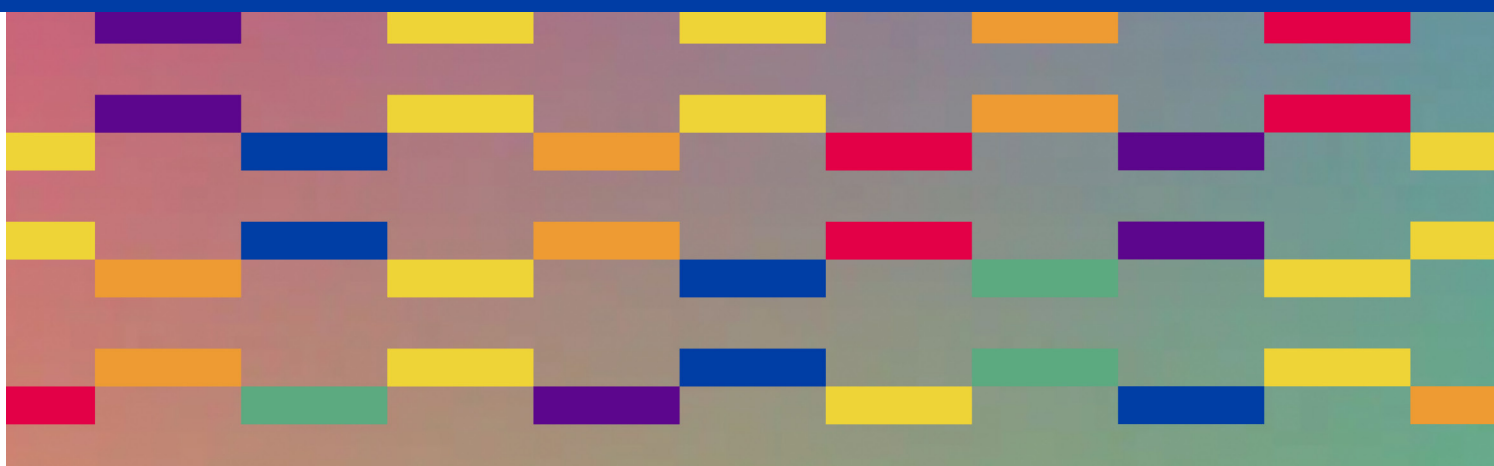




# Intersex Rights in Canada

Literature Review



September 2020



# Acknowledgements

Founded in 1986, Egale is Canada's national LGBTQI2S human rights organization. Egale works to improve the lives of LGBTQI2S people in Canada and to enhance the global response to LGBTQI2S issues by informing public policy, inspiring cultural change, and promoting human rights and inclusion through research, education, awareness and legal advocacy. Egale's vision is a Canada, and ultimately a world without homophobia, biphobia, transphobia, and all other forms of oppression so that every person can achieve their full potential, free from hatred and bias.

## Our Mission

To improve the lives of LGBTQI2S people in Canada and to enhance the global response to LGBTQI2S issues. Egale will achieve this by informing public policy, inspiring cultural change, and promoting human rights and inclusion through research, education, awareness and legal advocacy.

## Our Vision

A Canada, and ultimately a world, without homophobia, biphobia, transphobia, and all other forms of oppression so that every person can achieve their full potential, free from hatred and bias.

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# Introduction

Intersex people in Canada continue to face undue harm within medical institutions and Canada's justice system. Many people with intersex characteristics experience particularly violent forms of systemic discrimination, prejudice, social exclusion, traumatic experiences with medicalization, and verbal and physical violence.<sup>1</sup> One of the most pressing issues for intersex people is Canada's on-going practice of intersex genital mutilation by medical doctors. The ongoing practice of non-consensual "sex normalizing surgeries," which we refer to as *intersex genital mutilation* across this document, represents a glaring failure on the part of the federal and provincial governments and medical regulatory bodies to protect the human rights of intersex people.

**"Because their bodies don't comply with typical definitions of male or female, intersex children and adults are frequently subjected to forced sterilization and irreversible surgery, and suffer discrimination in schools, the workplace and other settings."<sup>2</sup>**

The majority of current advocacy work reduces intersex people and transgender people into the same category, or their needs are placed in opposition to one another. This ignores the fact that not every intersex person identifies as LGBTQ or 2S, nor will every intersex person want to align themselves with LGBTQI2S communities. We believe that Egale can play a role in protecting the rights and safety of all people marginalized based on their gender, sexuality, or sex characteristics in Canada and globally, and for this reason we pursue efforts to lift the voices of intersex advocates in Canada.

## These efforts include:

- In 2018, [Egale organized Canada's first national intersex conference](#) bringing together academics, researchers, intersex children, youth, and parents to identify the needs of the intersex people in Canada.
- In 2018, [Egale put forward a submission to the United Nations Committee Against Torture](#) ahead of International Intersex Awareness Day to report Canada's total disregard for international human rights law concerning the protection of intersex people.<sup>3</sup>
- In 2019, [Egale created the "Parents Reaching Out" resource document](#) for parents seeking to better advocate for their intersex children, based on a community consultation survey to identify the most vital issues in medical advocacy for intersex people today.

1 Orr, C. E. (2018). Exorcising Intersex and Crippling Compulsory Dyadism (Doctoral dissertation, University of Ottawa, 2018). Ottawa. Retrieved from: [https://ruor.uottawa.ca/bitstream/10393/37597/3/Orr\\_Celeste\\_E\\_2018\\_thesis.pdf](https://ruor.uottawa.ca/bitstream/10393/37597/3/Orr_Celeste_E_2018_thesis.pdf) p.72

2 UN Office of the High Commissioner for Human Rights (OHCHR), Opening Statement by Zeid Ra'ad Al Hussein, United Nations High Commissioner for Human Rights : Geneva, 14 September 2015.

3 Egale's [Submission to the UN Committee Against Torture \(UN CAT\) for Intersex Rights](#), October 11, 2018.

**This review provides an overview of the current landscape of intersex rights and experiences in Canada by offering a summary of the following topics:**

- 1. Canadian contexts for intersex rights**
- 2. Systemic violence against intersex people**
- 3. Intersex human rights on a global scale**

Throughout these sections, we consider advocacy efforts undertaken by intersex rights activists and scholars, highlighting the immediate need to prohibit instances of intersex genital mutilation in Canada and across the globe. Lastly, we offer future visions toward the promotion of intersex rights, calling on government and regulatory bodies to cease practices of intersex genital mutilation and to provide sufficient resources to intersex people and advocates across Canada.

## Key Terms<sup>4</sup>

### Intersex

Refers to a person whose chromosomal, hormonal, or anatomical sex characteristics fall outside the conventional classifications of male or female.<sup>5 6</sup> It is important to note that advocates have identified the term “intersex” as the best language to use to describe this group and we mirror this language across this document, however, “intersex” was “never formally adopted by physicians as a diagnostic term”<sup>7</sup> (see ‘Disorders of Sexual Development’, below). On occasion, the terms intersexual or intersexuality are also used to describe intersex traits.

### Intersex Genital Mutilation

Intersex genital mutilation is the term we will be using across this document to refer to the non-consensual, permanent, surgical interventions inflicted upon 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.<sup>8</sup> This language mirrors that which is used by advocates for intersex rights that work in partnership with Egale.<sup>9</sup>

4 For a comprehensive list please see the Glossary – Appendix A

5 Egale Canada. (2019). [Glossary of Terms](#). Egale Canada.

6 Cresti, M., Nave, E., & Lala, R. (2018). Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment. *Journal of Bioethical Inquiry*, 15(4), 557–568. doi:10.1007/s11673-018-9880-7 p.558

7 Cresti, M., Nave, E., & Lala, R. (2018). Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment. *Journal of Bioethical Inquiry*, 15(4), 557–568. doi:10.1007/s11673-018-9880-7 p.558

8 Ghattas, D. (2019) Protecting Intersex People in Europe: A toolkit for law and policymakers. ILGA-Europe and OII-Europe. Retrieved from: <https://www.ilga-europe.org/resources/ilga-europe-reports-and-other-materials/protecting-intersex-people-europe-toolkit> p.9

9 Surgical interventions are often used as part of a larger course of treatment that may simultaneously employ drug or hormone-based therapies, as well as psychological interventions aimed to align an intersex infant with the gender most typically associated with the sex they are assigned. This distinction will be further elaborated upon later in this review.

# 1.1 Canadian Context: Intersex Human Rights

Canadian federal and provincial governments' efforts toward LGBTQI2S rights and inclusion continue to fall short in the case of intersex rights.<sup>10</sup> Intersex genital mutilation continues to be practiced in Canada. Canada's failure to protect and support the rights of intersex people is witnessed in the following areas:

1. Canada's permissive policies and legislation concerning non-consensual intersex genital mutilation (elaborated below);
2. The lack of protective legislation, supportive infrastructure, research, and resources for intersex people in Canada, and
3. Canada's silence and lack of advocacy for the right to self-determination for intersex individuals on an international scale.

Currently, intersex people in Canada have no formal recognition of their rights under federal or provincial law. Section 3(1) and Idem 3.1 of the Canadian Human Rights Act prohibits discrimination based on "sex, sexual orientation, gender identity and expression,"<sup>11 12 13</sup> and all provinces and territories similarly include gender identity and expression as prohibited grounds of discrimination across their human rights legislations.<sup>14</sup> However, there is no explicit recognition of discrimination based on difference in sex characteristics in any of this legislation. As a result of this omission, intersex people in Canada continue to experience violence, harassment, stigma across their lifetime,<sup>15</sup> and are continuously subject to non-consensual medical interventions at birth.

10 Egale Canada. (2018, Oct 26) "Egale Canada urges the Federal Government to meet domestic and International Human Rights requirements of Intersex People on International Intersex Awareness Day." Toronto, ON. Retrieved from: <https://egale.ca/wp-content/uploads/2018/10/Intersex-Awareness-Day-Press-Release.pdf>

11 Canadian Human Rights Act, 1985, R.S.C., 1985, c. H-6. Prohibited grounds of discrimination, 3 (1): "For all purposes of this Act, the prohibited grounds of discrimination are race, national or ethnic origin, colour, religion, age, sex, sexual orientation, gender identity or expression, marital status, family status, genetic characteristics, disability and conviction for an offence for which a pardon has been granted or in respect of which a record suspension has been ordered."

12 Canadian Human Rights Act, 1985, R.S.C., 1985, c. H-6 Multiple grounds of discrimination, 3.1: "For greater certainty, a discriminatory practice includes a practice based on one or more prohibited grounds of discrimination or on the effect of a combination of prohibited grounds."

13 See Appendix B for full legislation

14 Prohibition of discrimination based on "gender identity": The Northwest Territories, Human Rights Act, S.N.W.T. 2002, c.18; The Saskatchewan Human Rights Code, SS 1979, c. S-24.1. , Repealed by Chapter S-24.2 of the Statutes of Saskatchewan, 2018 (effective October 1, 2018);

Manitoba, The Human Rights Code, C.C.S.M., c. H175.; Prohibition of discrimination based on "gender identity" and "gender expression": British Columbia, Human Rights Code, RSBC 1996, c. 210.; Alberta Human Rights Act, Revised Statutes of Alberta 2000, Chapter A-25.5.; Ontario, Human Rights Code, R.S.O. 1990, c. H.19; Quebec, Charter of human rights and freedoms, CQLR, c. C-12.; Prince Edward Island, RSPEI 1988, c. H-12.; Nova Scotia, Human Rights Act, RSNS 1989, c. 214.; New Brunswick, Human Rights Act, 2011-c.171.; Newfoundland and Labrador, Human Rights Act, SNL 2010, c. H-13.1.;

15 Egale Canada. (2019). [65 Reasons](#). Egale Canada

It is also vital to note that under Section 2 of the Canadian Human Rights Act,<sup>16</sup> the intent of the document is to ensure that individuals are entitled to “an opportunity equal with other individuals to make for themselves the lives they are able and wish to have.”<sup>17</sup> As such, all intersex individuals deserve to be afforded the same liberties and rights, free from discrimination regardless of their sex characteristics. Section 7 of the Canadian Charter of Rights and Freedoms [see Appendix C] further states that “Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.”<sup>18</sup> <sup>19</sup> Intersex people hold these rights in Canada at this very moment, and the use of non-consensual surgical interventions on intersex infants prevents intersex people from their right to refuse medical treatment. We assert that protecting the right to bodily autonomy for intersex infants is necessary to ensure equal opportunity for intersex people in Canada.

At this time, physicians who perform intersex genital mutilation on intersex infants are protected from criminal liability for aggravated assault under Subsection 268(3) of the Canadian Criminal Code.<sup>20</sup> <sup>21</sup> This exemption implicitly functions to affirm that intersex genital mutilation may fall under a broader category of assault while explicitly stating that medical doctors and physicians who perpetrate the assault are not liable for any of the harm it causes; a contradiction for which the federal government should be held accountable. This law deprives intersex people of their right to bodily autonomy by protecting the doctors who perform irreversible surgeries on their genitals without explicit consent.

## 1.2 Gaps in Intersex Research

The majority of non-medical research regarding intersex people centers concerns about intersex genital mutilation, more specifically, the physical and emotional trauma that intersex people experience as a result of these

<sup>16</sup> See Appendix C for complete section of the Canadian Human Rights Act

<sup>17</sup> Canadian Human Rights Act, 1985, R.S.C., 1985, c. H-6. Section 2: “The purpose of this Act is to extend the laws in Canada to give effect, within the purview of matters coming within the legislative authority of Parliament, to the principle that all individuals should have an opportunity equal with other individuals to make for themselves the lives that they are able and wish to have and to have their needs accommodated, consistent with their duties and obligations as members of society, without being hindered in or prevented from doing so by discriminatory practices based on race, national or ethnic origin, colour, religion, age, sex, sexual orientation, gender identity or expression, marital status, family status, genetic characteristics, disability or conviction for an offence for which a pardon has been granted or in respect of which a record suspension has been ordered.”

<sup>18</sup> Canadian Charter of Rights and Freedoms, s 7, Part 1 of the Constitution Act, 1982, being Schedule B to the Canada Act 1982 (UK), 1982, c 11.

<sup>19</sup> See *R. v. Marmo Levine*, [2003] 3 S.C.R. 571. and *Bedford v. Canada (A.G.)*, [2013] 3 S.C.R. 1101. See paras 75,76.

<sup>20</sup> R.S., 1985, c. C-46, s. 268(1997), c. 16, s. 5, subsection 238(c). Retrieved from <https://laws-lois.justice.gc.ca/eng/acts/c-46/section-268.html>

<sup>21</sup> See Appendix D for complete subsection of the Criminal Code.

non-consensual genital surgeries.<sup>22 23 24</sup> For this reason, the remainder of this literature review will focus upon the ongoing discussions of intersex genital mutilation and provide insights into the experiences of intersex people more generally. Our review of the research literature yielded multiple gaps currently haunting research on intersexuality. While an in-depth discussion of such gaps falls outside of the purview of this review, this section provides a brief overview of these concerning absences in intersex research worth future exploration.

The literature presents a number of **institutional barriers and gaps in research specific to the medical field**, due to the fact that researchers may experience administrative barriers in accessing patient data at an institutional level. Researchers note that they experience challenges due to medical doctors' unwillingness to engage with intersex rights advocates and researchers,<sup>25</sup> and that they experience additional challenges due to the stigma and erasure of or inconsistent language referring to intersex traits in patient charts.<sup>26</sup> A further extension of the erasure of intersexuality across medical research is witnessed in the lack of large-scale population-based health data for intersex people.<sup>27 28</sup> Medical research often relies on the binary of male/female sex classification, leaving intersex people out of research that may concern their intersex traits—researchers note that this is particularly harmful in the field of cancer research.<sup>29</sup> Lastly, greater research is needed to investigate patient-centered models for intersex healthcare.<sup>30</sup> Without research to support these treatment frameworks, doctors are likely to continue using pathologizing models for intersex care.<sup>31 32</sup>

In addition to the research gaps present in the medical field, the literature under review identified a number of areas of concern for **future directions in socio-cultural research and advocacy toward intersex rights**. Researchers

22 Jones, C. (2019). Intersex, infertility and the future: Early diagnoses and the imagined life course. *Sociology of Health & Illness*, 42(1), 143-156. doi:10.1111/1467-9566.129902019 p154.

23 Jones further notes that medical research in particular is more likely to center techniques for medical intervention and/or case studies concerning the “results” of intersex genital mutilation.

24 Ghattas, D. (2019) Protecting Intersex People in Europe: A toolkit for law and policymakers. ILGA-Europe and OII-Europe. Retrieved from: <https://www.ilga-europe.org/resources/ilga-europe-reports-and-other-materials/protecting-intersex-people-europe-toolkit> p.16

25 Egale Canada (2020) Knowledge sharing day. Egale Canada. Ottawa, ON.

26 Egale Canada (2020) Knowledge sharing day. Egale Canada. Ottawa, ON.

27 Zeeman, L., Sheriff, N., Brown, K., Mcglynn, N., Mirandola, M., Gios, N., . . . Health4LGBTI Network. (2019). A review of lesbian, gay, bisexual, trans and intersex (LGBTI) health and healthcare inequalities. *European Journal of Public Health*, 29(5), 974-980.p 979

28 This same study simultaneously acknowledged a similar lack in population-based data for transgender communities.

29 Zeeman, L., Sheriff, N., Brown, K., Mcglynn, N., Mirandola, M., Gios, N., . . . Health4LGBTI Network. (2019). A review of lesbian, gay, bisexual, trans and intersex (LGBTI) health and healthcare inequalities. *European Journal of Public Health*, 29(5), 974-980.p 979

30 Dushyant Utamsingh, P., Richman, L., Martin, J. L., Lattanner, M. R., & Chaikind, J. R. (2016). Heteronormativity and practitioner-patient interaction. *Health Communication*, 31(5), 566-574. p566

31 Dushyant Utamsingh, P., Richman, L., Martin, J. L., Lattanner, M. R., & Chaikind, J. R. (2016). Heteronormativity and practitioner-patient interaction. *Health Communication*, 31(5), 566-574. p566

32 Dreger, A. (n.d.). Shifting the Paradigm of Intersex Treatment. Intersex Society of North America. Retrieved from <https://isna.org/pdf/compare.pdf>

suggest that there are large gaps concerning the needs of specific groups under the intersex umbrella. The intersex people most negatively affected by their experiences of medicalization may be less likely to participate in research because of the harm and trauma they have already been exposed to in the medical field.<sup>33</sup> This leads to the creation of a research landscape that does not adequately address the most pressing needs for those who have already experienced medical harm. Researchers further expressed the need for intersex inclusion in larger “LGBTI” or “LGBTQI2S” research, where intersex people are often referenced in an acronym without being meaningfully included in the participant sample. This results in a body of research that appears to be inclusive of intersex experience but cannot speak to the needs of intersex people.<sup>34</sup> There is also a distinct lack of current research addressing the specific needs of racialized intersex people in North America. This literature review found this issue to be particularly salient for Black intersex people,<sup>35</sup> as the pathologization of genital difference has historically served as a means to further stratify, scrutinize, and distance Black bodies from whiteness.<sup>36</sup> Notably, there was no research available across this scan that spoke specifically to the experiences of Indigenous or Two Spirit intersex people. This lack of attention extends to intersex advocacy and activism. For instance, Sean Saifa Wall, founder of the *Intersex Justice Project*,<sup>37</sup> notes that

**“the concerns of intersex People of Colour are ignored, and overlooked... we [want] to fight for a space for intersex People of Colour, and specifically... Black intersex leadership in the movement.”<sup>38</sup>**

Each of these concerns point to a broader need for meaningful consultation with and the inclusion of intersex people in research and advocacy that concerns their bodies and rights. The remainder of this review will focus on unpacking the contexts through which intersex people are subject to violence and scrutiny based on their perceived or assigned sex, and on their experiences of non-consensual medical interventions, often including intersex genital mutilation.

33 Ghattas, D. (2019) Protecting Intersex People in Europe: A toolkit for law and policymakers. ILGA-Europe and OII-Europe. Retrieved from: <https://www.ilga-europe.org/resources/ilga-europe-reports-and-other-materials/protecting-intersex-people-europe-toolkit> p.16

34 Jones, T. (2018). Intersex Studies: A Systematic Review of International Health Literature. *SAGE Open*, 8(2). doi:10.1177/2158244017745577 p.10

35 Jones, C. (2019). Intersex, infertility and the future: Early diagnoses and the imagined life course. *Sociology of Health & Illness*, 42(1), 143-156. doi:10.1111/1467-9566.12990 p.154

36 Magubane, Z. (2014). Spectacles and Scholarship: Caster Semenya, Intersex Studies, and the Problem of Race in Feminist Theory. *Signs: Journal of Women in Culture and Society*, 39(3), 761-785. doi:10.1086/674301 p.769

37 The Intersex Justice Project was created to better represent the needs of intersex people of colour.

38 Sean Saifa Wall. (2020). End the war on Black trans lives. Webinar, Transgender Law Centre

## 2.1 Systemic Violence and the Erasure of Intersex People

Some research suggests that approximately 1.7% to 4% of the global population is born with intersex traits,<sup>39 40</sup> understood to be a range of sex characteristics that fall outside of the expected categorization of male or female. These figures are likely conservative<sup>41 42</sup> due to the erasure of intersexuality across western medical traditions.<sup>43</sup> During the 20<sup>th</sup> century, doctors established medical protocols for “normalizing” interventions.<sup>44</sup> These protocols subject intersex infants to invasive, permanent medical and/or surgical interventions to conform their bodies, particularly their genitals, to more closely resemble one of the binary sex categories.<sup>45</sup> As noted above, surgical interventions are often referred to as intersex genital mutilation. Advocates and researchers working toward establishing the rights of intersex people note the explicit harm and trauma resulting from these interventions.<sup>46</sup> It is important to note, however, that people with intersex traits are similarly of varied opinions and needs across intersex advocacy groups.<sup>47 48</sup> Not all people with intersex variations have experienced non-consensual medical interventions. Some people with intersex traits are not disappointed with the results of surgical interventions, while others experience these interventions as embodied trauma.<sup>49 50</sup> There is an urgent need, therefore, to not invoke intersexuality as a monolithic experience or community in research and advocacy alike.

39 Jones, T. (2018). Intersex Studies: A Systematic Review of International Health Literature. *SAGE Open*, 8(2). doi:10.1177/2158244017745577 p.1

40 Office of the High Commissioner for Human Rights (OHCHR), United Nations for LGBT Equality, FREE & EQUAL, Fact Sheet.

41 Jones, T. (2018). Intersex Studies: A Systematic Review of International Health Literature. *SAGE Open*, 8(2). doi:10.1177/2158244017745577 p.1

42 Office of the High Commissioner for Human Rights (OHCHR), United Nations for LGBT Equality, FREE & EQUAL, Fact Sheet.

43 For example, some people who have experienced medical interventions were never informed by their medical doctors or parents about those interventions; some intersex conditions relate to secondary sex characteristics—hormones or chromosomes—and some intersex people may never encounter or pursue tests to determine these characteristics. Further, intersex traits may or may not have been included in patient records.

44 Carpenter, M. (2016). The human rights of intersex people: Addressing harmful practices and rhetoric of change. *Reproductive Health Matters*, 24(47), 74–84. doi:10.1016/j.rhm.2016.06.003 p.75

45 Ammaturo, F. R. (2016). Intersexuality and the ‘Right to Bodily Integrity’: Critical Reflections on Female Genital Cutting, Circumcision, and Intersex ‘Normalizing Surgeries’ in Europe. *Social & Legal Studies*, 25(5), 591–610. P.601

46 Ghattas, D. (2019) Protecting Intersex People in Europe: A toolkit for law and policymakers. ILGA-Europe and OII-Europe. Retrieved from: <https://www.ilga-europe.org/resources/ilga-europe-reports-and-other-materials/protecting-intersex-people-europe-toolkit>

47 InterACT, (n.d.) Tips #4intersex People and Allies Talking to Journalists and Media. Retrieved from: [4intersex.org](http://4intersex.org).

48 Note: Some may consider their intersexuality in the contexts of solidarity movements with LGBTQ2S people, while others do not.

49 Orr, C. E. (2018). Exorcising Intersex and Crippling Compulsory Dyadism (Doctoral dissertation, University of Ottawa, 2018). Ottawa. P.70

50 InterACT, (n.d.) Tips #4intersex People and Allies Talking to Journalists and Media. Retrieved from: [4intersex.org](http://4intersex.org)

**Those working across intersex advocacy hold that people with intersex variations have the right to make their own autonomous decisions regarding their bodies and lived gender.** Academic and institutional support for the rights of intersex people to make their own autonomous decisions regarding medical intervention is growing.<sup>51 52</sup> Researchers concerned for the safety of intersex children do not position themselves against surgical interventions in cases where intersexuality poses serious risks to the survival of the infant. Their arguments instead speak directly to practices of medically unnecessary “sex normalizing” interventions, or intersex genital mutilation, which represent the majority of such surgeries on infants.<sup>53 54</sup>

At Egale Canada, we follow the lead of intersex researchers, activists, and advocates, asserting that it is not the place of physicians, or any level of government to discern what normal reproductive functions or normal sexual appearance may be in cases where an intersex infant’s health is not at risk. The following sections detail the contexts through which harmful treatment protocols for surgical interventions on intersex infants were created. Further, it examines the greatest concerns for the bodily autonomy of intersex infants across the available literature.

## 2.2 Intersex as Emergency: An Ongoing History of Medical Violence

The standard protocols for the treatment of intersex bodies in North America over the 20<sup>th</sup> century and into the early 21<sup>st</sup> century rely upon the notion of “normalizing processes.”<sup>55 56</sup> It is important to note that while intersex genital mutilation is the current language most commonly used to describe surgical interventions on intersex infants, surgery is often only one component of a broader course of treatments aimed at eradicating intersexuality. This treatment may also include hormone therapies and psychological interventions to ensure intersex infants establish normative gender roles and identities expected of them into their childhood.<sup>57 58</sup>

51 Ferrara, M., & Casper, M. (2018). Genital Alteration and Intersex: A Critical Analysis. *Current Sexual Health Reports*, 10(1-6). p4

52 Jones, T. (2018). Intersex Studies: A Systematic Review of International Health Literature. *SAGE Open*, 8(2). doi:10.1177/2158244017745577 p9-10

53 Cresti, M., Nave, E., & Lala, R. (2018). Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment. *Journal of Bioethical Inquiry*, 15(4), 557-568. doi:10.1007/s11673-018-9880-7 p559

54 Sexual Rights as Human Rights: A Guide for the World Association for Sexual Health Declaration of Sexual Rights

55 Danon, L. M. (2018). Comparing contemporary medical treatment practices aimed at intersex/DSD bodies in Israel and Germany. *Sociology of Health & Illness*, 41(1), 143-164. doi:10.1111/1467-9566.12812 p. 144

56 Ghattas, D. (2019) Protecting Intersex People in Europe: A toolkit for law and policymakers. ILGA-Europe and OII-Europe. Retrieved from: <https://www.ilga-europe.org/resources/ilga-europe-reports-and-other-materials/protecting-intersex-people-europe-toolkit> p.9

57 Danon, L. M. (2018). Comparing contemporary medical treatment practices aimed at intersex/DSD bodies in Israel and Germany. *Sociology of Health & Illness*, 41(1), 143-164. doi:10.1111/1467-9566.12812 p. 144

58 Ghattas, D. (2019) Protecting Intersex People in Europe: A toolkit for law and policymakers. ILGA-Europe and OII-Europe. Retrieved from: <https://www.ilga-europe.org/resources/ilga-europe-reports-and-other-materials/protecting-intersex-people-europe-toolkit> p.9

This course of treatment, the “optimum gender of rearing” (OGR) was established at John’s Hopkins University by Dr. John Money in the 1950’s.<sup>59</sup> The OGR approach emphasizes that the wellness of intersex children and their future social acceptance depends on their attachment to the unambiguous gender identity that is typically associated with the sex they are assigned at birth. For intersex infants, this sex assignment is further concretized, or determined, through surgery. Surgical or medical courses of treatment utilize interventionist approaches<sup>60</sup> to intersex traits, treating these sex characteristics as “an emergency”<sup>61 62 63</sup> that must be resolved immediately. When intersex traits are conceptualized as a “risk,” medical doctors assume that intersex infants will experience more harm if their bodies are not “visibly normal”<sup>64</sup> than they would from the trauma of surgical and medical intervention. However, these approaches center the anxieties of physicians and parents concerned about an intersex infant or child’s genital difference prohibiting their ability to be “visibly normal”<sup>65</sup> over the needs of intersex infants and their eventual adult selves. Interventionist approaches are predicated on the faulty assumption that there is a particular and natural genital appearance to adhere to in the first place,<sup>66 67</sup> and that medical interventions do not cause harm. Comparatively, researchers advocating for intersex rights assert that medical interventions often result in a significant amount of both physical and psychological trauma.<sup>68</sup> Interventionist courses of treatment are still widely used today,<sup>69 70</sup> and medical doctors continue to practice intersex genital mutilation across the world, including in Canada.

Additionally, Magubane (2014) argues that the OGR course of treatment inherently perpetuates racism. They suggest that racism is visible not only in how the studies informing the treatment for intersex traits were exclusively

59 Danon, L. M. (2018). Comparing contemporary medical treatment practices aimed at intersex/DSD bodies in Israel and Germany. *Sociology of Health & Illness*, 41(1), 143-164. doi:10.1111/1467-9566.12812 p. 144

60 Cresti, M., Nave, E., & Lala, R. (2018). Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment. *Journal of Bioethical Inquiry*, 15(4), 557-568. doi:10.1007/s11673-018-9880-7 P.560

61 Holmes, M. M. (2008). Mind the Gaps: Intersex and (Re-productive) Spaces in Disability Studies and Bioethics. *Journal of Bioethical Inquiry*, 5(2-3), 169-181. doi:10.1007/s11673-007-9073-2 p.170

62 Cresti, M., Nave, E., & Lala, R. (2018). Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment. *Journal of Bioethical Inquiry*, 15(4), 557-568. doi:10.1007/s11673-018-9880-7 p.559

63 Ladee-Levy, J. (1984). Ambiguous Genitalia as a Psychosocial Emergency. *European Journal of Pediatric Surgery*, 39(03), 178-181. doi:10.1055/s-2008-1044205

64 Earp, B. D., & Steinfeld, R. (2018). Genital Autonomy and Sexual Well-being. *Current Sexual Health Reports*, 10, 7-17. P.9

65 Ferrara, M., & Casper, M. (2018). Genital Alteration and Intersex: A Critical Analysis. *Current Sexual Health Reports*, 10(1-6). P.3

66 Holmes, M. (2008). Mind the Gaps: Intersex and (Re-productive) Spaces in Disability Studies and Bioethics. *Journal of Bioethical Inquiry*, 5(2-3), 169-181. doi:10.1007/s11673-007-9073-2 P.170

67 Morland, I. (2009)“What Can Queer Theory Do for Intersex?” *GLQ* 15(2):p: 285-312. P.300

68 Ghattas 2013 p17

69 Ammaturo, F. R. (2016). Intersexuality and the ‘Right to Bodily Integrity’: Critical Reflections on Female Genital Cutting, Circumcision, and Intersex ‘Normalizing Surgeries’ in Europe. *Social & Legal Studies*, 25(5), 591-610. P.601

70 Danon, L. M. (2018). Comparing contemporary medical treatment practices aimed at intersex/DSD bodies in Israel and Germany. *Sociology of Health & Illness*, 41(1), 143-164. doi:10.1111/1467-9566.12812 p.144

founded with white, upper-middle class families with access to Johns Hopkins University research,<sup>71</sup> but also in the way that the “emergency” through which intersexuality is framed is predicated on notions of acceptability founded in whiteness. Magubane notes that “the ambiguously gendered white body needed to be corrected to retain its whiteness, whereas [in North America] an ambiguously gendered Black body was seen as confirming the essential biological difference between whites and Blacks.”<sup>72</sup> <sup>73</sup> The *Intersex Justice Project* works to incorporate the complexities of racist and colonial medical history with current movements toward intersex rights and inclusion, emphasizing the necessity for the intersex movement to work in solidarity across other movements, including: reproductive justice, prison abolition, Black liberation, and Indigenous sovereignty.<sup>74</sup>

Other scholars similarly trace the regulation of intersex bodies to the structural violence of colonialism and state-sanctioned racism.<sup>75</sup> <sup>76</sup> The longstanding fear of difference and impulse to control, mitigate, or erase difference can be traced across western medical history, which intersex scholars, feminist theorists, critical race theorists, critical disability studies scholars, and queer and trans studies scholars have argued against and proposed significant challenges to.<sup>77</sup> Disability activism and scholarship has similarly challenged the harmful nature of medical and psycho-social approaches aimed to conform people and their bodies into a society not created for them, rather than working collectively to build a society supportive of all of its members.<sup>78</sup> It is important to acknowledge that at its very core, intersex genital mutilation is a pathologizing and violent intervention that makes visible our society’s refusal to acknowledge, and instead to proactively punish, difference.

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71 Magubane, Z. (2014). Spectacles and Scholarship: Caster Semenya, Intersex Studies, and the Problem of Race in Feminist Theory. *Signs: Journal of Women in Culture and Society*, 39(3), 761-785. doi:10.1086/674301 p.769

72 Magubane, Z. (2014). Spectacles and Scholarship: Caster Semenya, Intersex Studies, and the Problem of Race in Feminist Theory. *Signs: Journal of Women in Culture and Society*, 39(3), 761-785. doi:10.1086/674301 p.781

73 In this same work, Magubane details the ways in which Money’s protocols and scholarship were based on the experiences of white children and affluent parents, as his work was based out of John’s Hopkins

74 <http://www.intersexjusticeproject.org/about-us.html>

75 Magubane, Z. (2014). Spectacles and Scholarship: Caster Semenya, Intersex Studies, and the Problem of Race in Feminist Theory. *Signs: Journal of Women in Culture and Society*, 39(3), 761-785. doi:10.1086/674301 p.769

76 Malatino, H. (2012). Situating Bio Logic, Reconfiguring Sex: Intersexuality and coloniality. In M. Holmes (Ed.), *Critical Intersex*. Ashgate Publishing. P.87, p.91

77 Magubane, Z. (2014). Spectacles and Scholarship: Caster Semenya, Intersex Studies, and the Problem of Race in Feminist Theory. *Signs: Journal of Women in Culture and Society*, 39(3), 761-785. doi:10.1086/674301 p.769

78 Orr, C. E. (2018). *Exorcising Intersex and Crippling Compulsory Dyadism* (Doctoral dissertation, University of Ottawa, 2018). Ottawa.

Orr, C. E. (2018). *Exorcising Intersex and Crippling Compulsory Dyadism* (Doctoral dissertation, University of Ottawa, 2018). Ottawa. P.4

## 2.3 Mental and Physical Health Implications for Intersex People

Intersex rights advocates across various fields of research assert that medical and surgical interventions on intersex children cause “significant trauma and mental health concerns”<sup>79</sup> that are often unaddressed and unacknowledged by medical and paramedical practitioners in the field.

Bodily trauma is the direct result of non-consensual intersex genital mutilation. Intersex infants are subject to surgeries specifically because their bodies do not comply with normative definitions of male or female. The purpose of these interventions is to surgically manipulate their existing genitals to more closely resemble either one of two sets of genitals doctors have deemed acceptable.

Intersex genital mutilation is often irreversible and frequently results in negative impacts upon young people’s health and wellbeing.<sup>80</sup> According to one US study, 30–80% of intersex children undergo one or as many as five surgeries,<sup>81</sup> which reintroduces further bodily trauma throughout their childhood. Surgeries often result in sterilization,<sup>82</sup> <sup>83</sup> incontinence, and scarring,<sup>84</sup> and can reduce an intersex person’s capacity for pleasure<sup>85</sup> <sup>86</sup> or complicate intimate relations for other reasons.<sup>87</sup> Although surgical interventions have severe implications, medical practitioners consider them to be a worthwhile cost compared to the possibility of living in a body that falls outside of the normative sex/gender binary.<sup>88</sup>

In addition to the physical trauma that intersex people endure when they are subjected to non-consensual genital mutilation, intersex people experience undue hardship and shame as a direct result of these interventions. Among other difficulties, these experiences often result in depression<sup>89</sup> and potential lack of trust in medical systems, among other difficulties. Further, the medical interventions that people with intersex variations are subject to

79 Ghattas, D. (2019) Protecting Intersex People in Europe: A toolkit for law and policymakers. ILGA-Europe and OII-Europe. Retrieved from: <https://www.ilga-europe.org/resources/ilga-europe-reports-and-other-materials/protecting-intersex-people-europe-toolkit> p13

80 Jones, T. (2018). Intersex Studies: A Systematic Review of International Health Literature. *SAGE Open*, 8(2). doi:10.1177/2158244017745577 p9

81 Holmes, M., & Hunt, R. (2011). Intersex Health. Retrieved from Rainbow Health Ontario website: [https://www.rainbowhealthontario.ca/wp-content/uploads/woocommerce\\_uploads/2014/08/Intersex.pdf](https://www.rainbowhealthontario.ca/wp-content/uploads/woocommerce_uploads/2014/08/Intersex.pdf)

82 Carpenter, M. (2016). The human rights of intersex people: Addressing harmful practices and rhetoric of change. *Reproductive Health Matters*, 24(47), 74–84. doi:10.1016/j.rhm.2016.06.003 p.75

83 Ross, L. J. (2017). Reproductive Justice as Intersectional Feminist Activism. *Souls*, 19(3), 286–314. doi:10.1080/10999949.2017.1389634 p.291

84 Cresti, M., Nave, E., & Lala, R. (2018). Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment. *Journal of Bioethical Inquiry*, 15(4), 557–568. doi:10.1007/s11673-018-9880-7 p.560

85 Sexual Rights as Human Rights: A Guide for the World Association for Sexual Health Declaration of Sexual Rights

86 Morland, I. (2009). “What Can Queer Theory Do for Intersex?” *GLQ* 15(2): 285–312. P.300

87 Danon, L. M. (2018). Comparing contemporary medical treatment practices aimed at intersex/DSD bodies in Israel and Germany. *Sociology of Health & Illness*, 41(1), 143–164. doi:10.1111/1467-9566.12812 p.144

88 Earp, B. D., & Steinfeld, R. (2018). Genital Autonomy and Sexual Well-being. *Current Sexual Health Reports*, 10, 7–17. P.9

89 Cresti, M., Nave, E., & Lala, R. (2018). Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment. *Journal of Bioethical Inquiry*, 15(4), 557–568. doi:10.1007/s11673-018-9880-7

results in the erasure of intersexuality throughout policy and across legal and cultural spheres.<sup>90</sup>

Discrimination in healthcare access persists throughout an intersex person's lifetime. Medical doctors lack the skills and knowledge of how to treat intersex bodies, and intersex people may experience prejudice or demeaning behavior when seeking medical supports.<sup>91</sup> Zeeman et al. attribute the lack of knowledge about both physical intersex traits and the appropriate language to use when discussing or speaking to intersex patients to heteronormativity<sup>92</sup> within healthcare settings.<sup>93</sup>

When the Intersex Society of North America (ISNA) was established, activists were given a platform to express the harm caused by non-consensual surgeries. They asserted that they experienced

**“secrecy, shame and social alienation, all of which... medical policy aimed to prevent with surgery interventions.”<sup>94</sup>**

**It is important to distinguish the difference between the harm caused specifically by the non-consensual treatment of intersex traits and the harm that intersex people experience because of the stigma that exists culturally.<sup>95</sup>**

While one may inform the other, intersex advocates speak to the specific psychic harms of surgical intervention. One scholar writes,

**“I was teased *not* because of intersex characteristics that remained after surgery but specifically because of scars *caused* by surgery.”<sup>96</sup>**

Research suggests that some intersex people who have experienced non-consensual surgery in their early lives report being unhappy with the results of their surgeries.<sup>97</sup> Non-consensual surgeries can also result in an intersex person's body not coinciding with their lived gender, or their interest in how

90 Monro, S., Crocetti, D., & Yeadon-Lee, T. (2019). Intersex/variations of sex characteristics and DSD citizenship in the UK, Italy and Switzerland. *Citizenship Studies*, 23(8), 780-797. doi:10.1080/13621025.2019.1645813 p.782

91 Zeeman, L., Sheriff, N., Brown, K., Mcglynn, N., Mirandola, M., Gios, N., . . . Health4LGBTI Network. (2019). A review of lesbian, gay, bisexual, trans and intersex (LGBTI) health and healthcare inequalities. *European Journal of Public Health*, 29(5), 974-980. P.976

92 See glossary

93 Zeeman, L., Sheriff, N., Brown, K., Mcglynn, N., Mirandola, M., Gios, N., . . . Health4LGBTI Network. (2019). A review of lesbian, gay, bisexual, trans and intersex (LGBTI) health and healthcare inequalities. *European Journal of Public Health*, 29(5), 974-980. P.976

94 Danon, L. M. (2018). Comparing contemporary medical treatment practices aimed at intersex/DSD bodies in Israel and Germany. *Sociology of Health & Illness*, 41(1), 143-164. doi:10.1111/1467-9566.12812 p.144

95 Zeeman, L., Sheriff, N., Brown, K., Mcglynn, N., Mirandola, M., Gios, N., . . . Health4LGBTI Network. (2019). A review of lesbian, gay, bisexual, trans and intersex (LGBTI) health and healthcare inequalities. *European Journal of Public Health*, 29(5), 974-980. P.976

96 Morland, Iain. 2009. "What Can Queer Theory Do for Intersex?" *GLQ* 15(2): 285-312. P.301

97 Cresti, M., Nave, E., & Lala, R. (2018). Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment. *Journal of Bioethical Inquiry*, 15(4), 557-568. doi:10.1007/s11673-018-9880-7 p.656

their gender might appear.<sup>98</sup> Zeeman and colleagues report that intersex people show a raised incidence of suicide attempts and suicidal ideation, with 19% of respondents having experienced a suicide attempt and 60% having experienced suicidal ideation, compared to 3% in cisgender, dyadic, and heterosexual populations.<sup>99</sup> Here, it is vital to note that the harm and suffering that people with intersex traits experience are a direct result of structural and material failures to protect their bodily autonomy. These statistics do not represent qualities inherent to intersex people, they are a direct result of the violence perpetrated on their bodies. Similarly, we must consider the ways in which people with intersex traits exist outside of such medical and cultural pain and suffering, living their lives with resilience, pride, and dignity despite medical and cultural stigma.

There is substantial evidence that non-consensual surgeries on intersex infants cause harm and there is a notable dearth of research that presents the therapeutic benefits of these interventions.<sup>100</sup> For this reason, Egale implores decision-making bodies across the fields of medicine, public policy, education, and criminal justice systems to reflect on the consequences of intersex genital mutilation: the trauma, violation, lack of trust, stigma, physical pain, erasure of experience, and suffering that intersex people are subject to as a result of non-consensual and medically unnecessary surgical interventions on their bodies.

## 2.4 Medical Mismanagement and Parental Consent

Today, medical practitioners have been inflating the necessity for medical intervention as required for an infant's health or the perceived psycho-social implications of living in an intersex body. Though unnecessary, doctors continue pressing for surgery in cases where it is not of vital concern for a child's health and wellbeing.<sup>101 102</sup> Scholars across the field of intersex studies note that:

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98 Diamond, M., and J. Garland. 2014. Evidence regarding cosmetic and medically unnecessary surgery on infants. *Journal of Pediatric Urology* 10(1): 2–7.

99 Zeeman, L., Sheriff, N., Brown, K., McGlynn, N., Mirandola, M., Gios, N., . . . Health4LGBTI Network. (2019). A review of lesbian, gay, bisexual, trans and intersex (LGBTI) health and healthcare inequalities. *European Journal of Public Health*, 29(5), 974–980. P.976

100 Monro, S., Crocetti, D., & Yeadon-Lee, T. (2019). Intersex/variations of sex characteristics and DSD citizenship in the UK, Italy and Switzerland. *Citizenship Studies*, 23(8), 780–797. doi:10.1080/13621025.2019.1645813 p.784

101 Ghattas, D. (2019) Protecting Intersex People in Europe: A toolkit for law and policymakers. ILGA-Europe and OII-Europe. Retrieved from: <https://www.ilga-europe.org/resources/ilga-europe-reports-and-other-materials/protecting-intersex-people-europe-toolkit> p4

102 Earp, B. D., & Steinfeld, R. (2018). Genital Autonomy and Sexual Well-being. *Current Sexual Health Reports*, 10, 7–17.

1. Doctors most often rely on current medical standards for intervention based on Money's "Optimal Gender of Rearing," contrary to the recommendation of intersex advocates and many other practitioners that explicitly support the rights of intersex patients.<sup>103 104</sup>
2. These practitioners may have never encountered, or have explicitly rejected, information about patient-centred approaches to intersex treatment in their training.<sup>105 106</sup>
3. A practitioner's value system may be the dominant social narrative that privileges adhering to strict binary logics of gender and heterosexual norms, often referred to as either "compulsory heterosexuality"<sup>107</sup> or "heteronormativity" in the literature.<sup>108 109 110</sup>

Receiving parental consent is the current standard in medical protocols concerning intersex infants, specifically surgical or other biomedical interventions to conform an intersex infant's body or genitals.<sup>111</sup> **The failure to provide all relevant medical information and documentation that would accurately and completely inform parents when making decisions on behalf of their children does not meet the ethical requirements of informed consent.**<sup>112</sup> As a result, the objective standards of free and informed consent, i.e., informed consent without coercion, misrepresentation, and undue influence,<sup>113</sup> are deeply compromised in a doctor-parent relationship in this setting.

There is supporting evidence that parental decision-making is heavily impacted by the information they receive from medical practitioners.<sup>114</sup> Holmes

103 Danon, L. M. (2018). Comparing contemporary medical treatment practices aimed at intersex/DSD bodies in Israel and Germany. *Sociology of Health & Illness*, 41(1), 143-164. doi:10.1111/1467-9566.12812 p.144

104 Ammaturo, F. R. (2016). Intersexuality and the 'Right to Bodily Integrity': Critical Reflections on Female Genital Cutting, Circumcision, and Intersex 'Normalizing Surgeries' in Europe. *Social & Legal Studies*, 25(5), 591-610 p.601

105 Dushyant Utamsingh, P., Richman, L., Martin, J. L., Lattanner, M. R., & Chaikind, J. R. (2016). Heteronormativity and practitioner-patient interaction. *Health Communication*, 31(5), 566-574. p.566

106 Dreger (n.d.). Shifting the Paradigm of Intersex Treatment. Intersex Society of North America. Retrieved from: <https://isna.org/pdf/compare.pdf>

107 Rich, A. (1980). Compulsory Heterosexuality and Lesbian Existence. *Signs: Journal of Women in Culture and Society*, 5(4), pp.631-660.

108 Ferrara, M., & Casper, M. (2018). Genital Alteration and Intersex: A Critical Analysis. *Current Sexual Health Reports*, 10(1-6). P.1

109 Cresti, M., Nave, E., & Lala, R. (2018). Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment. *Journal of Bioethical Inquiry*, 15(4), 557-568. doi:10.1007/s11673-018-9880-7 p.560

110 See glossary

111 Egale Canada. (2019). [65 Reasons](#). Egale Canada

112 Dickens, B. M. (2018). Management of intersex newborns: Legal and ethical developments. *International Journal of Gynecology & Obstetrics*, 143(2), 255-259. doi:10.1002/ijgo.12573 p.256

113 UN General Assembly, Right of everyone to the enjoyment of the highest attainable standard of physical and mental health : note / by the Secretary-General, Transmits report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Anand Grover, submitted in accordance with Human Rights Council resolution 6/29, 10 August 2009, A/64/272.

114 Ferrara, M., & Casper, M. (2018). Genital Alteration and Intersex: A Critical Analysis. *Current Sexual Health Reports*, 10(1-6) p.4

asserts that a parent's own heterosexist biases are similarly imposed onto the bodies of their intersex children. Holmes further argues that intersex traits are

**“likely to prove unacceptable to most parents”<sup>115</sup> because “what the medical establishment and the parents really fear... is a child who cannot be stamped as ‘straight.’”<sup>116</sup>**

Whether by training, default, or through personal bias, research suggests that western medical doctors hold a vested interest in courses of treatment that “normalize” intersex bodies, either through intersex genital mutilation or other interventions. Further evidence suggests that parental consent is compromised in doctor-parent settings. The unreliability of medical practitioners and parents due to bias, lack of information about intersexuality, along with their lack of personal experiences of intersexuality, cast reasonable ethical doubt concerning the power that they hold to make informed decisions to modify an intersex infant's or child's body.

## 3.1 Intersex Rights: Bodily Autonomy and Intersex Rights

Critical debates regarding the medical management of intersex traits in infants and children highlight the necessity for individual autonomy concerning permanent, involuntary medical and surgical interventions. One specific argument presents children as “future adults,” where the permanence of medical and surgical intervention necessitates an individual's informed and age-appropriate consent.<sup>117 118</sup> This argument suggests that **the autonomy of intersex infants and children should be respected while they are young specifically because their inability to provide informed consent is temporary, while medical and surgical procedures are often permanent.**<sup>119</sup>

Legal scholars and human rights based researchers simultaneously argue that the human rights of intersex infants and children should be protected regardless of their position as “future adults,” with an understanding that **medically**

115 Holmes, M.. (2008). Mind the Gaps: Intersex and (Re-productive) Spaces in Disability Studies and Bioethics. *Journal of Bioethical Inquiry*, 5(2-3), 169-181. doi:10.1007/s11673-007-9073-2 p.171

116 Holmes, M. (1997). Is Growing up in Silence Better than Growing up Different? *Chrysalis: The Journal of Transgressive Gender Identities*, 2(5). p. 7.

117 Ghattas, D. (2019) Protecting Intersex People in Europe: A toolkit for law and policymakers. ILGA-Europe and OII-Europe. Retrieved from: <https://www.ilga-europe.org/resources/ilga-europe-reports-and-other-materials/protecting-intersex-people-europe-toolkit>

118 Earp, B. D., & Steinfeld, R. (2018). Genital Autonomy and Sexual Well-being. *Current Sexual Health Reports*, 10, 7-17. P.7

119 Cresti, M., Nave, E., & Lala, R. (2018). Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment. *Journal of Bioethical Inquiry*, 15(4), 557-568. doi:10.1007/s11673-018-9880-7 p.560

**unnecessary surgical interventions infringes upon the bodily autonomy of young intersex people.**<sup>120</sup> As such, larger debates around the rights, citizenship, and bodily autonomy of children are of vital importance in the discussion of intersex treatment<sup>121</sup> which we unpack further in this document when considering the global contexts of intersex rights. The decisions surrounding a person's sexual and reproductive organs are “*fundamental life choices*”<sup>122</sup> that have permanent impacts on one's expression of personhood with implications in spheres of physical, sexual, and mental health. Because the rights of children are central to these arguments, scholars assert the value of respecting their stakes in irreversible decisions concerning their bodies.<sup>123 124</sup>

As previously discussed, doctors and parents have their own biases and investments surrounding an intersex infant's genital mutilation, but they are not subject to living in a body altered by medical intervention as a result of their decisions. Intersex people are the only people able to make a concrete decision based on their own personal experience and knowledge of their own needs. Cresti (2018), among other scholars, argues that for these reasons, **“postponing interventions on the bodies of intersex individuals is the only scientifically sound and ethical way to ensure that the surgery coincides with each child's gender identity and interests in how [their] body might appear.”**<sup>125 126</sup> This approach mirrors the demands of intersex activists who have maintained the fight for bodily autonomy since the 1990's.<sup>127</sup> Ammaturo (2016) asserts that “the shift from medicalization to juridification of intersexuality can only happen if the [human rights of the] child becomes the focus of attention.”<sup>128</sup> In October 2017, The American Academy of Pediatrics issued a statement recognizing Intersex Awareness Day:

**“Current surgical practices on infants and children with intersex variations lack an evidence base. Human rights violations occur routinely in US hospitals, and elsewhere in the world.”**<sup>129</sup>

120 Monroe, S., Crocetti, D., & Yeadon-Lee, T. (2019). Intersex/variations of sex characteristics and DSD citizenship in the UK, Italy and Switzerland. *Citizenship Studies*, 23(8), 780-797. doi:10.1080/13621025.2019.1645813 p.784

121 Monroe, S., Crocetti, D., & Yeadon-Lee, T. (2019). Intersex/variations of sex characteristics and DSD citizenship in the UK, Italy and Switzerland. *Citizenship Studies*, 23(8), 780-797. doi:10.1080/13621025.2019.1645813 p.784

122 Supreme Court of Canada, Blencoe v. British Columbia (Human Rights Commission), 2000 SCC 44, [2000] 2 S.C.R. 307., Date: 2000-10-05.

123 Earp, B. D., & Steinfeld, R. (2018). Genital Autonomy and Sexual Well-being. *Current Sexual Health Reports*, 10, 7-17. P.7

124 Ammaturo, F. R. (2016). Intersexuality and the 'Right to Bodily Integrity': Critical Reflections on Female Genital Cutting, Circumcision, and Intersex 'Normalizing Surgeries' in Europe. *Social & Legal Studies*, 25(5), 591-610. P.603

125 Diamond, M., and J. Garland. 2014. Evidence regarding cosmetic and medically unnecessary surgery on infants. *Journal of Pediatric Urology* 10(1): 2-7.

126 Earp, B. D., & Steinfeld, R. (2018). Genital Autonomy and Sexual Well-being. *Current Sexual Health Reports*, 10, 7-17. P.7

127 Meoded-Danon, L., Intersex Activists in Israel: Their Achievements and the Obstacles They Face, *Bioethical Inquiry*, 2018, 15: 569-578, at p. 569

128 Ammaturo, F. R. (2016). Intersexuality and the 'Right to Bodily Integrity': Critical Reflections on Female Genital Cutting, Circumcision, and Intersex 'Normalizing Surgeries' in Europe. *Social & Legal Studies*, 25(5), 591-610. P.603

129 American Academy of Pediatrics statement on Intersex Awareness Day, 27 October 2017, available at: <https://intersexday.org/en/aap-statement-2017/>

In 2017, InterACT and Human Rights Watch released a formal report on intersex genital mutilation, *“I Want to Be Like Nature Made Me”: Medically Unnecessary Surgeries on Intersex Children in the US*. In this document, InterACT offers a comprehensive list of recommendations to various political and legislative offices, medical regulatory bodies, and research institutes. Their recommendations stress the prohibition of non-consensual intersex genital mutilation on intersex infants, intersex community involvement in decision-making concerning ethical and legal standards for human research, and the further encouragement of formal inquiries into the practice of medically unnecessary surgeries on intersex infants.<sup>130</sup>

Community-focused academic researchers and community activists nearly unanimously support moves to delay permanent decisions about intersex genital surgeries until an intersex person is able to consent to and participate fully in their course of treatment.<sup>131</sup> Research continuously stresses the severe and negative consequences of non-consensual, medically unnecessary intersex genital mutilation. **The sharp focus on eliminating intersex genital mutilation across the literature is indicative of the pressing need for medical researchers and doctors, medical regulatory bodies, and hospitals to take action now** to prohibit non-consensual intersex genital mutilation and to instead offer courses of treatment that best suit the needs of intersex persons.

## 3.2 Global Context: Intersex Human Rights

### The Malta Declaration

The *Malta Declaration* represents “the unanimous demands of the international intersex human rights movement” set at the 3<sup>rd</sup> International Intersex Forum in 2013. The declaration asserts that

**“[members] affirm that intersex people are real, and we exist in all regions and all countries around the world. Thus, intersex people must be supported to be the drivers of social, political and legislative changes that concern them.”<sup>132</sup>**

The declaration calls on international, regional and national governmental bodies and human rights institutions, funding, and media agencies to take action to address the invisibility of intersex human rights issues. The list of 17 demands include improved access to medical records, equal access to

130 Human Rights Watch, & InterACT. (2017). *I Want to Be Like Nature Made Me: Medically Unnecessary Surgeries on Intersex Children in the US* (Rep.) p.154-158

131 Jones, T. (2018). *Intersex Studies: A Systematic Review of International Health Literature*. *SAGE Open*, 8(2). doi:10.1177/2158244017745577 p.9-10

132 Third International Intersex Forum. (2013, December). *Malta Declaration*. Retrieved from <https://oieurope.org/malta-declaration/>

participation in sports, the creation of inclusive government identification, and the depathologizing of intersex traits across medical and social institutions.<sup>133 134</sup>

## The Yogyakarta Principles

The *Yogyakarta Principles* were created in 2006, where human rights experts congregated in Yogyakarta, Indonesia to create a set of international principles regarding sexual orientation and gender identity. In 2017, the document was amended to create a set of principles reflective of the violence specific to gender expression and sex characteristics, created in consultation with experts and community stakeholders, which became *The Yogyakarta Principles + 10*.<sup>135</sup> The additional principles emphasize the right to state protection, legal recognition, freedom from criminalization, and the enjoyment of human rights, among other areas of concern related to sexual orientation, gender identity, gender expression, and sex characteristics.<sup>136</sup>

## The United Nations

In 2013, the UN Special Rapporteur of the Human Rights Council on torture and other cruel, inhuman or degrading treatment or punishment, first acknowledged the existence and harmful consequences of irreversible, involuntary medical treatment to “fix” intersex children.<sup>137</sup> Earlier, the same office reported that

**“medical treatments of an intrusive and irreversible nature, when they lack a therapeutic purpose, or aim at correcting or alleviating a disability, may constitute torture and ill-treatment if enforced or administered without the free and informed consent of the person concerned.”<sup>138</sup>**

At the time, this statement did not recognize concerns specific to intersex genital mutilation. However, the Rapporteur’s statement served to acknowledge the centrality of both free and informed consent in and of medical necessity (i.e., therapeutic purpose) in instances of irreversible medical treatments in an official capacity for the first time on an international level.

133 Third International Intersex Forum. (2013, December). Malta Declaration. Retrieved from <https://oieurope.org/malta-declaration/>

134 See Appendix E

135 International Service for Human Rights and ARC International. (2017, November 10). *The Yogyakarta Principles 10*. Retrieved from [http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5\\_yogyakartaWEB-2.pdf](http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5_yogyakartaWEB-2.pdf)

136 See Appendix F for the principles added in 2017 to reflect the needs of intersex communities

137 UN General Assembly, Torture and other cruel, inhuman or degrading treatment or punishment : note / by the Secretary-General, Report of the Special Rapporteur of the Human Rights Council on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Mendez, submitted in accordance with General Assembly resolution 62/148. 28 February 2013, [A/HRC/22/53](https://www.unhcr.org/refugees/article/48c12121.html)

138 Para 47, at page 11, UN General Assembly, *Torture and other cruel, inhuman or degrading treatment or punishment : note / by the Secretary-General*, Transmits interim report of the Special Rapporteur of the Human Rights Council on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, submitted in accordance with General Assembly resolution 62/148. 28 July 2008, [A/63/175](https://www.unhcr.org/refugees/article/48c12121.html).

Intersex activists and advocates make further arguments that the non-consensual surgical interventions on intersex infants (i.e., intersex genital mutilation) violate a number of articles under the United Nations Convention of the Rights of the Child, specifically Articles 2, 3, 12, 16, 24, and 37.<sup>139 140</sup>

We believe that the perpetuation of violence against intersex people is also in violation of the United Nations Committee Against Torture (UNCAT), and Canada is a signatory member accountable to their work. The UNCAT establishes a positive obligation of the state to:

**“[...] prohibit, prevent and redress torture and ill-treatment in all contexts of custody or control, for example, in prisons, hospitals, schools, institutions that engage in the care of children, the aged, the mentally ill or disabled... and other institutions as well as contexts where the failure of the State to intervene encourages and enhances the danger of privately inflicted harm.”<sup>141</sup>**

In addition to this stated obligation, we assert that the use of non-consensual, medically unnecessary intersex genital mutilation constitutes torture according to the definition set by the UN as it is representative of:

**“Any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for ... any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.”<sup>142</sup>**

The UN Convention on the Rights of Persons with Disabilities provides insights that we believe apply to cases of intersex genital mutilation. While some research explores the commonalities between disabled and intersex populations,<sup>143</sup> both experience violence in the health and medical fields, and discussion across both groups explores themes of personal autonomy.<sup>144</sup> Medical research may frame intersex traits as a collection of disorders, which further contributes to similar experiences of pathologization across both intersex and disabled populations. It is important to note, however, that community-centred literature concerning intersex people rarely uses the language of disability, and intersex individuals may or may not consider their intersex traits a form of disability. The UN Convention on the Rights of Persons with Disabilities

139 Bauer and Truffer 2014 in Monro, S., Crocetti, D., & Yeadon-Lee, T. (2019). Intersex/variations of sex characteristics and DSD citizenship in the UK, Italy and Switzerland. *Citizenship Studies*, 23(8), 780–797. doi:10.1080/13621025.2019.1645813

140 See Appendix G

141 Para 15, UN Committee Against Torture (CAT), General Comment No. 2: Implementation of Article 2 by States Parties, 24 January 2008, CAT/C/GC/2.

142 UN General Assembly, Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, 10 December 1984, United Nations, Treaty Series, vol. 1465, p. 85.

143 Jones, C. (2019). Intersex, infertility and the future: Early diagnoses and the imagined life course. *Sociology of Health & Illness*, 42(1), 143–156. doi:10.1111/1467-9566.12990 p.2

144 Orr, C. E. (2018). Exorcising Intersex and Crippling Compulsory Dyadism (Doctoral dissertation, University of Ottawa, 2018). Ottawa. P.10

directly addresses medical care and informed consent under *Article 25: Health*, and this frame can be mobilized in the protection of intersex infants:

**“Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care”<sup>145</sup>**

*ILGA World’s 2018 Treaty Bodies’ SOGIESC Annual Report* remarked on the increase of mentions of intersex issues across the majority of UN treaty bodies, documenting 74 intersex-inclusive references and 15 stand-alone intersex references.<sup>146</sup> In particular, the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) analysed not only direct medical aspects of the situation of intersex persons such as intersex genital mutilation, but also the broader topic of discrimination.<sup>147</sup> This indicates a shift in attention toward intersex rights across UN treaty bodies.

## 4.0 Conclusion: Future Horizons for Intersex Rights and Justice

At this moment, the Intersex Rights Movement is becoming formally acknowledged as the “next civil rights frontier”<sup>148</sup> as the experiences of violence faced by intersex people become more prevalent on an international human rights level.<sup>149</sup> Eliminating non-consensual intersex genital mutilation is the first and most vital aim of intersex groups and individuals, which has been made clear across the literature. Intersex people in Canada and across North America continue to be subject to non-consensual genital mutilation and/or other medical interventions. These interventions result in both embodied and psychic trauma, for which intersex people receive little support nor restitution for their losses or their suffering. We understand intersex genital mutilation and the subsequent harms that it causes to be a dire human rights concern that must be addressed immediately in Canada.

145 Un General Assembly, The UN Convention on the Rights of Persons with Disabilities, 13 December 2006, p.16

146 International Lesbian, Gay, Bisexual, Trans and Intersex Association: Kirichenko K, Ihler M. *United Nations Treaty Bodies: References to sexual orientation, gender identity, gender expression and sex characteristics: Annual Report 2018* (Geneva: ILGA World, February 2020)

147 International Lesbian, Gay, Bisexual, Trans and Intersex Association: Kirichenko K, Ihler M. *United Nations Treaty Bodies: References to sexual orientation, gender identity, gender expression and sex characteristics: Annual Report 2018* (Geneva: ILGA World, February 2020) p. 17

148 Andrews, Charlotte Richardson. “Why intersexuality will be the next civil rights frontier.” Huck, 14 Apr. 2017, <http://www.huckmag.com/perspectives/intersexuality-will-next-civil-rights-frontier/>. Accessed 18 Apr. 2017.

149 Orr, C. E. (2018). *Exorcising Intersex and Crippling Compulsory Dyadism* (Doctoral dissertation, University of Ottawa, 2018). Ottawa. P.3

Egale Canada calls on all levels of government, medical, and academic institutions to take immediate action to support intersex human rights in Canada. The federal government must immediately repeal Bill 268(3) of the Canadian Criminal Code, which protects medical practitioners from criminal liability for aggravated assault for instances of intersex genital mutilation.<sup>150 151</sup> Similarly, healthcare is governed by provincial regulations, and as such we call on every province and territory to take action to prohibit practices of intersex genital mutilation and to provide sufficient funding and resources toward supports for intersex people.

We simultaneously call on provincial colleges of doctors, midwives, and nurses to mandate comprehensive education regarding patient-centered treatment paradigms for intersex infants and children. Academic researchers and medical doctors in the field have their own role to play in the advocacy for intersex people, including ensuring that intersex populations are meaningfully included in their research whenever relevant. We encourage researchers to move beyond the “moment of intersex 101”<sup>152</sup> into active, meaningful advocacy for intersex rights, and we encourage physicians and medical practitioners to build their treatment protocols around patient-centered approaches to intersex care that necessitates prioritizing the personal autonomy of intersex individuals<sup>153 154</sup>

Egale Canada looks to the leadership of intersex scholars and advocacy groups operating in North America and trans-nationally. We encourage readers to do the same by taking up the work of many intersex-specific advocacy organizations, including InterACT,<sup>155</sup> *Intersex Justice Project*,<sup>156</sup> and Organization Intersex International (OI).<sup>157</sup> Intersex groups connect individuals with incredible amounts of energy, support, and networks of care. These advocacy organizations display both resiliency and meaningful commitment to challenge the normative frameworks that structure how western society regulates gender, sexuality, sex characteristics, medicalization, and the ethics of consent. At Egale, we celebrate the wisdom of all those who work tirelessly for intersex rights advocacy. We will continue our work in solidarity with the intersex movement toward the shared aim of protecting the rights and safety of all people marginalized based on their gender, sexuality, or sex characteristics in Canada and across the globe.

150 R.S., 1985, c. C-46, s. 2681997, c. 16, s. 5, subsection 238(c). Retrieved from <https://laws-lois.justice.gc.ca/eng/acts/c-46/section-268.html>

151 See Appendix D

152 Dr. Morgan Holmes, Egale Knowledge Sharing Day, March 4 2020

153 Cresti, M., Nave, E., & Lala, R. (2018). Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment. *Journal of Bioethical Inquiry*, 15(4), 557-568. doi:10.1007/s11673-018-9880-7

154 Jones, C. (2019). Intersex, infertility and the future: Early diagnoses and the imagined life course. *Sociology of Health & Illness*, 42(1), 143-156. doi:10.1111/1467-9566.12990 p.5

155 <https://interactadvocates.org>

156 <http://www.intersexjusticeproject.org/>

157 <https://oiiinternational.com/>

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- UN General Assembly, *Torture and other cruel, inhuman or degrading treatment or punishment : note / by the Secretary-General*, Report of the Special Rapporteur of the Human Rights Council on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Mendez, submitted in accordance with General Assembly resolution 62/148. 28 February 2013, [A/HRC/22/53](https://www.refworld.org/docid/3ae6b38f0.html)
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Standard of Physical and Mental Health, Anand Grover, submitted in accordance with Human Rights Council resolution 6/29, 10 August 2009, A/64/272.

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# Appendices

## Appendix A – Glossary

### Intersex

Refers to a person whose chromosomal, hormonal, or anatomical sex characteristics fall outside the conventional classifications of male or female.<sup>158 159</sup>

Intersex is not an identity category that anyone can claim,<sup>160</sup> but instead a descriptor of a variety of embodied sex characteristics. 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.<sup>161 162</sup> Physicians may identify intersexuality at birth, where medical practitioners frame intersex traits as a diagnosis requiring correction, while some people may be identified 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.<sup>163</sup>

It is important to note that advocates have identified the term “intersex” as the best language to use to describe this group and we mirror this language across this document, however, “intersex” was “never formally adopted by physicians as a diagnostic term”<sup>164</sup> (see ‘Disorders of Sexual Development’, below).

On occasion, the terms intersexual or intersexuality are also used to describe intersex traits.

### Dyadic

This word is used to describe a person whose chromosomal, hormonal, or anatomical sex characteristics do align with the conventional classifications of male or female. In other words, this term describes those who are not intersex.<sup>165</sup>

158 Egale Canada. (2019). [Glossary of Terms](#). Egale Canada.

159 Cresti, M., Nave, E., & Lala, R. (2018). Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment. *Journal of Bioethical Inquiry*, 15(4), 557-568. doi:10.1007/s11673-018-9880-7 p.558

160 Feder in Morland, Iain. 2009. “What Can Queer Theory Do for Intersex?” *GLQ* 15(2): 285–312. p.295

161 Carpenter, M. (2016). The human rights of intersex people: Addressing harmful practices and rhetoric of change. *Reproductive Health Matters*, 24(47), 74–84. doi:10.1016/j.rhm.2016.06.003 p.74

162 Dr Dreger, A. D., & Herndon, A. M. (2009). PROGRESS AND POLITICS IN THE INTERSEX RIGHTS MOVEMENT: Feminist Theory in Action. *GLQ: A Journal of Lesbian and Gay Studies*, 15(2), 199-224. doi:10.1215/10642684-2008-134 p.200

163 Jones, T. (2018). Intersex Studies: A Systematic Review of International Health Literature. *SAGE Open*, 8(2). doi:10.1177/2158244017745577 p.1

164 Cresti, M., Nave, E., & Lala, R. (2018). Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment. *Journal of Bioethical Inquiry*, 15(4), 557-568. doi:10.1007/s11673-018-9880-7 p.558

165 Egale Canada. (2019). [Glossary of Terms](#). Egale Canada.

## 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.”<sup>166</sup> 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.<sup>167</sup> Pathological categorization is used to justify the normalizing of intersex bodies, leading to further stigma, and medical and social discrimination for intersex people.<sup>168</sup>

## 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.

## Transgender

A person who does not identify either fully or in part with the gender associated with the sex assigned to them at birth—often used as an umbrella term to represent a wide range of gender identities and expressions.<sup>169</sup>

## Cisgender

A person whose gender identity corresponds with the social expectations associated with the sex assigned to them at birth.<sup>170</sup> As an example, cisgender describes a woman who was assigned female at birth, or a man who was assigned male at birth.

166 Danon, L. M. (2018). Comparing contemporary medical treatment practices aimed at intersex/DSD bodies in Israel and Germany. *Sociology of Health & Illness*, 41(1), 143-164. doi:10.1111/1467-9566.12812 p.146

167 Ghattas, D. (2019) Protecting Intersex People in Europe: A toolkit for law and policymakers. ILGA-Europe and OII-Europe. P.20

168 Danon, L. M. (2018). Comparing contemporary medical treatment practices aimed at intersex/DSD bodies in Israel and Germany. *Sociology of Health & Illness*, 41(1), 143-164. doi:10.1111/1467-9566.12812 p.144

169 Egale Canada. (2019). [Glossary of Terms](#). Egale Canada

170 Egale Canada. (2019). [Glossary of Terms](#). Egale Canada

## Sex/Gender Binary

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

## Heteronormativity/Compulsory Heterosexuality

Both of these terms are used to describe the ways that heterosexuality is both implicitly and explicitly treated as the normal or natural ways that humans exist in the world, where alternative ways of existing or embodying difference must be corrected. Lesbian Feminist scholar Adrienne Rich (1980) created the term “compulsory heterosexuality” to encompass the ways in which people that do not fit legibly into expected gender and sexual norms are deemed “deviant to abhorrent or simply rendered invisible”<sup>171 172</sup> across society. Heteronormativity is a term created by Michael Warner (1991), building on the work of Adrienne Rich. It is used to describe how “heterosexuality [exists] as the default, normal, and natural sexual orientation...[P]rivileged as an unalterable ideal to such a degree that it is unmarked and thus may go unnoticed in research practice.”<sup>173</sup> Doctors may inadvertently communicate heteronormative approaches through their everyday practices and interactions with patients.<sup>174</sup>

## 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.<sup>175</sup>

## LGBTQI2S

Egale uses the acronym LGBTQI2S to refer to anyone who is not both heterosexual (i.e., “straight”; a boy who is only attracted to girls, or a girl who is only attracted to boys) and cisgender (someone whose gender matches the binary sex they were assigned at birth). The ‘L’ in LGBTQI2S usually refers to lesbian, the ‘G’ to gay, the ‘B’ to bisexual, the ‘I’ to intersex, the ‘2S’ to Two Spirit. This is one version of an acronym that is often used to refer to a broad

171 Rich, A. (1980). Compulsory Heterosexuality and Lesbian Existence. *Signs: Journal of Women in Culture and Society*, 5(4), pp.631-660.

172 Here, Rich was speaking directly of the experiences of lesbians

173 Kerpen, S., & Marston, K. (2019). Heteronormativity. In P. Atkinson, S. Delamont, A. Cernat, J.W. Sakshaug, & R.A. Williams (Eds.), SAGE Research Methods Foundations. doi: 10.4135/9781526421036767642

174 Dushyant Utamsingh, P., Richman, L., Martin, J. L., Lattanner, M. R., & Chaikind, J. R. (2016). Heteronormativity and practitioner–patient interaction. *Health Communication*, 31(5), 566-574.

175 UN General Assembly, Right of everyone to the enjoyment of the highest attainable standard of physical and mental health : note / by the Secretary-General, Transmits report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Anand Grover, submitted in accordance with Human Rights Council resolution 6/29, 10 August 2009, A/64/272

spectrum of identities related to gender, as well as sexual and romantic attraction. This acronym takes many forms and can include as many letters as: 2SLGBPTTIQQAAS+ and beyond

## **Intersex Genital Mutilation**

Intersex genital mutilation is the term we will be using across this document 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.<sup>176</sup> This language mirrors that which is used by advocates for intersex rights that work in partnership with Egale.

## **Appendix B – Canadian Human Rights Act**

*Sections referenced in the text, as formally written*

### **Short title**

**1** This Act may be cited as the *Canadian Human Rights Act*.  
1976-77, c. 33, s. 1.

Purpose of Act

### **Purpose**

**2** The purpose of this Act is to extend the laws in Canada to give effect, within the purview of matters coming within the legislative authority of Parliament, to the principle that all individuals should have an opportunity equal with other individuals to make for themselves the lives that they are able and wish to have and to have their needs accommodated, consistent with their duties and obligations as members of society, without being hindered in or prevented from doing so by discriminatory practices based on race, national or ethnic origin, colour, religion, age, sex, sexual orientation, gender identity or expression, marital status, family status, genetic characteristics, disability or conviction for an offence for which a pardon has been granted or in respect of which a record suspension has been ordered.

R.S., 1985, c. H-6, s. 2; 1996, c. 14, s. 1; 1998, c. 9, s. 9; 2012, c. 1, s. 137(E); 2017, c. 3, ss. 9, 11, c. 13, s. 1.

<sup>176</sup> Ghattas, D. (2019) Protecting Intersex People in Europe: A toolkit for law and policymakers. ILGA-Europe and OII-Europe. P.9

## PART I

### Proscribed Discrimination

#### General

#### **Prohibited grounds of discrimination**

**3 (1)** For all purposes of this Act, the prohibited grounds of discrimination are race, national or ethnic origin, colour, religion, age, sex, sexual orientation, gender identity or expression, marital status, family status, genetic characteristics, disability and conviction for an offence for which a pardon has been granted or in respect of which a record suspension has been ordered.

#### **Idem**

**(2)** Where the ground of discrimination is pregnancy or child-birth, the discrimination shall be deemed to be on the ground of sex.

#### **Idem**

**(3)** Where the ground of discrimination is refusal of a request to undergo a genetic test or to disclose, or authorize the disclosure of, the results of a genetic test, the discrimination shall be deemed to be on the ground of genetic characteristics.

R.S., 1985, c. H-6, s. 3; 1996, c. 14, s. 2; 2012, c. 1, s. 138(E); 2017, c. 3, ss. 10, 11, c. 13, s. 2.

#### **Multiple grounds of discrimination**

**3.1** For greater certainty, a discriminatory practice includes a practice based on one or more prohibited grounds of discrimination or on the effect of a combination of prohibited grounds.

1998, c. 9, s. 11.<sup>177</sup>

## **Appendix C – Canadian Charter of Rights and Freedoms**

*Sections referenced in text, as formally written*

### Legal Rights

<sup>177</sup> Canadian Human Rights Act, 1985, R.S.C., 1985, c. H-6.

Life, liberty and security of person

7. Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.

Equality Rights

Equality before and under law and equal protection and benefit of law

15. (1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

## Appendix D – Section 268 and 268(3) of the Canadian Criminal Code

*Sections referenced in text, as formally written*

### Aggravated assault

268 (1) Every one commits an aggravated assault who wounds, maims, disfigures or endangers the life of the complainant.

### Punishment

(2) Every one who commits an aggravated assault is guilty of an indictable offence and liable to imprisonment for a term not exceeding fourteen years.

### Excision

(3) For greater certainty, in this section, “wounds” or “maims” includes to excise, infibulate or mutilate, in whole or in part, the labia majora, labia minora or clitoris of a person, except where

(a) a surgical procedure is performed, by a person duly qualified by provincial law to practice medicine, for the benefit of the physical health of the person **or for the purpose of that person having normal reproductive functions or normal sexual appearance or function;** or

(b) the person is at least eighteen years of age and there is no resulting bodily harm.<sup>178</sup>

178 R.S., 1985, c. C-46, s. 268(1997, c. 16, s. 5, subsection 238(c) retrieved from <https://laws-lois.justice.gc.ca/eng/acts/c-46/section-268.html>

## Appendix E – The Declaration of Malta (2013)

This declaration offers the “list of unanimous demands of the intersectional intersex human rights movement”

- To put an end to mutilating and “normalising” practices such as genital surgeries, psychological and other medical treatments through legislative and other means. Intersex people must be empowered to make their own decisions affecting own bodily integrity, physical autonomy and self-determination.
- To put an end to pre-implantation genetic diagnosis, prenatal screening and treatment, and selective abortion of intersex fetuses.
- To put an end to infanticide and killings of intersex people.
- To put an end to non-consensual sterilisation of intersex people.
- To depathologise variations in sex characteristics in medical guidelines, protocols and classifications, such as the World Health Organization’s International Classification of Diseases.
- To register intersex children as females or males, with the awareness that, like all people, they may grow up to identify with a different sex or gender.
- To ensure that sex or gender classifications are amendable through a simple administrative procedure at the request of the individuals concerned. All adults and capable minors should be able to choose between female (F), male (M), non-binary or multiple options. In the future, as with race or religion, sex or gender should not be a category on birth certificates or identification documents for anybody.
- To raise awareness around intersex issues and the rights of intersex people in society at large.
- To create and facilitate supportive, safe and celebratory environments for intersex people, their families and surroundings.
- To ensure that intersex people have the right to full information and access to their own medical records and history.
- To ensure that all professionals and healthcare providers that have a specific role to play in intersex people’s wellbeing are adequately trained to provide quality services.
- To provide adequate acknowledgement of the suffering and injustice caused to intersex people in the past, and provide adequate redress, reparation, access to justice and the right to truth.

- To build intersex anti-discrimination legislation in addition to other grounds, and to ensure protection against intersectional discrimination.
- To ensure the provision of all human rights and citizenship rights to intersex people, including the right to marry and form a family.
- To ensure that intersex people are able to participate in competitive sport, at all levels, in accordance with their legal sex.<sup>179</sup>

## Appendix F – Yogyakarta Principles+10 (2017)

*Additional principles amended in 2017 to explicitly protect on grounds of gender expression and sex characteristics.*

### Principle 30

**THE RIGHT TO STATE PROTECTION:** Everyone, regardless of sexual orientation, gender identity, gender expression or sex characteristics, has the right to State protection from violence, discrimination and other harm, whether by government officials or by any individual or group.

### Principle 31

**THE RIGHT TO LEGAL RECOGNITION:** Everyone has the right to legal recognition without reference to, or requiring assignment or disclosure of, sex, gender, sexual orientation, gender identity, gender expression or sex characteristics. Everyone has the right to obtain identity documents, including birth certificates, regardless of sexual orientation, gender identity, gender expression or sex characteristics. Everyone has the right to change gendered information in such documents while gendered information is included in them.

### Principle 32

**THE RIGHT TO BODILY AND MENTAL INTEGRITY:** Everyone has the right to bodily and mental integrity, autonomy and self-determination irrespective of sexual orientation, gender identity, gender expression or sex characteristics. Everyone has the right to be free from torture and cruel, inhuman and degrading treatment or punishment on the basis of sexual orientation, gender identity, gender expression and sex characteristics. No one shall be subjected to invasive or irreversible medical procedures that modify sex characteristics without their free, prior and informed consent, unless necessary to avoid serious, urgent and irreparable harm to the concerned person.

<sup>179</sup> Third International Intersex Forum. (2013, December). *Malta Declaration*. Retrieved from <https://oieurope.org/malta-declaration/>

### Principle 33

#### **THE RIGHT TO FREEDOM FROM CRIMINALISATION AND SANCTION ON THE BASIS OF SEXUAL ORIENTATION, GENDER IDENTITY, GENDER EXPRESSION, OR SEX CHARACTERISTICS:**

Everyone has the right to be free from criminalisation and any form of sanction arising directly or indirectly from that person's actual or perceived sexual orientation, gender identity, gender expression or sex characteristics.

### Principle 34

**THE RIGHT TO PROTECTION FROM POVERTY:** Everyone has the right to protection from all forms of poverty and social exclusion associated with sexual orientation, gender identity, gender expression and sex characteristics. Poverty is incompatible with respect for the equal rights and dignity of all persons, and can be compounded by discrimination on the grounds of sexual orientation, gender identity, gender expression and sex characteristics.

### Principle 35

**THE RIGHT TO SANITATION:** Everyone has the right to equitable, adequate, safe and secure sanitation and hygiene, in circumstances that are consistent with human dignity, without discrimination, including on the basis of sexual orientation, gender identity, gender expression or sex characteristics.

### Principle 36

#### **THE RIGHT TO THE ENJOYMENT OF HUMAN RIGHTS IN RELATION TO INFORMATION AND COMMUNICATION TECHNOLOGIES:**

Everyone is entitled to the same protection of rights online as they are offline. Everyone has the right to access and use information and communication technologies, including the internet, without violence, discrimination or other harm based on sexual orientation, gender identity, gender expression or sex characteristics. Secure digital communications, including the use of encryption, anonymity and pseudonymity tools are essential for the full realisation of human rights, in particular the rights to life, bodily and mental integrity, health, privacy, due process, freedom of opinion and expression, peaceful assembly and association.

### Principle 37

**THE RIGHT TO TRUTH:** Every victim of a human rights violation on the basis of sexual orientation, gender identity, gender expression or sex characteristics has the right to know the truth about the facts, circumstances and reasons why the violation occurred. The right to truth includes effective, independent and impartial investigation to establish the facts, and includes all forms of

reparation recognised by international law. The right to truth is not subject to statute of limitations and its application must bear in mind its dual nature as an individual right and the right of the society at large to know the truth about past events.

## Principle 38

### **THE RIGHT TO PRACTISE, PROTECT, PRESERVE AND REVIVE CULTURAL**

**DIVERSITY:** Everyone, individually or in association with others, where consistent with the provisions of international human rights law, has the right to practise, protect, preserve and revive cultures, traditions, languages, rituals and festivals, and protect cultural sites of significance, associated with sexual orientation, gender identity, gender expression and sex characteristics. Everyone, individually or in association with others, has the right to manifest cultural diversity through artistic creation, production, dissemination, distribution and enjoyment, whatever the means and technologies used, without discrimination based on sexual orientation, gender identity, gender expression or sex characteristics. Everyone, individually or in association with others, has the right to seek, receive, provide and utilise resources for these purposes without discrimination on the basis of sexual orientation, gender identity, gender expression or sex characteristics.

*Other more general state obligations or amendments to previously included principles can also be found in this document.<sup>180</sup>*

## **Appendix G – The UN Declaration of the Rights of the Child (1988)**

*Sections referenced in text: articles 2, 3, 12, 16, 24, and 37, as formally written*

### **Article 2**

1. States parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.
2. States Parties shall take all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians, or family members.

<sup>180</sup> International Service for Human Rights and ARC International. (2017, November 10). *The Yogyakarta Principles 10*. Retrieved from [http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5\\_yogyakartaWEB-2.pdf](http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5_yogyakartaWEB-2.pdf)

### **Article 3**

1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.
2. States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.
3. States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.

### **Article 12**


1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

### **Article 16**

1. No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence, nor to unlawful attacks on his or her honour and reputation.
2. The child has the right to the protection of the law against such interference or attacks.

### **Article 24**

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

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2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:
    - a. To diminish infant and child mortality;
    - b. To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;
    - c. To combat disease and malnutrition, including within the framework of primary health care, through, inter alia, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;
    - d. To ensure appropriate prenatal and post-natal health care for mothers;
    - e. To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents;
    - f. To develop preventive health care, guidance for parents and family planning education and services.
  3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.
  4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.

### **Article 37**

States Parties shall ensure that:

- a. No child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment. Neither capital punishment nor life imprisonment without possibility of release shall be imposed for offences committed by persons below eighteen years of age;
- b. No child shall be deprived of his or her liberty unlawfully or arbitrarily. The arrest, detention or imprisonment of a child shall be in conformity with the law and shall be used only as a measure of last resort and for the shortest appropriate period of time;

- c. Every child deprived of liberty shall be treated with humanity and respect for the inherent dignity of the human person, and in a manner which takes into account the needs of persons of his or her age. In particular, every child deprived of liberty shall be separated from adults unless it is considered in the child's best interest not to do so and shall have the right to maintain contact with his or her family through correspondence and visits, save in exceptional circumstances;
- d. Every child deprived of his or her liberty shall have the right to prompt access to legal and other appropriate assistance, as well as the right to challenge the legality of the deprivation of his or her liberty before a court or other competent, independent and impartial authority, and to a prompt decision on any such action.<sup>181</sup>

## Appendix H – Gaps in Intersex Research

The needs of intersex people across health, social supports, and research more generally are unique, and this scan of literature offers a number of specific gaps in research for intersex people:

1. **Researchers experience administrative barriers in accessing patient data at the institutional level, which leads to gaps in understandings about the medicalization of intersex people.**<sup>182</sup> Doctors / Institutions often unwilling to work with intersex scholars or advocates, often citing patient safety and confidentiality concerns.<sup>183</sup> This perpetuates a harmful cycle with no accountability, where further violence is enabled behind closed doors.
2. **There is a lack of current research addressing the specific needs of racialized intersex people, noticeable particularly in the areas of “(in) fertility” research,<sup>184</sup> and in how race and nation are addressed in feminist intersex scholarship.**<sup>185</sup> This is especially concerning because of the ways that the pathologizing of genital difference, and medicine more broadly, have historically served as a means to further stratify, scrutinize, and distance Black bodies from whiteness, a trend visible in texts as early as 1863.<sup>186</sup>

181 UN General Assembly, *Convention on the Rights of the Child*, 20 November 1989, United Nations, Treaty Series, vol. 1577, p. 3, available at: <https://www.refworld.org/docid/3ae6b38f0.html>

182 Egale Canada (2020) Knowledge sharing day. Egale Canada. Ottawa, ON.

183 Egale Canada (2020) Knowledge sharing day. Egale Canada. Ottawa, ON.

184 Jones, C. (2019). Intersex, infertility and the future: Early diagnoses and the imagined life course. *Sociology of Health & Illness*, 42(1), 143-156. doi:10.1111/1467-9566.129902019 p.154

185 Cresti, M., Nave, E., & Lala, R. (2018). Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment. *Journal of Bioethical Inquiry*, 15(4), 557-568. doi:10.1007/s11673-018-9880-7p761

186 Magubane, Z. (2014). Spectacles and Scholarship: Caster Semenya, Intersex Studies, and the Problem of Race in Feminist Theory. *Signs: Journal of Women in Culture and Society*, 39(3), 761-785. doi:10.1086/674301 p.769

3. **There is a need for large-scale population research addressing the general health and cancer-specific health for both trans and intersex people.**<sup>187</sup> Intersex people are erased from medical literature that distinctly categorizes bodies into a male/female binary, which can cause a significant lack of information specific to the health of intersex people.
4. **There are large gaps in research considering the needs of intersex people most negatively affected by their experiences of medicalization.**<sup>188</sup> Ghattas suggests that the harm and trauma intersex people experience lead the “most negatively affected by medical treatments [un]willing to take part”<sup>189</sup> in research.<sup>190</sup>
5. **Ensure that research operating with a larger LGBTQI2S umbrella includes intersex people.** LGBTQI2S research that does not adequately represent intersex experience results in a pool of research that appears inclusive of intersex experience that cannot speak directly to the needs of the community.<sup>191</sup>
6. **Further gaps in research about the medicalization of intersex people due to inconsistent language and stigma across the field.** Medical interventions and treatment protocols most commonly used attempt to erase or eradicate evidence of intersexuality, both on the body and in medical documentation.<sup>192</sup>
7. **The field of intersex research itself may exacerbate gaps in research.** Scholars across disciplines use different theoretical lenses to evaluate the needs of intersex people and set advocacy priorities.<sup>193</sup> This points to the potential value of building opportunities for cross-disciplinary scholarship specific to intersex rights<sup>194</sup>.
8. **Greater research is needed to investigate patient-centered models for intersex care.**<sup>195</sup> Without research to support these treatment frameworks,

187 Zeeman, L., Sheriff, N., Brown, K., Mcglynn, N., Mirandola, M., Gios, N., . . . Health4LGBTI Network. (2019). A review of lesbian, gay, bisexual, trans and intersex (LGBTI) health and healthcare inequalities. *European Journal of Public Health*, 29(5), 974–980. P.979

188 Ghattas, D. (2019) Protecting Intersex People in Europe: A toolkit for law and policymakers. ILGA-Europe and OII-Europe. Retrieved from: <https://www.ilga-europe.org/resources/ilga-europe-reports-and-other-materials/protecting-intersex-people-europe-toolkit> p.16

189 Ghattas, D. (2019) Protecting Intersex People in Europe: A toolkit for law and policymakers. ILGA-Europe and OII-Europe. Retrieved from: <https://www.ilga-europe.org/resources/ilga-europe-reports-and-other-materials/protecting-intersex-people-europe-toolkit> p.16

190 Ghattas, D. (2019) Protecting Intersex People in Europe: A toolkit for law and policymakers. ILGA-Europe and OII-Europe. Retrieved from: <https://www.ilga-europe.org/resources/ilga-europe-reports-and-other-materials/protecting-intersex-people-europe-toolkit> p.16

191 Jones, T. (2018). Intersex Studies: A Systematic Review of International Health Literature. *SAGE Open*, 8(2). doi:10.1177/2158244017745577 p.10

192 Egale Canada (2020) Knowledge sharing day. Egale Canada. Ottawa, ON.

193 Jones, T. (2018). Intersex Studies: A Systematic Review of International Health Literature. *SAGE Open*, 8(2). doi:10.1177/2158244017745577 p.2

194 Egale Canada (2020) Knowledge sharing day. Egale Canada. Ottawa, ON.

195 Jones, T. (2018). Intersex Studies: A Systematic Review of International Health Literature. *SAGE Open*, 8(2). doi:10.1177/2158244017745577 p.10

doctors are likely to continue using pathologizing models for intersex care.<sup>196</sup> <sup>197</sup> Researchers further noted the importance of long-term follow-up and counselling options for services that do work to address the above issue.<sup>198</sup>

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196 Dushyant Utamsingh, P., Richman, L., Martin, J. L., Lattanner, M. R., & Chaikind, J. R. (2016). Heteronormativity and practitioner–patient interaction. *Health Communication, 31*(5), 566–574. P.566

197 Dreger, A. (n.d.). Shifting the Paradigm of Intersex Treatment. Intersex Society of North America. Retrieved from <https://isna.org/pdf/compare.pdf>

198 Zeeman, L., Sheriff, N., Brown, K., McGlynn, N., Mirandola, M., Gios, N., . . . Health4LGBTI Network. (2019). A review of lesbian, gay, bisexual, trans and intersex (LGBTI) health and healthcare inequalities. *European Journal of Public Health, 29*(5), 974–980.p 979

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