

LGBTI fact sheet 7 - Intersex people

Additional considerations for intersex people

The experiences of intersex people may overlap with those of LGBT communities however other aspects are unique to their intersex status. Not all intersex people identify with the LGBTI community (1).

- The diversity of individual experiences associated with the forty different known intersex variations that are included in this group must be acknowledged.
- While it is beyond the scope of this resource to capture the diversity of all these individual experiences, it is important to highlight the potential for these to impact on the management of BPSD.

Fear

- Older intersex people have often grown up with a feeling of violation and fear of being an 'oddity' and having no control over who had access to their body.
- They may have been treated as a medical curiosity as a child and subjected to medical examinations and/or interventions that were unnecessary for their health, without their consent (2-7).
- Fear may be exacerbated when an intersex person develops dementia and/or requires assistance with personal care, increasing the potential for BPSD to occur.

***Note:** Clinical knowledge and expertise in the field of intersex ageing is often limited because little attention has been paid to the special needs of this group (4, 7, 8).

Medical intervention

- In the past surgical interventions were routinely conducted on intersex infants to make their bodies appear more typical (9, 10).
- Surgery was frequently followed by secrecy as doctors believed this would help the child develop a 'normal' sexuality and gender identity as a heterosexual boy or girl.
- Such treatments often resulted in debilitating complications such as ongoing pain, scarring, incontinence, sterility, the need for further surgeries and loss of sexual function as well as depression and anxiety (2, 4, 8, 11-14).
- Intersex people who have physical scarring as a result of surgery may have isolated themselves to avoid questions from others. Ongoing mistrust of health professionals is often the result.
- While surgical intervention for intersex infants was consistent with the thinking of the medical profession in the 1950s and remains common practice in many parts of the world including Australia, this is now regarded by many human rights activists as unethical, unnecessary and a violation of their human rights (4, 5, 15-18).
- In many situations waiting until the child has developed the ability to consent to

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any medical interventions is the preferred option, although the medical profession in Australia and most of the western world continue to resist this protocol.

- Surgery or other medical treatments required at puberty can have a long-term impact on education and social networks for intersex people at that time of their life (13, 17, 19, 20).
- Intersex people may have been told lies about their bodies by their family and/or the medical profession in their youth reinforcing the idea that intersex is an 'error' of nature, shameful and 'something to be fixed' (21).
- For older intersex people invisibility may have been a long term strategy to avoid discrimination and judgement. The stigmatisation of intersex characteristics may have left them with a lifetime experience of isolation, secrecy and shame (17).
- Many intersex people have experienced stigmatisation and institutional abuse by medical, health and welfare services throughout their lifetime (4, 13). These negative and often traumatic experiences can result in avoidance and distress when an intersex person or their carer needs services in relation to dementia and BPSD.
- Where surgery has been conducted on intersex infants to modify or 'normalise' their genitalia and they later identify as a gender other than the one assigned by surgery, the intersex person may also experience some of the issues of a transgender person (16).

- Where an intersex person rejects the sex they were assigned at birth, they are generally not considered 'transgender' or 'gender diverse'. Some may nonetheless consider themselves in this way so it is best to politely ask rather than assume (1).
- Some intersex people reject the sex they were raised as because they reject a binary gender (see *glossary*) and they seek to be 'what nature made them' (4, 7).

Lack of support

- Support services and positive peer support are frequently lacking (17), particularly for older intersex people because the intersex community remains largely hidden, under-resourced and under-researched (22).
- Older parents of intersex children may likewise have lacked support networks throughout their lives, potentially prompting guilt and trauma which can be exacerbated if dementia develops.

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See *Fact sheet 1 – Overview* for details.

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