

INFORMATION SHEET: Children born with intersex variations

This information sheet has been prepared for parents and families of children born with intersex variations. The tendency to categorise all people 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 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. Importantly, having an intersex variation is not a mental health issue, but mental health issues may arise due to social and cultural ideas about sex. Additional mental health issues can emerge as a result of unnecessary surgeries and hormone treatments that may be imposed on infants and young people throughout childhood and adolescence. Further, many laws and other institutional barriers currently discriminate against intersex people and do not properly acknowledge their existence.

This information sheet covers the following questions:

- What does it mean for a child to have an intersex variation?
- What issues might a child with an intersex variation face?
- How can parents/families support their child with an intersex variation?
- How can parents/families seek affirming professional assistance?
- What are some useful resources?

What does it mean for a child to have an intersex variation?

Intersex is an umbrella term used to describe a wide range of variations and diversity. Children born with intersex variations have chromosomes, genitals, and/or reproductive organs that do not fit into narrow ideas of what constitutes 'male' or 'female'. Organisation Intersex International Australia (2014) 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, participants reported over 40 intersex variations (Jones et al. 2016). Some examples of intersex variations are:

- Congenital adrenal hyperplasia
- 5-alpha-reductase deficiency
- Partial androgen insensitivity
- Complete androgen insensitivity
- Klinefelter syndrome
- Turner syndrome.

(for details of these and more intersex variations see American Psychological Association, 2006; Jones et al., 2016 – Glossary; World Health Organization, n.d.)

While intersex variations may be identified during pregnancy or at birth (particularly genital variations), in some cases they may only become clear at puberty, or 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 the Australian study by Jones and colleagues (2016) learned they had intersex variations before they turned 18. However, some people with intersex variations are not aware of them (Free & Equal, n.d.).

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.

It is also 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 (Jones et al., 2016). 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.

Children who are transgender or gender diverse are different from children who have intersex variations (although a small number are both). Intersex refers specifically to being born with variations in chromosomes, genitals, and/or reproductive organs, and not to a person's gender.

What issues might a child with an intersex variation face?

The diversity amongst people born with intersex variations means that issues and impacts are likely to be different for each person.

A significant issue facing people born with an intersex variation is surgery, often performed on infants, children and young people, and sometimes 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 (OII Australia) Position Statement on Genital Cutting (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 will self-correct as the child matures. It is therefore important to get 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).

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.

How can parents/families support their child born with an intersex variation?

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. As mentioned above, 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. 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 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.

Seek support from an affirming mental health professional for your child.

Although mental health professionals (such as psychologists, social workers or counsellors) may have some knowledge of intersex variations, most mental health professionals have not 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 mental health professional is likely to be useful in:

- Helping your child understand their intersex variation
- Exploring your child's issues and feelings relating to their body
- Discussing any wishes your child might have for medical intervention, including in relation to puberty.

This is not to suggest that having an intersex variation is a mental illness, but that a mental health professional familiar with this area may help to talk through your child's issues and feelings. Mental health professionals (and specifically psychiatrists) can also be important in accessing surgery or interventions. You can screen prospective mental health professionals by asking questions about their attitudes toward people with intersex variations and medical intervention. If you feel pressured to consent to any intervention solely for the purpose of making your child 'normal', or if you are not given information about intersex-led organisations or support groups, you may wish to seek help elsewhere.

Seek support from an affirming mental health professional for yourself.

Mental health professionals may also help parents themselves to better 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, parents may feel that having a child with an intersex variation is very challenging. Psychoeducation may help to combat this feeling through a better understanding of intersex variations as a normal part of human variation.

Enlist the help of an affirming school psychologist or counsellor. If your child is having issues at school relating to having an intersex variation, such as bullying by other children, it may be useful for them to see a school psychologist/counsellor. However, not all school psychologists/counsellors will necessarily be knowledgeable or affirming about intersex variations. The [Safe Schools Coalition](#) may be a useful additional support. In most cases, it is not necessary for those other than close family members to know about your child's intersex variation, though some children and adults may choose to be public and vocal about having an intersex variation.

How can parents/families seek affirming professional assistance?

Seeking professional assistance from an affirming mental health professional may be helpful for children with intersex variations and their parents/families. A psychologist can be found by a referral from your GP or via the Australian Psychological Society's 'Find a Psychologist' service. Again, as many psychologists have not been trained in how to respond to people with intersex variations in an affirming way, ask screening questions that go beyond a person's knowledge of medical facts to find out whether they are aware of intersex organisations or individual adults with intersex variations. Visit the APS website <http://www.psychology.org.au/FindaPsychologist/> or phone 1800 333 497 (outside Melbourne) or (03) 8662 3300 (in Melbourne).

What are some useful resources?

Websites – Australian

Organisation Intersex International Australia (OII Australia) <https://oii.org.au/>

OII Australia – Information for parents <https://oii.org.au/parents>

Safe Schools Coalition Australia <http://www.safeschoolscoalition.org.au/>

Support groups

Androgen Insensitivity Syndrome Support Group Australia (AISSGA) <http://aissga.org.au/>

Turner Syndrome Association of Australia <http://www.turnersyndrome.org.au/>

Congenital Adrenal Hyperplasia Support Group Australia <http://www.cah.org.au/>

Australian X and Y Spectrum Support <http://axys.org.au/>

Websites – International

Intersex Society of North America (ISNA) <http://www.isna.org/>

The UK Intersex Association <http://www.ukia.co.uk/>

interACT youth <http://interactyouth.org/>

Pamphlets

AISSGA – A guide for parents of children with ambiguous genitalia
http://aissga.org.au/Ambiguous_Genitalia_Parents_Guide.pdf

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