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Judicial Affairs and Education Committee
Parliament of Iceland

November 2, 2020



HRW.org

RE: Protecting the rights of children with variations in their sex characteristics

Dear Committee Members:

We understand your committee is considering a bill to amend the Act on Sexual Autonomy (2019 no. 80), which would protect the rights of children with variations in their sex characteristics, including through regulating the practice of medically unnecessary, irreversible surgeries. We commend you for this positive step toward engaging and protecting a vulnerable and long-marginalized community and urge you to ensure this legislation is in line with international human rights standards.

As you may know, the fundamental rights of children born with variations in their sex characteristics have been the subject of extensive analysis in recent years. This letter intends to outline the considerations international human rights bodies have deemed essential to protect this population from harm.

Variations in sex characteristics—sometimes called intersex or differences of sex development—is an umbrella term that refers to a range of natural variations of sex characteristics that differ from social norms. Human Rights Watch uses these terms interchangeably. As many as 1.7 percent of babies have bodies that are different from those of a “typical” boy or a girl. Their chromosomes, gonads, internal or external genitalia in these children differ from social expectations.

Around the world, these children are often subjected to medically unnecessary, irreversible “normalizing” surgeries before they are old enough to consent. These surgeries, such as operations to remove gonads, reduce the size of the clitoris, increase the size of the vagina, or re-position the urethra, are high-risk and medically unnecessary. Except in very rare cases, babies born with these variations in sex traits are born healthy—just different.¹

Based on a now-discredited medical theory popularized in the United States in the 1960s and spread throughout the world, some doctors continue to perform medically unnecessary “normalizing” surgeries on children with variations in their sex characteristics—typically in infancy. The results are often catastrophic, and the supposed benefits are largely unproven. Human rights

¹ For further analysis, please see Human Rights Watch’s 2017 report: Human Rights Watch, “‘I Want to Be Like Nature Made Me’: Medically Unnecessary Surgeries on Intersex Children in the US,” <https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us>.

institutions that have considered these surgeries have condemned them as a human rights violation, and a growing number of health and medical bodies have also criticized the practice.

While certain surgical interventions on intersex children are undisputedly medically necessary, such as when a child cannot pass urine, the majority of intersex infants are born healthy. Some of the unnecessary surgeries can sterilize the intersex person, usually before a child is old enough to give meaningful consent, and result in otherwise unnecessary lifelong hormone replacement therapy. Operations undertaken to alter the size or appearance of infants' genitals can cause incontinence, scarring, lack of sensation, and psychological trauma equivalent to that experienced by childhood sexual abuse victims.² These surgical procedures are irreversible. Genital or gonadal surgeries on children too young to declare their gender identity carry the risk of surgically assigning the wrong sex, as has been documented in the medical literature.³

In 2020, 35 states, including Iceland, issued a joint statement to the United Nations Human Rights Council, asserting: "We call on governments as a matter of urgency, to protect the autonomy of intersex adults and children and their rights to health, and to physical and mental integrity so that they live free from violence and harmful practices."⁴

We hope the information included in this letter and annex, which sets out the international human rights law guidance from relevant expert human rights bodies, will encourage you to pass the legislation before you and ensure the rights of children with variations in their sex characteristics in Iceland are protected.

Sincerely,



Måns Molander
Nordic Director
Human Rights Watch



Graeme Reid
Lesbian, Gay, Bisexual, and Transgender Rights Director
Human Rights Watch

² John Money, "Genital Examinations and Exposure Experienced as Nonsocomial Sexual Abuse in Childhood." *The Journal of Nervous and Mental Disease* Vol. 175(12): pp. 713-721.

³ See, e.g., Ieuan Hughes et al., *Consensus Statement on Management of Intersex Disorders*, 91 ARCHIVES OF DISEASE IN CHILDHOOD 554 (2006) (recognizing rates of gender assignment rejection up to 40 percent); P.S. Furtado et al., *Gender Dysphoria Associated with Disorders of Sex Development*, NAT. REV. UROL. (October 9, 2012), available at: doi:10.1038/nrurol.2012.182 (reporting rates of gender assignment rejection up to 20 percent); A. Binet et al., *Should We Question Early Feminizing Genitoplasty for Patients with Congenital Adrenal Hyperplasia and XX Karyotype?*, *Journal of Pediatric Surgery* 51:3: 465-468 (2016) (reporting that 14 percent of CAH patients in this study had a gender identity different from the sex assigned at birth).

⁴ Statement by the Kingdom of the Netherlands, Follow-up and implementation of the Vienna Declaration and Programme of Action General Debate - Item 8, October 1, 2020, <https://www.permanentrepresentations.nl/permanent-representations/pr-un-geneva/documents/speeches/2020/10/1/united-nations-human-rights-council---45th-session>.

Annex

Legal Protections for Children with Intersex Variations

In 2015, Malta became the first country in the world to legally ban non-consensual medically unnecessary surgeries on intersex children. Under the heading of the “Right to bodily integrity and physical autonomy,” Malta’s law states:

It shall be unlawful for medical practitioners or other professionals to conduct any sex assignment treatment and/or surgical intervention on the sex characteristics of a minor which treatment and/or intervention can be deferred until the person to be treated can provide informed consent.⁵

The law specifies that it is illegal to perform a “medical intervention which is driven by social factors without the consent of the minor” and that in cases where the child requests surgical procedures, the government must “ensure that the best interests of the child as expressed in the Convention on the Rights of the Child be the paramount consideration.”

Emerging Health and Human Rights Consensus

In 2013, the World Health Organization (WHO) publicly opposed unnecessary genital surgeries on intersex children in its report, “Eliminating forced, coercive and otherwise involuntary sterilization,” stating:

Intersex persons, in particular, have been subjected to cosmetic and other nonmedically necessary surgery in infancy, leading to sterility, without informed consent of either the person in question or their parents or guardians.⁶

In the United States, where the paradigm of conducting early unnecessary “normalizing” surgeries was popularized, health and human rights organizations have in recent years begun advocating for an end to the practice. In 2016, after reviewing the available medical and ethics literature, the American Medical Association (AMA) Board of Trustees issued a report urging deferral of surgery until individuals can consent.⁷ GLMA: Health Professionals Advancing LGBTQ Equality, a US-based organization, also passed a policy in 2016 recommending deferral of surgeries until the individual can offer informed consent for themselves.⁸ The North American Society for Pediatric and Adolescent Gynecology issued its policy recommending delay of non-emergency surgeries in 2017.⁹ The American Academy of Family Physicians, one of the oldest and largest organizations in the US, made a similar recommendation in 2018.¹⁰

⁵ Government of Malta, “Gender Identity, Gender Expression and Sex Characteristics Act,” <http://justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=12312&l=1>.

⁶ WHO, OHCHR, UN Women, UNAIDS, UNDP, UNFPA, and UNICEF, “Eliminating forced, coercive and otherwise involuntary sterilization,” May 2014, http://www.who.int/reproductivehealth/publications/gender_rights/eliminating-forced-sterilization/en/

⁷ American Medical Association House of Delegates, Report of Reference Committee on Amendments to Constitution and Bylaws, i-16, <https://assets.ama-assn.org/sub/meeting/documents/i16-ref-comm-conby.pdf>.

⁸ GLMA, “Medical and Surgical Interventions of Patients with Differences of Sex Development,”

<http://glma.org/index.cfm?fuseaction=document.viewdocument&ID=CEB9FEE4B8DD8B7F4F7575376BD476C3A433379DD853BEA17913AFCCB8270299C0731320B03D2F5E1022F1C15602FBEA>

⁹ NASPAG, “NASPAG Position Statement on Surgical Management of DSD,”

https://cdn.vmeaws.com/www.naspag.org/resource/resmgr/pdfs/NASPAG_Statement_on_DSD_PES_.pdf

¹⁰ The American Academy of Family Physicians, “Genital Surgeries on Intersex Children,” <https://www.aafp.org/about/policies/all/genital-surgeries-intersexchildren.html>.

In July 2017, three former US surgeons-general, including one who was a pediatric endocrinologist, wrote to oppose early unnecessary surgeries because “there is insufficient evidence that growing up with atypical genitalia leads to psychosocial distress,” and “the surgery itself can cause severe and irreversible physical harm and emotional distress.”¹¹

In a 2017 statement, Physicians for Human Rights, an international NGO, said:

Carrying out an irreversible and medically unnecessary surgery before a child is old enough to meaningfully consent violates informed consent requirements, and flies in the face of the central medical ethics principle to, first and foremost, do no harm.¹²

Deferring medically unnecessary surgeries has also been endorsed by a consensus group of physicians in the European Union,¹³ the Council of Europe Committee on Bioethics,¹⁴ and the Parliamentary Assembly of the Council of Europe.¹⁵ In 2018, a European Parliament resolution stated that the parliament: “Strongly condemns sex-normalising treatments and surgery; welcomes laws that prohibit such surgery, as in Malta and Portugal, and encourages other Member States to adopt similar legislation as soon as possible.”¹⁶

Torture and Other Cruel, Inhuman, and Degrading Treatment

The UN Committee against Torture, the independent international monitoring body for the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, has condemned medically unnecessary non-consensual surgeries on intersex infants six times.¹⁷ Iceland ratified the treaty in 1996.

The Committee’s critiques ranged from concerns over “cases where gonads have been removed and cosmetic surgeries on reproductive organs have been performed that entail lifelong hormonal medication without effective, informed consent of the concerned individuals or their legal

¹¹ M. Joycelyn Elders, David Satcher, and Richard Carmona, “Re-Thinking Genital Surgeries on Intersex Infants,” *The Palm Center*, June 2017, <http://www.palmcenter.org/wp-content/uploads/2017/06/Re-Thinking-Genital-Surgeries-1.pdf>

¹² Physicians for Human Rights, “Unnecessary Surgery on Intersex Children Must Stop,” October 20, 2017, <http://physiciansforhumanrights.org/press/press-releases/intersex-surgery-must-stop.html>

¹³ “Caring for individuals with a difference of sex development (DSD): a Consensus Statement,” July 2018, <https://www.ncbi.nlm.nih.gov/pubmed/29769693>.

¹⁴ Council of Europe, “Study on the rights of children in biomedicine,” 2017, <https://www.coe.int/en/web/children/-/study-on-the-rights-of-children-in-biomedicine>.

¹⁵ PACE, “Promoting the human rights of and eliminating discrimination against intersex people,” <http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=24232&>.

¹⁶ European Parliament, European Parliament resolution on the rights of intersex people (2018/2878(RSP)), http://www.europarl.europa.eu/doceo/document/B-8-2019-0101_EN.pdf?redirect.

¹⁷ The UN Committee against Torture, which reviews state compliance with the Convention against Torture, has referenced several articles in its analysis of intersex surgeries. These are: article 2 (legislative, administrative, judicial or other measures to prevent acts of torture), article 10 (education and information regarding the prohibition against torture included in the training of... medical personnel), article 12 (systematic review [of] methods and practices with a view to preventing any cases of torture), article 14 (legal redress for torture) and article 16 (prevention of acts of cruel, inhuman or degrading treatment) in its analysis of intersex surgeries. Some patterns emerge in the committee’s critique of state practices and recommendations for action. Committee against Torture, Concluding observations of the Committee against Torture, Germany, CAT/C/DEU/CO/5, December 12, 2011; Committee against Torture Concluding observations on the seventh periodic report of Switzerland, CAT/C/CHE/CO/7, September 7, 2015; Committee against Torture Concluding observations on the sixth periodic report of Austria, CAT/C/AUT/CO/6, January 27, 2016; Committee against Torture Concluding observations on the fifth periodic report of China with respect to Hong Kong, China, CAT/C/CHN-HKG/CO/5, February 3, 2016; Committee against Torture Concluding observations on the combined sixth and seventh periodic reports of Denmark, CAT/C/DNK/CO/6-7, February 4, 2016; Committee against Torture, Concluding observations on the seventh periodic report of France, CAT/C/FRA/CO/7, June 10, 2016).

guardians,” to cases in which “intersex children are subjected to unnecessary and irreversible surgery to determine their sex at an early stage.”

In a 2013 report, the UN Special Rapporteur on torture noted:

Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, “in an attempt to fix their sex,” leaving them with permanent, irreversible infertility and causing severe mental suffering.¹⁸

Children’s Rights

Iceland ratified the Convention on the Rights of the Child (CRC) in 1992. The Committee on the Rights of the Child, which oversees implementation of the convention, has condemned surgery on intersex children 17 times, including in reviews of New Zealand,¹⁹ South Africa,²⁰ Switzerland,²¹ Chile,²² France,²³ Ireland,²⁴ the UK,²⁵ Nepal,²⁶ Denmark,²⁷ Spain,²⁸ Argentina,²⁹ Belgium,³⁰ Italy,³¹ Malta,³² Portugal,³³ Australia,³⁴ and Austria.³⁵

Regarding the rights of children with intersex traits, the Committee has called on governments to guarantee “the rights of children to bodily integrity, autonomy and self-determination, and provide families with intersex children with adequate counselling and support.” In its country reviews, the Committee repeatedly references a 2014 joint General Comment with the Committee

¹⁸ United Nations Human Rights Council, “Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Juan E. Méndez,” A/HRC/22/53, February 1, 2013.

¹⁹ United Nations Committee on the Rights of the Child, “Concluding observations on the fifth period report of New Zealand,” CRC/C/NZL/CO/5, September 30, 2016.

²⁰ United Nations Committee on the Rights of the Child, “Concluding observations on the second periodic report of South Africa,” CRC/C/ZAF/CO/2, September 30, 2016.

²¹ United Nations Committee on the Rights of the Child, “Concluding observations on the combined second to fourth periodic reports of Switzerland,” CRC/C/CHE/CO/2-4, February 26, 2015.

²² United Nations Committee on the Rights of the Child, “Concluding observations on the combined fourth and fifth periodic reports of Chile,” CRC/C/CHL/CO/4-5, October 30, 2015.

²³ United Nations Committee on the Rights of the Child, “Concluding observations on the fifth periodic report of France,” CRC/C/FRA/CO/5, 29 January 29, 2016.

²⁴ United Nations Committee on the Rights of the Child, “Concluding observations on the combined third and fourth periodic reports of Ireland,” CRC/C/IRL/CO/3-4, January 29, 2016.

²⁵ United Nations Committee on the Rights of the Child, “Concluding observations on the fifth periodic report of the United Kingdom of Great Britain and Northern Ireland,” CRC/C/GBR/CO/5, June 3, 2016.

²⁶ United Nations Committee on the Rights of the Child, “Concluding observations on the third to fifth periodic reports of Nepal,” CRC/C/NPL/CO/3-5, June 3, 2016.

²⁷ United Nations Committee on the Rights of the Child, “Concluding observations on the fifth periodic report of Denmark,” CRC/C/DNK/CO/5, October 26, 2017.

²⁸ United Nations Committee on the Rights of the Child, “Concluding observations on the combined fifth and sixth periodic reports of Spain,” CRC/C/ESP/CO/5-6, February 2, 2018.

²⁹ United Nations Committee on the Rights of the Child, “Concluding observations on the combined fifth and sixth periodic reports of Argentina,” CRC/C/ARG/CO/5-6, October 1, 2018.

³⁰ United Nations Committee on the Rights of the Child, “Concluding observations on the combined fifth and sixth reports of Belgium,” CRC/C/BEL/CO/5-6, February 1, 2019.

³¹ United Nations Committee on the Rights of the Child, “Concluding observations on the combined fifth and sixth periodic reports of Italy,” CRC/C/ITA/CO/5-6, February 1, 2019.

³² United Nations Committee on the Rights of the Child, “Concluding observations on the combined third to sixth periodic reports of Malta,” CRC/C/MLT/CO/3-6, June 26, 2019.

³³ United Nations Committee on the Rights of the Child, “Concluding observations on the combined fifth and sixth periodic reports of Portugal,” CRC/C/PRT/CO/5-6, December 9, 2019.

³⁴ United Nations Committee on the Rights of the Child, “Concluding observations on the combined fifth and sixth periodic reports of Portugal,” CRC/C/PRT/CO/5-6, December 9, 2019.

³⁵ United Nations Committee on the Rights of the Child, “Concluding observations on the combined fifth and sixth periodic reports of Austria,” CRC/C/AUT/CO/5-6, March 6, 2020.

on the Elimination of Discrimination against Women, which calls on states parties to: “ensure that no-one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to children concerned, and provide families with intersex children with adequate counselling and support.”³⁶

Women’s Rights

Iceland ratified the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) in 1985. The CEDAW Committee has in several instances criticized governments for not protecting the rights of children born with intersex traits.

For example, in its 2016 review of the Netherlands, the Committee raised concern about “[m]edically irreversible sex-assignment surgery and other treatments [that] are performed on intersex children” and recommended that the government “[d]evelop and implement a rights-based health-care protocol for intersex children which ensures that children and their parents are properly informed of all options and that children are, to the greatest extent possible, involved in decision-making about medical interventions and that their choices are fully respected.”³⁷

In its 2016 review of Switzerland, the CEDAW Committee condemned “[t]he pressure placed on parents of intersex children by medical professionals, the media and society at large,” which “often forces them to give their consent for so called ‘medical procedures’ justified by psychosocial indications.” The Committee called on the government to ensure that no child is subjected to unnecessary medical treatment, and medical professionals receive training on the harmful impact of unnecessary surgical interventions on intersex children.³⁸

Right to Bodily Autonomy

The Committee on the Rights of Persons with Disabilities has commented eight times on medically unnecessary surgeries on intersex children. The Committee found these surgeries to be a violation of the integrity of the person and exploitation, violence and abuse under the Convention on the Rights of Persons with Disabilities (CRPD).³⁹ Iceland ratified the CRPD in 2016.

For example, in its 2016 review of Chile, the CRPD Committee urged the government to ensure free and informed consent for “especially those [procedures] of an invasive nature and whose effects are irreversible, such as sterilization and procedures on intersex children.”⁴⁰ In its 2016 review of Italy, the Committee called on the government to “guarantee bodily integrity, autonomy and self-determination to the children concerned, and provide families with intersex children with adequate counselling and support.”⁴¹

³⁶ Joint general recommendation No. 31 of the United Nations Committee on the Elimination of Discrimination against Women/general comment No. 18 of the Committee on the Rights of the Child on harmful practices, CEDAW/C/GC/31-CRC/C/GC/18.

³⁷ United Nations Committee on the Elimination of Discrimination against Women, “Concluding observations on the sixth periodic report of the Netherlands,” CEDAW/C/NLD/CO/6, November 18, 2016.

³⁸ United Nations Committee on the Elimination of Discrimination against Women, “Concluding observations on the combined fourth and fifth periodic reports of Switzerland,” CEDAW/C/CHE/CO/4-5, November 18, 2016.

³⁹ International Convention on the Protection and Promotions of the Rights and Dignity of Persons with Disabilities, G.A. Res. 61/106, Annex I, U.N. GAOR, 61st Sess., Supp. No. 49, at 65, U.N. Doc. A/61/49 (2006), *entered into force* May 3, 2008.

⁴⁰ United Nations Committee on the Rights of Persons with Disabilities. “Concluding observations on the initial report of Chile,” CRPD/C/CHL/CO/1, April 13, 2016.

⁴¹ United Nations Committee on the Rights of Persons with Disabilities, “Concluding observations on the initial report of Italy,” CRPD/C/ITA/CO/1, August 31, 2016.

In its 2019 review of India, the Committee urged the government to: “Adopt measures to prevent sex-assignment or ‘sex-normalizing’ surgery, stigmatization and bullying against intersex children and ensure their right to respect for their physical and mental integrity.”⁴²

Right to Health and Informed Consent

Human Rights Watch considers medically unnecessary surgeries on intersex children to interfere with the right to the highest attainable standard of health. While the technical aspects of some of these procedures have evolved and improved, there remains no evidence that these surgeries are necessary or that the ostensible medical benefits outweigh the harms.

In a 2009 report, the UN Special Rapporteur on the right to health said that “[h]ealth-care providers should strive to postpone non-emergency invasive and irreversible interventions until the child is sufficiently mature to provide informed consent,” noting that “[t]his is particularly problematic in the case of intersex genital surgery, which is a painful and high-risk procedure with no proven medical benefits.”⁴³

The Committee on Economic, Social and Cultural Rights (CESCR) has indicated that the International Covenant on Economic, Social and Cultural Rights (ICESCR) proscribes any discrimination in access to health care and the underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of sexual orientation and gender identity.⁴⁴ Iceland ratified the ICESCR in 1979. The CESCR Committee emphasized in its General Comment 14 that:

The right to health contains both freedoms and entitlements. The freedoms include the right to control one’s health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation.⁴⁵

In its 2017 review of Australia, the CESCR Committee said it was “concerned that children born with intersex variations are subject to early surgeries and medical interventions before they are able to provide full and informed consent.”⁴⁶ In its 2017 review of the Netherlands, the Committee expressed concern over the “[p]ractice of early surgeries and medical interventions on intersex children, that are not necessary for physical health and alters their sex characteristics, [and] do not respect their right to free, prior and informed consent.”⁴⁷

Informed consent is a fundamental aspect of medical ethics—protected by international human rights law and enshrined in medical standards.

⁴² United Nations Committee on the Rights of Persons with Disabilities, “Concluding observations on the initial report of India,” CRPD/C/IND/CO/1, October 29, 2019.

⁴³ United Nations Human Rights Council, “Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Juan E. Méndez.”

⁴⁴ International Covenant on Economic, Social and Cultural Rights, G.A. res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 49, U.N. Doc. A/6316 (1966), 993 U.N.T.S. 3, *entered into force* January 3, 1976.

⁴⁵ United Nations Committee on Economic, Social and Cultural Rights, “General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12),” <http://www.refworld.org/pdfid/4538838d0.pdf>.

⁴⁶ United Nations Committee on Economic, Social and Cultural Rights, “Concluding Observations on Australia, June 23, 2017,” E/C.12/AUS/CO/5.

⁴⁷ United Nations Committee on Economic, Social and Cultural Rights, “Concluding Observations on the Netherlands, June 23, 2017,” E/C.12/NLD/CO/6.

The Universal Declaration on Bioethics and Human Rights, issued by UNESCO in 2005, outlines ethical issues related to medicine and the life sciences, and provides a framework of principles and procedures to guide states when they formulate policies in the field of bioethics. It states: “Any preventive, diagnostic and therapeutic medical intervention is only to be carried out with the prior, free and informed consent of the person concerned, based on adequate information.”⁴⁸

In a 2009 report to the UN General Assembly, the Special Rapporteur on the right to health stated: “Guaranteeing informed consent is fundamental to achieving the enjoyment of the right to health,” emphasizing that governments are required to “ensure that information is fully available, acceptable, accessible and of good quality,” and that information should be “imparted and comprehended by means of supportive and protective measures such as counselling and involvement of community networks.”⁴⁹

⁴⁸ United Nations Education, Scientific and Cultural Organization (UNESCO), “Universal Declaration on Bioethics and Human Rights,” October 19, 2005, http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html

⁴⁹ United Nations, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, A/64/272, August 10, 2009, <https://documents-dds-ny.un.org/doc/UNDOC/GEN/N09/450/87/PDF/N0945087.pdf?OpenElement>