

TIPS FOR WORKING WITH INTERSEX PEOPLE

- Most intersex people will identify as a man or a woman, and some will identify as non-binary or use a self-designated gender descriptor. Be aware that intersex people are not an homogenous 'third sex'.
- Human anatomical and physiological variations do not in themselves constitute medical problems. Medical language, (such as using 'disorders', or 'conditions' for normal variations), can alter or undermine people's informed consent to medical treatment.
- People with intersex variations may describe themselves as intersex, but may also use other terms. It is preferable to use the term 'intersex' unless asked otherwise. Avoid leading with terms such as 'hermaphrodite', or 'disorders of sex development' which can convey negative connotations about intersex people.
- Intersex is about physical sex characteristics, so avoid language that confuses intersex with transgender, or with sexuality. For example, avoid referring to someone's intersex status as their gender. Terms like 'diverse gender and sexuality' do not include intersex. Talk about 'intersex' and 'bodily diversity' specifically.
- With appropriate timing and manner, you could ask 'how do you see yourself, what language do you prefer?' Be guided by the language the person uses, including use or non-use of pronouns. Ask privately whenever possible, and ensure you are asking for sound reasons, and in context.
- Avoid using terms that are often used to describe LGBT people's sexuality, such as 'coming out'. Most intersex people do not have the type of experiences often associated with LGBT people's coming out. Intersex people are often informed by parents or medical professionals who may have held (or withheld) this information for some time, rather than a coming out process of self discovery.
- Inform yourself, and while creating openness to talk about many aspects of being intersex, be careful not to place the onus of your education upon the people you are supporting. Be aware of the context of asking questions to ensure you are not asking

for your own curiosity or from judgement. Refer to information from intersex-led organisations to assist you to work in respectful, client-directed ways.

- As with any client, it is intrusive to ask about intimate details such as genitals or sex and reproductive organs. Most people, including intersex people consider their physical characteristics as personal information that would not be disclosed in general conversation.
- Many intersex people may have only discussed their intersex experiences and bodies in medical contexts. Speaking of these experiences in counselling settings may be useful for later sharing in other settings and relationships, and may help individuals to develop non-medical ways of discussing being intersex. Be affirming about intersex as a natural variation.
- If a person learns of their intersex status later in life, they may need support to help understand their variation, as well as how it relates to their past, to current relationships and to their understanding of themselves.
- Some people may have health needs arising from their intersex variation or medical interventions. These can include developmental delays, pain, trauma and bone health issues relating to medical interventions.
- In working with sex and intimacy, be aware that intersex related surgeries and treatments may have affected sexual function and sensation. This can have effects on self esteem, sexual wellbeing and relationships.
- Families and carers of intersex infants, children and adolescents also need affirmative support, and may also benefit from counselling. Access to peers and adults with intersex variations can help families and individuals to make better, more informed, choices about health needs.

INTERSEX

A Q LIFE GUIDE FOR HEALTH PROFESSIONALS

People are born with many kinds of bodies, and natural differences in sex characteristics are far more common than might be widely recognised. Intersex is an umbrella term for a wide range of natural variations, including genetic, hormonal or physical sex characteristics.

Intersex people are born with physical sex characteristics that don't fit medical and social norms for female or male bodies.



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DEFINING INTERSEX

Up to 1 to 2% of people may have an intersex variation, and intersex people exist in all cultures and throughout history. Intersex people are born with genetic and other variations related, for example, to genitals, gonads and chromosomal patterns. There may be 40 or more distinct intersex variations, each with a different genetic or other basis. While intersex variations are naturally occurring, they remain associated with stigma and secrecy in medical, social and family settings. This stigma contributes to a lack of accurate population figures about people with intersex characteristics and a lack of reporting on the number of medical interventions carried out in infancy or childhood.

While intersex variations can be apparent prenatally (such as via IVF or amniocentesis) or at birth, some variations may not be recognised until puberty or into adulthood. Some people learn of intersex variations when seeking medical advice, such as when becoming sexually active or trying to conceive, or due to other related or unrelated health matters. It is not uncommon for intersex people themselves to remain unaware of having intersex traits until told by parents or medical practitioners into late childhood or adulthood. For people learning later of their intersex status, it can be difficult to gain accurate information about past medical history and interventions, due to stigma and poor medical records systems.

BODIES, GENDER AND SEXUALITY

Intersex people, as any people, have diversity of gender, gender identity and sexual orientation. These may be informed by a person's intersex characteristics, but are distinct from being intersex.

To avoid misunderstandings about people's intersex status, it is necessary to understand the differences between 'sex characteristics' and 'gender' or 'gender identity', as well as sexuality and sexual orientation.

Sex characteristics relate to an individual's physical, bodily characteristics and traits. In Australia, most intersex people describe their sex as male or female, some as non-binary, and some in other ways. A person's legal sex classification can appear on legal documents including birth certificates and passports and this is usually based on assigned sex at birth. In Australia, federal gender classifications include 'female', 'male', and 'X', a third legal option

first introduced from 2002. In some cases, initial sex assignment can be incorrect. This can be particularly damaging where an original sex assignment was surgically reinforced during infancy or childhood.

Gender and gender identity can be understood as socially constructed, and may include assigned gender or legal sex (at birth) and self-determined gender.

Sexuality for intersex people, as for everyone, is not determined by physical sex characteristics or gender identity. Intersex people may be heterosexual, and some may be same-sex attracted. Some may identify as gay, lesbian, bisexual, queer or asexual.

THE IMPACT OF MEDICALISATION

The birth of an intersex child is often treated by health professionals as a psycho-social emergency and there may be a sense of urgency conveyed for parents to consent to medical interventions. Often, limited avenues of support and information are available to parents or children themselves and there may not be referral to support outside of the medical system, such as from intersex-led organisations. These processes can result in decisions for surgeries during infancy or early childhood being made without a full understanding of the long-term physical and psychological implications, or without information about the options to delay decisions until a child can consent themselves.

Surgical procedures and other interventions are based on an intention to 'normalise' intersex people's bodies; to have appearances that are more in line with male or female norms. Some surgeries are presented as preventative for future risks despite evidence that these decisions could in most cases be safely delayed until a child can consent.

The prioritisation of physical appearance over the risks to intervention reflects an adherence to sex and gender norms, and an over-valuing of societal norms about genital appearance, as though nonconformity and natural variations carry more risks to wellbeing than intervention. Evidence shows that most decisions could be delayed until a child is old enough to consent, but interventions continue in Australia today, despite avoidable physical and psychological effects and concerns about ethics.

INTERSEX STATUS AND AUSTRALIAN LAW

People with intersex characteristics have had a long struggle to claim human rights. However, things have begun to change. From 1st August 2013, the Sex Discrimination Act (Sexual Orientation, Gender identity and Intersex Status) provided the first federal protection in Australia from discrimination on the basis of gender identity and intersex status. The Act recognises the distinction between sex, gender identity and intersex status. Australia also was the first country in the world to conduct a parliamentary inquiry into involuntary or coerced medical interventions on intersex people (2013).

“The Darlington Statement” (2017) is a joint consensus statement by intersex organisations in Australia and Aotearoa/New Zealand and independent activists. It outlines legal reform, access to affirmative health care and the importance of peer support for the wellbeing of intersex people.

WORKING WITH PEOPLE WITH INTERSEX CHARACTERISTICS

Many intersex people have experienced trauma from medical procedures and examinations, often in the developmental stages of childhood or in adolescence. This can include surgeries, medical photography, being subjected to teaching situations, and being talked about in intimate and pathologising ways. Because of this, intersex people may be reluctant to ask for psychological help and other forms of support due to feelings of mistrust, anger, shame and/or embarrassment. Some people with intersex bodies report that intrusive examinations combined with stigma and secrecy within the family left them vulnerable to sexual abuse as children, with added impact on mental health and willingness to trust others.

It is essential that medical and psychological support ensures that intersex people are listened to and able to make decisions about their own body. When working with intersex people of all ages, it is critical that they and any loved ones involved in their care are assured that intersex bodies are a natural human variation and that intersex

people do not have to conform to prevalent norms about bodies or sex classifications, nor restrictive norms about sexuality and gender.

It is important to use a person centred approach and to actively work against shame and stigma when working with intersex people. This approach affirms intersex bodies as naturally occurring, including openness about the diversity of bodies, genders and sexualities for all people including intersex people. When facing choices about medical intervention, intersex people should be supported to make informed decisions. Informed consent should include access to peer support and accurate information about the possible and likely outcomes of medical interventions and their alternatives (including non-intervention). All work with intersex people should be underpinned by the intent to support rights to bodily autonomy and self-determination.

THE 'I' IN LGBTI

In Australia, there has been growing inclusion of 'I' for intersex in LGBT-focussed spaces, as seen in the use of LGBTI. While Intersex is not specifically about sexuality and gender diversity in the way that LGB and T are, there is common ground for intersex and LGBT people due to stigma related to not 'fitting' conventional sex and gender norms. Discrimination towards intersex people can occur based on fixed, narrow notions of gender and sexuality, regardless of an intersex person's gender identity or sexual orientation.

As with all the separate, intersecting populations in L,G,B,T and I, it is important to use each letter with care; for example, if speaking about LGBTI people and communities ensuring that the context is relevant for Intersex people, or whether it may be about a different population eg: sexuality related to LGB, or sexuality and gender related to LGBT.



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