

## Human Rights Watch Submission to the Inquiry Regarding People Born with Variations in Sex Characteristics

October 2, 2018

Human Rights Watch thanks the Australian Human Rights Commission for its timely and relevant inquiry, and respectfully submits the following information regarding our research and analysis of the rights of people born with variations in sex characteristics.

As you may know, Human Rights Watch is an international research and advocacy organization that monitors the human rights situation in more than 90 countries worldwide. We have had an official presence in Australia since 2013. Our research on the rights of people born with variations in sex characteristics (we used the term 'intersex') focused principally on the situation in the United States. However, given that the human rights violations faced by intersex people in industrialized countries worldwide are quite similar, and noting that the current medical paradigm of encouraging and performing medically unnecessary surgeries on intersex children before they are old enough to consent was popularized largely by US-based doctors starting in the 1960s, we would like to submit our analysis for your consideration.

In 2017, we published two in-depth reports on the treatment of intersex youth in the United States. These reports, the result of 10 months of intensive research, include policy recommendations for medical professional associations as well as government entities.

Our research confirmed what is widely known. Based on a dangerous and baseless medical theory popularized in the United States in the 1960s, some doctors continue to perform medically unnecessary genital assignment surgeries on intersex children—typically in infancy. The results are often catastrophic, the supposed benefits are largely unproven, and the procedures are only rarely intended to address urgent health considerations requiring immediate, irreversible intervention.

Major health and human rights organizations, including several United Nations treaty bodies and human rights experts<sup>1</sup>, the World Health Organization<sup>2</sup>, Amnesty International<sup>3</sup>, and Physicians for Human Rights<sup>4</sup> have condemned these surgeries when performed before an intersex person can provide their consent. US medical associations including GLMA: Healthcare Professionals for LGBT Equality<sup>5</sup>, the North American Society for Pediatric and Adolescent Gynecology<sup>6</sup>, and the American Academy of Family Physicians, have issued policies urging the regulation of these operations. In July 2017, three former US Surgeons General, including one who was a pediatric endocrinologist, wrote to oppose this practice because "there is insufficient evidence that growing up with atypical genitalia leads to psychosocial distress," and "the surgery itself can cause severe and irreversible physical harm and emotional distress."8

https://www.amnestv.org/en/latest/campaigns/2017/05/intersex-rights/.

<sup>&</sup>lt;sup>1</sup> Concluding observations of the UN Committee against Torture, Germany, CAT/C/DEU/CO/5, December 12, 2011; CAT observations on the seventh periodic report of Switzerland, CAT/C/CHE/CO/7, September 7, 2015; CAT Concluding observations on the sixth periodic report of Austria, CAT/C/AUT/CO/6, January 27, 2016; CAT Concluding observations on the fifth periodic report of China with respect to Hong Kong, China, CAT/C/CHN-HKG/CO/5, February 3, 2016; CAT Concluding observations on the combined sixth and seventh periodic reports of Denmark, CAT/C/DNK/CO/6-7, February 4, 2016; CAT, Concluding observations on the seventh periodic report of France, CAT/C/FRA/CO/7, June 10, 2016. UN Committee on the Rights of the Child, "Concluding observations on the fifth period report of New Zealand," CRC/C/NZL/CO/5, September 30, 2016; CRC "Concluding observations on the second periodic report of South Africa," CRC/C/ZAF/CO/2, September 30, 2016; CRC "Concluding observations on the combined second to fourth periodic reports of Switzerland," CRC/C/CHE/CO/2-4, February 26, 2015; CRC "Concluding observations on the combined fourth and fifth periodic reports of Chile," CRC/C/CHL/CO/4-5, October 30, 2015; CRC "Concluding observations on the fifth periodic report of France," CRC/C/FRA/CO/5, January 29, 2016; CRC "Concluding observations on the combined third and fourth periodic reports of Ireland," CRC/C/IRL/CO/3-4, January 29, 2016; "Concluding observations on the fifth periodic report of the United Kingdom of Great Britain and Northern Ireland," CRC/C/GBR/CO/5, June 3, 2016; CRC "Concluding observations on the third to fifth periodic reports of Nepal," CRC/C/NPL/CO/3-5, June 3, 2016. United Nations Committee on the Rights of Persons with Disabilities, "Concluding observations on the initial report of Germany," CRPD/C/DEU/CO/1, May 13, 2015; UNCRPD, "Concluding observations on the initial report of Chile," CRPD/C/CHL/CO/1, April 13, 2016; UNCRPD, "Concluding observations on the initial report of Italy," CRPD/C/ITA/CO/.1, August 31, 2016. United Nations Committee on the Elimination of Discrimination against Women, "Concluding observations on the combined fourth and fifth periodic reports of Switzerland," CEDAW/C/CHE/CO/4-5, November 18, 2016; UN CEDAW, "Concluding observations on the combined seventh and eighth periodic reports of France," CEDAW/C/FRA/CO/7-8, July 22, 2016.

<sup>&</sup>lt;sup>2</sup> United Nations World Health Organization, et. al., "Eliminating Forced, Coercive and Otherwise Involuntary Sterilization—An Interagency Statement." Office of the High Commissioner for Human Rights, joint statement, "United Nations entities call on States to act urgently to end violence and discrimination against lesbian, gay, bisexual, transgender and intersex (LGBTI)1 adults, adolescents and children," September

<sup>2015,</sup> https://www.ohchr.org/Documents/Issues/Discrimination/Joint\_LGBTI\_Statement\_ENG.PDF (accessed April 22, 2017).

<sup>3</sup> Amnesty International, "First, Do No Harm: Ensuring the Rights of Children Born Intersex," May 2017,

<sup>4</sup> Physicians for Human Rights, "Unnecessary Surgery on Intersex Children Must Stop," October 20, 2017, https://phr.org/news/unnecessary-surgery-on-intersex-children-must-stop/.

<sup>5</sup> GLMA, "Medical and Surgical Intervention of Patients with Differences in Sex Development," October 2016, http://glma.org/index.cfm?fuseaction=document.viewdocument&ID=CEB9FEE4B8DD8B7F4F7575376BD476C3A433379DD853BEA1791 3AFCCB8270299C0731320B03D2F5E1022F1C15602FBEA.

<sup>&</sup>lt;sup>6</sup> Human Rights Watch, "Pediatrics Bodies Support Intersex Child Autonomy," November 8, 2017, https://www.hrw.org/news/2017/11/08/pediatrics-bodies-support-intersex-child-autonomy.

<sup>7</sup> Human Rights Watch, "US Medical Association Stands Against Unnecessary Intersex Surgeries," September 17, 2018, https://www.hrw.org/news/2018/09/17/us-medical-association-stands-against-unnecessary-intersex-surgeries.

<sup>8</sup> M. Joycelyn Elders, David Satcher, and Richard Carmona, "Re-Thinking Genital Surgeries on Intersex Infants," June 2017, Michael J. Palm Center, https://www.palmcenter.org/wp-content/uploads/2017/06/Re-Thinking-Genital-Surgeries-1.pdf.

While certain surgical interventions on intersex children are undisputedly medically necessary, the majority of intersex infants are born perfectly healthy. Unnecessary surgeries often sterilize the intersex person and result in otherwise unnecessary lifelong hormone replacement therapy. Operations undertaken to alter the size and/or appearance of infants' genitals can cause incontinence, scarring, lack of sensation, and psychological trauma equivalent to that experienced by childhood sexual abuse victims. The procedures are irreversible and most physicians recognize that a child can be raised as either sex and surgery delayed until the individual is able to participate in the decision. Patient advocacy organizations frequently interact with families raising happy, healthy intersex children who were not subjected to surgery. On the other hand, genital or gonadal surgeries on intersex children too young to declare their gender identity carry the risk of surgically assigning the wrong sex, as has been in the case in several publicized cases.

In August 2018, the California state legislature passed Senate Concurrent Resolution-1109, which calls on the medical community to issue policy protecting children born with variations in their sex characteristics from medically unnecessary surgeries. While the resolution is non-binding, it stands as positive affirmation from a government body that intersex people should be celebrated as part of a diverse society, and that medical associations should heed evidence and ethics to formulate policy rather than allow the field to remain unregulated and reckless.

We enclose copies of our reports for your consideration, and urge the Commission to craft recommendations in line with Australia's international human rights obligations and the growing medical consensus that, absent medical need, children born with variations of their sex characteristics should not be subjected to surgery until they can give their own informed consent for the procedure.

3

<sup>&</sup>lt;sup>9</sup> Human Rights Watch, "California: Resolution Affirms Intersex Rights," August 28, 2018, <a href="https://www.hrw.org/news/2018/08/28/california-resolution-affirms-intersex-rights">https://www.hrw.org/news/2018/08/28/california-resolution-affirms-intersex-rights</a>.