its complementary character and aimed to improve clinical experience with better scientific evidence (Sackett et al. 2000).

Informed consent: Informed Consent requires that a decision maker: 1) has capacity to make the decision, 2) is adequately informed, that is, given all relevant information that a reasonable person would require to make a decision, and 3) the resultant decision must be voluntary and free of coercion. In Canada, these requirements were set by the 1980 *Reibl V Hughes* case that determined simple consent to be inadequate for medical interventions, and that meaningful consent had to include the right to refuse.

Intersex/intersexualized: Refers to a person whose chromosomal, hormonal, or anatomical sex characteristics fall outside the conventional classifications of male or female. These biological variations are context-specific, based on how sex categorization is undertaken in a specific time or place, and there are more than 40 different ways that a body may exhibit intersex traits. Physicians may identify intersexuality at birth, where medical practitioners frame intersex traits as a diagnosis requiring correction, while some people may be diagnosed as intersex at puberty or later in life. For these reasons, among others examined in this report, it can be difficult to trace intersexuality across population data.

Note on the use of “intersex” and “intersexualized”:

While many advocates (including the author of this report) regularly use “intersex” as a neutral descriptive term for differences in sex characteristics, this document also aims to underscore that intersex is not transhistorical but is rather the product of a deliberate cultural commitment to binary sex categories and a concomitant medical pathologization of any variation that is *perceived* as “outside of the expected”. The report author uses “intersexualization/intersexualize,” coined by Lena Eckert (2016), to draw attention to intersex as a product of medical power, not a simple expression of biological difference. Recognizing that a person can experience the process of intersexualization without referring to that person as “intersex” avoids essentializing the person but leaves open the possibility for any individual subjected to intersexualization to (re)claim “intersex” as an identity.

Klinefelter Syndrome (KS): Most people with KS are assigned male and have at least one extra X chromosome in the 23rd pair: XXY. Frequently subjected to surgical intervention for hypospadias, boys and men with KS may also be subjected to traumatizing genital exams throughout childhood and may also be subjected to other interventions to “normalize” their appearance.

Lawson-Wilkins Pediatric Endocrinology Society (LAWPES): The primary medical organization that participated in the development of DSD terminology outlined in the Chicago Consortium Statement. Please refer to the [2020 literature review](#) and for more on this document and the development of DSD language.

Intersex genital mutilation: Intersex genital mutilation is the term used across Egale documents to refer to the non-consensual, permanent, “normalizing” surgical interventions on intersex infants and children. Through surgery and drug treatment, the intersex person’s body is mutilated in order to conform to expected and limited categories of ‘male’ and ‘female’ sex characteristics. These interventions are most often medically unnecessary and have negative consequences for intersex people across their lives. This language mirrors that which is used by advocates for intersex rights that work in partnership with Egale.

(to) Pathologize: This concept refers to the expansion of medicine into areas of life that are not unhealthy *per se*, but which medicine sees as undesirable. Neutral differences in experience, perception, mobility, sexual desire, cognition, and so on are transformed from variations into disorders and diseases, subject to assessment and efforts to “cure”. The recent history of the creation of “homosexuality” as a form of “psychiatric disorder” (DSM I, II, III; removed from DSM IV) is a pertinent example for this report. The expansion of medical professions relies on the process of transforming differences into diseases. Another famous example is the creation of pediatrics, a specialty focused on the diseases of childhood, but which was established in the 20th Century only after children had become more likely than ever before to survive into adulthood because of access to better food, nutrition, sanitation, and vaccination. The

pathologization of infancy and childhood in general is also pertinent to this report as the damage done to intersexualized persons is generally carried out under sub-specializations in pediatrics.

2SLGBTQI: Please see Egale’s glossary of terms: [2SLGBTQI Glossary of Terms | Glossaire des termes - Egale](#).

Note:

Morgan Holmes, author of this report, during work as a bioethics consultant in a Canadian children’s hospital, encountered the multidisciplinary team specializing in intersex when it aimed to impose the western diagnostic framework onto the bodies of *some* Indigenous Two Spirit children. Horrified by that colonialist effort, Dr. Holmes counselled the team not to impose a diagnostic framework that would harm a community by introducing a pathologizing view to a neutral variation. Ever cognizant of this threat, this report aims not to impose a White, western framework onto Indigenous cultures. Any impulse to map Two Spiritedness and intersex onto each other should be avoided.¹

¹ For a longer discussion of the fetishizing and colonizing appropriation of Indigenous meaning systems and the imposition of “third gender” ideologies onto both intersexualized and diverse cultures containing non-dyadic gender systems, see Holmes (2008).

Part One: A Qualitative Needs Assessment by and for Intersexualized Adults in Canada

Introduction

Every year in Canada, where we pride ourselves on protecting the rights of children, an unknown number of infants and children too young for capacity to provide consent are subjected to medical interventions that the UN has defined as “medical torture”. Most provinces do not track their numbers, and neither Health Canada nor the Public Health Agency of Canada (PHAC) has access to the numbers. Toronto’s Hospital for Sick Children denied a 2018 Freedom of Information (FOI) request made by the author of this report to access non-identifying records that would show how many “normalizing” genital surgeries had taken place between 2010 and 2015. Only the province of Quebec has released data for the use of these interventions, and the frequency is alarming.²

Why does the intervention happen? The various medical and surgical interferences are carried out to “correct” the bodies of children who receive a diagnosis of a “Disorder of Sexual Development” (DSD), that is, a condition that used to be classified as “intersex” in the literature, until the arrival of the contemporary Intersex Human Rights movement in the 1990’s sought to de-medicalize that framework. In essence, the harms inflicted on this population are carried out to force a child’s anatomical appearance to meet binary expectations for genitals. The rationale for intervention continues to be motivated by heteronormative cisgenderism.

This report assesses the ethical failures of standard treatment in Canada. To do so it draws on qualitative interviews with eight survivors of medicalization completed with a researcher who is also an “embedded subject”, that is, a person who belongs to the same community as those interviewed. The qualitative study marks the first of its kind to be completed in Canada

² The specific data release is addressed beginning on page 14 of this report.

and provides information that is grounded in the unique insights of the only “stakeholders” who should matter, but who have been silenced and marginalized since the current surgical and medical management norms were established in the mid-twentieth century.

The report functions in two distinct sections. The first section introduces readers to the issues in rights claims, research gaps, and the implications for the health and well-being of intersexualized people. The second section speaks to the data acquired from the first qualitative study that is both led and informed by intersexualized persons, for intersexualized persons.

In the fall of 2020, Egale Canada published a literature review on intersex human rights issues that focus on the matter of clinical/surgical approaches to intersex differences, and on the importance of intersex-led, international rights movements (Egale Canada, 2020). A central observation in the report is that intersex persons have no protections under the law in Canada. Because it is not a form of “gender expression,” but is rather a spontaneously arising embodied difference that is read and managed as a medical “problem,” intersex difference is not protected by the 2017 legislative changes in Canada’s *Human Rights Act* that protect gender expression against discrimination.

In Canadian law:

“Gender expression” refers to characteristics that can be either intended or perceived, or both, that communicate the social features of gender. Things like pronoun use, mode of dress, use of make-up, manners of speech, and habits of embodiment that can be understood as “gendered comportment” all fall under “gender expression”. As a matter for human rights, Canada’s passing of Bill C-16 into law means that it is illegal to discriminate against a person based on perceived expression or intended expression of one’s gender. Intended specifically for the protection and recognition of the right of “transgender and other gender-diverse persons [to] live according to their gender identity” (Department of Justice; Government of Canada), this feature of human rights protections in Canada does not address the violations that



are carried out specifically against the bodies of infants and children in order to effect a desired, normative concordance between the surgically altered body and what the medical interdisciplinary team guesses will be the most likely gender to be achieved in maturity.

This report provides readers an opportunity to the needs of intersexualized persons from their own perspectives, to avoid making the common mistake that intersex is just a synonym for “nonbinary” or “non-conforming” gender expression, and so solved by existing human rights legislature.

Introduction to Main Rights Issues and Research Gaps

Those learning about intersex for the first time tend to be curious about the same things over and over again. How common is it? And how often do the surgeries happen?

Although frequencies may be astonishing, frequency in itself is not pertinent to the moral grounds on which human rights are recognized. Human rights are an “absolute category”: their violation is criminal regardless of how rare, and their universality is agreed upon as the entitlement of every person.³ That principle guides efforts around the world to make sure that human rights principles are founded on the view that what harms or impedes the rights of one is a threat of harm or impediment to all. In addition, the recent (Bennecke et al., 2021) publication detailing a survey indicating that 67% of CAH patients surveyed indicating satisfaction with their early childhood interventions misses the crucial point that evidence to show that any given number of people is happy with the outcomes of a procedure cannot provide the ethical or moral grounds for imposing a potential harm on someone else.

Catherine Clune-Taylor, a philosopher who specializes in bioethics, has argued as much in a recent talk that tackled precisely the issue of such misuses of EBM (November 2021, Princeton University). Bennecke and her co-authors –

3 For a more complete definition and application of human rights see the UN Universal Declaration of Human Rights (1948). It is from the Universal Declaration that dozens of treaties have followed, and it is to the UN Human Rights Council (UN HRC) that many intersex rights efforts are directed around the world. Thus far, organizations and activists around the world have not succeeded in securing a treaty to protect the rights of intersexualized persons. Reports such as this one can be used in the service of acquiring full human rights protections for intersex persons.

a collection of pediatric clinicians and surgeons, and the “DSD-Life” support group (a group frequently criticized in intersex activist circles for its privileging of parents’ views) – suggest that because of the 67% percent who report general satisfaction with their outcomes a general moratorium on surgery cannot be supported *based on the evidence*. Instead, Bennecke et al. suggest going forward on a “case-by-case” basis. The primary problem with Bennecke et al.’s advice is that we cannot know on a case-by-case basis who will comprise the population harmed to make someone else satisfied. From an ethics perspective, the recommendation endorses practice tantamount to a gamble with an irreversible outcome for those harmed. The secondary problem with studies (e.g., Bennecke et al.) is the reliance on populations coming from groups with strong parental influence on what is said and how it is said. In other words, a physical harm inflicted against some cannot be morally justified because a certain number of people are happy or content with their different outcomes from the same procedure(s).

Children who are legal minors but who wish to use medical technologies to effect gender-affirming changes to their bodies are increasingly listened to regarding the use (or not) of surgery and hormones to shape the bodies they want; there is no reason to avoid taking the same principled approach to children who have been intersexualized. Put simply, there might be some minimal harm in delaying a surgery that an intersexualized child wishes to have, but waiting does not constitute an irreversible harm. By contrast using surgical interference to pin down a sex assigned by outside observers of the child’s body inflicts an irreversible harm if the child rejects the assignment later. One of the respondents in my group of interviewees faces exactly this form of harm as a person whose adult gender expression matches the body he was born with, but not the one he was surgically forced into. Another struggles with experiences of disassociation if not outright rejection of the body he was left with following surgical interference as a baby and toddler, even though he does not reject his gender assignment. Everyone in my interview group expressed a wish to have been allowed to wait to an age at which they could have

meaningfully participated in informed decision-making about all aspects of their care.

When Canada implemented the Family Law Reform Act in the 1970s, the legislature determined that wives and children could no longer be treated as “chattel” – as the property of husbands/fathers. Regardless of whether children were aware of that standing, and whether many women had no objections to that standing, the law determined that there were inherent and unacceptable dangers in holding chattel status. Canada recognized at the level of law that holding some persons as the property of others was both inconsistent with larger human rights that would enter our charter in 1982, and that it was inherently endangering to women and children not to grant them human rights as persons independent from husbands and as humans on the way to becoming autonomous persons independent of their fathers (and by extension, of their families). It is from these principles that the freshly legislated (2021) ban on conversion therapy in Canada stems. In effect: parents do not hold the right to determine the developing autonomy and future sexualities of their children. Rather, the parental duty is to accept and to care for the persons that their children are becoming. To do otherwise is recognized in most of Canada’s family law as an unjustifiable harm.⁴

It is Clune-Taylor’s argument that all acts to “normalise” the bodies of intersexualized infants and children are efforts to protect a “cisgender future,” and the expense exacted on the bodies and emotional lives of the children is considered an ordinary extension of any kind of parenting or medical “care provision” (Clune-Taylor, 2019). She writes that like models that dominate “standards of care” prior to the 2005 LAWPEs adoption of the DSD model, the current approach still casts intersexualized bodies as “disordered” and “continues to be driven by problematically heterosexist and transphobic assumptions regarding the value and normalcy of cisgendered life, while practically and discursively constituting it as such” (2019, p. 1).

4 The Court Challenge that Egale has undertaken and filed in 2021 addresses the unique failure of section 286(c) of the Criminal Code that expressly permits parents to consent to the physical injury of their intersex children, and the central strength of our claim in the Challenge is that allowing this surgery to take place is both rooted in and fosters both homophobic and transphobic attitudes toward intersexualized infants and children.



What intersex activists and our allies seek is to follow the same legal principle: that we not treat children as property, that we protect the development of *all children* into fully autonomous adults, not reserving some as outputs of parental commands or desires to become only one kind of person (heterosexual, cisgendered, etc.).

Frequency does not, in terms of legal principles, determine whether something is allowable. But the marginalization of intersex as “rare” effects its dismissal as a matter not worth consideration. In no other realm of experiences of assault do we decide that it is allowable because most people will not complain about it or will recover from it. We aim for catastrophic violations to be relatively rare and maintain that a rare assault when it happens is still significant. Intersexualized persons also deserve preservation of the right to freedom from harm, from assault, from irreversible damage. It is fundamentally on these grounds that Egale Canada is the champion of the current Charter Challenge to remove the protection of surgeons from criminal prosecution for causing harm to intersexualized infants and children.

Intersexualized persons in Canada, however, remain subject to uniquely violent interventions on their bodies in the name of their normalization, and poor outcomes are dismissed as a minority of outcomes in an already rare population. As with any minority or marginalized group, the argument central to 2SLGBTQI human rights has always held at its core that frequency is not the key issue. The key issue is the fundamental recognition of our humanity, personhood, and autonomy being worthy and equally deserving of the same liberties as the dominant group. Given the persistence of assertions that intersexualized persons are a “rare” population, the frequency of surgical interference against our bodies and developing selves may surprise readers even of this report.

Nevertheless, Montréal’s *Le Devoir* newspaper recently acquired and published the number of “normalising” surgeries carried out between 2015 and 2021, for the purposes of “correcting” anatomical features of intersex difference:

1385 interventions chirurgicales ont été pratiquées sur des enfants de moins de 14 ans présentant une variation du développement sexuel ; 838 d'entre elles sur des enfants de moins de deux ans, selon les chiffres de la Régie de l'assurance maladie du Québec (Nadeau, 2022, para. 2). [There were 1385 surgical interventions practiced on children under the age of 14 years who presented with a variation of sex development; of these, 838 were children under the age of 2 years, according to the department of Health Insurance in Quebec].⁵

This release of the number of surgeries carried out in the province of Quebec over a roughly five-year period, came as the result of a request from Université du Québec à Montréal Professor Janik Bastien-Charlebois, and marks the first successful effort in Canada to obtain that information. The author of this report, Morgan Holmes, made a similar request in 2018 under the Freedom of Information Act in Ontario, but that request was denied as being “not in the public interest”. However, we can extrapolate from the Quebec numbers that “standards of care” being the same across North America, that there will only be more infants and children with their bodies similarly “intervened” upon since 2015.

Attention to the Quebec data indicates that roughly half of the total number operated upon since 2015 will still be minors somewhere between 8 and 11 years old now, not consulted when they were infants, and still young enough to be subjected to further surgical interventions, especially for hypospadias and vaginal surgeries, both known to have high failure rates.⁶ Bodies reporting to the EU legislature, special independent reporters to the UN (Méndez, 2015), and Human Rights Watch in the US (HRW, 2017), have all characterized these interventions as “medical torture”. The Special Rapporteur connects the torture and rights violations of intersexualized persons to the larger LGBTQ+ population explicit when he explains:

⁵ Translation by Morgan Holmes.

⁶ See the lengthy discussion of types and prevalence of failure in Anne Tamar-Mattis' chapter, “Medical Treatment of People with Intersex Conditions as Torture and Cruel, Inhuman, or Degrading Treatment or Punishment” in *Torture in Healthcare Settings: reflections on the Special Rapporteur on Torture's 2013 thematic report*.



[...] intersex persons are frequently denied medical treatment and subjected to verbal abuse and public humiliation, psychiatric evaluations, forced procedures such as sterilization, [to] hormone therapy and genital-normalizing surgeries under the guise of “reparative therapies”. These procedures are rarely, if ever, medically necessary, lead to severe and life-long physical and mental pain and suffering and can amount to torture and ill-treatment. The criminalization of same-sex relationships and pervasive discrimination against lesbian, gay, bisexual, transgender and intersex persons lead to the denial of health care, information and related services, including the denial of HIV care, in clear violation of international human rights standards such as the Yogyakarta Principles on the Application of International Human Rights Law in relation to Sexual Orientation and Gender Identity. (Méndez, 2015, p. 13)

Additionally, as the whole point of the treatment is to make intersex differences disappear, these children will grow up learning quite specifically *not to discuss* what has happened to them, and that “queerness” is punishable, even in settings that are supposed to provide “care”.

For those of us who have been working in critical intersex studies and activism over the past 25 years or so, these observations come as no surprise; however, Egale’s unique commitment to bringing intersex into the mission of securing human rights protections and extensions for the LGBTI community is one of extremely few such serious efforts in Canada. In Canada, the Association of Ontario Midwives (AOM) stands as the other unique example of an organization that has made a productive effort to improve the conditions of healthcare and rights recognitions for intersex infants and children in Canada. The AOM issued policy in 2017 to mandate the delay of any surgical modifications for cosmetic purposes until the infant in their care has reached an age at which to decide for themselves if they wish any alterations.⁷

⁷ Making a point in agreement with the UN regarding normalizing surgeries as a fundamental violation of a child’s rights, the OAM Position Statement declares that “As an Association, we believe that healthy children should not be subjected to unnecessary and harmful interventions. We are committed to respecting the human rights of all people, including the rights of intersex people.” (<https://www.ontariomidwives.ca/aom-position-statement-intersex-child-autonomy>)



Other organizations, by contrast, have mostly focused on whether we can solve the matter of “intersex rights” simply by creating “I” markers or imposing the “X” marker on intersex infants’ vital statistics registrations and personal identification documents (birth certificates, passports and so forth).⁸ An obvious problem with the “simple solution” is that it requires medicalization to validate such alternative markers and so begins with a pathologizing framework. Moreover, as the Quebec scholar Janik Bastien-Charlebois has found, the German model for delaying a sex-marker on an infant’s documents has led to parents *rushing* to impose the surgery in order to acquire a sex designation for the child precisely because they do not want their children to be among the very few who would not belong to dominant social categories.⁹

As I will expand upon later, my recent fieldwork with adult intersexualized persons to determine their needs as defined by them underscores that it is not only parents who seek a binary sex for the intersexualized child, but that intersex persons ourselves most frequently identify as males or females, men or women, who have experienced intersexualization. Intersex is not, then, a primary sex identity, but rather an imposed threat to identity. In addition, as succinctly explained here by the Intersex Human Rights Australia organization (in consultation over many meetings with other global partners) mapping intersex and nonbinary identifications onto each other can constitute both conceptual erasure and harm:

Often [...] we encounter assumptions that to be intersex is to be nonbinary, or to be nonbinary is to be intersex. These assumptions are harmful. They fail to recognise the diversity of the intersex population, and in this case even the existence of intersex girls and boys, and intersex women and men. These misconceptions can be experienced as stigmatising, and suppress disclosure and stories that need to be told. They harm community organising. They harmfully *reduce intersex human rights issues to a matter of legal gender recognition*. They do

8 Canada’s Department of Justice, for example, asked me in October of 2017 whether on the heels of Bill C-16 passing into law we ought to be using the “X” marker for intersex birth registrations.

9 Janik Charlebois, personal communications with author, 2021.

not reflect intersex diversity, and nor do they reflect the diversity of the nonbinary population. (Carpenter, 2019, para. 7, emphasize added)

Far more useful and pragmatic is the Court Challenge filed on June 15, 2021¹⁰ by Power Law on behalf of Egale, Janik Bastien-Charlebois and Morgan Holmes. With the Court Challenge, Egale has launched the first ever application to remove the legal protections in Canada's Criminal Code (section 286-C) that grant surgeons special exemptions to perform "normalizing" surgeries on the genitals of infants for whom it is deemed "medically necessary." As Canada's national organization committed to the elimination of bias and hatred directed at 2SLGBTQI persons, and with a focus on securing the human rights of persons and groups against the harms of homophobia, biphobia, and transphobia, Egale is the first and only organization to have recognized the need for persons with a medicalized experience of an intersexualized body to be protected from practices rooted in heteronormative demands. The premise of the case is to "challenge the constitutionality of exemptions in the *Criminal Code* that permit 'normalizing' aesthetic surgeries on intersex infants and children prior to these individuals being old enough to [...] consent to such surgeries" (Egale Canada, 2021, p. 1).

History and Terminology

Although the international intersex rights movement is generally thought to have started with the establishment of the Intersex Society of North America in 1993, and having expanded around the globe in the years since then to include rights-seeking and justice-seeking intersex advocacy groups in Asia, South-Asia, Europe, Australia, New Zealand, countries in Sub-Saharan Africa and Latin America as well as in Europe, there remains a general lack of clarity in the general population about what "intersex" refers to. Egale offers the fairly neat and tidy explanation that "intersex refers to a person whose chromosomal, hormonal, or anatomical sex characteristics fall outside the conventional classifications of male or female" (Egale Canada, 2021, para. 1). This definition is not a bad place to start, but it has the vulnerability of accepting the medical

¹⁰ See the Egale Press Release on the grounds for the application for a Court Challenge at: <https://egale.ca/egale-in-action/ontario-superior-court-intersex-human-rights/>



framework as neutral; therefore, this report underscores at multiple points that while there are certain biological facts unique to intersex, those facts *alone* do not constitute a person as intersex. What is required is a medical commitment to seeing those facts as problems in need of “correction.” In short, to be apprehended as “intersex” (or, even more troublingly, as having a “Disorder of Sex Development”—a “DSD”) requires not only that certain facts of the body be present, but also that those facts have a particular medical/pathologized meaning imposed upon them. It treats the body of the child or infant as the problem while our human rights response seeks to position medical authority as the problem.

The international effort to secure human rights for intersexualized person has sought to wrest the term “intersex” back from the medical domain, and to claim it in much the way that many in the 2SLGBTQ community have reclaimed “queer,” not as an epithet, but as a refusal to acquiesce to heteronormative demands that would extend rights to us only to the extent that we would *behave ourselves*.

Egale’s Court Challenge does not contest the biological facts (nor should it), but generalist readers of this report need to understand that the facts only gain a negative meaning, an “ambiguous” meaning, because of the stigma imposed upon them. In Canada, since the Criminal Code was explicitly altered in the late 1990s to allow the relatively recent medical problematization of intersex to persist, and to violate the human rights of infants and children perceived in “intersex” terms, the meaning of intersex differences has been legally codified as negative, thus upholding the medical view of intersex differences as negative and in need of “correction”. The human rights violations as a primary problem are related to a second that intersex is poorly understood, and even some of the “best” understandings are deeply biologized, and thus, vulnerable to biological “solutions.”

Welsh scholar Iain Morland (2009) has worked on the manner in which the phantasmic character of intersex plays out. I will only mark the point briefly, but Morland’s general idea is that “intersex” is not real, though its effects in culture

and subjectification are quite real. The take-away point is that there is no unity in the designation “intersex.” Just as all the “other” supposedly “normal” bodies vary in appearance, so do intersexualized bodies vary.

Intersex, then, is nothing more than a diagnosis of appearance that has crossed a tolerance threshold in the diagnosing physician and, where applicable, the diagnosing multidisciplinary team. Furthermore, we need to keep in mind that the attitudes that inform diagnosis are regionally and culturally specific. What counts as anatomy “ambiguous” enough to compel a diagnosis is not universal. Some cultural contexts are more rigid, and others are less so. In some places in time or space, girls can have generously endowed external genitalia, and, in some contexts, they cannot. That some people with CAIS will have external female genitalia that meet the current Western idealization of hairlessness and “tidy” diminutive genital appearance has been a feature worthy of some pause in critical intersex scholarship precisely because women with CAIS are diagnosed with intersex not because genital appearance, but because the absence of menarche provokes a series of tests that reveal XY chromosomes instead of XX chromosomes.

From a critical intersex point of view, the response to a female body-type paired with so-called “male” chromosomes provokes nothing more than “And...so...?”. What matters from a critical intersex point of view, in other words, is not “what does this mean to medical experts?” but, “what does this mean for those who live in and with such bodies?” (We might question medical values and their impact, but more frequently the objective is to center the experiences, needs, and knowledges of the intersexualized person).

Critical intersex studies thus reframe the dominant characterizations of which questions and answers matter, removing the medical from the central position on matters that are not best or properly understood through a bio/anatomical lens, but rather through a personal and experiential lens. This lens, however, cannot be grounded and framed from within the usual ableist view; instead that view becomes part of what a critical intersex phenomenology recasts by centering the experiences and narratives of those whose bodies have been

made as “intersex” and then erased, both philosophically in the language of pathology and through surgical “interventions”.

So, how can critical disability studies help us to reframe intersex? I want to suggest (pointing in the general direction of the essays collected in my edited volume, *Critical Intersex*, [Holmes, 2009]) that taking a critical disability studies approach—that is, one that embraces disability as part of human life—that we can do more than just have that responsive/subordinate position regarding the power and practice of the clinic. We can challenge the idea of what it means to “pass” (as not intersexualized) by reclaiming the diagnosis as a neutral description; we can refuse the pathologizing language of “Disorders of Sex Development” (shortened routinely to “DSD” in the medical literature) or its odious euphemism “Differences of Sex Development” (and I say that it is odious because it leaves in place that all males are the same and that all females are the same, that there are no differences within those sex categories). To refuse the pairing of pathology and appearance, we note that metabolic concerns that correspond with some kinds of so-called intersex bodies are distinct from sex development. Indeed, “differences of sex development” or “variations in sex development” are problematic euphemisms that land us back in a clinical framing. After all, all sex characteristics are “variable” and all individual anatomy always has its unique distinctions, but only *some of us get labelled* as beyond the pale.

Even if we grant that CAH and AIS variance do have some capacity to express problems in skeletal health, growth, and in metabolic function,¹¹ these correlations do not have to be framed as disorders of sex characteristics. These health considerations require some investigation and medical, not necessarily

11 It remains a popular misconception in medicine that AIS persons have an increased risk for testicular cancer and that testes should be removed as early as possible in childhood to prevent cancer from developing. However, decades of research had established by the mid-1990s that any increase in cancer risk was insignificant and paled compared to the harms of removing testes. These harms include loss of estrogen production and attendant deterioration in bone-health. More and more often, clinicians now recommend a “watchful” approach of monitoring testicular health, but not removing the testes from people with AIS; however, practice still depends on the individual views of the surgeon involved. I recently attended a lecture by Dr. Catherine Clune-Taylor in which a surgeon from the audience vigorously defended the standard removal of testes. For persons with CAH, there is a possibility of reaching puberty at a young age, thus ceasing or curtailing the usual growth patterns of childhood. Persons with CAH can, in some cases, have difficulty with retaining enough salt as part of a metabolic problem associated with some forms of CAH; generally referred to as a “salt-wasting crisis” or an “adrenal crisis,” the problems with salt-wasting CAH can be life-threatening in situations of severe dehydration or shock, etc.

surgical, management; they have nothing to do with the purported “urgency” or “emergency” status of an infant or child apprehended as intersex.

It is helpful to draw an analogy between intersex and eye colour to make the point: just as blue eyes are less common than are brown and black eyes, and their appearance correlates with the presence of myopia, we have a general understanding that blue eyes are not diseased and do not require alteration to make them appear brown (which would not actually improve vision anyway). We accept that there is variation.

Part Two: Restoring Epistemic Justice to a Dismissed Population

Unlike our close governmental cousins in the UK and Australia, Canada does not track frequencies of intersex births or later diagnoses. Health Canada merely oversees the funds transfers for healthcare from federal budgets for provincial disbursements for services, but Health Canada does not even know what those services are in each province.

As noted in the introduction to the previous section, in the winter and spring of 2018, using a Freedom of Information (FOI) request, I tried to remedy the absence of information for our most populated province with an FOI request to the Hospital for Sick Children and ran up against a refusal to release non-identifying data on surgeries from 2010 to 2015.¹² The privacy commissioner could not help because, their officer explained in a phone call in winter 2018, intersex was not a well-known enough concern to meet the “public concern” threshold. In sociological terms, a factual violation of human rights had not—and has not—become a recognized social problem.

Two further research agendas did, however, hit the desks of granting agencies at Canadian Institutes of Health Research (CIHR), both focusing on intersex persons’ health outcomes. The first required a research base in a clinical setting, headed by a clinical researcher. I worked as a member of that team until about

¹² See Appendix II

eight months after the grant was won and at that point the primary investigator (PI) still had not been granted access to the data required to assess transitions-in-care needs. Transitions-in-care refers to the movement of patients from one category to another—in this case from pediatrics to adult. A second grant was announced for competition in the summer of 2018. That one was announced as the first ever intersex-specific, Patient-Oriented Research (POR) grant. CIHR however did not anticipate the PI applicant *being* an intersexualized person and could not grasp the principle of ethnography done by an “embedded subject”. The role of the embedded subject is highly principled and central to the critical disability studies and disability rights framework “nothing about us without us” which has been central to race and sexuality research design. That it remains *unthinkable* to our health research granting agencies speaks to the professional power that continues to feel entitled to act against us and without us.

My recent review of the publicly announced winners of that round of CIHR grants revealed that nobody had been successful in the specific competition for POR funding on intersex issues. This study is a version of what I had proposed to CIHR – minus collaborations with medical professionals and no *particular* education/knowledge-transfer modules promised.

Methods

Recruitment was done via Egale Canada whose offices sent out invitations to all the attendees at the intersex pre-conference for the international IDENTITY Conference hosted by Egale Canada in Toronto in 2018.¹³ From that set of invitations, I had seven responses resulting in six interviews. From word of mouth, using the snowball method I had another three responses, resulting in two more interviews, for a final total of eight participants. Interest that did not result in interviews had to do with:

- Being too stressed by COVID-19 conditions,
- Not having access to a computer or smartphone, or,

13 To learn more about the IDENTITY Conference, see the conference report here: <https://egale.ca/awareness/identity-conference-report/>

- Not being resident of or having treatment history in Canada.

I conducted interviews at one-week intervals over the summer of 2021 with one longer interruption to handle external problems with health and/or tech that a participant was experiencing. By the end of July, I was able to begin transcribing using a modified Jefferson method. Because the Jefferson method is extremely arduous, I began with a simplified method and then returned to make the Jeffersonian notations. Jeffersonian notations help researchers not only to read back on what was said, but also *how* it was said. It allows us to note things like pauses, manner of breathing, laughter, crying; interruptions and thoughts that trail off, etc.

In writing for a general audience, I work with my richly transcribed notes to relay the content of what people said in clear terms: the *what* was said, rather than the *how* it was said. The transcripts do indicate that as far as working specifically with me as an interviewer, participants had few difficulties with concerns about stigma. Knowing that I too have an intersexualized history suspended concerns endemic to the group, namely: fears of being judged as “broken” or “delusional,” or of failing to understand their own circumstances. Fears about being read as unreliable witnesses to our own histories is well known to the community, and Quebec scholar Janik Bastien-Charlebois explains that the undermining of intersexualized persons’ self-knowledge is a form of “epistemic injustice”:

Lorsque des membres de groupes opprimés tentent de donner un sens à certaines expériences et de l’exprimer auprès de membres de groupes dominants, ils éprouvent souvent les effets d’une déflation de crédibilité. Le déficit de crédibilité dû à l’injustice testimoniale se conjugue à l’inintelligibilité de l’expérience, de la perspective ou de l’analyse soumises, ce qui inhibe fortement la prise de parole. Ces risques de déflation sont un double frein à la subjectivation politique. (Bastien-Charlebois, 2017, para. 7) [When members of oppressed groups try to explain their experiences and express their meanings to members of dominant groups, they often have their credibility

discounted/devalued. [This] lack of credibility due to testimonial injustice combines with the unintelligibility of the experience, perspective or analysis submitted and powerfully inhibits speaking out. The risks of this discounting/devaluation of the testimony of oppressed persons is a double brake on access to a political position as a knowing subject.^{14]}

Participants *do* want to tell their stories but do not want to perform “fascinating object” for clinicians, and do not want to have to do cognitive/emotional labour of “identity management” with researchers. That became very clear during the eight completed interviews. I also consider it an accomplishment of interview design and of my own situatedness that permitted the completion of discussions about difficult experiences without producing a voyeuristic fetishization of pain. The people I interviewed unanimously reported positive feelings about themselves and about the interview process at the conclusion of our conversations.

It is a significant accomplishment that Egale Canada has made possible the first completed set of qualitative interviews exclusively with residents in Canada. For a country with no ready organizations such as [InterAct](#) or [Interface](#), it is amazing that I have bicoastal and Western province, Ontario, and Quebec respondents among my participants.

Demographic Data:

In terms of the population, there were three immigrants to Canada, one with experiences of treatment from an Arab country, one from a former USSR country, and one from the UK. The participants for this series range in age from mid 30s to late 70s with three respondents in their 30s, two respondents in their 40s, two respondents in their 50s, and one respondent in their 70s.

Current limitations imposed by my Research Ethics Board (REB) because of COVID-19 required the use of Microsoft Teams for interviews and while that was not optimal for rapport, it did have some benefits: participants could choose

¹⁴ Translation by Morgan Holmes.

their own most comfortable locations from which to log on to and participate in our discussion and travel costs for fieldwork were a moot point.

In terms of forms of intersex, even in this small group, the frequencies are consistent with global populations:

- Five of eight were from the AIS group:
 - 1 PAIS originally assigned female, now presenting as male.
 - 4 CAIS assigned female and happy with that role, presenting socially as woman.
- One probable KS assigned male: removal of one gonad in childhood, assigned male and content to present socially as a man.
- One respondent with unknown “etiology” and surgical “correction” of “masculinized genitals,” presenting as nonbinary.
- One person with CAH, assigned female and happy in that presentation, never labelled as “intersex” per se, but her narrative underscored the problem of belittlement from being repeatedly told that her differences were “aesthetic”—not subjected to genital surgery. However, what emerges in her interview overlaps with other participants reporting on the damaging experience of being repeatedly assessed in negative and/or stigmatizing language.

Each of my participants was *invited* to share their pronouns, and explicitly not commanded to share. A significant number of intersexualized persons find it consistent with the longer arc of invasions into our/their personal experiences as “confusing” and “not completely human” to have to declare our pronouns. As one of my participants explained:

I don’t know what to think about it, but I don’t like to be—I identify as “she and her”—but I don’t like to be asked; I don’t like being asked... particularly when it’s been brought up to a room. I remember one time in particular, and somebody I think was trying to “do the right thing”



and half way through this, like, group, was like, “Oh, let’s go around and say our pronouns,” but because the person said that half way through, I was, like, feeling like maybe they saw my body and made an assumption and it was trying to do the right thing, but I just felt more singled out. [All that doubt] entered my head. So, long story short: I don’t like it.

In other words, even when well-intentioned, if the desire to know pronouns is produced as a demand along the lines of “Introduce yourself and tell us your pronouns,” the framing can dredge up feelings of being unintelligible, and therefore under threat of punishment. To be *invited* to share or not gave my participants explicit room to think talk about their identities having been shaped in a medicalized context that frequently undermined their sense that they had been entitled to the identities they shared. This sense of being undermined by medicine as the arbiter of identity emerged across the sharing, regardless of the identity that a person declared.

After hearing about the stories and feelings of my research participants, I would share a little of my own narrative to reassure them that I understand their perspective and respect it. With the above participant, for example, I shared the following:

I understand how you feel. As I was getting ready for the camera for this interview, I was straightening little bits of hair at the back of my neck, and I was thinking about how in my medical file it says that my hair grows in a masculine pattern, that I am “hirsute.” So, you know, I have massive anxieties about my eyebrows, about the hair on my arms, so questions about my pronouns can cause me to have an automatic fear response of like, “Oh, no! is my beard showing?” and it feels like I’m failing, failing, failing... even though I’m very happy to be in many “behavioural” ways, gender non-conforming—at least as far as my female relatives are concerned... and boy have they ever been “concerned”.



Whether the initial sex assignment in childhood had been rejected or not, every participant discussed the manner in which “tell us your pronouns” was haunted by an awareness that medical professionals had told us and our families that we were “unfinished,” “ambiguous,” suffering an “aesthetic” expression, and so on. The undermining of identity is a continuing harm for intersexualized people, regardless of surgical wounds healing and scarring over, regardless of whether there has been surgical intervention or not. In short, the matter of emotional labour that intersexualized people have to engage in around pronouns is an expression of the violation of the right to autonomous development inherent in the intersexualization of the minor child.

Unlike recently published data (Rosenwohl-Mack et al., 2020) in the US—a survey of 198 people from across all the continental States—my data revealed no current respondents with poor educational outcomes or insecure housing. There are in my small sample, however, some problems with unemployment in a group in which educational attainment levels far exceed the national average. These challenges in employment, however, have to be read in the context of COVID-19 disruptions to working conditions for many residents in Canada. Every respondent had completed some post-secondary, and all but 1 had adequate employment until COVID-19 hit. Two had experienced COVID-19 related reductions in employment. Worthy of note is that one respondent indicated that a lengthy history of complex mental illness he attributes to the trauma of how he was treated in childhood is the main reason for his inadequate employment despite having an achieved doctorate.

While few intersexualized people I have worked with experience such disruptive levels of mental distress that they cannot hold employment, one of eight is an over-representation compared to the general population. Based on my own anecdotal information over 28 years of activism, this participant’s struggles are unsurprising when I consider the frequency of suicides and preventable death¹⁵ in the relatively small number of intersexualized activists I have known.

¹⁵ A preventable death is one that could have been avoided with proper medical care. In the cases I am thinking of, one person had been so traumatized by medical intervention that she did not seek care until end-of-life hospice care, and another was denied access to appropriate medical care until they had become extremely, visibly ill. Both died young, with aggressive cancers. As with other sexual minority groups who face prejudice and ignorance in medical settings, we know amongst ourselves in intersex peer circles that avoiding regular medical care is common.



The difference in my small group sample and the large US sample should not be read as a sign that our population is less injured, but only that we have fewer impediments to healthcare, to education, and to employment. Moreover, two of my respondents completed at least one degree outside of Canada, and so Canada cannot claim their successes as a product of our education system. For a host of policy reasons, both foreign and domestic, the general intersexualized population faces more hurdles and it is no surprise that intersexualized persons in the US would express those vulnerabilities.

What the group reiterated in many ways were problems I can group thematically as:

- Loss (of physical features, but also of personal potential),
- Pain (both physical from surgical damage, and mental from medical violation of their integrity), and
- Frustration (at their experiences of abandonment).

Participants reported barriers to self-knowledge, not only because of medical blocking, but also because parents who had been entrusted with medical records had purposely destroyed the records and claimed an inability to recall their specifics about diagnoses, examination, and surgical procedures etc.

I do not yet have a complete theory to account for this loss of access to self-knowledge, or to other harms I will note momentarily; however, I have stopped thinking about these issues only as sexual minority rights. Consequently, I structured my 21 interview questions not to focus on sexuality per se, and to learn instead what kinds of health and well-being needs intersexualized persons would identify for themselves. My five questions on background and experience and seven questions that asked participants to evaluate their healthcare providers revealed that regardless of identity every respondent had had their sexual autonomy undermined. My resulting interpretation of the narratives is that *all* perceived intersex are treated from ableist and eugenic impulses that collide with heterosexist imperatives to render all intersexualized states as undesirable. The result is a lived experience in which my participants

report being literally and figuratively cut off from aspects of self-knowledge and from various aspects of sexual agency (both intra and interpersonal).

The inclusion in my study of participants' broad range of forms of intersex and a fairly uniform "medical management" history reveals that medicine is not wedded to a binary view of biology. Rather, it is wedded to a binary *social* presentation. Bioscience and medicine already know that sex biology is not binary. Their position is that our society is binary and that viable subjects must adhere to that regardless of biology. Appeals to biology will not free us and can endanger us if biosciences seek simply to eliminate unruly biologies. The criteria for infant and childhood sex assignment followed in every case a question of whether the infant *appeared* more convincingly "male" or "female" with only one male assigned male at birth. The surgeons and endocrinologists *are unconcerned* about the existence of biological variation; they are concerned with moving those variations into binary gender categories. We will not secure rights for the intersexualized by explaining to medics that biology is nonbinary; they already know that and consider it to be beside the point. It is, therefore, not a surprise that seven of my eight participants have assigned positions that contradict their "biological sex" as a central feature and consequence of their medicalization.

Discussion

Various forms of painful experience emerged as a common thread for all my participants. This "pain" falls into a few categories: (a) physical pain secondary to surgical injury (reported by three participants), (b) psychic pain secondary to stated negative perceptions of physical features, including invasive/repeated inspections of bodily features (not only genital), and (c) grief over losses that range from trust of one's family, trust of healthcare system, and/or loss of: (i) access to the bodies they were born with, (ii) security in interactions with medicine, (iii) self-assurance about matters of appearance, and/or (iv) bodily capacities, because of gonad removals or because of genital surgeries imposed as part of female assignments.



At multiple points in most interviews, participants talked about struggling for “legitimacy” with their medical care providers to achieve recognition of needs they had defined for themselves, and to have those needs served. One struggled for decades to have their physical pain recognized as real, as an effect of early surgical and medical interference on his young body and reported that the pain was constructed by his care providers instead as a feature of mental illness. The framework for “mental illness” individualized and isolated this person, and the distress was not recognized as being rooted in surgical trauma. These failures delayed relief from mental anguish until very recently, and left physical pain dismissed as “in his head”. The decades of failure on the part of professional health settings to deliver care contrasted for this participant with the power of peer recognition to improve his day-to-day life.

Among the events that this participant reported had been most helpful in integrating a feeling of self-acceptance were the 2018 intersex pre-conference hosted by Egale, and a conference at which he had presented a scholarly paper a year or so later overseas. Being in settings that restored narrative and expert authority to intersex people had been very restorative and liberating for him. On that point, however, he and others who were at the 2018 conference indicated that having a “peer circle” discussion led by a person not trained in trauma care had created palpable emotional distress for many attendees. It seems, therefore, to be a clear need – a priority area, to provide “trauma-informed” catalyst professionals for peer group meetings. In other words, we need to have our own expertise recognized by those who seek to reshape our bodies and silence our voices; sharing trauma with each other is not particularly useful and can be harmful.

Some participants reported that they are at stages in their lives in which their experiences of being intersexualized are no longer central in their day-to-day thinking and they do not need “support groups” at all anymore. They did unanimously agree, however, that in their late adolescence and young adulthood they really would have benefitted from therapy and group supports to combat the isolation and stigma they lived with at the time. Furthermore,

on this point my participants unanimously agreed that, as one participant succinctly stated:

[a hospital organized group] isn't about giving people a sense of empowerment and isn't about sort of honouring their integrity; it's about making them [understand that] their 'difference' needed to be handled. And—you know—it's coercion, basically...the purpose is to see that what the doctors did was the best they could, and you needed it.

Another of my participants reported on the problem of medical coercion being the driver of other self-doubts and lost capacities. Unique in this group, but not entirely unique in the global community, this participant had provided legal consent at age of majority for a final intervention, one intended to alter their appearance. However, on reflection this person reported that they had been coerced, subjected to scare-tactics about being disqualified from a future dating life, and so made to feel ashamed of a body that had long been subjected to cruel scrutiny.

By contrast, every participant in the CAIS group had known family members— aunts, cousins, sisters—who also lived with these differences. While none had escaped medical interference, they were protected from the common refrain that “you will never meet anyone like you”. The overall implication is that while having family with “the same condition” can protect against a fair amount of stigma, it cannot provide the knowledge or power that we are seeing *some* younger people with AIS being able to exercise. In other words, every person in my CAIS population had had their gonads removed, but not one of them had a clear understanding of what had happened until years after the fact. Not one had the opportunity for a risk-benefit assessment, not even those who had been at the age of majority on removal.

Pointedly, one participant from the AIS group reported that while she had been comfortable with her decision to have internal testes removed in her twenties, that she had not been aware of the unintended or undesired effects that it could have on her:

I lost a lot of my sex drive [after the surgery] and I was on Premarin¹⁶ and it was giving me hot flashes and I just was not a happy person. [So] then they gave me like...an oral estrogen...a synthetic...and it just wasn't great. So I just stopped. I probably shouldn't have, but I did. And it actually made me feel a lot better.

However, this same participant explained that she had not been aware of why she “probably shouldn't have” stopped taking hormone replacements, or that it might have been possible to keep her internal testes for a longer period of time. This sense of self-admonishment repeats what I have heard many times over 25 years in activist groups: that patients do not receive adequate information about why HRT is important after the removal of gonads, which implies that they also are not told what jobs their gonads are still performing before they are removed. The discussions to acquire consent from this respondent, like many others I have heard about, did not meet the requirements for a properly informed consent. One respondent reported really feeling left out of any informational conversations:

Nobody helped me to understand...I don't really remember being addressed. I don't think I was addressed. It was just sort of something happening between my mom and the doctor. And then I was just sort of the subject of, you know, their conversation. They were doing the talking.

Feeling Like "Bad" Patients

When intersexualized persons are left out of the conversations, we can be on our own making later decisions, and there is a risk of feeling culpable for any negative consequences.

This is apparent in the issue of the participant who relayed deciding to cease taking HRT. For her, a negative consequence was the loss of sex-drive. However, in trying to remedy that problem she encountered a new expression of poor

¹⁶ Intersexualized persons who have their gonads removed need to have hormone replacement therapy (HRT) to protect both heart health and bone health, but as this participant noted, sexual health doesn't figure into the conversation.

care when she sought the help of an endocrinologist (a medical speciality in hormone and metabolic regulation) who performed an internal exam on her:

He wanted to do an internal, which I was fine with... But afterwards, I thought, I had... you know... a feeling that he was just kind of curious more than really needing to do that. He's an endocrinologist; it should be more about my [hormones] and not what's going on down there.

The 1984 *Reibl v. Hughes* case in Canada determined that simply obtaining consent for medical and/or surgical treatment was insufficient, and that patients had to be permitted the opportunity to assess for themselves whether a proposed intervention offered a reasonable solution in a context of reasonable risk-benefit assessment. Seizing the privilege to look at people's genitals to satisfy clinical curiosity is part of that array of practices that harm intersexualized persons. To "take a look" in the manner described by this participant violates several features of consent in medical settings: first, as noted above in her reflection, an endocrinology assessment does not require an anatomical exam; second, without a conversation regarding the purpose of the internal exam the endocrinologist failed to obtain an informed consent for that procedure; finally, lumping the internal exam in with the general discussion for HRT management exploited a power difference between the doctor and patient, and took advantage of a vulnerable person seeking care.

That clinicians proceed without having proper risk/benefit conversations, access our bodies without obtaining properly informed consent, and proceed to make recommendations without themselves being specifically trained to do so is a set of problems that repeatedly surfaced in my interviews. The interviews in this report reflect treatment arcs that extend to the present, thus belying carefully crafted assertions that surgical techniques and other treatments have significantly improved and are no longer damaging.

The 2005 Consortium guidelines are already seventeen years old and many of their "wait and see" recommendations are based on research that had established in the 1990s that the removal of internal tests and undifferentiated

gonads was an overly aggressive approach that was not indicated in the absence of evidence of dysfunction. Yet damaging interventions in childhood and young adulthood persist, while adequate follow-up remains absent.

Finally, across every group, intersexualized people struggle to find knowledgeable primary care physicians, ones who are willing to learn with them, who are good at avoiding stigmatizing treatment, and so on. More often, even in this small group, my participants reported that they tend to be treated as curiosities, and that their physicians have not been good at avoiding re-pathologizing them in their encounters. Whether that pathologization happens by dismissing concerns and experiences as “histrionic” or by performing exams that are unwarranted, or by failing to provide supportive follow-up care for metabolic/hormonal health is specific to the different needs that my participants reported having in adulthood. The failure of clinicians to deliver appropriate and supportive care is, however, a universally shared experience in this group.

One participant reported being too old to worry anymore about “sharing information” and was neither in need of a “community” or a good specialist but still felt that many years of her adulthood had been spent unnecessarily on her own, with only partial self-knowledge.

The sole participant with a CAH diagnosis did indicate that she has a trusted general practice doctor now, but that her adult care had not always been well-informed, and that she had been prescribed dexamethasone for years without it helping with her own concerns, and without a clear reason to take it.

At this time, she takes no medications intended to “manage” CAH and has not endured any surgical interventions. However, in our interview she returned repeatedly to knowing/being repeatedly informed that she was “very lucky” to have a form of CAH that had produced “only aesthetic issues”. That framing of her differences seemed to invade the self-perception of a young, brilliant, and attractive woman, and the cognitive interference struck me as both persistent and painful. On the whole, however, she has a rich life, professionally and

personally and experiences herself in the world as healthy and desirable. Readers may be struck here by the correspondence of this woman's thriving and a minimum medicalization of her differences.

Her comments also should remind us that nobody is ever told that they have an "intersex" diagnosis, body, appearance, etc. Parents used to be told that the sex of their child was only somewhat obscured or was merely "unfinished" in its development (Davis, 2015; Holmes, 2008; Karkaziz, 2008; Reis, 2009). The language of intersex was, until its excavation in the 1990's by Suzanne Kessler, solely used by clinicians, surgeons, and sexologists to communicate with each other. Since the 2006 arrival of the Consensus Statement, parents are 'educated' to understand that their child has a DSD and that the disorder can be fixed, and the development 'completed' with a few 'minor' but 'necessary' surgical interventions.

Conclusion

This report has been delivered in two parts, the first largely conceptual, and the second drawn from qualitative research that has sought to restore and then deliver the voice of expertise of those with "lived experience" to inform the delivery of appropriate care across the lifespan for persons who have been subject to intersexualization.

Part One of the report introduced "intersex" not as a simple biological fact, nor as the "proof" that biology is nonbinary (which still sets up intersex on the one hand as 'opposite' to the putatively immutable categories of male and female). The reader should then understand that intersex is a product of a time and place and of a profession—medicine—that has come to dominate how people define themselves in Euro-American contexts. Medical commitments to taxonomy, to sexual and bodily conformity with prevailing norms, and to functional abilities that conform to modernist logics have created intersex as a disordered way of being in the world that must be erased.



That the erasure of traits constructed as intersex requires the violation of the foundational human rights to bodily autonomy and to the development of self-knowledge and autonomous decision-making about one's own life is a concern that Egale has taken up with the current Court Challenge. This report also moves Egale and its allies toward other commitments: to consider the dangers to all of our lives when the elimination technologies of medicine move from erasure on living bodies to the eugenic removal of certain kinds of bodies from our futures, and to address the ongoing needs for healthcare to be delivered that actually meets the needs of intersexualized persons according to their own needs assessments.

Part Two of the report draws specifically and deeply on the needs assessments of adults at different stages of the lifecourse, reflecting on what has been harmful in their experience so far, and making recommendations about what they need going forward. The second half of the report, then, focuses on restoring expertise to the intersexualized, to speak for ourselves rather than to be objects of (depending on the scenario) either derision or fetishization.

There are several key takeaways from this project and several recommendations stemming from the takeaways. Because we have no studies like this in Canada, these data-informed recommendations have inherent confirmation value. The study allows us to see that current needs in Canada are consistent with those seen in the very limited research from elsewhere. To provide a high-level summary:

- There are other forms of harm than surgical.
- Many participants reported that a lot of decisions were made early that would have been better left to an age when they could have decided for themselves and that they “should not have been in that examination room” at all with the adults talking around them, inspecting them, etc.
- Medicalization/intersexualization can turn parents and children into adversaries (two participants reported that mothers were tasked with bribing them or otherwise persuading them to allow physicians to

perform genital exams on them). Participants reported that this felt like “being trapped”.

- A persistent challenge exists in finding good Primary Care Practitioner (PCP) and specialist care.
- Intersexualized persons must do a lot of “identity management” work so that others (parents, clinicians) do not have to feel uncomfortable.
- As with “general population,” advanced age correlates with increasing acceptance of oneself and one’s situation – but waiting over 40 years to move past an unnecessary harm is an abuse of personhood.
- Group support is needed across the lifespan starting in adolescence, to address what respondents had reported was missing in their own maturation process. The support should be professionally led by an intersex-positive person with trauma-informed training. Creating formalized support groups with priorities and resources determined by intersexualized persons will help young people navigating the transition to adulthood and mitigate against the problems of “ageing out” of a system that aims to have everyone erase intersexualization processes/ experiences.¹⁷
- Egale Canada could be very helpful if the organization could develop a list of intersex-affirming specialists, especially for surgical repair for adults and for referrals to endocrinology clinics across the country. At least one respondent still must travel out of province for any care.

¹⁷ Evidence of the persistent aim of clinicians to erase the evidence of a child’s intersexualization is, for example obvious in the current document for parents, produced and published by BC Children’s Hospital in Vancouver: When Your Baby is Born with Genitals that Look Different: First Days (www.bcchildrens.ca/endocrinology-diabetes-site/documents/firstdays.pdf). This information booklet very quickly positions intersex as a disorder that can be solved with medical testing and management (including surgery); the infant is positioned as a problem to be solved and the focus is entirely on how difficult the birth of a child perceived as “ambiguous” is for parents and families to cope with. Resources the document refers parents to include the CARES foundation in the US, and DSDFamilies in the UK, both of which have been criticized by intersex-led human rights organizations around the world for positioning intersex as a pathology. By contrast, the Association of Ontario Midwives’ (AOM) statement positions intersexualized people as subject to trauma, prejudice, and oppression that the AOM seeks to prevent from the natal period forward. The AOM (2017) states that it is: “...committed to challenging cisnormativity and heteronormativity. Non-consensual, cosmetic and medically unnecessary genital or gonadal surgery in order to bring individuals into conformation with the gender binary has [many lasting](#) deleterious [effects](#). These surgeries can render an individual physically or psychologically unable to experience sexual pleasure, limits their reproductive choices, and can cause life-long dependency on hormone replacement therapy”.

- Most participants have had or are in positive long-term relationships, even if widowed now, or presently on their own, but most feel that getting there could have been less difficult had pathologization not so disrupted their sense of self.

Intersexualized people in Canada continue to live in isolation from others who share their experiences. The isolation perpetuates a lack of access to healthcare services and information that could improve intersexed persons decision-making, general autonomy, and self-perception. The intersexualized population is difficult to access and, therefore, difficult to serve across the life course. This difficulty is baked into the standard biomedical approach that actively stigmatizes differences in appearance.

Asked to assess their own needs, this group was remarkably consistent: they benefited most when they were able to receive respectful and collaborative care. They struggled most with practices that were belittling or treated them with disregard for their own knowledge and perceptions. The community struggles after “aging out” of pediatric care to find clinicians who are both adequately trained and respectfully interested in helping intersex adults to repair earlier damage and to proceed with their activities of living.

To acquire things in adulthood against the backdrop of intersexualization and medicalization requires extra effort and can still leave us without all that we need to live fully as ourselves. To acquire what is needed requires that those who claim to provide our care must:

- Deliver care that is not pathologizing.
- Cease producing material that centres parents and guardians as the central stakeholders.
- Cease gatekeeping to prevent peer-support networks from being recognized as valid.
- Cease silencing and discrediting the self-knowledge that intersexualized people and communities have from living with the effects of pathologization.

Outside of the medical environment, we need to:

- Develop targeted programmes and supports inside mature organizations like Egale.
- Build advocacy for policy change in tracking health data for intersexualized persons.
- Open doors to persons impacted by marginalization and discrediting dehumanization so that the epistemic worlds of intersex persons can achieve value (similar to feminist and queer health movements).
- Lobby for the end of the violation of human rights to bodily autonomy, the access to informed consent (and the right to refuse), access to truth about one's diagnosis/es, treatments and interventions, and access to truth about the existence of others like us.
- Develop education programmes for the general public as well as for medical professionals to increase the welcoming of intersex into larger communities (e.g., family, school, religious life, etc.) and to reframe intersex as a neutral variation instead of a biological aberration.

In its entirety, this report explains the *raison-d'être* of Egale's expanded efforts to protect and enhance the human rights of intersexualized persons, makes the case for why the larger population of allies should be similarly committed to these efforts *and to listening to intersexualized persons rather than speaking for them or constructing them in the service of arguments about identity*. The report also sets the stage for further research aimed at fulfilling the needs and recommendations brought forward by those who participated in this project. Listening to the expertise of intersexualized persons brings us closer to the restoration of self-knowledge, of the restoration of the right to speak about ourselves without being subject to power-plays by medical hegemony in clinical, research, and funding practice, and of the right to security of the person. We hope that our readers will join us in these efforts, and will take this report as a departure point rather than a destination.

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Appendix I.

Interview questions.

In addition to seven demographic questions that helped me to record regional, age, education, and employment profiles for my respondents, I asked 14 qualitative questions that probed multiple features of healthcare needs and healthcare delivery experiences.

The demographic questions provided me with an opportunity to look for any similarities with the survey findings from the Rosenwohl et al. study on outcomes in the US population. While the participants in this study did not report reduced educational or employment opportunities in any *pattern*, I did encounter reports of other kinds of harms and losses across all the interviews, but these did not emerge in the demographic data.

Experiential/background questions:

1. Did you understand what was happening at the time that you became aware of your difference? How did professionals providing your care help you to understand? What could they have done better?
2. Do you think that you were treated with respect? Can you give some detail to your answer?
3. If you have sought more information, has it been easy to acquire? Has it been explained to you fully and to your satisfaction?
4. Do you think you received enough information to fully understand your medical history? ... and your health needs going forward?
5. What are your biggest health concerns now?... for the future?

Evaluative Assessments from the participants:

1. Do you have a trusted healthcare provider now? If yes, what is it about that person and the care they provide that you value?

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2. Do you have medication that you take (for example, HRT, or a metabolism regulator)? If yes, is that medication monitored? Is your medication covered through some form of insurance plan, or do you have to pay out of pocket?
 3. What would you identify as a best practice in your medical care?
 4. What about worst practice?
 5. Do you have concerns about new or future anticipated healthcare: needs/ settings/providers?
 6. When it comes to Canadian health policy and rights protections for intersex persons, what types of issues do you think are most important?
 7. Hospitals and clinics sometimes provide “closed group” networks to support people with specific diagnoses. Do you have experience with any of these kinds of groups? How would you characterize that service (positive/negative, why?).
 8. In 2018, Egale hosted a national gathering for intersex persons and our families. If you attended that meeting, did you find it helpful? Can you elaborate on your answer?
 9. Is there anything we have not discussed that you would like to add?

Appendix II.

The following is the body of the single paragraph request permitted on the FOI form submitted in 2018 to the Hospital for Sick Children in Toronto:

“As part of an environmental data survey we are seeking discharge notes for every surgical patient treated between January 1, 2010 and January 1, 2015 at The Hospital for Sick Children for pediatric gynecology and pediatric urology procedures categorized as sex assignments for diagnoses of “disorder of sex development,” including surgical correction of any of the following sub-types: genital ambiguity/ambiguous genital appearance; clitoral hypertrophy; epispadias and hypospadias; or micropenis. Please remove all identifying patient information leaving only applicable discharge notes and surgical reports.”

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