

March 13, 2023

The Honorable Xavier Becerra  
Secretary

U.S. Department of Health & Human Services  
200 Independence Avenue, S.W.  
Washington, D.C. 20201

Re: Notices for Advancing Health Equity for Intersex Individuals; FR Doc. 2023-02826

Dear Secretary Becerra:

The Federal LGBTQI Health Policy Roundtable is grateful for the opportunity to submit these comments to inform the Department's crucial work on intersex health equity. Below, we will address some of the known health disparities faced by intersex people, as well as sources of harm in historical and current medical practice that we hope the Department's report will examine. We will also discuss areas of overlap as well as distinctions in the healthcare experiences of intersex people and LGBTQI people more broadly, including some that may be overlooked in policy contexts.

*Health disparities in the intersex community*

Intersex people, who have innate variations in their physical sex characteristics, face disparities in physical and mental health that stem from a combination of factors including practices imposed on intersex individuals (especially infants and young children) that directly limit bodily autonomy and future self-determination; a lack of access to competent care to meet adult medical needs and improve health outcomes; and pervasive anti-intersex bias, discrimination, and erasure that are intertwined with homophobia and transphobia. The ongoing and intensifying anti-LGBTQI+ campaigns and legislation sweeping the country are also a source of harm and stigma that can impact well-being.

Although data collection is another area in which meaningful intersex inclusion is currently lacking,<sup>1</sup> the data that do exist show that people with intersex variations have higher rates of medical diagnoses that indicate more compromised physical health (as compared to general population data from the BRFSS survey),<sup>2</sup> as well as common mental health challenges including symptoms consistent with anxiety, depression, and post-traumatic stress disorder as well as an increased incidence of suicidality.<sup>3</sup> Certain specific physical health diagnoses may be linked to genetic factors associated with a person's underlying intersex variation in some cases,<sup>4</sup> or they may be the result of a combination of factors including minority stress,<sup>5</sup> discrimination in healthcare, employment, and public life,<sup>6</sup> and the sequelae of childhood medical interventions which have demonstrated consequences for physical and mental health.<sup>7</sup>

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<sup>1</sup> 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>.

<sup>2</sup> 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).

<sup>3</sup> *Id.*; Henrik Falhammar, "Health Status in 1040 Adults with Disorders of Sex Development (DSD): A European Multicenter Study," 7 *Endocrine Connections* 466 (2018).

<sup>4</sup> See, e.g., Maria Felicia Faienza et al, "Bone Fragility in Turner Syndrome Mechanisms and Prevention Strategies," 7 *Frontiers in Endocrinology* 34 (2016); Shanlee M. Davis et al, "Population-Based Assessment of Cardiometabolic-Related Diagnoses in Youth with Klinefelter Syndrome: A PEDSnet Study," 19 *Journal of Clinical Endocrinology and Metabolism* e1850 (2022).

<sup>5</sup> Jane Ussher et al, "LGBTQI Cancer Patients' Quality of Life and Distress: A Comparison by Gender, Sexuality, Age, Cancer Type and Geographical Remoteness," *Frontiers in Oncology* (2022).

<sup>6</sup> Caroline Medina and Lindsay Mahowald, "Key Issues Facing People With Intersex Traits," *Center for American Progress* (2021), available at: <https://www.americanprogress.org/article/key-issues-facing-people-intersex-traits/>.

<sup>7</sup> Katinka Schweizer et al, "Coping with Diverse Sex Development: Treatment Experiences and Psychosocial Support During Childhood and Adolescence and Adult Well-being," 42 *Journal of Pediatric Psychology* 504 (2017); 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); Ahmed Torkey et al,

The landmark 2020 National Academies report on LGBTQI+ health observed: “Intersex health disparities appear to be driven in large part by the medical approach to intersex traits, which has been informed by the same stigmas experienced by SGD populations” overall.<sup>8</sup> Several studies have linked a history of gonadectomy specifically to prevalence of suicidal ideation in intersex patients.<sup>9</sup> There is also evidence that intersex youth are especially likely to experience so-called “conversion” practices that expressly seek to change their sexual orientation or gender identity.<sup>10</sup>

Intersex health equity is integral to broader LGBTQI+ equity; therefore, health equity initiatives must advance the rights, health, and dignity of intersex people alongside other sexual and gender minority populations, as well as in contexts that are intersex-specific. For example, federal, state, and local initiatives to promote health equity through public health promotion and prevention activities, cultural competence standards, professional education and training, quality measures and improvement activities, and payment incentives incorporating equity components should not only use broadly inclusive terminology—including LGBTQI+ and sexual orientation, gender identity, and sex characteristics (SOGISC)—but should also include specific content, requirements, activities, examples, and best practices addressing intersex populations.

Research and data collection efforts should also prioritize intersex inclusion to better inform and facilitate further health equity initiatives that may be undertaken to improve outcomes for intersex people, in accord with the requirements of Executive Order 14075 and recommendations of the National Academies.<sup>11</sup> Health-related data collections should include measures of variations in sex characteristics to identify intersex populations and contribute to an improved understanding of their experiences and needs, and health research agendas should advance inclusion of intersex populations in clinical studies and promote ethically conducted intersex-focused research that is informed by community priorities (with appropriate consideration of community concerns regarding exploitative research practices that have been carried out previously).<sup>12</sup>

### *Non-consensual surgical interventions undermine the health and well-being of intersex people*

Leading human rights organizations and health researchers have documented how genital surgeries and gonadectomies, in the absence of medical necessity, continue to be performed on intersex infants and children prior to their ability to offer their input on the proposed intervention—most commonly before age two.<sup>13</sup> This practice is increasingly recognized as a violation of intersex children’s rights and autonomy, but clinics in the United States have largely failed to renounce it or modify their policies regarding medical interventions on variations in sex characteristics; this is true even in otherwise

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“Cardiovascular Disease Risk Factors and Metabolic Morbidity in a Longitudinal Study of Congenital Adrenal Hyperplasia,” 106 *Journal of Clinical Endocrinology and Metabolism* e5247 (2021).

<sup>8</sup> National Academies of Sciences, Engineering, and Medicine, *Understanding the Well-Being of LGBTQI+ Populations*, 27 (2020). Washington, DC: The National Academies Press. <https://doi.org/10.17226/25877>.

<sup>9</sup> Karsten Schutzmann et al, “Psychological Distress, Self-Harming Behavior, and Suicidal Tendencies in Adults with Disorders of Sex Development,” 38 *Archives of Sexual Behavior* 16 (2007); Schweizer et al, *supra* note 7.

<sup>10</sup> The Trevor Project, “The Mental Health and Well-being of LGBTQ Youth who are Intersex” (2021), <https://www.thetrevorproject.org/wp-content/uploads/2021/12/Intersex-Youth-Mental-Health-Report.pdf>.

<sup>11</sup> National Academies of Sciences, Engineering, and Medicine. 2022. *Measuring Sex, Gender Identity, and Sexual Orientation*, 139-50. Washington, DC: The National Academies Press. <https://doi.org/10.17226/26424>.

<sup>12</sup> See interACT: Advocates for Intersex Youth, “interACT Policy Statement on Participation in Research” (Feb. 2, 2023), available at: <https://interactadvocates.org/interact-policy-on-participation-in-research/>.

<sup>13</sup> See, e.g., 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>; Aimee M. Rolston et al, “Disorders of Sex Development (DSD): Clinical Service Delivery in the United States,” 175 *American Journal of Medical Genetics* 268 (2017); J.D. Roth et al., “Characteristics of Female Genital Restoration Surgery for Congenital Adrenal Hyperplasia Using a Large-scale Administrative Database,” 115 *Urology* 162 (2018).

LGBTQI+-affirming health systems and programs.<sup>14</sup> These early surgeries have a long and well-documented list of risks and adverse consequences,<sup>15</sup> including nerve damage, numbness, and chronic pain; urinary complications including urethral strictures and fistulas, recurrent urinary tract infections, and chronic incontinence; loss of future sexual sensation and function, as well as pain that limits sexual desire and activity; sterilization and loss of fertility options, including those that may have been available through future technological advances; psychological consequences including trauma, depression, and anxiety; and—as will be discussed in more detail below—the possibility that surgery will enforce a sex assignment that the patient will not ultimately identify with.

Neither scientific evidence nor ethical principles support imposing elective surgical procedures on the basis of proxy consent when they implicate such personal considerations as sexual function, gender identity, and reproductive potential, and are not necessary to treat or prevent any illness, injury, or disease, or immediate risk thereof.<sup>16</sup> Instead, the motivation to operate on intersex infants and young children is primarily grounded in cementing the initial sex assignment by making the child’s physical characteristics conform more closely to stereotypes and expectations associated with that sex category, including expectations associated with “gender-appropriate” (heterosexual) behavior.<sup>17</sup> Recognizing shared elements of harmful practices towards LGBTQI+ youth, the 2020 National Academies report concluded: “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.”<sup>18</sup>

### *Non-consensual surgeries are the antithesis of gender-affirming care*

Unlike cases in which parents support their children in accessing gender-affirming interventions that they have sought on the basis of their own self-determined needs, parents consenting to surgeries on their young intersex children are acting on the basis of speculation and assumptions about what their child will ultimately want in the future. In addition, biases and fears related to perceived gender nonconformity can influence the decision-making process, whether these feelings originate with the child’s parents, medical providers, or both. Such fears can be particularly salient when children have visible genital variations, or internal organs (such as gonads) that differ from expectations based on outward appearance. In these cases, a sense of pressure to “resolve ambiguity” may drive doctors’ recommendations and parents’ choices more than consideration of the impact of potential surgery on the child’s health and autonomy.<sup>19</sup> For example, multiple publications discuss gonadectomy as a means to “reinforce” and promote “retention” of a female sex assignment in intersex children with specific variations in which pubertal androgen production is hypothesized to increase the odds of developing a male gender identity.<sup>20</sup> However, approximately 40% to 60% of female-assigned children with these variations have been

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<sup>14</sup> See Human Rights Campaign, *Healthcare Equality Index 2022 – Medical Decision-Making* (2022), available at: <https://reports.hrc.org/hei-2022#medical-decision-making> (noting that “Only 2% of HEI participants have a policy related to postponing medically unnecessary procedures on intersex children.”).

<sup>15</sup> See Human Rights Watch, *supra* note 9.

<sup>16</sup> M. Joycelyn Elders, David Satcher, & Richard Carmona, *Re-Thinking Genital Surgeries on Intersex Infants*, Palm Center (June 2017), available at <https://www.palmcenter.org/wp-content/uploads/2017/06/Re-Thinking-Genital-Surgeries-1.pdf>; A.A. Kon, “Ethical Issues in Decision-Making for Infants with Disorders of Sex Development,” 47 *Hormone and Metabolic Research* 340 (2015).

<sup>17</sup> See, e.g., 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).

<sup>18</sup> National Academies of Sciences, Engineering, and Medicine, *Understanding the Well-Being of LGBTQI+ Populations*, 380(2020). Washington, DC: The National Academies Press. <https://doi.org/10.17226/25877>.

<sup>19</sup> See, e.g., *id.*; 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).

<sup>20</sup> 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); 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).

documented to transition to male—including a significant number who transition despite having been subjected to prior gonadectomy.<sup>21</sup> Regarding infants with the variation Congenital Adrenal Hyperplasia, Weill Cornell bases its recommendations for genital surgery on the notion that “female patients are able to undergo a more natural psychological and sexual development when they have a normal appearing vagina.”<sup>22</sup> This clinic favors 3 to 6 months of age as the optimal time to initiate clitoral and labioscrotal reduction along with vaginoplasty.<sup>23</sup> Somewhere between 5% and 30% of these children will likely be dissatisfied with their female sex assignment, and may transition.<sup>24</sup>

To be clear, there is no proven benefit associated with surgically “aligning” a patient’s sex assignment and physical sex characteristics, when the patient themselves has not indicated that they want or need this intervention to fulfill their own embodiment priorities. As gender identity cannot be accurately predicted on the basis of any physical characteristic, these surgeries carry an obvious risk of undermining, rather than affirming, the patient’s eventual identity and needs. (It also bears noting that, even if an individual does identify with the sex assigned to them at birth, this does not indicate that they would necessarily want or need the surgical interventions that may have been associated with that sex assignment from the perspective of their care providers.) Furthermore, if surgery has removed phallic (or other genital) tissue or hormone-producing gonads, options for any gender-affirming care that the intersex individual may seek in the future will be limited as a result of these past decisions that were implemented without individual consent. Similarly, if childhood surgeries were performed to provide for a particular sexual function (e.g., penetrative intercourse) that the intersex individual ultimately does not wish to engage in,<sup>25</sup> other possibilities may have been sacrificed in the process—and complications of surgery may have arisen—all as a result of their proxy decision-makers having accepted a heterosexual, cisgender identity as a foregone conclusion (or as an engineerable outcome). Considering these scenarios, it is imperative that protections from involuntary sterilization, sex-based discrimination, and other similar harms be strengthened (if necessary) and properly applied and enforced when intersex individuals have undergone or are at risk of undergoing interventions that jeopardize their rights and autonomy on the basis of their variations in sex characteristics, perceived sexual orientation or gender identity, or nonconformity with sex stereotypes.

Like transgender youth, the World Professional Association for Transgender Health (WPATH) now recommends that intersex youth be afforded an open future and autonomy to make personal decisions about potential medical interventions for themselves, assuming no urgent medical concern requires surgery for physical health reasons before that time.<sup>26</sup> Transgender and intersex individuals alike deserve to make these choices based on their own understanding of their gender, body, and priorities for future sexual and reproductive function; surgery may or may not align with their needs and goals. We agree with WPATH’s broad recommendation, and urge the Department to explore options to assist

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<sup>21</sup> Peggy Cohen-Kettenis, “Gender Change in 46,XY Persons with 5 $\alpha$ -Reductase-2 Deficiency and 17 $\beta$ -Hydroxysteroid Dehydrogenase-3 Deficiency,” 34 *Archives of Sexual Behavior* 399 (2005); Chuang et al, *supra* note 16.

<sup>22</sup> Weill Cornell Medicine, *Genitoplasty – Treatment Options* (accessed March 8, 2023), available at: <https://urology.weillcornell.org/clinical-conditions/pediatric-urology/genitoplasty/treatment-options>.

<sup>23</sup> *Id.*

<sup>24</sup> Katinka Schweizer et al, “Gender Experience and Satisfaction with Gender Allocation in Adults with Diverse Intersex Conditions (Divergences of Sex Development, DSD),” *Psychology and Sexuality* (2013); Vickie Pasterski et al, “Increased Cross-Gender Identification Independent of Gender Role Behavior in Girls with Congenital Adrenal Hyperplasia: Results From a Standardized Assessment of 4- to 11-Year-Old Children,” 44 *Archives of Sexual Behavior* 1363 (2015); Melissa Hines et al, “Androgen and Psychosexual Development: Core Gender Identity, Sexual Orientation and Recalled Childhood Gender Role Behavior in Women and Men With Congenital Adrenal Hyperplasia (CAH),” 41 *Journal of Sex Research* 75 (2004); Tanvir Kabir Chowdhury et al, “Male Gender Identity in Children With 46,XX DSD With Congenital Adrenal Hyperplasia After Delayed Presentation in Mid-Childhood,” 50 *Journal of Pediatric Surgery* 2060 (2015).

<sup>25</sup> Erica M. Weidler et al, “Evolving Indications for Surgical Intervention in Patients with Differences/Disorders of Sex Development: Implications of Deferred Reconstruction,” 29 *Seminars in Pediatric Surgery* 150929 (2020) (explaining that “Vaginal penetration may not be desirable for the patient; thus, surgery may not be necessary.”).

<sup>26</sup> E. Coleman et al, “Standards of Care for the Health of Transgender and Gender Diverse People, Version 8,” 23 *International Journal of Transgender Health* S1 (2022).

providers and clinics in adopting and following these guidelines as to intersex youth. At the same time, policies that aim to safeguard and expand access to gender-affirming care must take care to distinguish non-consensual interventions on intersex children, which are not gender-affirming procedures, and ensure that protective measures for patients and providers of gender-affirming care do not create (or imply the existence of) a safe harbor for procedures that cause harm to intersex youth.

Federal, state, and local governments should take action to end these harmful practices and to promote truly affirming, evidence-based care for intersex people throughout the lifespan. In particular (as the Roundtable has outlined in prior correspondence), the Department should take action to (1) disseminate basic, affirming information to families and providers about diversity of sex characteristics and the benefits of deferring non-emergent genital and sterilizing surgeries;<sup>27</sup> (2) provide guidance to states and providers to ensure federal funds are not used for such nonconsensual procedures, in accordance with federal and state quality, informed consent, and civil rights requirements; and (3) open civil rights compliance reviews of major surgery centers engaged in these practices.

### Lack of access to quality, affirming healthcare

Intersex people, like other members of LGBTQI+ communities, face barriers to accessing needed healthcare services for reasons that range from overt discrimination to prohibitive care costs to a dearth of trained, culturally competent providers.<sup>28</sup> This contributes to an ironic pattern in which intersex people often suffer the consequences of being a medically “overserved” population in infancy and early childhood, while struggling as an “underserved” group later in life. This experience can feel especially cruel for intersex patients who have acquired specific medical complications or care needs as a result of previous unnecessary and non-consensual procedures. For example, a history of childhood gonadectomy may leave some intersex individuals in need of hormone replacement, assisted reproduction, and bone density scans—but providers offering this care may not be geographically convenient to access, or may not have adequate education and training on intersex variations and patients’ needs.<sup>29</sup> Increasing the quality and standardization of provider training will be an important component of a comprehensive health equity initiative for intersex people. Medical education and other health professional training should include, at a minimum, basic, accurate, and non-stigmatizing information about the existence of innate variations in sex characteristics and caring for patients with these variations.

State and federal governments, as well as hospitals and healthcare systems, should also take action to ensure that discrimination on the basis of variations in sex characteristics is not tolerated in patient care (including in contexts such as informed consent requirements and coverage decisions), prevent its occurrence, and promptly address any incidents that do occur.

### Conclusion

The LGBTQI Health Policy Roundtable appreciates this opportunity to furnish information to the Department regarding matters of concern as well as promising avenues for action in the context of intersex health equity. We eagerly anticipate continued cooperation on the objectives that we, and other stakeholders, have identified as priorities for research, policy, education, and accountability in this area.

Signed,

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<sup>27</sup> See, e.g., NYC Health, “Intersex Health,” <https://www.nyc.gov/site/doh/health/health-topics/intersex-health.page>.

<sup>28</sup> Rosenwohl-Mack et al, *supra* note 2; Medina and Mahowald, *supra* note 6; Jennifer J. Liang et al, “Observed Deficiencies in Medical Student Knowledge of Transgender and Intersex Health,” *Endocrine Practice* 897 (2017).

<sup>29</sup> Liang et al, *supra* note 23; Courtney Finlayson et al, “Fertility in Individuals With Differences in Sex Development: Provider Knowledge Assessment,” 35 *Journal of Pediatric and Adolescent Gynecology* 558 (2022).

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ACCESS REPRODUCTIVE JUSTICE

Arianna's Center

Athlete Ally

Caribbean Equality Project

CA LGBTQ Health and Human Services Network

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