

MEMORANDUM

TO: Melanie Fontes Rainer, Counselor to the Secretary of Health and Human Services
Hannah Katch, Senior Advisor, Centers for Medicare and Medicaid Services
Lisa Pino, Director, Office for Civil Rights
ADM Rachel Levine, Assistant Secretary for Health
VADM Vivek Murthy, U.S. Surgeon General

CC: Karen Parker, Daniel Dodgen, Brian Altman, Co-Chairs, LGBTQI+ Coordinating Committee
Sarah Boateng, Chief of Staff, Office of the Assistant Secretary for Health

FROM: The LGBTQI+ Federal Health Policy Roundtable¹
Contact: Daniel Bruner, dbruner@whitman-walker.org, (202) 669-3388

RE: HHS Action to End Non-Consensual, Medically Unnecessary Surgeries and Ensure Informed Consent for Children with Intersex Traits

DATE: June 2, 2022

Thank you again for your continued collaboration and dialogue with us on advancing the health and well-being of LGBTQI+ people. We appreciate your continuing efforts to recognize the needs of LGBTQI+ communities and to make progress in areas including nondiscrimination enforcement, increasing access to gender-affirming care, improving cultural competence and quality of care, LGBTQI+ data collection and research, ending the HIV/AIDS epidemic, and addressing attacks by state officials on LGBTQI+ youth, families, and care workers.

As we start Pride month, we write to urge you to ensure that this robust LGBTQI+ health equity agenda includes protecting the rights, health, and bodily autonomy of intersex infants and children, specifically by taking meaningful actions to end medically unnecessary “normalizing” surgeries on children with variations in their sex characteristics who are too young to participate in these deeply personal decisions. We applaud the Biden-Harris Administration for taking important initial steps to recognize intersex people’s rights and dignity at the federal level for the first time. Now, more concrete action is needed to address the most urgent health issue facing this population. We look forward to meeting with you to discuss these recommendations, and how we may be of assistance in moving them forward.

“Normalizing” surgeries on intersex infants and children and the need for federal action

Millions of Americans are born with differences in physical sex traits (such as chromosomes, genitals, reproductive anatomy, or hormone function), commonly referred to as variations in sex characteristics or intersex traits.² These variations are only rarely related to any immediate health concerns, much less often any concerns that would require surgical intervention in infancy or early childhood. Yet leading human rights organizations and health researchers have documented how “normalizing” surgeries continue to be performed to alter the genitals or remove the gonads of these children to conform their bodies to sex stereotypes, most commonly before the age of two, absent any evidence of medical need.³

Unlike other cases in which parents consent to interventions on behalf of their children, early intersex surgeries violate inherent human rights and raise major ethical concerns due to the high rate of

¹ The Roundtable is a coalition of national advocacy organizations and LGBTQ-focused health centers.

² Melanie Blackless, Anthony Charuvastra, Amanda Derryck, Anne Fausto-Sterling, Karl Lauzanne, & Ellen Lee, How Sexually Dimorphic Are We? Review and Synthesis, *12 AM. J. HUM. BIOL.* 151 (2000).

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>.

complications and other lifelong impacts on a person's health and reproductive choices – concerns that are compounded by the lack of medical necessity of these interventions in the first place. In addition, parents often receive insufficient information regarding the risks associated with such surgeries as well as alternatives to immediate surgery, and many are never offered psychosocial support oriented around accepting their healthy children as they are. A 2020 National Academies of Sciences consensus study summarized:

Overall, there is mixed evidence that [early intersex] 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.⁴

The NASEM report thus concludes that these infant and childhood surgeries, including gonadectomies, are not medically appropriate unless needed to address an immediate threat to health. Notably, the report compares these practices to efforts to change an individual's sexual orientation or gender identity, stating:

CONCLUSION 12-3: 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.⁵

There are increasing calls from within the medical community to end these practices, including from prominent medical associations.⁶ Additionally, in 2017, three former US Surgeons General wrote:

[Intersex] babies are being born who rely on adults to make decisions in their best interest, and this should mean one thing: 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 surgery. Those whose oath or conscience says 'do no harm' should heed the simple fact that, to date, research

⁴ National Academies of Sciences, Engineering, and Medicine. 2020. *Understanding the Well-Being of LGBTQI+ Populations*. Washington, DC: The National Academies Press at 378-79, <https://doi.org/10.17226/25877>.

⁵ *Id.* at 380.

⁶ See, e.g., Massachusetts Medical Society, Evidence-Based Care of Individuals Born with Differences in Sex Development (DSD)/Intersex (Dec. 7, 2019); <http://www.massmed.org/News/Press-Releases/Massachusetts-Medical-Society-announces-policies-on-opioid-use-disorder,-intersex-children-and-e-cigarettes/#.Xz7jNS2z0nU>; Michigan State Medical Society, Opposing Surgical Sex Assignment for Infants with Differences of Sex Development, Res. 12-18 (2018), <https://www.msms.org/hodresolutions/2018/12.pdf>; GLMA: Health Professionals Advancing LGBTQ Equality, Medical and Surgical Intervention of Patients with Differences in Sex Development (Oct. 3, 2016), <http://glma.org/index.cfm?fuseaction=Feature.showFeature&CategoryID=1&FeatureID=796>; American Academy of Family Physicians, Genital Surgeries in Intersex Children (Jul. 2018), <https://www.aafp.org/about/policies/all/genital-surgeries-intersexchildren.html>.

does not support the practice of cosmetic infant genitoplasty.⁷

Major hospitals have moved to prohibit these practices, including Lurie Children's Hospital in Chicago, Boston Children's Hospital, and the New York City Health & Hospitals system.⁸

United Nations agencies recognize that these practices violate core principles of informed consent, equality, and bodily autonomy.⁹ They may also violate federal and state laws against genital mutilation and forced sterilization.¹⁰ Courts in several states have concluded that the general parental right to consent to medical treatment for a child does not extend to elective sterilization.¹¹ Yet these practices continue, often with inadequate or inaccurate information provided to families about the demonstrated risks and the poor evidence for any purported benefits.¹²

The federal government has long recognized these harms but failed to act

At least as early as 2016, the US State Department recognized that "[i]ntersex persons routinely face forced medical surgeries that are conducted at a young age without free or informed consent. These interventions jeopardize their physical integrity and ability to live free."¹³ In September 2020, the United States joined over 50 nations in a joint statement. The statement recognized that: "In many countries around the world, intersex people are subjected to medically unnecessary surgeries, hormonal treatments and other procedures in an attempt to change their appearance to be in line with gendered societal expectations of male and female bodies without their full and informed consent." The statement concludes that government must act, "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."¹⁴

In recent years, the US State Department has criticized other countries, such as China and Russia, for

⁷ M. Joycelyn Elders, David Satcher, and Richard Carmona, *Re-Thinking Genital Surgeries on Intersex Infants* (June 2017), <https://www.palmcenter.org/wp-content/uploads/2017/06/Re-Thinking-Genital-Surgeries-1.pdf>

⁸ Human Rights Watch, *New York City Hospitals Prohibit Unnecessary Intersex Surgeries* (Jul. 16, 2021), <https://www.hrw.org/news/2021/07/16/new-york-city-hospitals-prohibit-unnecessary-intersex-surgeries> (describing new policy for city public hospitals); Lurie Children's Hospital, *Intersex Care at Lurie Children's and our Sex Development Clinic* (Jul. 28, 2020), <https://www.luriechildrens.org/en/blog/intersex-care-at-lurie-childrens-and-our-sex-development-clinic/>; Kimberly Zieselman, *Boston Children's Hospital's Change on Intersex Surgeries was Years in the Making* (Oct. 23, 2020), <https://interactadvocates.org/boston-childrens-hospital-intersex-surgery/>.

⁹ See, e.g., UN Ofc. of High Comm'ner Hum. Rts., *Background note on human rights violations against intersex people* (2019), <https://www.ohchr.org/EN/Issues/Discrimination/Pages/BackgroundViolationsIntersexPeople.aspx>; UN OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF & WHO, *Eliminating forced, coercive or otherwise involuntary sterilization: An interagency statement* (2014), http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf; UN OHCHR, *Report of the Special Rapporteur on Torture, Juan E. Mendez*, UN Doc. A/HRC/22/53 (2013), http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf.

¹⁰ See, e.g., 18 U.S.C. § 116 (prohibiting "any procedure performed for non-medical reasons that involves partial or total removal of" external genitalia, with exception when "necessary to the health of the person on whom it is performed"); Sylvan Fraser, *Constructing the female body: using female genital mutilation law to address genital-normalizing surgery on intersex children in the US*, 9 *INT'L J. HUM. RTS. HEALTH*. 62 (2016); Anne Tamar-Mattis, *Sterilization and Minors with Intersex Conditions in California Law*, 3 *CAL. L. REV. CIRCUIT* 126 (2012).

¹¹ See, e.g., *Am. Acad. of Pediatrics v. Lungren*, 940 P.2d 797, 814–16 (Cal. 1997); *In re Moe*, 432 N.E.2d 712, 715–18 (Mass. 1982); *In re Terwilliger*, 450 A.2d 1376, 1381–83 (Pa. Super. Ct. 1982).

¹² Human Rights Watch, *Protest Demands End to Harmful Surgeries on Intersex Children: Hospital Should Halt Medically Unnecessary Surgeries* (Sept. 1, 2021); <https://www.hrw.org/news/2021/09/01/protest-demands-end-harmful-surgeries-intersex-children>.

¹³ US Department of State, *Press Statement in Recognition of Intersex Awareness Day* (Oct. 26, 2016) <https://2009-2017.state.gov/r/pa/prs/ps/2016/10/263578.htm>.

¹⁴ Joint Statement led by Austria on the Rights of Intersex Persons (Sept. 30, 2020), <https://www.dfat.gov.au/international-relations/themes/human-rights/hrc-statements/45th-session-human-rights-council/joint-statement-led-austria-rights-intersex-persons>.

permitting these practices.¹⁵ In its readout of its historic Roundtable on Intersex Awareness Day 2021, the White House recognized “the toll that non-consensual medical interventions and surgeries performed on intersex children often have on people’s mental and physical health.”¹⁶ Also on Intersex Awareness Day 2021, the US State Department issued a statement recognizing: “Many intersex persons, including children, experience invasive, unnecessary, and sometimes irreversible medical procedures.”¹⁷ In a 2016 toolkit for gender integration in democracy and human rights programs, USAID encouraged its grantees to assess their nations’ laws, rules, and norms for protecting LGBTQI+ people’s human rights, including: “Does the state prohibit medically unnecessary surgery and procedures on the sex characteristics of intersex children, protect their physical integrity and respect their autonomy?”¹⁸ More recently, USAID’s website on “Advancing LGBTQI+ Inclusive Development” observes: “In many parts of the world, intersex people suffer from irreversible, harmful, and medically unnecessary medical interventions, often without fully informed consent.”¹⁹

Unfortunately, the United States remains one of those “parts of the world.” As recently noted by the Department of Justice, “[f]ederal agencies have engaged in a variety of initiatives aimed at protecting women and girls in the United States who have been subjected to or who may be at risk of FGM.”²⁰ Yet no federal effort has yet been made to prevent or discourage the practice of identical surgeries on children born with intersex traits, even where they fall under the same laws. Recently, the Departments of Justice, Education, and HHS have formally interpreted federal civil rights laws to outlaw discrimination based on sex characteristics, including intersex traits.²¹ These interpretations, along with observances such as Intersex Awareness Day, provide critical visibility and basic rights education—but are no substitute for actions that directly address persistent harmful practices.

HHS has also previously issued, and is currently updating, a landmark federal report on harmful attempts to change young people’s gender identity or sexual orientation,²² and has issued guidance making clear that federal child welfare funds may not be used for such harmful practices.²³ Similar efforts are sorely needed to protect intersex children and youth, particularly given that efforts to “normalize” intersex children and youth’s physical characteristics are often intertwined with efforts to change their gender identity or sexual orientation.²⁴ In a recent national survey, for example, LGBTQ

¹⁵ US Department of State, Country Reports on Human Rights Practices for 2020: China (Includes Hong Kong, Macau, and Tibet), <https://www.state.gov/report/custom/f9b484c098/>; US Department of State, Country Reports on Human Rights Practices for 2020: Russia (2021), <https://www.state.gov/report/custom/c9683947f1/>.

¹⁶ Readout of White House Roundtable on Intersex Awareness Day (Oct. 27, 2021), <https://www.whitehouse.gov/briefing-room/statements-releases/2021/10/27/readout-of-white-house-roundtable-on-intersex-awareness-day/>.

¹⁷ Press Statement of Department Spokesperson Ned Price, Intersex Awareness Day (Oct. 25, 2021), <https://www.state.gov/intersex-awareness-day/>.

¹⁸ US Agency for International Development, Gender Integration in Democracy, Human Rights, and Governance (DRG) (2016), <https://www.usaid.gov/sites/default/files/documents/2496/Gender%20Toolkit.pdf>.

¹⁹ US Agency for International Development, Advancing LGBTQI+ Inclusive Development, <https://www.usaid.gov/LGBTQI> (last updated June 21, 2021).

²⁰ US Department of Justice, DOJ, ICE and the FBI Recognize International Day of Zero Tolerance for Female Genital Mutilation (Feb. 4, 2022), <https://www.justice.gov/opa/pr/justice-department-ice-and-fbi-recognize-international-day-zero-tolerance-female-genital>.

²¹ HHS, Ensuring Access to Equitable, Affordable, Client-Centered, Quality Family Planning Services; Final rule, 86 FR 56144, 56159 (Oct. 7, 2021); US Department of Justice, Title IX Legal Manual (updated Aug. 12, 2021), <https://www.justice.gov/crt/title-ix#Bostock> (“Title IX’s prohibition on sex discrimination includes discrimination based on gender identity, intersex traits, and sexual orientation”); US Department of Education, Supporting Intersex Students: A Resource for Students, Families, and Educators (Oct. 2021), <https://www2.ed.gov/about/offices/list/ocr/docs/ocr-factsheet-intersex-202110.pdf>.

²² Substance Abuse and Mental Health Services Administration, Ending Conversion Therapy: Supporting and Affirming LGBTQ Youth (2015), <http://store.samhsa.gov/shin/content/SMA15-4928/SMA15-4928.pdf>.

²³ Administration for Children and Families, IM-22-01: Guidance for Title IV-B and IV-E Agencies When Serving LGBTQI+ Children and Youth (Mar. 2, 2022), <https://www.acf.hhs.gov/sites/default/files/documents/cb/im2201.pdf>.

²⁴ 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>.

youth born with intersex traits were slightly more likely than their non-intersex LGBTQ peers to report that someone had tried to convince them to change their sexual orientation or gender identity—and *twice* as likely to report experiencing such efforts *from a medical or mental health care provider*.²⁵ Just as with non-intersex LGBTQ youth, outside attempts to change their core identities appear to be risk factors for suicidality, while acceptance from parents and others around them is a significant protective factor.²⁶

Dangerous new state laws and actions make federal action increasingly urgent

Even as medical and human rights experts increasingly condemn these non-consensual, medically unnecessary early surgeries, federal action is becoming ever-more urgent due to an unprecedented wave of targeted actions by state lawmakers and officials, as well as extreme political rhetoric.

To date, fifteen states have enacted legislation aimed at banning transgender girls from school athletics, but these laws also affect intersex girls by either expressly banning them from participation on the basis of their sex characteristics or inviting invasive scrutiny of their bodies to “verify” their sex.²⁷ These laws either expressly require students and families to proactively disclose sensitive medical information about their sex characteristics; permit any third party to initiate an investigation into a student’s sex characteristics for virtually any reason; or delegate sweeping discretion to state or school officials for such inquiries based on vague language. The only court to consider such a law to date held that it is likely unconstitutional because it both “preclud[es] women and girls who are transgender and many who are intersex from participating in women’s sports,” and “burdens all female athletes with the risk and embarrassment of having to ‘verify’ their ‘biological sex’ in order to play women’s sports.”²⁸

Even more disturbing, three states have recently enacted, and lawmakers in several other states have proposed, legislation that singles out intersex children’s bodies by prohibiting (and in one state, criminalizing) gender-affirming care that transgender adolescents want and need, while expressly permitting harmful “normalizing” surgeries on young intersex children to continue – without regard to medical necessity. These laws, which do unprecedented harm to both communities, use identical language to exempt the usually non-consensual procedures on “persons born with a medically verifiable disorder of sex development, including a person with external biological sex characteristics that are irresolvably ambiguous” or any person who “does not have normal sex chromosome structure, sex steroid hormone production, or sex steroid hormone action” from the otherwise sweeping prohibition on enumerated medical procedures that are often part of consensual gender-affirming care.²⁹ Proposed legislation in Congress and other states uses identical language.³⁰ These laws represent a novel government imprimatur on the increasingly disapproved practice of “normalizing” surgery on intersex children, and invite unethical providers to use this broad language as a shield against scrutiny notwithstanding generally applicable laws governing informed consent, medical malpractice, sterilization, and genital mutilation or cutting.

Accompanying and supporting this new wave of state legislation is a growing political rhetoric that seeks to deny and eliminate the existence of transgender people and in the process misrepresents the natural diversity represented by intersex variations. This rhetoric pathologizes people with intersex “disorders” as a “tragic fact,”³¹ not because of any actual threat to individual health associated with having intersex traits, but rather because intersex people are supposedly “very rare exceptions” to the

²⁵ Price, M.N., Green, A.E, DeChants, J.P, & Davis, C.K., The mental health and well-being of LGBTQ youth who are intersex (The Trevor Project, 2021).

²⁶ *Id.*

²⁷ Movement Advancement Project, LGBTQ Youth: Bans on Transgender Youth Participation in Sports (Apr. 13, 2022) (collecting statutes) <https://www.lgbtmap.org/img/maps/citations-sports-participation-bans.pdf>.

²⁸ *Hecox v. Little*, 479 F. Supp. 3d 930, 944 (D. Idaho 2020), *remanded on other grounds*, (9th Cir. June 24, 2021).

²⁹ Alabama SB 184, engrossed as Act 289 (2022); Arizona SB 1138, engrossed as Chapter 104 (2022); Arkansas HB 1570, engrossed as Act 626 (2021).

³⁰ See H.R.1927/S.777, End Taxpayer Funding of Gender Experimentation Act.

³¹ *Hecox v. Little*, Intervenor’s Memorandum in Opposition to Plaintiffs’ Motion for Preliminary Injunction, No. 1:20-cv-00184 (D. Idaho, filed June 9, 2020).

“common sense” that “everyone is clearly either male or female.”³² The political campaigns behind these bans on gender-affirming care that specifically exempt intersex surgeries seek to reinforce the view that variations in sex characteristics are categorically “true medical problems,” even as the medical community retreats from this view and positive intersex visibility is at an all-time high.³³ The same fringe medical voices consistently relied upon to defend anti-transgender laws and justify conversion therapy (and sometimes recognized as unreliable by courts³⁴) characterize intersex people as “grappling” with a “disorder” rather than representing a “‘spectrum’ of biological sex”³⁵—or, in other words, as “unfortunate cases” saddled with an “anomalous condition” of “unsuccessful assimilation to either male or female.”³⁶ The unsurprising endpoint of this rhetoric is that intersex variations are cast as “medical abnormalities ... requiring intervention to steer the child and parents toward an acceptable choice between male and female.”³⁷

These disturbing developments—making intersex children targets of harsh legislation and political rhetoric at a moment of unprecedented visibility—threaten to undermine recent progress in destigmatizing intersex variations, improving intersex-affirming medical care, and providing for better quality-of-life outcomes across the intersex community. As a result, federal action to promote awareness and acceptance of the natural diversity of sex characteristics, and to protect intersex infants’ and children’s bodily autonomy, is increasingly urgent.

We specifically call on the federal government to take the following actions:

ACTION: Create a public education campaign for health professionals, families, and service providers on supporting intersex children and youth.

HHS should follow the lead of state and local jurisdictions in the US and allied nations in planning a national public education campaign to inform both families and health care professionals about the natural diversity in sex characteristics, best practices for affirming care, and the potential benefits of avoiding non-emergency surgical interventions in infancy.³⁸ This campaign should build on the 2020 NASEM report referenced above, as well as on the 2017 report by three former US Surgeons General. In that report, those medical experts concluded that “cosmetic infant genitoplasty is not justified absent a need to ensure physical functioning” as “evidence does show that the surgery itself can cause severe

³² Jay W. Richards & Jared Eckert, Biden’s Latest Proposal Would Force Insurers to Pay for Gender “Transition,” Heritage Foundation (Feb. 7, 2022) <https://www.heritage.org/gender/commentary/bidens-latest-proposal-would-force-insurers-pay-gender-transition>.

³³ Family Policy Alliance, Frequently Asked Questions About Gender Dysphoria and Minor Transition (2022), <https://familypolicyalliance.com/help-not-harm/>.

³⁴ See *Grimm v. Gloucester Cty. Sch. Bd.*, 972 F.3d 586, 596 n. 3 (4th Cir. 2020) (“It goes without saying that one can always find a doctor who disagrees with mainstream medical professional organizations on a particular issue. Aspects of Dr. Van Meter’s report blatantly contradict the views of ... the American Academy of Pediatrics and our other medical *amici*”); *DeBoer v. Snyder*, 973 F. Supp. 2d 757 (E.D. Mich.), rev’d, 772 F.3d 388 (6th Cir. 2014), rev’d sub nom. *Obergefell v. Hodges*, 576 U.S. 644 (2015) (“The Court finds Regnerus’s testimony entirely unbelievable and not worthy of serious consideration”).

³⁵ R.G. & G.R. HARRIS FUNERAL HOMES, INC., v. EQUAL OPPORTUNITY EMPLOYMENT COMMISSION, BRIEF OF SCHOLARS OF FAMILY AND SEXUALITY AS AMICI CURIAE IN SUPPORT OF PETITIONER, NO. 18-107 (U.S., filed Aug. 23, 2019).

³⁶ *Meriwether v. Trustees of Shawnee State University*, Brief of *Amicus Curiae* Dr. Paul R. Mchugh, M.D., and Other Medical and Scientific Experts in Support of Plaintiff-Appellant, No. 20-3289 (6th Cir. Filed June 3, 2020).

³⁷ David Coppedge, Science Is Being Corrupted by Politics, Creation-Evolution Headlines (Feb. 4, 2021), <https://crev.info/2021/02/science-corrupted-by-politics/>.

³⁸ See N.Y.C. Int. No. 1748-A (2021) (directing Department of Health to develop campaign), <https://legistar.council.nyc.gov/LegislationDetail.aspx?ID=4918989&GUID=A4DF9183-978A-40F0-985B-6D5C7D84E43E>; State of Victoria, Department of Health, Health of people with intersex variations (2019) (collection of educational resources, including fact sheets for families), <https://www.health.vic.gov.au/populations/health-of-people-with-intersex-variations>; see also State of Victoria, Department of Health, (i) *Am Equal: Future Directions for Victoria’s Intersex community* (2021) (statewide plan for intersex equity including a “suite of resources” for families, youth, and provider, a health resource hub, training, research and data collection, and patient protections), <https://www.health.vic.gov.au/publications/i-am-equal>.

and irreversible physical harm and emotional distress,” and urged providers and families that “the practice should stop.”³⁹

Such a campaign could be spearheaded by SAMHSA, the Office of Population Affairs, HRSA's Maternal and Child Health Bureau, and/or the Office of the Surgeon General. HHS should work with intersex-led patient groups and with medical and ethical experts with a demonstrated commitment to affirming intersex bodily autonomy. HHS could also use a new or expanded grant to leverage the capacity of one or more of its training and technical assistance providers for this initiative.

The HHS component(s) leading this project should coordinate with other agencies, including the Office for Civil Rights (OCR), Administration for Children and Families (ACF), Centers for Medicare & Medicaid Services (CMS), Indian Health Services (IHS), and the Partnership Center, to ensure it reaches diverse health and child welfare professionals, state and local government, and community stakeholders, and is integrated into existing HHS health and child welfare clearinghouses and information centers.

ACTION: End the use of federal funds for non-emergency genital and gonadal surgeries on intersex children too young to consent (or object).

Just as HHS is moving to end the use of federal funds for harmful, unscientific, and discriminatory “conversion therapy,” it should work to ensure that federal health care and foster care funds are not used for harmful, nonconsensual surgeries on intersex infants and children.

Most importantly, CMS should provide guidance to state Medicaid and CHIP officials on ensuring federal funds are not used for non-emergent genital or sterilizing surgeries until youth are able drive decision-making and provide meaningful, informed consent or assent.⁴⁰

ACF should provide guidance regarding the use of Title IV-E foster care funds to ensure protection of children who are wards of the state, similar to its recent guidance on conversion therapy.⁴¹

OCR should issue guidance to federal-assistance health programs and activities on intersex patients’ nondiscrimination and health information privacy rights under laws such as the Affordable Care Act, the Rehabilitation Act, and the Health Insurance Portability and Accountability Act (HIPAA). For example:

- A covered hospital may impermissibly engage in sex or disability discrimination where it applies patient protection policies or procedures to some child patients but not others on the basis of intersex traits (such as policies or procedures to ensure informed consent, or limiting or requiring administrative or judicial approval of sterilizing procedures).
- A covered hospital may violate HIPAA privacy or access rights where it withholds or conceals protected health information (PHI) from a patient related to their own intersex traits, or makes unauthorized use of PHI as a “teaching tool” for students.

ACTION: Initiate hospital civil rights and HIPAA compliance reviews.

Non-consensual, unnecessary early intersex surgeries are performed by a limited (and shrinking)

³⁹ M. Jocelyn Elders, David Satcher, & Richard Carmona, Re-thinking genital surgeries on intersex infants (Palm Center, June 2017), <https://www.palmcenter.org/wp-content/uploads/2017/06/Re-Thinking-Genital-Surgeries-1.pdf>.

⁴⁰ Cf., e.g., Australian Capital Territory, Treasury & Economic Development Directorate, *Protecting the rights of intersex people in medical settings: Regulatory options paper* (June 2021), <https://www.cmtedd.act.gov.au/policystrategic/the-office-of-lgbtqi-affairs/protecting-the-rights-of-intersex-people-in-medical-settings> (proposing prior authorization of certain procedures by an expert panel); Icelandic Act on Gender Autonomy No 80 /2019 as amended by Act No. 154/2020 (similar requirements).

⁴¹ Administration for Children and Families, IM-22-01: Guidance for Title IV-B and IV-E Agencies When Serving LGBTIQ+ Children and Youth (Mar. 2, 2022), <https://www.acf.hhs.gov/sites/default/files/documents/cb/im2201.pdf>.

number of major medical institutions in the United States.⁴² The highly specialized nature of the procedures and the programs conducting them can serve to insulate them from scrutiny of clinical, ethical, and administrative practices. As such, targeted compliance efforts could make a major impact in protecting intersex patient rights and improving care.

OCR should initiate robust compliance reviews of one or more hospitals known to perform early intersex surgeries to determine whether they are complying with civil rights and HIPAA requirements. OCR could model such an effort on its National HIV/AIDS Compliance Review Initiative and its ongoing Right of Access Initiative.

ACTION: Address intersex populations in health equity, cultural competence, and research initiatives.

While targeted action is needed to address this unique issue, all HHS agencies can and should help to advance health and equity for intersex children and youth by ensuring meaningful intersex inclusion—especially in the areas of maternal and child health, sexual health, family planning, mental health, and health disparities. HHS agencies should:

Review grant announcements and resource guides, trainings, reports and technical assistance publications, policy guidance, and webpages to ensure they meaningfully include consideration of populations with intersex traits, informed by engagement with intersex people.

Review definitions of terms such as “equity,” “underserved populations,” and “health disparity populations” to ensure inclusion of intersex populations.

Test and implement standalone measures for data collection on intersex populations, consistent with recommendations of the National Academies March 2022 consensus study report on “Measuring Sex, Sexual Orientation, and Gender Identity.”

Include, and collect disaggregated data on, people with intersex traits in federally funded or federally conducted research studies on health and child well-being.

Include intersex organizations and community members in stakeholder outreach, events, focus groups, storytelling projects, prevention programs, and other public-facing initiatives.

Conclusion

We greatly appreciate your commitment, and that of President Biden, “to advancing justice, opportunity, and safety for intersex Americans.”⁴³ We look forward to working with you to turn this commitment into action to protect the health, dignity, and bodily autonomy of children with intersex traits.

Please let us know if you would like additional information or if we can be of assistance in any other way. You can reach the Roundtable by contacting Dan Bruner at dbruner@whitbman-walker.org or (202) 669-3388.

Signed,

AIDS United
Autistic Self Advocacy Network
Callen-Lorde Community Health Center
Center for American Progress

⁴² Kyle Knight, Protest Demands End to Harmful Surgeries on Intersex Children, Human Rights Watch (Sept. 1, 2021), <https://www.hrw.org/news/2021/09/01/protest-demands-end-harmful-surgeries-intersex-children>.

⁴³ Readout of White House Roundtable on Intersex Awareness Day (Oct. 27, 2021), <https://www.whitehouse.gov/briefing-room/statements-releases/2021/10/27/readout-of-white-house-roundtable-on-intersex-awareness-day/>.

Fenway Health
GLMA: Health Professionals Advancing LGBTQ Equality
Howard Brown Health
interACT: Advocates for Intersex Youth
Lyon-Martin Community Health Services
National Black Justice Coalition
National Center for Transgender Equality
National LGBT Cancer Network
National LGBTQ Task Force
National Women's Law Center
Transgender Law Center
Transgender Legal Defense & Education Fund
Transhealth Northampton
Whitman-Walker Institute