

Office of the Secretary
Department of Justice
15 October 2020

To the Office of the Secretary;

My name is Simone-lisa Anderson, and I am the Tasmanian Representative for IPSA (Intersex Peer Support Australia). IPSA are a nationwide peer-led support organisation for people with variations to their sex characteristics; we work with national and international organisations and agencies, state and federal government, parents, and other people with variations to their sex characteristics to support better outcomes for our community.

Firstly, I would like to thank the government for moving forward on the very important work of formalizing Advance Care Directives in Tasmania. Unfortunately, there are many other issues in the Guardianship and Administration Act (the Act) and its implementation that also need to be fixed urgently, for the welfare and health of the community I represent – both as infants unable to consent to life changing surgeries, and as young people and adults dealing with the consequences to their psychological and physical health throughout their lives.

Non-consensual interventions on infants with variations to sex characteristics

Currently, many infants with variations to their sex characteristics are subjected to deferrable interventions without consent- surgeries to alter the appearance or function of their genitalia, gonads, or other sex characteristics. All these deferrable interventions are conducted for reasons relating to social, cultural, psychosocial and economic rationales. Parents of children born with variations in their sex characteristics currently do not have access to lived-experience advice or support, and without being given other options, are pressured by surgeons to consent to these deferrable surgeries. When they later connect to IPSA, many parents tell us “it seemed [at the time] like the right thing to do”. They were not supported at the time to access all the information they needed, and were not protected by our state’s medical consent structures.

Many of these forced interventions are designed to make children of this community’s bodies appear more “typically” female or male – to fit medical, cultural, or social rationales for female or male bodies. One rationale that has been used is for the ability to have penetrative sex; another for future marriage prospects; another so the child can stand to urinate - although I can tell you, from personal parenting observation, any child with hypospadias can indeed stand to pee. While some surgeries on infants with variations in sex characteristics are urgent necessities- such as managing an evidenced inability to urinate, or evidenced imminent cancer risk or salt wasting- the majority are not, which is clear from the

fact they are often rationalised in terms of an infant child's hypothetical future sexual prospects. This majority of surgeries currently forced on children with variations in sex characteristics could be safely deferred until the child has become a young person capable of expressing their own identity, and providing informed consent themselves.

Unfortunately, many surgeries on infants and young children with variations in sex characteristics lead to the necessity of more surgeries, due to many factors. These include:

- **“Pioneering” surgery:** Experimental surgery that hasn't been done before- as many variations are unique- which then requires follow-up surgeries;
- **Scar tissue from initial or previous surgeries:** Scar tissue does not grow, but children do, causing significant pain and complications that require further intervention;
- **Failure of first surgery:** Additional surgery is needed to fix the first round, which then becomes a merry-go-round of surgeries for the child to endure.

I have included a chart of select procedures in persons aged under 20 years at the end of this submission. Please note how many repairs are done for Hypospadias after the initial surgery- repairs that would never have been needed at all, had the child been allowed to grow first, and give consent themselves when they were ready. Also note the increasing amount of vulvoplasty surgery; this surgery name hides a wide range of procedures including but not limited to: labia majora, mons pubis, labia minora, clitoris, bulb of vestibule, vulva vestibule, greater and lesser vestibular glands and the opening to the vagina.

Many of these deferrable surgeries forced on infants without consent end with a lifetime of consequences, including pain, trauma, shame, loss of sexual function, reduced sensation, incontinence and urgency, experiences of violation and sexual assault, reinforcement of incorrect sex assignment, loss of autonomy, loss of choice, intolerable 'aftercare', psychological scarring and much more- all of which leads to increased long-term public health costs.

When deferrable interventions are deferred until the child or young person is able to consent, and if the child or young person wishes to have interventions, there is a remarkable change in the persons “owning” of their decision/surgery. There is no longer any psychological trauma from what the surgery is changing. I know from personal experience that deferring interventions has had a positive impact on my child – he is happy to discuss his surgery and has only one round, which was simple with no issues or complications. Many others of his peers who had early interventions still have internalised stigma regarding the loss of their right to bodily autonomy, and continuing health problems from the actual interventions due to the inherent nature of performing surgery on small infants.

Relevance to the Guardianship and Administration Act

Surgeries on infants and young children who cannot consent should be covered under the Guardianship and Administration Act.

The Act in its current form theoretically covers anyone with an impairment to their decision-making; this includes age-related impairment for older persons, and there is no reason why it should not also extend to age-related impairment for young children. The Tasmanian Law Reform Institute's (TLRI) prior review of the Act included as recommendation 6.1 that the Act be reworded to no longer talk in terms of "disability", but rather to make it explicit that the Act covers everyone in Tasmania. This would formalise the inclusion and protection of my community under the Act.

Many of the medical treatments forced upon intersex infants & children are already Special Treatments under the current definitions of the Act (as they are "likely to result in sterilisation"), meaning that parental consent is not enough, and the Guardianship and Administration Board is the proper decision-maker. However, in practice, this is not currently implemented. As discussed above, parents are instead pressured to consent to Special Treatment surgeries on their children, which legally they should not.

Please note that decision-making by the Board on these matters would not override the ability of the Family/Supreme Court to continue to make determinations about medical treatment of children when necessary. However, decision-making by the Board on these matters could help to protect both infants and parents, and would constitute a less restrictive (and less traumatic) option than full court hearing if this could be avoided.

Broadening the scope of the Amending Bill

Expanding this Amending Bill to a broader reform of the Act and its regulations could protect children with variations in sex characteristics from the trauma and human rights abuses of non-consensual surgeries that currently occur. Reframing the Act, so that it is clear that it applies to all people who may have an impaired decision-making ability, would support a reduction in these non-consensual surgeries.

Expanding the definition of "Special Treatment" to include all surgical interventions on primary or secondary variations to sex characteristics, and all irreversible hormonal treatments where the person cannot consent, would support the Intersex community—especially if there is a requirement that the Board consult with lived experience experts or organisations on matters concerning medical interventions to alter any variation to sex characteristics.

The parliamentary debate and readings on the Amending Bill are also an opportunity to make it clear that part of the intent of the bill is for children with variations to their sex characteristics to be protected, and that those decisions are under the scope of the Bill.

These considerations match the intent of the TLRI review's recommendations, notably 11.2, which recommends including the following in the Act:

“The decision-maker must consider whether the person is likely to become able to make their own decision, and if so, when. If the decision-maker considers that a decision can be delayed until the person gains the ability to make their own decision, without that delay causing harm, then the decision should be delayed”

*“Where the person's views, wishes and preferences cannot be determined, the decision-maker must give all practical and appropriate effect to what the person's views, wishes and preferences are likely to be, **based on all the information available**”*

“If it is not possible to determine the person's views, wishes and preferences, the decision-maker must ... act in a way least restrictive of their human rights”

Consideration of “all the information available” would include consulting with lived-experience experts and/or organisations on decisions around medical interventions to alter sex characteristics. Those lived-experience experts can provide a lifetime perspective on the long-term effects of such surgeries in a way that medical practitioners are unable to. And, of course, if the Board must act in a way least restrictive of human rights, they must consider the right to bodily autonomy, and for people to be involved in the decisions that affect their lives.

I would also like to point out that the TLRI has also more recently recommended the creation of a Consent to Medical Treatment Act and associated reforms to protect people born with variations in sex characteristics from non-consensual medical interventions. This will be a more comprehensive way of addressing these issues, particularly in creating criminal sanctions for anyone who forces such unnecessary surgeries on non-consenting infants. But we recognise that such a complex reform will take time, which some of our community just doesn't have; these surgeries continue to occur in the Tasmanian health system whenever infants are born with variations. Whereas the Guardian and Administration Act reform is happening now, and can help to protect Tasmanian children from medical abuse until the comprehensive reforms can be undertaken.

Kind Regards,

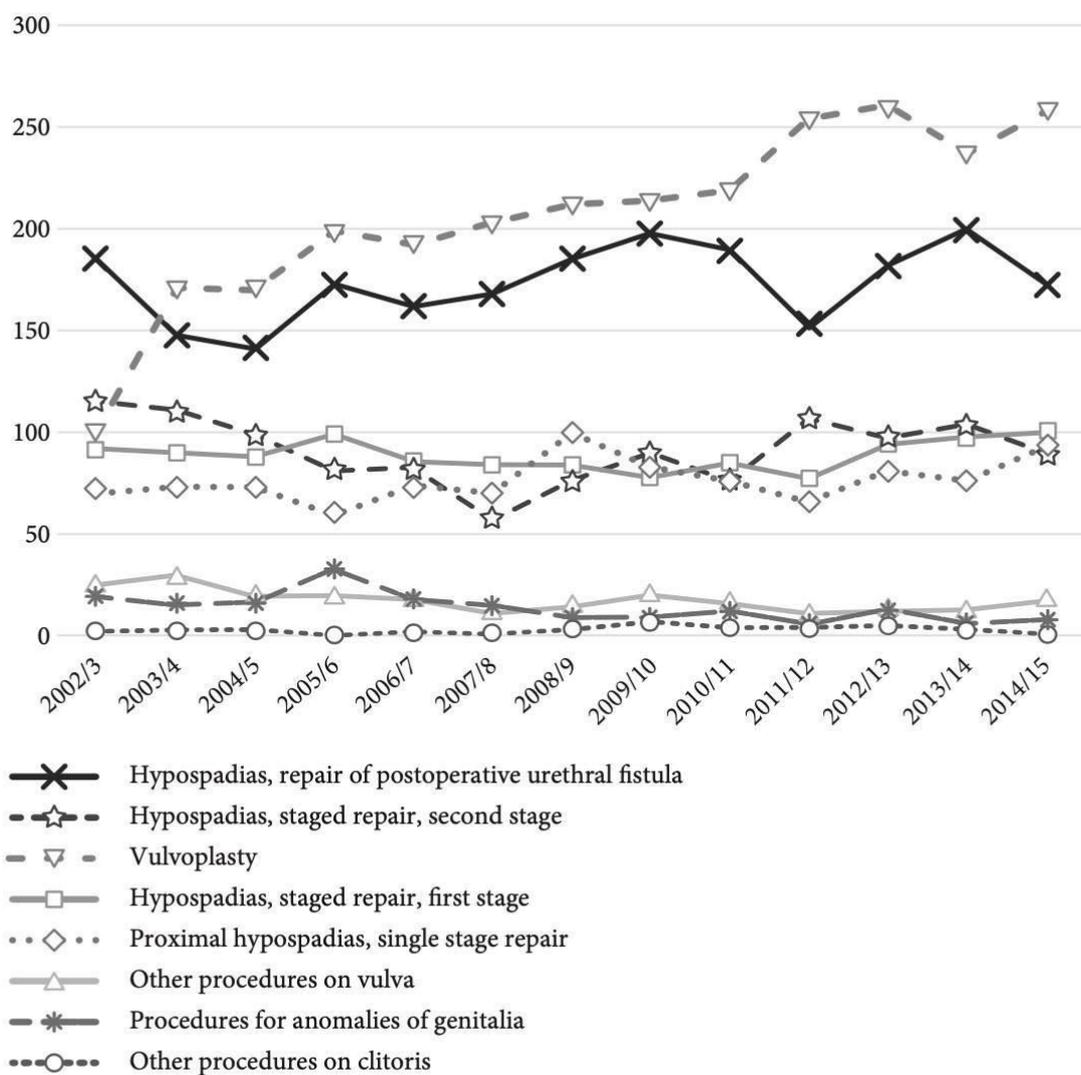
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Figure 1. Selected procedures in persons aged under 20, 2002/03 to 2014/15



Note: Data are for 0–19 year age groups.

Source: Produced by the author using data from the Australian Institute of Health and Welfare.¹³²

produced by Morgan Carpenter, co-executive director of Intersex Human Rights Australia, and published as part of his chapter 'The "Normalisation" of Intersex Bodies and "Othering" of Intersex Identities' in *The Legal Status of Intersex Persons*, edited by Jens Scherpe, Anatol Dutta, and Tobias Helms. Cambridge, England: Intersentia, 2018.