

Submission to the Australian Human Rights Commission Project

Research into the human rights of people born with variations in sex characteristics in the context of medical interventions

APS contact:
Heather Gridley
Manager, Public Interest
h.gridley@psychology.org.au
03 8662 3327

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Level 11, 257 Collins Street
Melbourne VIC 3000
PO Box 38
Flinders Lane VIC 8009
T: (03) 8662 3300
F: (03) 9663 6177
www.psychology.org.au

1. Introduction

The Australian Psychological Society (APS) welcomes the opportunity to make a submission to the Australian Human Rights Commission (AHRC) Project that considers how best to protect the human rights of people born with variations in sex characteristics — in the specific context of non-consensual medical interventions. The APS commends the AHRC for undertaking such an important project.

The APS is the largest national professional organisation for psychologists with more than 24,000 members across Australia. Psychologists are experts in human behaviour and bring critical skills, experience and understanding to support people to live well.

A key goal of the APS is to contribute psychological knowledge for the enhancement of community wellbeing. Psychology in the Public Interest is the section of the APS dedicated to the communication and application of psychological knowledge to enhance community wellbeing and promote equitable and just treatment of all members of society.

We refer the Commission to the APS information sheet [Children born with intersex variations](#) which was prepared for parents and families of children born with intersex variations and for psychologists and other mental health professionals who work with them. This is one of a series of information sheets prepared by the APS in relation to [LGBTI+ parenting and families](#).

This submission has been developed in consultation with the APS Diverse Bodies, Genders and Sexualities Interest Group, as well as other members with expertise in health psychology.

Having an intersex variation is not a mental health issue in itself, but mental health issues may arise due to perceived conflicts with social and cultural ideas about sex. Additional mental health issues can emerge as a result of surgeries and hormone treatments that may be imposed on infants and young people throughout childhood and adolescence. Further, many laws, customs and other institutional barriers currently discriminate against intersex people and/or do not properly acknowledge their existence.

Overall, the APS believes that decisions and processes regarding medical intervention need to focus primarily on the individual's wellbeing, over and above a concern for social integration which often means normalisation.

This Project is concerned specifically with the human rights protection available to people born with variations in sex characteristics in relation to the impacts of medical interventions, surgical and non-surgical, at various stages in their lives, across infancy, childhood and adulthood. We acknowledge that there are many other human rights issues relevant and of concern to people born with variations in sex characteristics (e.g. discrimination in education, workplaces and in sport, lack of support and adjustments in educational institutions and workplaces and issues around

legal classifications and documentation), but that these are beyond the scope of this Project.

We understand that the main aims of the Project are to:

- a) document and analyse existing approaches to medical interventions involving people born with variations in sex characteristics in Australia and overseas; and
- b) identify changes that should be made to these existing approaches, to ensure that decisions and processes regarding medical interventions involving people born with variations in sex characteristics respect and protect the human rights of those affected.

Our submission responds to the most relevant discussion questions in the consultation paper (that is, those most pertinent to psychology and psychologists), and is based on psychological evidence and the expertise of APS members.

2. Context

The tendency to categorise everyone as either 'female' or 'male' means that people with intersex variations may face social stigma and discrimination, often due to a lack of awareness about the existence of such variations. This can be made worse when parents do not fully understand a child's intersex variation due to a lack of clear and affirming information.

People born with intersex variations have chromosomes, genitals, and/or reproductive organs that do not fit into narrow ideas of what constitutes 'male' or 'female'. Intersex Human Rights Australia (2013) suggests that people with intersex variations make up 1.7% of births, but estimates range from 1 in 2,000 births (0.05%) to 8 in 200 (4%), and exact figures are unknown. In the largest study of Australians with intersex variations, 272 participants reported over 40 intersex variations (Jones et al. 2016).

While intersex variations may be identified during pregnancy or at birth (particularly genital variations), in some cases they only become clear at puberty, when trying to conceive, or by chance (Council of Europe, 2015; Free & Equal, n.d.; Jones et al., 2016). Two-thirds of the 272 participants in an Australian study by Jones and colleagues (2016) learned they had intersex variations before they turned 18. However, some people with intersex variations (e.g. a genetic male with an extra Y chromosome) may be completely unaware of their intersex status (Jones et al., 2016).

Most people who are born with intersex variations identify as female or male (which often fits with other people's expectations based on the sex they were assigned at birth), but some do not.

3. Terminology

- ***Is the term 'people born with variations in sex characteristics' appropriate, or is there a better way to describe the people who are the subject of this Consultation Paper? (Q1)***

The term 'people born with variations in sex characteristics' is appropriate in the context of this consultation.

The APS uses the term people 'born with intersex variations' in acknowledgement that 'intersex' is an umbrella term used to describe a wide range of variations and diversity. It is also the term commonly used in the majority of literature upon which APS resources like the information sheet referred to above are based.

It is important to recognise that people born with intersex variations may prefer different language to describe their variation (e.g. 'an intersex person', 'man with an intersex variation', 'woman with an intersex condition') and that they may prefer to use different words for themselves, with their family/friends, or when accessing medical services. For example, some people use medical terms with their doctor in order to receive care, but find those terms offensive and avoid them in their personal lives.

On this basis, the term 'people born with variations in sex characteristics' is an appropriate term in the context of this consultation, given that it is sufficiently inclusive to accommodate for the diversity of variations. It will never align to every individual's preferred term, but it does not have to and is not used in a way that would enforce exclusive use of this term.

4. Understanding lived experiences

- ***What are the current Australian sources of information and education about the experiences of people born with variations in sex characteristics? (Q3)***

The APS has identified and provided a list of formal resources in our information sheet [Children born with intersex variations](#). This is by no means a comprehensive list, and it is not known whether people with intersex variations use these resources or where they choose to get their information.

Websites – Australian

- Intersex Human Rights Australia (IHRA) - ihra.org.au
- IHRA Information for parents - ihra.org.au/parents
- Safe Schools Coalition Australia - www.safeschoolscoalition.org.au

Support groups

- Androgen Insensitivity Syndrome Support Group Australia (AISSGA) - aissga.org.au
- Turner Syndrome Association of Australia - www.turnersyndrome.org.au

- Congenital Adrenal Hyperplasia Support Group Australia - www.cah.org.au
- Australian X and Y Spectrum Support - axys.org.au

Websites – International

- Intersex Society of North America (ISNA) - www.isna.org
- The UK Intersex Association - www.ukia.co.uk
- interACT youth - interactyouth.org

Pamphlets

- AISSGA – aissga.org.au/parents.htm - A guide for parents of children with ambiguous genitalia

5. Consent

- ***What could enhance the capacity of people born with variations in sex characteristics or their caregivers to provide full and informed consent [to medical interventions]? (Q8)***

Facilitating access to an appropriately trained psychologist could enhance the capacity of people born with intersex variations and/or caregivers to provide informed consent. Although many psychologists may have some knowledge of intersex variations, few have received specific training in how to respond in an affirming and supportive way to parents of children with intersex variations. Those 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 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.

A psychologist is likely to be useful in:

- helping a child understand their intersex variation
- exploring a child's issues and feelings relating to their body
- discussing any wishes a child might have for medical intervention, including in relation to puberty.

Psychologists may also help parents to understand a child who has an intersex variation, and to work out the best ways to support their child. Considering the stigma and lack of awareness around intersex variations (Jones et al., 2016), parents may feel that having a child with an intersex variation is very challenging. Psycho-education may help to combat this feeling through a better understanding of intersex variations as a normal part of human variation.

More broadly speaking, 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. While community awareness and acceptance about sexual orientation is much greater than it has ever

been, there is still confusion as to how sexual orientation relates to variations in sexual characteristics, gender identity and other LGBTI identities. Being transgender or gender diverse is different from having intersex variations (although a small number of children are both). Intersex refers specifically to being born with variations in chromosomes, genitals, and/or reproductive organs, and not to a person's gender or sexual orientation.

6. Consent in the absence of legal capacity

- ***To what extent should parents and carers be involved in making decisions on behalf of their child? How can parents and carers be best supported to make these decisions? (Q9)***

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 (Council of Europe, 2015). 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.

7. Medical necessity

Psycho-social rationales for intervention (6.2 c (ii))

The Discussion Paper states the following:

"Interventions are often undertaken in an attempt to make bodies look more typically male or female. These rationales often reflect a presumption that an individual's womanhood or manhood is challenged by having genitalia that do not match what is expected of that sex."

Psycho-social rationales that have been advanced in favour of medical intervention in this context include:

- *Stigma, embarrassment and distress of having a body that does not match the sex of rearing;*
- *Mitigating the risk of gender-identity confusion;*
- *Risk the child will not be accepted by the parents, leading to impaired bonding between parent and child;*
- *Minimising family concern and distress;*
- *Risk of difficulties in forming intimate relationships;*
- *Gendered understandings of functional ability – for example, that a male should be able to stand to urinate;*
- *Gendered understandings of appropriate appearance of genitalia; for example, a clitoris that is considered too large may be reduced in size, although research has shown significant variations even among people not considered to have atypical genitalia; and*
- *Gendered understandings of which hormone replacements an individual requires.” (p.18-19)*
- ***What are the permissible rationales/considerations that should be taken into account when determining whether or not to undertake a medical intervention on behalf of those who lack the capacity to consent? (Q13)***

These rationales are all problematic and should not be a reason for treatment. ‘Medical necessity’ should never pertain to assumptions about ‘confusion’, ‘stigma’, ‘risk’, ‘difficulties’ etc, and should solely pertain (and most definitely for children) to function (for example, if a variation means a child cannot urinate then that needs treatment. If a child has a large clitoris then that does not need treatment).

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.

A significant issue facing people born with an intersex variation is surgery, often performed on infants, children and young people, and sometimes on adults. Children who are born with intersex variations are still subjected to physically and psychologically painful surgeries, hormones, and other medical interventions in order for them to fit narrow ideas of ‘female’ and ‘male’ (Council of Europe, 2015). Organisation Intersex International Australia’s Position Statement on Genital Cutting (IHRA, 2010) 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. 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 (Creighton et al., 2001).

8. Regulation

The discussion questions relating to clinical guidelines (regulation d(ii)) (Questions 15-18) are beyond the expertise of the APS given their medical focus. However, the focus on medicine does raise questions about whether such guidelines should extend beyond a medical focus to incorporate important psychosocial factors.

9. Lack of data

- ***What are the current Australian sources of data on: (Q19)***
 - ***the number and nature of medical interventions involving people born with variations in sex characteristics***
 - ***long-term outcomes of medical interventions involving people born with variations in sex characteristics***
 - ***long-term outcomes of people born with variations in sex characteristics not undertaking medical interventions?***
- ***How adequate are the current Australian sources of data for each of these areas? (Q20)***

The APS is not aware of all the current sources of data relating to medical interventions, nor the comprehensiveness and intricacies of this available data. However, as indicated previously, 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 (2016), 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).

Jones et al. (2016) found that 60% of respondents reported having had medical interventions related to their intersex variation. People with intersex variations may experience mental health concerns arising from the effects of early surgeries undertaken when they were infants that affect them throughout their life (e.g., in terms of sexual functioning, fertility, continence) (Fagerholm et al., 2012; Jones et al., 2016; Liao et al., 2015). Young people with intersex variations may also be given hormones to impose physical characteristics expected of the sex they were assigned. Unnecessary hormone treatments can also have negative impacts on people with intersex variations throughout life (Jones et al., 2016).

Some studies have indicated that differences in mental wellbeing between people born with and without intersex variations may only become apparent as people grow older, and relate particularly to medical intervention. The impact of early surgeries is especially noted by participants in research by

Fagerholm et al. (2012) who found that, overall, mental health, quality of life, and health-related quality of life was good for most participants, but for a significant minority there were concerns relating to unhappiness with the outcome of their surgery or current poor sexual function. This confirms that parents should be in a position to make fully informed consent prior to any early surgery, and that any such surgery should only be undertaken with great caution and if there is a clear medical need to do so.

In relation to experiences of people born with intersex variations who have not undergone any medical interventions, nine participants in Jones et al.'s study (2016) (out of 117 who provided written responses to a question about impacts of interventions) identified as having had no interventions and they all argued they had experienced positive impacts from not having had interventions.

10. Access to services, psychological support and community

- ***How can people born with variations in sex characteristics and their families and carers be more adequately supported? (Q25)***
- ***How can psychological and peer support be more integrated into decision making processes? (Q26)***
- ***What barriers exist to connecting individuals to support services? (Q27)***
- ***What barriers exist for individuals in accessing support services? (Q28)***

In Jones et al.'s (2016, p.121) study "42% of respondents had thought about self-harm on the basis of issues related to having a congenital sex variation, and 26% had engaged in self-harm on the basis of issues related to having a congenital sex variation. In addition, 60% had thought about suicide on the basis of issues related to having a congenital sex variation, and 19% had attempted suicide on the basis of issues related to having a congenital sex variation". This is a much higher rate than for the broader Australian population. Many participants directly linked negative wellbeing impacts to other people's negative responses to their intersex variation. Their comments considered "the effects of being unable to connect to people with the same or similar variations, feeling isolated by stigma or discrimination, family rejection, school bullying from peers and teachers, loss of romantic relationships or tension in relationships on the basis of the variation or related fertility issues, lacking positive social reinforcement, being unable to trust others or disclose to them, and anger or depression over broader socio-cultural rejection" (p.121-122). Participants also linked negative wellbeing impacts to issues around gender related to having an intersex variation. Their comments considered "the effects of being unable to express or understand one's gender identity, recklessness during gender dysphoric periods, and attempts at trying to relieve the disparity between gender identity and body which created inadvertent bodily harm" (p.123).

Jones and Lasser (2015) noted that therapy can potentially provide a space for people with an intersex variation to come to accept any physical

differences they may have, work through confusion about their sex or gender identity (if any is apparent), or issues related to any enforced surgeries if relevant. Furthermore, post-intervention support is very important, not just support for people prior to medical intervention. Despite the likely value of therapy, some participants in Jones et al.'s study (2016) reported never having been recommended to seek mental health services, despite recalling experiences of depression and suicidal thoughts. While this is concerning, it could be equally concerning if referrals were made based on a person having an intersex variation alone.

Barriers to connecting individuals to support services include a lack of information about what support services exist both for people with intersex variations as well as medical practitioners who might be referring them. Jones et al. (2016) suggested that for several participants who indicated that they had been intentionally misinformed, it "may instead have been a matter of doctors having inadequate information themselves" (p.108).

Over a third (35%) of people with intersex variations rated their overall experiences of health care providers' treatment of their variation negatively (Jones et al., 2016). The strongest theme around negative service delivery was an emphasis on the lack of information supplied to the participant about their variation. The second strongest theme was the need for participants to educate their own health care practitioners to manage their lack of knowledge (e.g. about their specific intersex variation, or addressing misunderstandings about an intersex variation as a sexual disorder or fetish). Related to this was a frequently cited sense of frustration about having to educate many practitioners many times.

In relation to positive service delivery, participants in the Jones et al study clearly appreciated attempts made by practitioners to educate themselves or to support the participant's control of their own health management plan. The most common suggestions for strategies for health care services or practitioners included supporting people with intersex variations to choose their own treatment paths, if any; providing training/education for staff on intersex variations; providing more information on intersex variations to patients; and providing referrals to intersex support groups. Participants supported "improvements which would contribute to an overall approach in which patient rights, information-sharing and sensitive treatment featured more strongly" (Jones et al., 2016, p.117).

Overall, participants' experiences of mental health services were mostly mixed, and they listed a range of ways to improve mental health services which included training. A popular theme was for mental health services to be supplied specifically for younger people with intersex variations which could empower and support them to have a say about any intervention. Having space to think away from parents was also identified as important.

This is not to suggest that having an intersex variation is a mental illness, but that a psychologist familiar with this area may help to talk through a child's issues and feelings. Psychologists can also play a role in assisting with

accessing surgery or interventions. Prospective psychologists can be screened by asking questions about their attitudes toward people with intersex variations and medical intervention. If parents or carers feel pressured to consent to any intervention solely for the purpose of making a child 'normal', or if they are not given information about intersex-led organisations or support groups, they should be encouraged to seek help elsewhere.

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