

March 15, 2023

The Honorable Xavier Becerra
Secretary
U.S. Department of Health & Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Re: Request for Information on Advancing Health Equity for Intersex Individuals

Dear Secretary Becerra:

The National Women’s Law Center and Ibis Reproductive Health appreciate the opportunity to comment on topics related to intersex health equity. We submit this letter with a particular focus on the reproductive rights of intersex people, including to raise concerns about harmful practices that undermine health equity by depriving intersex individuals of reproductive and sexual autonomy.

The National Women’s Law Center has fought for gender justice in the courts, in public policy, and in our society for almost fifty years. We protect women and families in core aspects of their lives, including employment, income security, education, and health and reproductive rights, with an emphasis on the needs of low-income women and those who face multiple and intersecting forms of discrimination.

Ibis Reproductive Health is a global nonprofit driving change through bold, rigorous research and principled partnerships that advance sexual and reproductive autonomy, choices, and health worldwide. We believe that research can catalyze change when the entire research process is viewed as an opportunity to shift power, is undertaken in partnership with the communities most affected, and includes a focus on how data can be most effectively used to make change.

Sterilization procedures without individual assent or consent

The most blatant violation of intersex people’s reproductive rights occurs in the form of medically unnecessary surgeries performed when a child is too young to assent. Many of these surgeries—especially gonadectomies—can result in lifelong consequences, often including permanent sterilization.

Forced sterilization, including the involuntary sterilization of intersex children, remains widely permitted in the United States. It is part of a broader pattern of restricting people’s reproductive freedoms based on identities and characteristics such as disability and race—including targeting them for involuntary sterilization. For example, a 2022 National Women’s Law Center study found that 31 states and Washington, D.C. currently have laws allowing the forced sterilization of disabled people, some of which were passed as recently as 2019.¹ And in

¹ National Women’s Law Center & Autistic Women and Nonbinary Network, *Forced Sterilization of Disabled People in the United States* (2022), available at: https://nwlc.org/wp-content/uploads/2022/01/%C6%92.NWLC_SterilizationReport_2021.pdf.

2020, a whistleblower revealed a practice of forced and coerced sterilization in an immigration detention center—echoing a long history of involuntary sterilization targeting immigrant women and women of color.² Such practices reflect an all-too-common belief that it is justifiable, even beneficial, to disregard the reproductive autonomy of certain individuals based on their innate traits—a belief that is often explicitly on display when intersex children are involuntarily sterilized.

We are concerned that protections against involuntary sterilization are not being applied equally to intersex and non-intersex children.³ Human Rights Watch has observed that “evidence suggests that gonadectomy, even when it results in sterilization, can be recommended for very young intersex children on the basis of weaker clinical data than would prompt the same recommendation for non-intersex children, and in situations where irreversible interventions could be safely delayed.”⁴ For example, multiple hospitals appear to promote unsupported or exaggerated concerns regarding cancer risk as a basis for gonadectomy in children with certain intersex variations⁵ when evidence has largely failed to establish a heightened risk of malignancy in these cases, and when alternatives such as “watchful waiting” would adequately address medical concerns while preserving fertility options.⁶ In addition, gonadectomy is sometimes performed solely to make an intersex infant’s body conform more closely to stereotypes associated with the initial sex assignment—often reflecting parents’ and doctors’ discomfort with anticipated “sex-discordant” hormone production at puberty⁷—or even to attempt to control the child’s eventual gender identity.⁸ Based on these practices, it appears that medical providers may be disregarding the importance of a person’s fertility simply based on the fact that that person is intersex, depriving them of their ability to make reproductive decisions in the future.

Genital surgeries without individual assent or consent

In addition to gonadectomies, surgeries to change intersex children’s genital variations—such as clitoral reductions, vaginoplasties, and surgeries to reroute the urethra or modify penile

² See Amicus Brief of the National Women’s Law Center et al., *Oldaker v. Giles*, 7:20-cv-00224 (M.D. GA, filed March 4, 2021).

³ See, e.g., 42 CFR §§ 50.201 et seq., 441.250 et seq.

⁴ Human Rights Watch, *“I Want to be Like Nature Made Me”: Medically Unnecessary Surgeries on Intersex Children in the US* (2017), available at: <https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us>.

⁵ See, e.g., Boston Children’s Hospital, *Androgen Insensitivity* (accessed March 5, 2023), <https://www.childrenshospital.org/conditions/androgen-insensitivity>; Rady Children’s Hospital San Diego, *Conditions Treated* (accessed March 5, 2023), <https://www.rchsd.org/programs-services/endoocrinology-diabetes/services/differences-of-sexual-development-clinic/conditions-treated>; Pratik Kanabur et al., PD02-12: “The Risk of Gonadal Malignancy in Patients with Androgen Insensitivity Syndrome,” 207 *The Journal of Urology Supplement* e40 (2022).

⁶ Erica M. Weidler et al., “A Management Protocol for Gonad Preservation in Patients with Androgen Insensitivity Syndrome,” 32 *Journal of Pediatric and Adolescent Gynecology* 605 (2019).

⁷ National Academies of Sciences, Engineering, and Medicine, *Understanding the Well-Being of LGBTQI+ Populations*, 371-372 (2020). Washington, DC: The National Academies Press. <https://doi.org/10.17226/25877>; Heather M. Byers et al., “Unexpected Ethical Dilemmas in Sex Assignment in 46,XY DSD due to 5-alpha Reductase Type 2 Deficiency,” 175 *American Journal of Medical Genetics* 260 (2017).

⁸ Janet Chuang et al., “Complexities of Gender Assignment in 17B-hydroxysteroid Dehydrogenase Type 3 Deficiency: Is There a Role for Early Orchiectomy?” *International Journal of Pediatric Endocrinology* (2013).

shape—continue to be performed in U.S. hospitals, often in the first two years of life.⁹ Alongside cosmetic reasons, purported rationales may include the “facilitation” of future reproductive or sexual function.¹⁰ However, as these considerations do not become relevant until later in a person’s life, operations on these bases appear to serve no purpose in infancy. Rather, performing surgery preemptively introduces unnecessary risks. Not only might the (proxy-)chosen surgery differ from the individual’s embodiment goals, but surgeries ostensibly intended to benefit future sexual function (e.g., by enabling penetrative intercourse) risk *permanently damaging* function and sensation when performed in early childhood,¹¹ and might impair future fertility as well.¹² Even for some procedures that providers may perform prematurely based on the belief that they are “inevitable” (such as vaginal surgeries to facilitate menstruation for intersex youth who have a uterus), the existence of alternative options that patients may prefer (such as menstrual suppression) justifies deferral.¹³ But because of pervasive assumptions that “normal” anatomy is automatically preferable, these options may not even be presented.

Notably, federal and state laws exist that prohibit subjecting minors to clitoral or labial surgeries when not based on medical necessity but rather based on cultural or social reasons.¹⁴ Many forms of genital surgery on intersex children would fit the definitions of these unlawful practices, and they are not needed to treat or prevent any illness, injury, or disease.¹⁵ Yet these laws are not often contemplated as a protection for intersex children.

Disparities, care needs, and research directions

The 2020 NASEM report recognized that “[i]ntersex health disparities appear to be driven in large part by the medical approach to intersex traits,” and appear in physical and mental health outcomes as well as social determinants of health.¹⁶ A study of U.S. intersex adults showed overall poor health and functional status compared to the general population, as well as

⁹ N.J. Nokoff et al., “Prospective Assessment of Cosmesis Before and After Genital Surgery,” 13 *Journal of Pediatric Urology* 28.e1 (2017); David A. Diamond 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,” 14 *Journal of Pediatric Urology* 416 (2018); Avi Baskin et al., “Post-Operative Complications Following Feminizing Genitoplasty in Moderate to Severe Genital Atypia: Results from a Multicenter, Observational Prospective Cohort Study,” 16 *Journal of Pediatric Urology* (2020); Christopher J. Long et al., “Post-Operative Complications Following Masculinizing Genitoplasty in Moderate to Severe Genital Atypia: Results From a Multicenter, Prospective Cohort Study,” 17 *Journal of Pediatric Urology* 379 (2021).

¹⁰ P.D. Mouriquand et al., “Surgery in Disorders of Sex Development (DSD) With a Gender Issue: If (Why), When, and How?” 12 *Journal of Pediatric Urology* 139 (2016).

¹¹ See, e.g., Peter Lee et al., “Review of Recent Outcome Data of Disorders of Sex Development (DSD): Emphasis on Surgical and Sexual Outcomes,” *Journal of Pediatric Urology* (2012).

¹² Roy J. Levin, “The Clitoris—An Appraisal of its Reproductive Function During the Fertile Years: Why Was It, and Still Is, Overlooked in Accounts of Female Sexual Arousal,” 33 *Clinical Anatomy* 136 (2019).

¹³ Paula Adams Hillard, “Menstrual Suppression: Current Perspectives,” 6 *International Journal of Women’s Health* 631 (2014) (Menstrual suppression medications are a possible alternative to “definitive surgery” in cases of congenital variations).

¹⁴ Sylvan Fraser, “Constructing the Female Body: Using Female Genital Mutilation Law to Address Genital-Normalizing Surgery on Intersex Children in the United States,” 9 *International Journal of Human Rights in Healthcare* 62 (2016).

¹⁵ *Id.* This distinguishes gender-affirming medical treatments, which are sought and needed by adults or adolescents for gender dysphoria, from interventions on intersex children who do not present with gender dysphoria and often are unable (due to their age) to even express a gender identity.

¹⁶ National Academies of Sciences, *supra* note 7.

high rates of mental health diagnoses such as depression and anxiety.¹⁷ In a 2022 Center for American Progress survey, intersex adults experienced high rates of discrimination in medical settings, including alarming rates of refusals of reproductive and other health care, underscoring the need for robust enforcement of Section 1557's protections against discrimination based on sex characteristics.¹⁸ Furthermore, when intersex people do seek care, they may be unable to find providers who have the expertise (and cultural competence) to treat them. All of these taken together contribute to a risk of poor health and quality of life outcomes, and must be holistically addressed by comprehensive efforts to advance health equity for intersex communities.

Intersex inclusion in key health equity areas such as reproductive and sexual health, and maternal and infant health, is especially important. Many intersex people with uteruses can become pregnant and will therefore need access to the same scope of reproductive care as non-intersex patients, and may also face elevated risks for certain complications, potentially requiring specialist management.¹⁹ Intersex people are also more likely to need assisted reproductive technology for the purpose of establishing a pregnancy. For example, recent recommendations have emerged to offer gonadal tissue cryopreservation to intersex patients undergoing gonadectomy.²⁰ While some health systems do currently offer this option for intersex patients, many do not, or do not do so in all cases where it may be appropriate.²¹ Importantly, continuing research will be required to further develop best practices to tailor fertility preservation and assisted reproduction services for intersex populations as technology advances.²² We also echo the National Academies' identification of other priority areas for intersex-inclusive reproductive and sexual health research, including: variations in rates of lifetime cancer risks across subpopulations; rates of routine cancer screenings; rates of HIV and other STIs; more comprehensive sexual health studies; and research on pregnancy complication rates for people with different intersex variations who become pregnant.²³

Conclusion

We thank the Department for the opportunity to comment on these important topics, and we look forward to ongoing collaborative efforts to advance reproductive rights and justice for intersex individuals as part of a comprehensive approach to improving health outcomes and supporting their ability to thrive.

¹⁷ Amy Rosenwohl-Mack et al., "A National Study on the Physical and Mental Health of Intersex Adults in the U.S.," 15 *PLoS ONE* e0240088 (2020).

¹⁸ Caroline Medina and Lindsay Mahowald, *Advancing Health Care Nondiscrimination Protections for LGBTQI+ Communities* (2022), available at: <https://www.americanprogress.org/article/advancing-health-care-nondiscrimination-protections-for-lgbtqi-communities>.

¹⁹ Jacqueline Yano Maher et al., "The Management of Congenital Adrenal Hyperplasia During Preconception, Pregnancy, and Postpartum," 24 *Reviews in Endocrine and Metabolic Disorders* 71 (2023); Jasmine Grewal et al., "Cardiovascular Outcomes of Pregnancy in Turner Syndrome," 107 *Heart* 61 (2021).

²⁰ Esther L. Finney et al., "Gonadal Tissue Cryopreservation for a Girl with Partial Androgen Insensitivity Syndrome," 3 *Journal of the Endocrine Society* 887 (2019); Rumana Islam et al., "Establishing Reproductive Potential and Advances in Fertility Preservation Techniques for XY individuals with Differences in Sex Development," 91 *Clinical Endocrinology* 237 (2019).

²¹ Aisha L. Siebert et al., "Differences in Gonadal Tissue Cryopreservation Practices for Differences of Sex Development Across Regions in the United States," 13 *Frontiers in Endocrinology* 990359 (2022).

²² *Id.*; National Academies, *supra* note 7.

²³ National Academies, *supra* note 7.