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REPORT ON LEGISLATION BY THE LESBIAN, GAY, BISEXUAL, TRANSGENDER AND QUEER RIGHTS COMMITTEE, CIVIL RIGHTS COMMITTEE, HEALTH LAW COMMITTEE AND SEX AND LAW COMMITTEE

Int. 1748-2019 Council Members Dromm, Rivera, Van Bramer, Ayala, Louis, Rosenthal, Menchaca

A Local Law to amend the administrative code of the city of New York, in relation to requiring the department of health and mental hygiene to implement a public information and outreach campaign regarding medically unnecessary treatments or interventions in infants born with intersex traits

THIS BILL IS APPROVED

The New York City Bar Association is an organization of over 24,000 lawyers and judges dedicated to improving the administration of justice. The Committees on Lesbian, Gay, Bisexual, Transgender and Queer Rights, Civil Rights, Health Law and Sex and Law (the "Committees") write in support of the bill before the City Council: Int. 1748-2019, requiring the Department of Health and Mental Hygiene to implement a public information and outreach campaign regarding medically unnecessary treatments or interventions in infants born with variations in their sex characteristics.

The Committees believe that the New York City Department of Mental Health and Hygiene (DOHMH) should work to end the practice of performing medically unnecessary genital and gonadal surgeries on intersex infants, which harm marginalized individuals, negate sexual and reproductive decision-making autonomy and contravene patient-centered care. This bill would require DOHMH to create informational resources that may be distributed when an infant is born with intersex traits—that is, a person born with reproductive or sexual anatomy that does not fit the typical definitions of male or female. DOHMH would design the resources for parents and/or guardians as well as medical practitioners. The materials would specifically address important considerations when deciding whether medical intervention may be safely delayed until the infant is older and can voice thoughts about the procedure.

¹ This statement relates only to intersex infants and children, and their autonomy to make decisions about their bodies if and when they choose. This statement should not be construed as taking a position on circumcision performed on persons with male sex characteristics for religious purposes, nor is this statement addressing a person's right to make decisions about their body during pregnancy.

Because the proposed materials are essential to the educations of parents and guardians, the Committees further recommend that the bill be modified to require that the educational resources that DOHMH creates be furnished to those contemplating surgeries, together with other forms, such as consent forms, that they must complete in order to authorize such surgeries. Requiring provision of these educational resources would further the bill's goal of ensuring parents or legal guardians are able to receive and consider them before making a decision.

Children with intersex traits are often subjected to medically unnecessary, irreversible, nonconsensual genital surgeries. Up to 1.7 percent of people around the world are born with sex characteristics—including gonads, genitals, hormones, and chromosomes—that do not fit typical notions of "male" or "female" bodies.² Almost always, these variations are healthy differences that require no urgent surgical intervention.³ However, medically unnecessary "normalization" surgeries remain common.⁴ In these surgeries, doctors attempt to "correct" healthy variations simply because intersex bodies do not conform to stereotypical expectations of male or female children. In New York State, surgeries such as clitoral reductions and vaginoplasties are routinely performed to "normalize" the bodies of intersex children. The practice is widespread, with many individuals referred to treatment centers in New York City,⁵ where surgeries are commonly performed on children between the ages of 3 and 6 months old.⁶

We advocate for the end of these unnecessary, nonconsensual, and irreversible surgeries inflicted upon intersex people and support the right of parents to receive accurate and timely information about medical interventions that they currently may feel pressured into consenting to without a full understanding of the life-long ramifications and known risks of these surgeries. In times of medical emergency, such as when an infant is born without the ability to pass urine, parents must be able to make decisions about their children's medical care, and this bill addresses only the unnecessary "normalizing" surgeries described above.

"Normalizing" surgeries on a child's genitals or reproductive organs can severely harm the child both physically and emotionally. Negative consequences can include "scarring, incontinence, loss of sexual sensation and function, psychological trauma including depression and post-traumatic stress disorder, the risk of anesthetic neurotoxicity attendant to surgical procedures on

report were last visited on February 10, 2020).

² HUMAN RIGHTS WATCH, 'I WANT TO BE LIKE NATURE MADE ME': MEDICALLY UNNECESSARY SURGERIES ON INTERSEX CHILDREN IN THE US 19 (2018), https://www.hrw.org/sites/default/files/report_pdf/lgbtintersex0717_web_0.pdf [hereinafter HRW]. (All links in this

³ Congenital Adrenal Hyperplasia (CAH), one of the most common intersex traits, can cause adrenal problems that can be dangerous or even life-threatening if not treated; however, these health risks do not come from the variations in sex characteristics that are also associated with CAH, and genital surgeries do not do anything to address the risk of adrenal crisis in children with CAH.

⁴ HRW, *supra* note 2, at 20-21.

⁵ See Weill Cornell Medicine, *Pediatric Urology*, https://urology.weillcornell.org/pediatric-urology (offering treatments for "[g]enital abnormalities" and "[d]isorders of sexual development (incomplete or otherwise atypical development of the genital organs, including ambiguous genitalia)").

⁶ See Weill Cornell Medicine, Genitoplasty – Treatment Options, https://urology.weillcornell.org/clinical-conditions/pediatric-urology/genitoplasty/treatment-options [hereinafter Genitoplasty].

young children, sterilization, the need for lifelong hormonal therapy, and irreversible surgical imposition of a sex assignment that the individual later rejects."

Procedures that modify the sex characteristics of non-consenting intersex children seek to impose conformity with cosmetic or behavioral gender norms for the sex assigned to that child, e.g., that clitoral reduction is "essentially a cosmetic procedure. The aim of surgery is to reduce the size of the clitoris whilst maintaining a feminine appearance," and hypospadias surgeries aim to achieve a "sex-typical manner for urination (i.e. standing for males)." The website of one prominent New York hospital explains that feminizing genitoplasties are performed on monthsold intersex patients with Congenital Adrenal Hyperplasia—over 10 percent of whom may not identify as women—for the sake of having a "normal appearing vagina." 10

Although these surgeries are routinely performed in New York State, they are widely condemned by national and international human rights organizations as practices that violate a range of fundamental rights, including freedom from torture and the rights to health, autonomy, and integrity.¹¹ These surgeries, when performed without the consent of the patient, have been condemned by the American Academy of Family Physicians, the World Health Organization, Physicians for Human Rights, Human Rights Watch, Amnesty International, Lambda Legal, the ACLU, the Trevor Project, GLSEN, the Gay & Lesbian Medical Association (GLMA), and every intersex-led organization in the world focusing on this population.¹² Multiple United Nations treaty committees and expert bodies have condemned these surgeries, some even likening them to a form of torture or ill-treatment.¹³In August 2018, the California legislature passed a resolution supporting and recognizing the diversity of intersex individuals and calling upon stakeholders to end medically unnecessary surgeries on intersex individuals by recommending deferral, as warranted, of medical interventions until the child is able to participate in decision making.¹⁴

Some doctors also report that they perform these surgeries because the child's parents desire it. While there are countless decisions that parents may, and must, make on behalf of their children in order to keep them safe and healthy, unnecessary "normalizing" procedures on their

⁷ HRW, *supra* note 2, at 89.

⁸ Sarah Creighton, et al. *Nature of Reconstructive Surgery for Disorders of Sex Development*, 8 J. OF PEDIATRIC UROLOGY 602, 603 (2012).

⁹ *Id*.

¹⁰ *Genitoplasty*, *supra* note 6.

¹¹ HRW, supra note 2, at 13.

¹² Kyle Knight, *US Medical Association Stands Against Unnecessary Intersex Surgeries*, HUMAN RIGHTS WATCH (Sept. 17, 2018), https://www.hrw.org/news/2018/09/17/us-medical-association-stands-against-unnecessary-intersex-surgeries.

¹³ See Sylvan Fraser, Constructing the Female Body: Using Female Genital Mutilation Law to Address Genital-Normalizing Surgery on Intersex Children in the United States, 9 INT'L J. HUM. RTS. HEALTHCARE 62, 67 (2016) ("Both the UN Special Rapporteur on Torture and the UN Special Rapporteur on Violence Against Women define [Female Genital Mutilation] as torture and have clarified that 'medicalizing' FGM does not immunize it from classification as a human rights violation.").

¹⁴ SCR-110 (Cal. 2018).

intersex child, however, are not among them. These irreversible procedures implicate fundamental matters including identity, sexuality, and reproductive freedom. The risks associated with these surgeries are troublingly high, and there is no evidence that these surgeries actually benefit the child when performed without individual consent. They fall into the same category as involuntary sterilization. A person's right to weigh such deeply personal decisions for themselves cannot be preempted absent an urgent medical necessity, even with parental consent. Surgeries that simply purport to spare the child from the hypothetical stigma of having an atypical body or aim to alleviate parental anxiety about having a child with a difference of sex development run afoul of important legal principles.

In conclusion, the Committees strongly oppose medically unnecessary surgeries on children born with variations in their sex characteristics, as these surgeries violate fundamental principles of patient autonomy and are rooted in stigma rather than medical necessity.

Lesbian, Gay, Bisexual, Transgender and Queer Rights Committee Noah E. Lewis and Geoffrey L. Wertime, Co-Chairs

Civil Rights Committee Zoey Chenitz, Chair

Health Law Committee Brian T. McGovern, Chair

Sex and Law Committee Mirah Curzer and Melissa Lee, Co-Chairs

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