

Protecting Informed Choice for Intersex Children: What Medical Experts Say

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People with variations in sex characteristics may comprise as much as 1.7% of the population,¹ and face documented but understudied health and social disparities.² Variations in sex characteristics are normal, healthy variations in human development that are only rarely related to immediate health concerns that would require immediate surgical intervention. Yet “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.³ Here’s what medical experts are saying about these practices and the rights of intersex children:

National Academies of Sciences, Engineering, and Medicine: “Overall, there is mixed evidence that surgery achieves its physical goals and scant evidence that it confers psychosocial benefit. The existing research does provide strong evidence of the risk of irreversible harm from early genital surgery, including immediate postoperative complications and later revisions, as well as the potentially catastrophic risk of incorrect, surgically reinforced gender assignment. ... Factoring in the human rights of children and evidence that individuals with diverse sexualities, bodies, and genders can and do thrive with affirmation and support from parents, peers, and communities, there is insufficient evidence of benefit to justify early genital surgery. Therefore, the deferral of surgery until a child can participate in the decision, except in scenarios with urgent medical need, such as urinary obstruction or immediate cancer risk, may optimize the benefits of informed consent, autonomy, and patients’ physical, social, and emotional well-being. ... **CONCLUSION 12-13:** Conversion therapy to change sexual orientation or gender identity and elective genital surgeries on children with intersex traits who are too young to participate in consent are dangerous to the health and well-being of sexual and gender diverse people.”⁴

American Academy of Family Physicians: “The American Academy of Family Physicians (AAFP) opposes medically-unnecessary genital surgeries performed on intersex children. Many intersex children are subjected to genitalia-altering surgeries in infancy and early childhood without their consent or assent. The surgery can lead to decreased sexual function and increased substance use disorders and suicide. Scientific evidence does not support the notion that variant genitalia confer a greater risk of psychosocial problems. ... Genital surgeries should only be recommended for intersex infants and children for the purpose of resolving significant functional impairment or removing imminent and substantial risk of developing a health- or life-threatening condition.”⁵

Former U.S. Surgeons General M. Joycelyn Elders, David Satcher and Richard Carmona: “When an individual is born with atypical genitalia that pose no physical risk, treatment should focus not on surgical intervention but on psychosocial and educational support for the family and child. Cosmetic genitoplasty should be deferred until children are old enough to voice their own view about whether to undergo the

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* 15(10):e0240088 (2020); 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).

³ 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/>.

⁴ National Academies of Sciences, Engineering, and Medicine. 2020. *Understanding the Well-Being of LGBTQI+ Populations*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/25877>.

⁵ American Academy of Family Physicians, *Genital Surgeries in Intersex Children* (2018 July BOD) <https://www.aafp.org/about/policies/all/genital-surgeries.html>.

surgery. Those whose oath or conscience says ‘do no harm’ should heed the simple fact that, to date, research does not support the practice of cosmetic infant genitoplasty.”⁶

Physicians for Human Rights: “Physicians for Human Rights calls for an end to all medically unnecessary surgical procedures on intersex children before they are able to give meaningful consent to such surgeries.”⁷

GLMA: Health Professionals Advancing LGBTQ Equality: “RESOLVED: that GLMA recommends delay of any surgical interventions and gender-related medical interventions for DSD that are not deemed medically necessary until the patient can provide informed consent/assent to these interventions.”⁸

Massachusetts Medical Society: “The MMS supports optimal management of Differences in Sex Development/Intersex through individualized, multidisciplinary care that (1) seeks to foster the well-being of the child and of the adult the child will become; (2) respects the rights of the patient to participate in decisions and, except when life-threatening circumstances require emergency intervention, defers medical or surgical intervention until the child is able to participate in decision making; and (3) provides psychosocial support to promote patient and family well-being.”⁹

Michigan Medical Society: “Resolved: That MSMS opposes the assignment of gender binary sex to infants with differences in sex development through surgical intervention outside of the necessity of physical functioning for an infant, and that children should have meaningful input into any gender assignment surgery.”¹⁰

American Medical Student Association: “AMSA echoes [other organizations] in calling for the deferment of elective surgical interventions to standardize genitals as strictly male or female on intersex children until they reach a level of maturity at which they can participate in this life-altering decision and provide (or withhold) informed consent to such treatment. As future medical professionals, we chose this path in order to help others, not to do harm. If current practices are harmful, we should not perpetuate them through inertia. We can—and must—change medical education and practice to safeguard vulnerable patients.”¹¹

World Health Organization: “A major concern for intersex people is that so-called sex normalizing procedures are often undertaken during their infancy and childhood, to alter their bodies, particularly the sexual organs, to make them conform to gendered physical norms, including through repeated surgeries, hormonal interventions and other measures. As a result, such children may be subjected to medically unnecessary, often irreversible, interventions that may have lifelong consequences for their physical and mental health, including irreversible termination of all or some of their reproductive and sexual capacity.

⁶ M. Joycelyn Elders, David Satcher, & Richard Carmona, Re-Thinking Genital Surgeries on Intersex Infants (Palm Center, 2017), <https://www.palmcenter.org/wp-content/uploads/2017/06/Re-Thinking-Genital-Surgeries-1.pdf>.

⁷ Physicians for Human Rights, Unnecessary Surgery on Intersex Children Must Stop, October 20, 2017, <https://phr.org/news/unnecessary-surgery-on-intersex-children-must-stop/>.

⁸ GLMA Policy: Medical and Surgical Intervention of Patients with Differences in Sex Development (2016), <https://www.glma.org/index.cfm?fuseaction=document.viewdocument&ID=CEB9FEE4B8DD8B7F4F7575376BD476C3A433379DD853BEA17913AFCCB8270299C0731320B03D2F5E1022F1C15602FBEA>.

⁹ Massachusetts Medical Society, Differences in Sex Development (DSD)/Intersex 12/7/19, [https://www.massmed.org/Governance-and-Leadership/Policies,-Procedures-and-Bylaws/MMS-Policy-Compendium-\(pdf\)](https://www.massmed.org/Governance-and-Leadership/Policies,-Procedures-and-Bylaws/MMS-Policy-Compendium-(pdf)). The AMA Board of Trustees recommended a nearly identical resolution in 2016. See American Medical Association, Board of Trustees Report 7-I-16: Supporting Autonomy for Patients with Differences of Sex Development (DSD) (2016), <https://assets.ama-assn.org/sub/meeting/documents/i16-bot-07.pdf>.

¹⁰ Michigan State Medical Society, Opposing Surgical Sex Assignment for Infants with Differences of Sex Development, Resolution 12-18 (2018), <https://www.msms.org/hodresolutions/2018/12.pdf>.

¹¹ AMSA Issues Statement to Defer Gender “Normalizing” Surgeries for Children Born as Intersex (Oct. 26, 2017), https://www.amsa.org/press_release/amsa-issues-statement-defer-gender-normalizing-surgeries-children-born-intersex/.

Medical procedures may sometimes be justified in cases of conditions that pose a health risk or are considered life-threatening. Such procedures, however, are sometimes proposed on the basis of weak evidence, without discussing and considering alternative solutions.”¹²

Committee on Bioethics for the Council of Europe: “Despite clinical attempts to find data supporting these practices, repeated systematic reviews of evidence have found no quality data confirming their safety and benefits for each affected child. ... Currently, all evidence-based reviews acknowledge that harms have occurred and may continue to occur for patients, including pain, dysfunction, error in gender assignment, and harm to their quality of life. On the scientific question of whether intervention is necessary, only three medical procedures have been identified as meeting that criteria in some infants... None of the aforementioned reviews have identified any other procedure as medically necessary or confirmed to have a balance of long-term benefits from gender-“normalizing” interventions in infancy.”¹³

Australian Medical Association: “Normalising cosmetic genital surgery on intersex infants should be avoided until a child can fully participate in decision making.”¹⁴

World Professional Association for Transgender Health (draft): “We suggest that health professionals counsel parents and patients with physical intersexuality (if cognitively sufficiently developed) to delay gender-confirming genital surgery, gonadal surgery, or both, when feasible, so as to optimize the child’s self-determination and ability to participate in the decision based on informed consent.”¹⁵

Please contact interACT at info@interactadvocates.org with any questions.

¹² World Health Organization, Sexual health, human rights and the law (2015), http://apps.who.int/iris/bitstream/handle/10665/175556/9789241564984_eng.pdf.

¹³ Zillén, K., Garland, J., & Slokenberga, S., The Rights of Children in Biomedicine: Challenges posed by scientific advances and uncertainties (Committee on Bioethics for the Council of Europe, 2017), <https://rm.coe.int/16806d8e2f>. The three interventions identified by the authors are: hormonal treatment to prevent salt-wasting, removal of streak gonads, and surgery for bladder or cloacal exstrophy. Each affect only some children with specific types of intersex variations.

¹⁴ Australian Medical Association, Position Statement on Sexual and Reproductive Health (2014), https://ama.com.au/sites/default/files/documents/position_statement_on_sexual_and_reproductive_health_2014_0.pdf.

¹⁵ World Professional Association for Transgender Health, DRAFT *Standards of Care*, Version 8 (2021), <https://www.wpath.org/media/cms/Documents/SOC%20v8/SOC8%20Chapters%20for%20Public%20Comment/SOC8%20Chapter%20Draft%20for%20Public%20Comment%20-%20Intersex.pdf>.