interACT
Advocates for Intersex Youth
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Office of the United Nations
High Commissioner for Human Rights (OHCHR)
Palais Wilson - 52, rue des Pâquis
CH-1201 Geneva (Switzerland)

February 4, 2022

RE: To inform the Independent Expert's report to be presented to the 50th Session of the United Nations Human Rights Council re: SDG 3

Dear Mr. Victor Madrigal-Borloz,

I write on behalf of interACT: Advocates for Intersex Youth, formerly known as Advocates for Informed Choice, an independent human rights NGO based in the United States. It is the first organization in the country exclusively dedicated to advocacy on behalf of children born with variations in their sex characteristics. interACT offers the following submission and applauds your consideration of the rights of LGBTQI persons affected by violence and discrimination to the enjoyment of the highest attainable standard of physical and mental health.

I. Issue Summary

The term "intersex" refers to variations in a person's sex characteristics, including chromosomes, genitals, hormone production, and internal organs, such that their body does not fit typical definitions of male or female. It is an umbrella term that includes many different medical diagnoses, as well as variations in sex characteristics without a diagnosable etiology. Conservative estimates of the frequency of intersex births are between one in 1,000 and one in 2,000, while higher estimates reach up to 1.7 percent.[1]

Intersex people in the United States continue to suffer human rights abuses that are inadequately addressed, causing deep mental and physical harm, with a recent US study indicating over 43% of intersex participants had fair/poor physical health and 53% reporting fair/poor mental health.[2] Three in 5 LGBTQ+ intersex individuals have avoided doctors' offices to avoid experiencing discrimination.[3] This is because their normal, healthy variations in human development are only rarely related to direct health risks, yet this population faces documented (but under-studied) health and social disparities driven by stigma, discrimination, and medical trauma.[4]

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[1] Blackless, M., et al., How Sexually Dimorphic Are We? Review and Synthesis, Am. J. Hum. Biol. 12:151 (2000).
[2] Rosenwohl-Mack A, et al., A national study on the physical and mental health of intersex adults in the U.S., *PLoS ONE* 5(10):e0240088 (2020).
[3] Caroline Medina et al., Key Issues Facing People With Intersex Traits (Center for American Progress, 2021), https://www.americanprogress.org/article/key-issues-facing-people-intersex-traits/
[4] Zeeman, L., & Aranda, K., A Systematic Review of the Health and Healthcare Inequalities for People with Intersex Variance, *Int. J. Environ. Res. Public Health*, 17:6533 (2020); National Academies, *Understanding the Well-Being of LGBTQI+ Populations*, (Washington, DC: National Academies Press

"Normalizing" surgeries are often performed to alter the genitals or remove the gonads of these children, typically before age two—absent any evidence of medical need, and with lifelong impacts on health, fertility, and function.[5] These children thus experience unnecessary interventions to make their bodies more closely conform to the sex assignment chosen for them by their parents or doctors, causing life-long physical and psychological pain, resulting in these interventions being deemed torture by multiple international human rights bodies. Despite ongoing calls from some within the US medical community to address the human rights of this population,[6] intersex people continue to suffer lasting harm.

II. History and Current Practices in the United States

In the U.S., the "treatment" paradigm of coercively altering intersex children's sex traits originated in the 1960s with psychologist John Money. Dr. Money believed that individual gender identity was malleable in infancy and that a child could be reared either male or female if their genitals were modified to "match" that sex assignment – and if the child was never told the truth about their body. Money tested this theory on a young boy named David Reimer whose penis was badly damaged in a circumcision accident, advising the parents to raise the child as a girl instead with the help of "feminizing" genital surgery. Known as the "John/Joan case," Money's experiment was believed to be a success and became the basis for the surgical alteration of intersex infants' bodies. Early surgery and secrecy were considered paramount if the child was to "accept" their assigned sex category. In the 1990s, Money's experiment was exposed as a failure – David Reimer had rejected his surgically-enforced female assignment, transitioned to male, and would later commit suicide. The practices inspired by his theory, however, continued to be carried out on intersex children, and they remain common even today.

A child who is deemed in infancy to be intersex or to have atypical sex characteristics is usually assigned a sex based on some combination of their genital anatomy, gonads, chromosomes, and other test results such as hormonal response. Surgeries are often performed – most commonly under the age of two – to make the child's body conform more closely to notions of what is typical for either male or female bodies. For children assigned female, these may include surgeries to enlarge or create a vaginal opening, to reduce the size of the clitoris, or to reduce or reshape the labia. For children assigned male, surgeries to relocate the urethral meatus and create a more "typical"-looking phallus are common. In either case, gonads and other internal organs may be removed if they are

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2020); Price, M.N., et al., *The mental health and well-being of LGBTQ youth who are intersex* (The Trevor Project, 2021), https://www.thetrevorproject.org/research-briefs/the-mental-health-and-well-being-of-lgbtq-youth-who-are-intersex dec-2021/

[5] Human Rights Watch, *"I Want to be Like Nature Made Me": Medically Unnecessary Surgeries on Intersex Children in the US* (2017), https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us; Amnesty International, *First, Do No Harm: Ensuring the Rights of Children Born Intersex* (2017), https://www.amnesty.org/en/latest/campaigns/2017/05/intersex-rights/.

[6] Grimstad F, Kremen J, Streed CG Jr, Dalke KB. The Health Care of Adults with Differences in Sex Development or Intersex Traits Is Changing: Time to Prepare Clinicians and Health Systems. LGBT Health. 2021 Oct;8(7):439-443. doi: 10.1089/lgbt.2021.0018. Epub 2021 Jun 30. PMID: 34191611.

not typical of the sex assigned (e.g., testes in a female-assigned child with Androgen Insensitivity Syndrome). However, intersex children, like all children, may grow up to identify with a gender other than the one in which they were raised. When this occurs, gender dysphoria may compound the irreversible damage done by procedures that altered the appearance and function of their bodies without their consent. Depending on the intersex trait, the chance that the child will ultimately not identify with their initially assigned sex ranges from 5 to over 60 percent.[7] Even when gender assignment rejection does not occur, there are many serious and documented risks associated with non-consensual medical interventions on intersex children, including scarring, chronic pain, urinary incontinence, loss of sexual sensation, loss of reproductive potential, PTSD, depression, and the need for lifelong hormone replacement therapy.

Much of the "treatment" performed on intersex individuals by physicians in the U.S. has already been recognized as torture.[8] Procedures where intersex children's gonads or other organs are removed without their consent can be sterilizing. Coerced sterilization can constitute torture and CIDT, and states' obligations to protect persons from such treatment extends into the private sphere, including where such practices are committed by private individuals. Further, the U.N. Committee on the Rights of the Child has addressed involuntary sterilization of persons with disabilities under the age of 18 as a form of violence, in violation of the child's right to physical integrity, causing life-long effects on physical and mental health. The Committee has called upon States to prohibit by law the involuntary sterilization of children on grounds of disability. No exception has been mentioned for children whose medical condition happens to cause atypical sex characteristics.

In addition to sterilization, many serious and documented risks accompany non-consensual medical interventions on intersex children. Removal of hormone-producing gonads often requires that the individual be placed onto lifelong hormone replacement therapy. Genital surgeries risk the irreversible loss of sexual sensation and function, urinary incontinence, and chronic pain.[1] Any procedure that alters a child's sex traits to conform to what is typical for the assigned sex enhances the risks of assigning a sex that doesn't match their gender identity.[2] Depending on the intersex diagnosis, the probability of assigning a sex with which the individual will not identify ranges from 5 up to 60 percent.[3] In the case of female genital mutilation (FGM), which encompasses the clitoral reduction surgeries carried out on many female-assigned intersex children,[4] the United Nations Special Rapporteur on Torture (SRT) has specifically pointed out that where this is performed in private clinics and physicians carrying out the procedure are not being prosecuted, the State de facto consents to the practice and is therefore accountable.[5] However, we are unaware of any jurisdiction in the U.S. that enforces FGM laws in cases where the girl undergoing clitoral cutting has an intersex trait.

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[7] P.S. Furtado et al., *Gender Dysphoria Associated with Disorders of Sex Development*, 9 Nat. Rev. Urol. 620 (Nov. 2012) (reporting average rates of gender dysphoria at 57% for 17-beta-HSD3 deficiency and 63% for 5-alpha-RD2 deficiency).

[8] Tamar-Mattis A, *Medical Treatment of People with Intersex Conditions as Torture and Cruel, Unhuman, or Degrading Treatment or Punishment* in Torture in Healthcare Settings: reflections on the Special rapporteur on Torture's 2013 Thematic report.

III. Response from the Medical Community in the United States

Following the actions of the SRT, the Societies for Pediatric Urology published a paper concerning their "standpoint on the surgical management" of intersex traits. They recognized that non-consensual and unnecessary interventions on intersex children have been classified as torture but nevertheless failed to call for a ban on such surgeries, instead stating that more information must be gathered and that surgery could be justified "to restore more normal visible anatomy, and avoid ambiguity which is often the parents' wish."[9] However, these subjective considerations cannot be ethical justifications for such surgery on nonconsenting individuals. Intersex advocates additionally pointed out that the urologists' paper "significantly understate[d] reported catastrophic outcomes including complete loss of sexual sensation, psychological trauma and PTSD, sterilization, and irreversible surgical restructuring of genitals not appropriate to the eventual gender identity."[10]

Thereafter, in 2015, the World Health Organization, UNICEF, OHCHR, UN Women, UNAIDS, UNDP and UNFPA explained, intersex children "are often subjected to cosmetic and other non-medically indicated surgeries performed on their reproductive organs, without their informed consent or that of their parents, and without taking into consideration the views of the children involved [...] As a result, such children are being subjected to irreversible interventions that have lifelong consequences for their physical and mental health."[11] The statement called for accountability, participation, and access to remedies for intersex people.

In 2016, a group of prominent physicians published a statement on the treatment of intersex children, and again failed to call for an end to these surgeries despite their recognition of "a number of agencies condemning or calling for a complete moratorium on elective genital surgery or gonadectomy without the individual's informed consent" and that "many guidelines deem children's participation and input indispensable to decisions, especially those that will have a life-long deeply personal impact on their lives, with heightened awareness that young children, in particular, may not be able to vocalize adverse reactions to many interventions."[12] The paper instructed physicians treating intersex patients merely to "be aware that the trend in recent years has been for legal and human rights bodies to increasingly emphasize preserving patient autonomy." However,

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[9] Mouriquand P., Caldamone A., Malone P., Frank J.D., Hoebeke P. *The ESPU/SPU Standpoint on the Surgical Management of Disorders of Sex Development (DSD)*, 10 JOURNAL OF PEDIATRIC UROLOGY 8 (2014).

[10] Anne Tamar-Mattis, *Patient Advocate Responds to DSD Surgery Debate*, 10 JOURNAL OF PEDIATRIC UROLOGY 788 (2014).

[11] WORLD HEALTH ORGANIZATION, *Eliminating forced, coercive or otherwise involuntary sterilization: An interagency statement* (OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO) (2014), available at: http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf?ua=1.

[12] Lee PA, Nordenström A, Houk CP, *Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care*, Hormone Research in Pediatrics 158-180 (2016). Available at: http://www.karger.com/Article/FullText/442975.

in direct defiance of preserving patient autonomy, medically unnecessary and non-consensual interventions on the sex traits of intersex children continue today.[13]

Physicians in support of the current paradigm argue there must be additional research prior to a change in practice, yet intersex patient advocates point out that there has never been sufficient research to show either that these surgeries benefit patients or that there is any harm from growing up with atypical genitals. Proponents of performing unnecessary surgery in childhood often rely on the presumed stigma and psychological distress related to having a body that may be considered atypical as justifications for operating before the individual can give informed consent. The *Journal of Pediatric Urology* published an article asserting that while "surgery has been restrictively considered by some to be 'cosmetic surgery,' the cosmetic aspect of genitalia and the related stigma risk are also important issues for many patients." One article cited "maintenance of ambiguous genital anatomy and its unknown psychological ramifications" as a disadvantage of not operating on intersex children's genitalia." Yet, recent research shows intersex children who are growing up *without* medically unnecessary surgery are not showing signs of psychological distress or expressing concerns related to their unaltered genitals, suggesting that such "justifications" for surgery are more reflective of doctors' and parents' concerns than those of the intersex individual.[14]

IV. Conclusion

Despite international condemnation from bodies including the World Health Organization, Amnesty International, multiple committees of the United Nations, and the explicit classification of intersex surgery as torture under several frameworks of human rights abuse, the non-consensual surgeries inflicted on intersex individuals in the U.S. continue in flagrant violation of intersex peoples' right to life free from violence and discrimination and to the enjoyment of the highest attainable standard of physical and mental health.

Sincerely,

Alesdair H. Ittelson, JD
Director of Law & Policy
interACT: Advocates for Intersex Youth

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[13] Diamond, D., Swartz, J., Tishelman, A., et al., *Management of pediatric patients with DSD and ambiguous genitalia: Balancing the child's moral claims to self-determination with parental values and preferences*, Journal of Pediatric Urology (2018) available at file:///Users/alissaweinberger/Downloads/1-s2.0-S1477513118302225-main.pdf.

[14] Bougneres P, Bouvattier C, Cartigny M, Michala L. Deferring surgical treatment of ambiguous genitalia into adolescence in girls with 21-hydroxylase deficiency: a feasibility study. International Journal of Pediatric Endocrinology. 2017;2017(3). doi: 10.1186/s13633-016-0040-8; Callens N, van der Zwan YG, Drop SLS, et al. Do surgical interventions influence psychosexual and cosmetic outcomes in women with disorders of sex development? ISRN Endocrinology. 2012:1-8. doi: 10.5402/2012/276742.