

Mandates of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health and the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment

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Dear Dr. Agliano,

We have the honour to address you in our capacities as Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health and Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, pursuant to Human Rights Council resolutions 33/9 and 34/19.

We understand that the American Medical Association (AMA) Council on Ethical and Judicial Affairs (CEJA), which you chair, is currently considering a policy regarding intersex¹ people. I am aware that the AMA Board of Trustees in 2016 recommended a course of action, which prompted review by the CEJA.

We write to express our encouragement for the AMA to adopt a policy that respects and upholds the human rights of intersex people and places them at the heart of medical practice. In particular, we have recommended², together with the Special Rapporteur on violence against women, its causes and consequences, the UN Committee on the Rights of the Child, the Special Representative of the United Nations Secretary-General on Violence against Children, the UN Committee against Torture, the UN Committee on the Rights of Persons with Disabilities, the UN Committee on the Elimination of Discrimination against Women, the UN Subcommittee on Prevention of Torture and other Cruel, Inhuman or Degrading Treatment or Punishment and the Inter-American Commission on Human Rights the following measures, in line with our mandates and international human rights law, norms and standards:

- As a matter of urgency, medically unnecessary surgery and procedures on intersex children should be prohibited.
- Intersex children and adults should be the only ones who decide whether they wish to modify the appearance of their own bodies – in the case of children, when they are old or mature enough to make an informed decision for themselves.
- Legislation, policies, standards and protocols, including those issued by regulatory and professional bodies, must integrate human rights principles and explicitly commit to respect for and upholding the rights of intersex children and adults, including the rights to health, to physical and mental integrity,

¹ My mandate and other United Nations human rights bodies have predominantly used the term “intersex”, on the basis of our dialogue with community groups and rights holders, to refer to people who are born with physical or biological sex characteristics (such as sexual anatomy, reproductive organs, hormonal patterns and/or chromosomal patterns) that do not fit the typical definitions for male or female bodies. We are aware that different terms are used by different community groups, as well as medical practitioners.

² Joint statement of UN and regional human rights experts, “End violence and harmful medical practices on intersex children and adults,” 24 October 2016, available at <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E>

to live free from violence and harmful practices and to be free from torture and ill-treatment.

- Intersex children and adults should have access to medical services that respond to their specific health needs and that are based on non-discrimination, informed consent and respect for their fundamental rights.
- Intersex children and their parents, and intersex adults, should be provided with support and counselling, including from peers.
- Intersex people should be protected from discrimination on ground of sex characteristics, including in access to healthcare.
- Awareness should be raised of the rights of intersex people, and measures taken to combat the root causes of human rights violations, including harmful stereotypes, stigma and pathologization.
- Training should be provided to health professionals in line with these human rights standards.

Nonconsensual surgery to ‘correct’ healthy sex characteristics

In countries around the world, intersex infants, children and adolescents are often subject to medically unnecessary surgeries in an attempt to forcibly change their appearance to be in line with societal expectations about typical female and male bodies. When, as is frequently the case, these procedures are performed without the full, free and informed consent of the person concerned, they amount to violations of fundamental human rights. These practices can have detrimental, long-lasting effects on their health and well-being; violate their basic rights to physical integrity, privacy and autonomy; and may violate the right to be free from torture and ill-treatment.

The practice has been addressed with concern by the aforementioned United Nations and regional human rights experts.³ It has also come under scrutiny by Physicians for Human Rights⁴, Amnesty International⁵, Human Rights Watch⁶, the

³ In addition to the aforementioned joint statement of United Nations and regional experts of 26 October 2016 that makes the above recommendations, United Nations bodies have condemned these practices on multiple other occasions, including: Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health – reports A/HRC/32/32 (2016), A/HRC/32/33 (2016), A/70/213 (2015) and A/64/272 (2009); Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment – reports A/HRC/31/57 (2016) and A/HRC/22/53 (2013); United Nations Committee on the Rights of the Child concluding observations in relation to New Zealand - CRC/C/NZL/CO/5 (2016), South Africa - CRC/C/ZAF/CO/2 (2016), Switzerland - CRC/C/CHE/CO/2-4 (2015), Chile - CRC/C/CHL/CO/4-5 (2015), France - CRC/C/FRA/CO/5 (2016), Ireland - CRC/C/IRL/CO/3-4 (2016), United Kingdom of Great Britain and Northern Ireland – CRC/C/GBR/CO/5 (2016), Nepal - CRC/C/NPL/CO/3-5 (2016); United Nations Committee against Torture concluding observations in relation to Denmark - CAT/C/DNK/CO/6-7 (2015), Switzerland - CAT/C/CHE/CO/7 (2015), Austria - CAT/C/AUT/CO/6 (2016), France - CAT/C/FRA/CO/7 (2016); United Nations Committee on the Rights of Persons with Disabilities concluding observations in relation to Italy - CRPD/C/ITA/CO/1 (2016), Germany - CRPD/C/DEU/CO/1 (2015), Chile - CRPD/C/CHL/CO/1 (2016), United Nations Committee on the Elimination of Discrimination against Women concluding observations on France - CEDAW/C/FRA/CO/7-8 – (2016), the Netherlands- CEDAW/C/NLD/CO/6 (2016) and joint general recommendation No. 31 on harmful practices, CEDAW/C/GC/31 - CRC/C/GC/18; UN Subcommittee on Prevention of Torture and other Cruel, Inhuman or Degrading Treatment or Punishment – Ninth Annual report CAT/OP/C/57/4 (2016).

⁴ <http://physiciansforhumanrights.org/press/press-releases/intersex-surgery-must-stop.html>

⁵ Amnesty International, “First, Do No Harm: Ensuring the Rights of Children Born Intersex,”

<https://www.amnesty.org/en/latest/campaigns/2017/05/intersex-rights/>

⁶ Human Rights Watch and interACT, “‘I Want to be Like Nature Made Me’: Medically Unnecessary Surgery on Intersex Children in the US,” July 2017, https://www.hrw.org/sites/default/files/report_pdf/lgbtintersex0717_web_0.pdf

Council of Europe Commission on Bioethics⁷, the World Health Organization⁸, the UN Office of the High Commissioner for Human Rights⁹, three former US Surgeons-General¹⁰, and most importantly, groups led by intersex people and parents of intersex children in the United States and around the world.¹¹

While acknowledging that there is an increase in voices from some medical practitioners to address these issues, there is a critical absence of legislation, policies and protocols that are aligned with human rights principles including the above recommendations, leading to a continuation of violations of the fundamental rights of intersex children and adults. The AMA's guidance in this matter is crucial.

Negative outcomes from early surgery

Profound negative impacts of these often-irreversible procedures have been reported, including permanent infertility, incontinence, loss of sexual sensation, causing life-long pain and severe psychological suffering, including depression and shame linked to attempts to hide and erase intersex traits.

For example, in a 2003 study in the United Kingdom, researchers found that, “The 18 women who had undergone clitoral surgery had higher rates of non-sensuality (78%) and of inability to achieve orgasm (39%) than did the ten who had not had surgery.”¹² Other studies have likewise shown diminished sexual sensation and function resulting from clitoral surgery.¹³ Vaginoplasty, a procedure undertaken to create a vaginal opening or to elongate a vagina that is considered “inadequate” for penetrative intercourse, has many risks and complications, including scarring at the introitus and growth of abnormal tissue (“neoplasia”), necessitating repeated intervention.¹⁴ In one study, of “57 46XY DSD adults who had undergone genital surgery, 47.1% were dissatisfied with functional results, 47.4% with clitoral arousal and 37.5% with overall sex life; 44.2% had sexual anxieties, 70.6% had problems with desire and 56.3% reported dyspareunia [painful intercourse].”¹⁵ Regarding psychological consequences of early surgery, one study found elevated rates of self-harming behavior and suicidal tendencies among intersex people comparable to those among women who have experienced physical or sexual abuse,¹⁶ and

⁷ The Committee on Bioethics of the Council of Europe, “The Rights of Children in Biomedicine: Challenges Posed by Scientific Advances and Uncertainties,” Council of Europe, January 16, 2017, <http://www.coe.int/en/web/children/-/studyon-the-rights-of-children-in-biomedicine>.

⁸ http://www.who.int/reproductivehealth/publications/gender_rights/eliminating-forced-sterilization/en/

⁹ United Nations High Commissioner for Human Rights report A/HRC/29/23 (2015)

¹⁰ <http://www.palmcenter.org/publication/re-thinking-genital-surgeries-intersex-infants/>

¹¹ <http://aisd.org/wp-content/uploads/2017/07/20170725-HRW-AISDSD-Press-Release.pdf>;

https://docs.google.com/document/u/1/d/16skW1o_ISP5pjdq9WUVcttJNgndO88W5cMZw3YwB3qc/pub?embedded=true (Intersex Awareness Day Resolution signed by over twenty international intersex-led organizations).

¹² Catherine Minto, et al., “The Effect of Clitoral Surgery on Sexual Outcome in Individuals Who Have Intersex Conditions with Ambiguous Genitalia: A Cross-sectional Study.” *The Lancet*, April 12, 2003,

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4559568/>

¹³ Creighton, S., Minto, C. L., & Steele, S. J. (2001). Objective cosmetic and anatomical outcomes at adolescence of feminizing surgery for ambiguous genitalia done in childhood. *The Lancet*, 358, 124–125; Crouch, N. S., Liao, L. M., Woodhouse, C. R. J., Conway, G. S., & Creighton, S. M. (2008). Sexual function and genital sensitivity following feminizing genitoplasty for congenital adrenal hyperplasia. *Journal of Urology*, 179(2), 634–638.

¹⁴ Hughes IA et al. Consensus statement on management of intersex disorders, *Archives of Disease in Childhood* 2006, 91:554-63.

¹⁵ Peter Lee et al., *Review of Recent Outcome Data of Disorders of Sex Development (DSD): Emphasis on Surgical and Sexual Outcomes*, *JOURNAL OF PEDIATRIC UROLOGY* (2012), available at <http://dx.doi.org/10.1016/j.jpurol.2012.10.017>

¹⁶ Schützmann et al. (2009), Psychological distress, suicidal tendencies, and self-harming behaviour in adult persons with different forms of intersexuality, *Arch Sex Behav.* 2009 Feb;38(1):16-33.

another compared the trauma of childhood surgery to that of childhood sex abuse.¹⁷ Depression, PTSD, and increased risks of suicide are also documented in qualitative interviews.¹⁸

No harm from lack of surgery/treatment

Some medical practitioners have advocated for early surgery and treatment on the basis of purported psychological benefits. However, there is an absence of evidence to support the existence of such purported benefits.¹⁹ Moreover, even should such evidence emerge, this would not justify medically unnecessary treatment and surgery without consent, particularly in light of the negative impacts and harms from these operations that have been documented. Conversely, there is growing evidence that intersex people who do not undergo surgery do not suffer psychological or physical harm as a result.

For example, a 2012 study by a group of doctors in the Netherlands and Belgium that featured 33 intersex participants who had not undergone surgeries found that women with complete absence of the vagina (e.g., CAIS) indicated no psychological or developmental problems until they reached menstruation and concluded vaginal surgery should be deferred until later in life.²⁰ A 2017 paper published in the *Journal of Pediatric Urology* documented in follow-up with seven girls with CAH up to age eight who did not have surgery that “girls and their parents have not expressed significant concerns regarding genital ambiguity.”²¹

Parents under pressure

Parents of children with intersex traits often face pressure to agree to such surgeries or treatments on their children. They are rarely informed about alternatives or about the potential negative consequences of the procedures, which are routinely performed despite a lack of medical indication, necessity or urgency. The rationale for these is frequently based on social prejudice, and stigma associated with intersex bodies. Human Rights Watch and interACT reported in 2017 that medical providers in the United States pressured parents in recent years to undertake irreversible surgical procedures, including surgery, and, the parents said, made them feel they were being unreasonable when they resisted or asked questions.²²

Lack of informed consent

¹⁷ Tamara Alexander, *The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse* (1997), available at <http://www.isna.org/articles/analogue>.

¹⁸ Marcus de Maria Arana, *A Human Rights Investigation into the Medical “Normalization” of Intersex People: A Report of a Public Hearing by the Human Rights Commission of the City and County of San Francisco* (April 28, 2005), available at http://sfhrc.org/site/uploadedfiles/sfhumanrights/Committee_Meetings/Lesbian_Gay_Bisexual_Transgender/HRC%20Intersex%20Report.pdf; Human Rights Watch and interACT, “I Want to be Like Nature Made Me’: Medically Unnecessary Surgery on Intersex Children in the US,” July 2017, https://www.hrw.org/sites/default/files/report_pdf/lgbtintersex0717_web_0.pdf

¹⁹ Hughes IA et al. Consensus statement on management of intersex disorders, *Archives of Disease in Childhood* 2006, 91:554-63; Karkazis K, Kon A, Tamar-Mattis A. Shared Decision-Making and Children with DSD, *Journal of Pediatric Endocrinology and Metabolism* 2010 July;23(3):789-806; Creighton S, et al., Timing and nature of reconstructive surgery for disorders of sex development – Introduction, *Journal of Pediatric Urology* 2012, <http://dx.doi.org/10.1016/j.jpuro.2012.10.001>; Anne Tamar-Mattis, *Patient Advocate Responds to DSD Surgery Debate*, 10 *JOURNAL OF PEDIATRIC UROLOGY* 788 (2014).

²⁰ Nina Callens, et al. “Do Surgical Interventions Influence Psychosexual and Cosmetic Outcomes in Women with Disorders of Sex Development?” *ISRN Endocrinology* 2012 (2012), Article ID 276742, <https://www.hindawi.com/journals/ism/2012/276742/>

²¹ Pierre Bougnères, “Deferring Surgical Treatment of Ambiguous Genitalia into Adolescence in Girls with 21-Hydroxylase Deficiency: A Feasibility Study,” *International Journal of Pediatric Endocrinology* 2017(3) (2017), DOI 10.1186/s13633-016-0040-8.

²² See, inter alia, Human Rights Watch and interACT, “I Want to be Like Nature Made Me’: Medically Unnecessary Surgery on Intersex Children in the US,” July 2017, https://www.hrw.org/sites/default/files/report_pdf/lgbtintersex0717_web_0.pdf

Guaranteeing informed consent is fundamental to achieving the enjoyment of the right to physical and mental health. All healthcare policies should ensure that information is fully available, acceptable, accessible and of good quality, and information should be imparted and comprehended by means of supportive and protective measures such as counselling and involvement of community networks.

In light of these fundamental human rights principles, the documented significant risk of harm and profound negative impacts of medically unnecessary surgeries and treatment, and the lack of any medical benefits²³, intersex children and adults should be the only ones who decide on the basis of full, free and informed consent whether or not they wish to modify the appearance of their own bodies. In the case of children, this means waiting until they are old or mature enough to make an informed decision for themselves.

Medical policy should guide physicians to protect

The American Medical Association plays a crucial role in guiding physicians, parents, and users of healthcare services in the United States and beyond, and should urgently take measures to advise against medically unnecessary surgery and procedures on intersex children. The American Medical Association has an important responsibility in this regard, including through its policy making function. I urge the American Medical Association to integrate the aforementioned human rights principles and recommendations that have been made by United Nations and regional human rights experts in your policy on protection and medical care for intersex children and adults.

Medicine has already grappled with these concepts, including for youth. Medical policy bodies, including the American Medical Association, have considered and developed policy regarding female genital cutting, sterilization of minors, informed consent and assent. For example in 2010, the AAP published a position statement opposing all forms of female genital cutting, and it made no explicit exception for girls with intersex traits.²⁴ And in 2014, the AAP published a provisional section which stated, in references to intersex children that “If it is not medically necessary, any irreversible procedure can be postponed until the child is old enough to agree to the procedure (e.g. genital surgery).”²⁵

Care for transgender youth also emphasizes the need for irreversible surgery not to be carried out until the person can request and make the decision themselves, based on informed consent. For example, policies supported by the AMA, the AAP, the World Professional Association for Transgender Health, and international health and human rights bodies encourage early in life care for transgender and gender non-conforming youth to focus on psycho-social support until the child is old enough to understand other possible procedures and their consequences, including those that will be irreversible such as genital surgery.

²³ A/64/272

²⁴ Policy Statement—Ritual Genital Cutting of Female Minors,” American Academy of Pediatrics 126(1) (2010).

²⁵ “Explaining Disorders of Sex Development & Intersexuality” on www.healthchildren.org, by the American Academy of Pediatrics. <https://www.healthchildren.org/English/health-issues/conditions/genitourinary-tract/Pages/ExplainingDisorders-of-Sex-Development-Intersexuality.aspx>

Conclusion

The American Medical Association is a crucial voice for protecting the rights and health of users of healthcare services, and guiding physicians in their quest to do so. As the AMA Principles of Medical Ethics principles I and VIII explain, “A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights” and “A physician shall, while caring for a patient, regard responsibility to the patient as paramount.”²⁶

We urge the AMA Council on Ethical and Judicial Affairs to adopt a policy to respect and uphold the fundamental human rights of intersex children and adults to health, to physical and mental integrity, to live free from violence and harmful practices and to be free from torture and ill-treatment, and to implement the urgent measures our mandates and other United Nations and regional experts have made in this regard.

Kindly note that a similar letter has also been sent to the American Academy of Pediatrics.

Please accept, Dr. Agliano, the assurances of our highest consideration.

Dainius Pûras

Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health

Nils Melzer

Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment

²⁶ <https://www.ama-assn.org/delivering-care/ama-principles-medical-ethics>