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Journal of Pediatric Urology (2016) xx, 1-2



Still ignoring human rights in intersex care

'Surgery in disorders of sex development (DSD) with a gender issue: If (why), when, and how?' reads like it was written 20 years ago. While the paper purports to address 'unanswered questions' regarding care for children born with atypical sex anatomies, most of these are the same questions that have prompted critical scrutiny of the standard of care since the mid 1990s. As the authors admit, there remains little 'evidence of the answers' that specialists provide to what they take to be an urgent problem presented by atypical sex anatomies in children [1]. The lack of evidence appears not to have had much impact on physicians' confidence in a standard of care that has remained largely unchanged.

More damningly, nowhere in this paper is there a discussion of respect for DSD patients' right to decide for themselves whether to have healthy sexual tissue removed. The authors simply ignored the violations of human rights entailed by the prevailing standard of care that have been identified in statements by the Swiss ethics council [2], the United Nations [3], and the Council of Europe [4]. Nowhere is there discussion of psychosocial (including peer) support for the child or family, despite the whole approach being predicated on concerns about 'stigma risk' and despite the claim that a main goal is 'to respond to the parents' desire to bring up a child in the best possible conditions.' Most concerning, the authors continue to act as if (heterosexual) penetrative intercourse and stable gender assignment are top among what clinicians should aim for as outcomes in these cases.

The lack of novel developments in this field is reflected by the ongoing failure to take seriously the conspicuous ethical questions that have been raised by countless critics in medicine, bioethics, law, social sciences, and humanities. The implicit logic of this paper reflects what bioethicist George Annas has called a 'monster ethics' [5], which can be summed up this way: babies with atypical sex are not yet fully human, and so not entitled to human rights. Surgeons make them human by making them recognizably male or female, and *only then* may they be regarded as entitled to the sexual and medical rights and protections guaranteed to everyone else by current ethical guidelines and laws.

Children with DSD can be raised as boys and as girls without being subjected to elective surgeries that lack evidence for necessity, safety, and efficacy, and more importantly that violate their rights. They and their parents deserve full psychosocial support, and physicians who understand the difference between atypical and unhealthy.

Conflict of interest

The authors report no conflicts of interest.

References

- [1] Mouriquand PDE, Gorduza DB, Gay C-L, Meyer-Bahlburg HFL, Baker L, Baskin LS, et al. Surgery in disorders of sex development (DSD) with a gender issue: if (why), when, and how? J Pediatr Urol 2016. http://dx.doi.org/ 10.1016/j.jpurol.2016.04.001.
- [2] Swiss National Advisory Commission on Biomedical Ethics. On the management of differences of sex development: ethical issues relating to 'Intersexuality'. 2012. Opinion No. 20. Berne, Switzerland, http://www.nek-cne. ch/fileadmin/nek-cne-dateien/Themen/ Stellungnahmen/en/NEK_Intersexualitaet_En. pdf [last accessed 03.03.16].
- [3] Méndez E. Report of the special rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment. United Nations General Assembly, 22nd session; February 1 2013. http://www.ohchr.org/Documents/HRBodies/ HRCouncil/RegularSession/Session22/A.HRC. 22.53_English.pdf [last accessed 29.04.16].
- [4] Agius S. Human rights and intersex people. Issue Paper. Council of Europe Commissioner for Human Rights; 2015. https://wcd.coe.int/ com.instranet.InstraServlet?command=com. instranet.CmdBlobGet&InstranetImage= 2909386&SecMode=1&DocId=2367288& Usage=2 [last accessed 29.04.16].
- [5] Annas GJ. Hastings Center Report. Siamese twins: killing one to save the other, 17; 1987. p. 27–9.

http://dx.doi.org/10.1016/j.jpurol.2016.05.017

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> 3 May 2016 Available online xxx