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Office of LGBTIQ+ Affairs  
Chief Minister, Treasury and Economic Development Directorate  
ACT Government

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To Whom It May Concern,

**Submission to the Discussion Paper: Key issues in the prohibition of deferrable medical interventions on intersex people**

The Australian Psychological Society (APS) welcomes the invitation to respond to the Discussion Paper 'Key issues in the prohibition of deferrable medical interventions on intersex people'.

The APS is the peak professional body for psychology in Australia, representing over 25,000 members nationally. A key goal of the APS is to actively contribute psychological knowledge for the promotion and enhancement of community wellbeing.

The Discussion Paper focuses on issues that directly affect the design of options to prohibit deferrable medical interventions in the ACT. The APS has made several statements and submissions relating to people with intersex variations which may be of use for developing options for how a prohibition might work:

- [TLRI Legal Recognition of Sex and Gender](#) (2019)
- [AHRC Project into people born with variations in sex characteristics](#) (2018)
- [Children born with intersex variations – APS information sheet](#)

Above all, and as stated in our previous submissions, the APS believes that decisions and processes regarding medical interventions need to focus primarily on the individual's wellbeing, over and above a concern for social integration which often means normalisation.

The APS has concerns about the human rights protection available to people born with variations in sex characteristics, particularly in relation to the impacts of unnecessary medical interventions, surgical and non-surgical.

The diversity amongst people born with intersex variations means that issues and impacts are likely to be different for each person. This necessitates that each individual's situation should be managed on a case-to-case basis.

## Decision-making and consent

Intersex Human Rights Australia's Position Statement on Genital Cutting<sup>1</sup> argues against surgery until a child is able to participate in making decisions. In a small number of cases early surgery may be necessary, such as to assist bladder or bowel functions. These are the cases which should be defined as 'emergency situations' and therefore exceptions in the legislation, though this should always occur in consultation with parents. Importantly, some surgeries are often treated as medically necessary – such as for hypospadias – when in fact perceived complications may self-correct as the child matures. 'Self-correct' does not necessarily mean that the issue will go away; rather it means that in many cases the person finds ways to happily live with the variation – an option that is denied if unnecessary treatment occurs. It is therefore important to have multiple assessments before any surgery is considered, particularly as surgery performed during infancy often requires repeated follow-up surgeries throughout childhood and adolescence, and parents may not be advised of this when first consenting to surgery.<sup>2</sup>

While it can be important to find ways to enhance parents' and carers' capacity, for example to seek accurate information or authorise necessary treatments, it is even more important that children (or their carers) and adults are not coerced into unnecessary treatments. Fundamentally, what would enhance that capacity is greater clinical awareness of variations, along with reassurance that in most instances no treatment (especially surgery) is required, certainly not on children.

It is important that parents and families are informed about their child's intersex variations and are supportive of their child's right to make decisions about their bodies. It is not recommended for infants to have surgery or take hormones unless medically necessary, meaning parents are advised to be careful about consenting to any medical interventions. Parents may need to negotiate with doctors to ensure any interventions are done with their child's informed consent, when the child is developmentally able to provide it. A European study found that while parents are asked for proxy consent to treat their child, they are often not well-informed or are not given sufficient information and time to make decisions.<sup>3</sup> Parents should generally wait until a child is able to communicate and participate in decisions about potential surgeries before proceeding. Many parents find that support groups run by and for people with intersex variations can be helpful and informative.

Facilitating access to an appropriately trained psychologist could enhance the capacity of people born with intersex variations and/or caregivers to provide informed consent. Psychologists who combine their knowledge with an affirming attitude toward people with intersex variations may be able to help parents explain to children that they have an intersex

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<sup>1</sup> Intersex Human Rights Australia. (2010). OII position statement on genital cutting. Newtown, NSW: IHRA. <https://ihra.org.au/7571/on-genital-surgeries/>

<sup>2</sup> Creighton, S. M., Minto, C. L., & Steele, S. J. (2001). Objective cosmetic and anatomical outcomes at adolescence of feminising surgery for ambiguous genitalia done in childhood. *The Lancet*, 358(9276), 124-125.

<sup>3</sup> Council of Europe. (2015). Human rights and intersex people. <https://book.coe.int/en/commissioner-for-human-rights/6683-pdf-human-rights-and-intersex-people.html>

variation and what this means. They can also confirm that people can live happy and fulfilling lives as adults without having surgery or hormones to change their bodies.

More broadly, there is a need for better community education and information about intersex variations – what they are, what it means, and the impact of social norms and stigma on decision-making. Addressing such social stigma and misconceptions is likely to have a huge impact on people’s decision-making about medical intervention.

### **Research on the perspectives of people with intersex variations**

Finally, it is important to be critical of the available evidence about the experience of intersex variations. Often the evidence has been driven by the views of health professionals rather than the views of people born with intersex variations themselves, and it is always imperative to question whose interests the research served. Tiffany Jones and colleagues, who have conducted the largest study to date of Australians with intersex variations (n=272), noted that there are “clear gaps in the literature around research on the perspectives of people with intersex variations” about interventions (p.101).<sup>4</sup>

If the Government requires further APS input, I may be contacted through my office on (03) 8662 3300 or by email at [z.burgess@psychology.org.au](mailto:z.burgess@psychology.org.au).

Yours sincerely



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Chief Executive Officer

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<sup>4</sup> Jones, T., Hart, B., Carpenter, M., Ansara, G., Leonard, W., & Lucke, J. (2016). Intersex: Stories and statistics from Australia. Cambridge, UK: Open Book Publishers.  
<http://oii.org.au/wpcontent/uploads/key/Intersex-Stories-Statistics-Australia.pdf>