

October 26, 2017

Citing Medical and Legal Standards, Lambda Legal Calls to End Medically Unnecessary Genital Surgeries on Intersex Infants and Children

To the American Medical Association, American Psychological Association, American Academy of Pediatrics, American Academy of Family Physicians, Association of American Medical Colleges, American College of Surgeons, North American Society for Pediatric and Adolescent Gynecology, Pediatric Endocrine Society, and Societies for Pediatric Urology:

We write today to supplement our letter of July 25, 2017, and further urge that you take immediate measures to end surgeries on intersex infants and children without their own free, informed and valid consent, except in medically necessary situations, e.g., for infants born with conditions that render them unable to void urine or born with organs outside the body.¹ As set forth below, such an approach is consonant not only with sound medical and ethical standards concerning the treatment of intersex people, but also with their rights to personal autonomy and bodily integrity, as protected under constitutional and human rights law, and as commonly protected through the application of state laws, as well, particularly given recent developments and available legal analyses. In short, standards for treating intersex infants and children have evolved, and it is quite arguable that available state and federal laws provide remedies for people subjected to early intersex surgeries.

We are heartened by growing attention to this important issue and especially by the American Medical Association's (AMA) early steps toward adopting proposed Resolution 3-A-16. We understand that the resolution proposed by the AMA's Board of Trustees in Report 7-1-16 recommends deferring medical or surgical intervention for people with "differences of sex development (DSD)" until the affected individuals can participate in decision-making, absent actual medical necessity.² We think this clear and specific approach is vital to protecting intersex infants and children, as well as surgeons and medical teams. This alignment is important for the entire constellation of people involved: intersex children, their families, and doctors who provide care.

The AMA's draft resolution aligns with the June 2017 report issued by three former U.S. surgeons general, who reviewed the available evidence and concluded that "cosmetic infant genitoplasty is not justified absent a need to ensure physical functioning."³ The *AMA Journal of Ethics* in August 2017 published an essay arguing that "physicians who recommend or perform genital surgeries that are not clinically indicated can be rightly blamed for, and are complicit in,

¹ Hayley Gorenberg & Yuvraj Joshi, *Citing Today's Report by Human Rights Watch and InterACT, Lambda Legal Renews Call to End Non-Emergency Genital Surgeries on Intersex Infants and Children* (July 25, 2017), available at https://www.lambdalegal.org/sites/default/files/legal-docs/downloads/ll_letter_re_hrw_interact_report_monday_final.pdf.

² *Supporting Autonomy for Patients with Differences of Sex Development (DSD) (Resolution 3-A-16)* (2016), available at <https://assets.ama-assn.org/sub/meeting/documents/i16-bot-07.pdf>.

³ M. Joycelyn Elders, David Satcher & Richard Carmona, *Re-Thinking Genital Surgeries on Intersex Infants* (2017), available at <http://www.palmcenter.org/wp-content/uploads/2017/06/Re-Thinking-Genital-Surgeries-1.pdf>.

both pathologizing natural variations in bodies and causing unnecessary iatrogenic harm.”⁴ Internationally, the World Health Organization and other agencies have noted the recommendation that “full, free and informed consent should be ensured in connection with medical and surgical treatments for intersex persons and, if possible, irreversible invasive medical interventions should be postponed until a child is sufficiently mature to make an informed decision, so that they can participate in decision-making and give full, free and informed consent.”⁵ The AMA and other medical associations should take this position, first and foremost to ensure that intersex people’s health and human rights are protected, and secondarily to guide their professional constituents against incurring liability.

The AMA’s proposed resolution aligns with existing and emerging legal standards. Constitutional law decisions of the U.S. Supreme Court have vindicated the rights to personal autonomy and bodily integrity in cases challenging sterilization, involuntary treatment, incursions against reproductive rights, and barriers to equality for lesbians, gay men, bisexuals and transgender people,⁶ creating legal precedent that has direct implications for surgeries on intersex children. For instance, Supreme Court justices have recognized that “[e]very violation of a person’s bodily integrity is an invasion of his or her liberty,” and that “[t]he invasion is particularly intrusive if it creates a substantial risk of permanent injury,”⁷ as is the case with surgeries performed on intersex infants and children that commonly result in scarring, nerve damage, loss of sexual sensation and function, diminished reproductive capacity or sterilization, the need for lifelong hormonal therapy, irreversible physical alteration to impose a sex assignment that the individual may later reject, and psychological trauma. Internationally, the United Nations Committee Against Torture has condemned medically unnecessary surgeries on intersex infants.⁸

The AMA’s proposed resolution both responds to and anticipates legal developments. In July 2017, a landmark lawsuit about genital surgery performed on an intersex baby, M.C., settled with a payment of \$440,000.⁹ In the case *M.C. v. Aaronson*, the U.S. Court of Appeals for the Fourth Circuit did not decide whether the surgery violated M.C.’s constitutional rights, and instead found that M.C.’s constitutional rights were not clearly understood by reasonable officials at the time of M.C.’s surgery – in 2006.¹⁰ We consider the *M.C.* court’s reading of the law, specific to

⁴ Samuel Reis-Dennis & Elizabeth Reis, *Are Physicians Blameworthy for Iatrogenic Harm Resulting from Unnecessary Genital Surgeries?*, AMA Journal of Ethics (Aug. 2017), available at <http://journalofethics.ama-assn.org/2017/08/msoc3-1708.html>.

⁵ See, e.g., Interagency Statement, World Health Organization, *Eliminating forced, coercive and otherwise involuntary sterilization* (2014), available at http://www.who.int/reproductivehealth/publications/gender_rights/eliminating-forced-sterilization/en/.

⁶ See, e.g., *Skinner v. Oklahoma*, 316 U.S. 535 (1942); *Washington v. Harper*, 494 U. S. 210 (1990); *Planned Parenthood of Southeastern Pennsylvania v. Casey*, 505 U.S. 833 (1992); *Lawrence v. Texas*, 539 U.S. 558 (2003).

⁷ *Washington v. Harper*, 494 U. S. 210, 237 (1990) (Stevens, J., joined by Brennan & Marshall, JJ.).

⁸ See, e.g., Committee against Torture, Concluding observations on the seventh periodic report of France, CAT/C/FRA/CO/7 (10 June 2016).

⁹ Azeen Ghorayshi, *A Landmark Lawsuit About An Intersex Baby’s Genital Surgery Just Settled For \$440,000*, BuzzFeed News (July 26, 2017), available at <https://www.buzzfeed.com/azeenghorayshi/intersex-surgery-lawsuit-settles>.

¹⁰ See *M.C. v. Aaronson*, No. 13-2178 (4th Cir. Jan. 26, 2015).

that jurisdiction, to be quite constrained, and expect that another court could very easily apply law that was clearly established in 2006 to furnish a basis for liability. Furthermore, recent constitutional decisions have affirmed and extended the fundamental rights to personal autonomy and bodily integrity, including landmark decisions that recognized and have significantly developed the rights to reproductive autonomy, same-sex intimacy, and marriage equality.¹¹ And intersex people’s legal claims are being recognized and upheld in courts, including in our lawsuit on behalf of an intersex client, Dana Zzyym.¹² In light of this legal trajectory and gains in awareness and understanding of the lives and rights of intersex people, it is entirely plausible that a future court presented with similar facts as those in *M.C.* will vindicate intersex people’s rights.

For many years, intersex advocacy organizations and health researchers have documented how medically unnecessary surgeries designed to make intersex children’s bodies conform to binary sex stereotypes violate their rights to personal autonomy and bodily integrity. Challenges to childhood intersex surgeries are further animated by the realizations and regrets of many parents of intersex children who were subject to unnecessary surgeries, as well as the misgivings of doctors who performed such surgeries. Indeed, *M.C.* was a case brought by M.C.’s adoptive parents against the officials and doctors who played a part in the decision to have M.C. undergo surgery. Future plaintiffs may include parents who felt pressured or misled in agreeing to such surgeries. A recent report by Human Rights Watch and interACT found that “[n]early every parent interviewed for this report said they were presented with medically unnecessary surgery as an urgent need at least once during their pursuit of care for their child.”¹³ Human Rights Watch also spoke with doctors who expressed discomfort with and regrets about conducting surgery on intersex children without consent, including one DSD specialist who posited that “there’s probably rare if any situations where surgery is absolutely necessary.”¹⁴

No current AMA policy directly addresses the issue of early intersex surgeries. In October 2017, the AMA’s Council on Ethical and Judicial Affairs issued Report 3-I-17 recommending that an existing Opinion E-2.2.1, “Pediatric Decision Making,” be amended *in lieu of* the proposed Resolution 3-A-16.¹⁵ We urge that such an amendment alone is inadequate, though we support the issuance of ethical guidance *in addition to and in accordance with* specific and clear medical guidance that the nation’s doctors and other medical professionals need in order to help them practice their professions in a manner that comports with medical, legal and ethical standards and

¹¹ See *Lawrence v. Texas*, 539 U.S. 558 (2003) (“When sexuality finds overt expression in intimate conduct with another person, the conduct can be but one element in a personal bond that is more enduring. The liberty protected by the Constitution allows homosexual persons the right to make this choice.”); *Obergefell v. Hodges*, 135 S. Ct. 2584 (2015) (“The Constitution promises liberty to all within its reach, a liberty that includes certain specific rights that allow persons . . . to define and express their identity.”); *Whole Woman’s Health v. Hellerstedt*, 579 U.S. ____ (2016) (affirming “a constitutional right to abortion because it ‘involve[s] the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy.’”).

¹² See *Zzyym v. Tillerson*, 2016 WL 7324157 (D. Colo, Nov. 22, 2016).

¹³ Human Rights Watch/interACT, “*I Want To Be Like Nature Made Me*”: *Medically Unnecessary Surgeries on Intersex Children in the US* (July 2017), available at <https://www.hrw.org/node/306688/>.

¹⁴ Human Rights Watch, *A Changing Paradigm: US Medical Provider Discomfort with Intersex Care Practices* (forthcoming October 26, 2017).

¹⁵ *Supporting Autonomy for Patients with Differences of Sex Development (DSD) (Resolution 3-A-16)* (2016), available at <https://assets.ama-assn.org/sub/meeting/documents/i16-bot-07.pdf> (emphasis added).

helps protect them against incurring liability for unnecessary and highly problematic surgeries. Above all, such guidance is necessary to safeguard the endangered fundamental rights of intersex people, including their rights to individual dignity, autonomy and health.

We look forward to working together, with intersex people, with Human Rights Watch and interACT, and with you, to end wrongful surgeries on intersex children and promote policies that address intersex people's true health needs. Please do not hesitate to contact us as you move forward to address this issue.

Sincerely,



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