

Title: Medical and Surgical Intervention of Patients with Differences in Sex

Development

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Introduced by: GLMA Policy and Government Affairs Committee

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Whereas, surgical intervention, including removal and reconstruction of sex organs, has been practiced for children born with atypical genitalia since the 1960s and has long been considered a mainstay of treatment in these individuals, despite often being considered medically unnecessary and potentially resulting in unwanted effects such as sterilization, and

Whereas, GLMA: Health Professionals Advancing LGBT Equality passed Resolution 105-98-105 in 1998, "Call for Research and Disclosure Regarding Intersex Surgery," indicating the organization's support for further advancement in research regarding the methods of care and biopsychosocial outcomes for patients with Differences of Sex Development (DSD), as well as reinforcing the need for frank and involved discussions between providers, patients, and family regarding the risks and benefits of treatment for these patients, ² and

Whereas, while further research has been conducted into the outcomes of medical, surgical, and psychological treatment for these individuals, there continues to be a need for further studies and a consensus on standard of care, and

Whereas, surgical interventions continue to represent a common plan of care for children with DSD but remain highly controversial among pediatric specialists³ and are largely condemned by the Intersex community, and

Whereas, research has provided varying rates of patient satisfaction in genital appearance, as well as diminished sexual function/satisfaction in adults after childhood surgical procedures intended to treat DSD; and future reconstructive surgical interventions remain common outcomes after initial childhood surgery,³ and

Whereas, justification for such treatments in infancy and childhood has included the presumption of better socialization and acceptance among peer-groups and psychological well-being throughout life; however, evidence to support this is lacking, and

Whereas, several prominent human rights organizations including the World Health Organization, Amnesty International, ^{6,7} the United Nations Special Rapporteur on Torture, and the United Nations High Commissioner for Human Rights, ⁵ have expressed concern about the violation of the human rights of individuals when medically unnecessary surgeries are performed

without their consent/assent and recommend postponing any surgeries until consent/assent may be given; and

Whereas, the decision for genital surgery in infants and children, for whom informed consent or assent cannot be attained, is placed upon parents, relies heavily on the relationship of the caretakers and healthcare providers, and requires comprehensive disclosure of risks and benefits as well as alternatives for intervention, including postponing interventions that do not have medical necessity; and

Whereas, parents or caretakers may often rely on social norms, binary gender concepts, personal convictions, and/or influence among outside parties in their decision-making process without understanding all avenues of treatment, including postponing treatment, therefore be it

RESOLVED: that GLMA: Health Professionals Advancing LGBT Equality recommends that patients and parents/caretakers are provided a comprehensive explanation of risks and benefits to surgical/medical intervention for Differences of Sex Development (DSD), as well as all alternatives to treatment, including postponement of interventions; and be it further

RESOLVED: that GLMA recommends delay of any surgical interventions and gender-related medical interventions for DSD that are not deemed medically necessary until the patient can provide informed consent/assent to these interventions; and be it further

RESOLVED: that GLMA encourages additional comprehensive retrospective and prospective biopsychosocial research on the long-term outcomes of patients born with differences of sex development; and be it further

RESOLVED: that the development and execution of research should involve, where available, the input of community representatives, psychiatrists, and other mental health practitioners from the intersex and DSD communities, and be it further

RESOLVED: that facilities that provide genital surgical interventions and gender-related medical interventions to patients with DSD adopt a multidisciplinary model to patient care that includes input from mental health specialists, medical and surgical specialists, bioethicists, and community/peer support organizations to deliver comprehensive biopsychosocial treatments that support all patients, their families, and any other caretakers, and be it further

RESOLVED: that GLMA urges development of cultural competency education for health care professionals and development of best practice guidelines regarding treatment of individuals with DSD, and be it further

RESOLVED: that GLMA adopts this policy as replacement and update of Resolution 105-98-105 (1998).

References:

- ¹ Creighton SM, et al. Timing and nature of reconstructive surgery for disorders of sex development introduction. *Journal of Pediatric Urology*. 2012; 8(6): 602-610
- ² GLMA: Health Professionals Advancing LGBT Equality, "Call for Research and Disclosure Regarding Intersex Surgery" Resolution 105-98-105, March 7, 1998
- ³ Lee PA, et al. Global disorders of sex development update since 2006: perceptions, approach and care. *Hormone Research in Pediatrics*. 2016; 85(3): 158-180
- ⁴ Karkazis K, Tamar-Mattis A, Kon AA. Genital surgery for disorders of sex development: implementing a shared decision-making approach. *Journal of Pediatric Endocrinology and Metabolism*. 2010; 23: 789-806
- ⁵ World Health Organization. Eliminating forced, coercive or otherwise involuntary sterilization: an interagency statement. 2014 [Statement of OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO];
- ⁶ United Nations Office of the High Commissioner for Human Rights. Free & Equal, Fact Sheet: Intersex. 2015.

⁷ Amnesty International. Policy statement on the rights of intersex individuals, 2013.

Referenced but not cited:

- ⁸ Liao LM, Wood D, Creighton SM. Parental choice on normalising cosmetic genital surgery: between a rock and a hard place. *British Medical Journal*. 2015; 351: h5124.
- ⁹ Wang LC and Poppas DP. Surgical outcomes and complications of reconstructive surgery in the female congenital adrenal hyperplasia patient: What every endocrinologist should know. *Journal of Steroid Biochemistry and Molecular Biology*. 2016