

INTERSEX RESOURCES AND FURTHER INFORMATION

Organisation Intersex International Australia oii.org.au | facebook.com/oii.au | @oiiaustralia
Employers guide to intersex inclusion (leaflet, 2014) <https://oii.org.au/employer/>
Making your service intersex friendly (leaflet, 2014) <https://oii.org.au/services/>

Val's Café valscafe.org.au | facebook.com/valscafeaus | @ValsCafe_AU

Films

Intersexion (2012) by Grant Lahood, John Keir & Mani Bruce Mitchell intersexionfilm.com
Caster Semanya: Too Fast to be a Woman? (2011) by Maxx Ginnane risefilms.com/films
Orchids: My Intersex Adventure (2010) by Phoebe Hart orchids-themovie.com
Both (2005) by Lisset Barcellos vimeo.com/68928530

Books

None of the Above (2015) by I.W. Gregorio
Golden Boy (2014) by Abigail Tarttelin
Intersex: A Perilous Difference (2008) by Morgan Holmes
Fixing Sex (2008) by Katrina Karkazis

References

1. **Organisation Intersex International Australia** (2015) www.oii.org.au
2. Lee, P; Houk, C; Ahmed, F & Hughes, L. (2006) **Consensus statement on management of intersex disorders** [sic]. *Pediatrics* 118. DOI 10.1542/peds.2006-0738.
<http://www.pediatrics.org/cgi/content/full/118/2/e488>
3. Department of Health, Victoria (2013) **Decision-making Principles for the Care of Infants, Children and Adolescents with Intersex Conditions**. <http://docs.health.vic.gov.au>
4. Department of Health and Ageing (2012) **National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy**. www.valscafe.org.au
5. Commonwealth of Australia (2013) **Australian Government Guidelines on the Recognition of Sex and Gender**. www.ag.gov.au
6. 'Summary of Intersex Health Issues' (2012) <https://oii.org.au/21019/intersex-health-issues/>

Using this resource as an educational tool

We suggest you use this resource in conjunction with 2 stories, along with some further information from OII in an educational session for staff of approximately 2 hours and involving the following 5 steps:

1. View the film 'What it's like to be intersex' <https://oii.org.au/28643/what-its-like-to-be-intersex/>
2. Read the first 2 pages of this resource
3. Read the leaflet 'Intersex for allies' <https://oii.org.au/21336/intersex-for-allies/>
4. Read sections 2 and 3 of this resource and discuss best practice in your service
5. Read the two stories and answer the discussion questions

The full narratives from Robert and Pat are a part of the forthcoming collection *Listen Up! Stories from Older LGBTI Australians*.

AN EVIDENCE-BASED GUIDE TO INTERSEX INCLUSIVE AGED CARE

This resource was developed as part of a research project partnership by Val's Café at the Australian Research Centre in Sex, Health and Society at La Trobe University and Organisation Intersex International (OII) Australia. The aim of the project was to understand intersex people's experiences of ageing and their needs, and to develop a resource that privileged the voices of intersex people. This guide is based on interviews conducted in 2014 with intersex people over 55 and is aimed at service providers (in ageing, health, and other human and social services). This resource contains some information on intersex, as well as:

1. Key issues in intersex ageing
2. A guide to intersex inclusive aged care
3. Further information and resources
4. Stories and discussion questions

What is intersex?

OII Australia defines intersex as: "People born with physical, hormonal or genetic features that are neither wholly female nor wholly male; or a combination of female and male; or neither female nor male". There are many different kinds of biological intersex variations. Approximately 1.7% of births are intersex babies (see oii.org.au).

A brief history

It is important to understand the historical experiences of ageing intersex people. As children, many intersex people were subjected to genital surgeries and other interventions to make their bodies conform to ideals of male or female. These practices were undertaken to minimise the concerns of families (though some parents felt coerced) and in the belief they would prevent gender identity confusion and protect the child from stigma (1). The view that intersex children can be 'fixed' or 'normalised' has long-term, adverse consequences. Some older intersex people have required a lifetime of surgical and other medical interventions to repair the damage from childhood surgeries. Older intersex people are likely to be suffering from the physical and emotional effects of forced surgeries or hormone treatments, as well as from the shame and secrecy that historically surrounds intersex variations (1).

These kinds of interventions on intersex children were formally challenged in 2006, when an international panel of paediatricians developed a 'Consensus Statement on Management of Intersex' (2). The Statement cautions against surgery for purely cosmetic reasons, yet infant genitals surgeries still take place in Australia and around the world. In 2013 the Department of Health in Victoria released 'Decision Making Principles for the Care of Infants, Children, and Adolescents with Intersex Conditions' (3). This document reiterates the importance of delaying 'normalising' surgeries to enable intersex children to make informed choices as adults. While these documents are promising, their impacts – particularly on current clinical practices – have yet to be determined.

While there is some discussion about the experiences and needs of intersex children, very little attention has been paid to intersex ageing and older intersex people. The development of a *National LGBTI Ageing and Aged Care Strategy* by the Australian Government Department of Health and Ageing in 2012 outlines the need for inclusive care for intersex adults as they age (4). The Strategy describes a commitment to ensuring the needs of older LGBTI people are understood, respected and addressed in Australia's aged care policies, programs and services. This resource documents the needs of intersex people and describes strategies for providing intersex inclusive aged care services.

Suggested citation

Latham, J & Barrett, C (2015) *"As we age": An Evidence-based Guide to Intersex Inclusive Aged Care*. Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne Australia.

Acknowledgements: This resource was funded by a grant from the Australian Department of Social Services. We would like to thank Tony Briffa, Morgan Carpenter and Gina Wilson for their work in developing this research project and resource and Pauline Crameri for assistance in drafting this resource.. We would like to thank the participants who shared their stories with us.



1. KEY ISSUES IN INTERSEX AGEING

Binary Sex

‘Binary sex’ refers to the way we are taught that there are only two sex categories (male or female). We also learn that males become men and females becomes women, and that their bodies look particular ways that are appropriately masculine or feminine. This way of thinking erases the realities of intersex people, who have genetic, hormonal, reproductive or physical features of neither or both males and females. While most intersex people identify as men or women, they may experience binary sex as oppressive.

Gender

Most intersex people identify as men or women, just like everybody else. Some intersex people identify as intersex and may prefer to be known by gender-neutral pronouns (e.g., ‘they’). It is important not to assume by how someone looks (or sounds on the phone) what their gender is. You might not be able to tell that someone is intersex by looking at them. If you don’t know which pronoun is best to use to describe someone, respectfully ask them their pronoun preference. It is never ok to call someone ‘it’ or ‘he-she’.

Sexuality

Intersex people may be heterosexual, homosexual, bisexual, queer or any other sexual identity category. Like the rest of the population, most intersex people are heterosexual. Because of the biological variation of their bodies, many (but not all) intersex people are infertile. Some intersex people look very different from other people; and they may have different sexual or erotic functions than other men or women.

Medical interventions

Many intersex people have experienced medical interventions on their bodies without their consent. This can include infant genital surgeries aimed at ‘normalising’ intersex genitals that vary from how we expect male or female genitals to look. Intersex people may also have had their reproductive organs unnecessarily removed before puberty or be coerced into taking hormonal supplements as a way for them to appear ‘normal’. For older intersex people, they may have experienced a lifetime of this kind of invasive and unwanted medical ‘treatment’. As a result, they may be suspicious of medical practitioners, as well as delay seeking care they need for fear of encountering discrimination within health services, or because they do not want medical interference in their lives because of their personal history.

Prejudice and discrimination

Many intersex people experience prejudice, discrimination, or rejection when their intersex status becomes known. This can include friends, family, and medical professionals. Intersex people deserve the respect of equal treatment. Since 2013 in Australia, it is unlawful to discriminate against someone because of their intersex status (5). Prejudice can take many forms and may include staring, being rude, asking unnecessary invasive questions or avoiding or ignoring someone.

Acting as an educator

Intersex people should not be expected to educate service providers from whom they need care. While some people may enjoy speaking about themselves and their own experiences, it is not appropriate to rely on clients for this information. The onus of responsibility for intersex knowledge is on all service providers. Many intersex people avoid using health services because service providers are uneducated on intersex issues, or they fear they will be used as a teaching prop.

Trans/intersex

Transgender people and intersex people may have similar experiences, yet they are different groups and their differences need to be understood. Trans people are people who socially and/or medically transition to a gender other than that which they were assigned at birth. Intersex people may pursue similar medical interventions to trans people, or may identify as transgender. Some transgender people may identify as intersex and this can be confusing. Intersex describes biological variations. There are some questions you can ask if someone says that they are intersex to clarify what they mean (‘Were you born with biological attributes of both sexes? Which intersex variation do you have?’)

2. INTERSEX INCLUSIVE AGED CARE GUIDE

It is important to provide intersex inclusive services whether or not you know of an intersex client. The goal of inclusive services is not to elicit disclosure but to ensure safe and respectful services for all people

Gender of preference

Intersex people may experience sex segregated spaces or activities as oppressive and discriminatory. Some intersex people may prefer a mixed space. Removing unnecessary sex segregated spaces can help alleviate this problem, for example by creating gender-neutral bathrooms (rather than specified male and female bathrooms). Activities should be open to all people regardless of gender. Like anyone else, intersex people may prefer the care of only male or only female workers and this preference should be respected.

Ensuring privacy

Intersex people may have additional privacy needs. This involves keeping their intersex status confidential, like any other medical information. If you become aware of a client’s intersex status, it is important to ask them how they would like this information documented and shared; it may not be relevant in many contexts. Intersex people may require a single bedroom or use of a private bathroom, and this request needs to be treated differently from other clients’. This is because intersex people may have special needs for privacy as their bodies may differ from expectations of normative male or female anatomy.

Supporting health and wellbeing

Most services are tailored to support healthy ageing by drawing on research and general knowledge about health and wellbeing as we age. However, little to none of this knowledge is intersex inclusive or intersex specific, so little is known about intersex ageing. Service providers must be committed to bridging this gap by proactively undertaking intersex specific education, keeping up to date on emerging research into intersex health and ageing, and by communicating to intersex people a willingness to be supportive of their individual needs (6). Intersex inclusive service providers can ask: What can I do to help? This may extend to advocating for the rights of older intersex clients.

Undertaking staff education

Intersex people deserve the confidence that services understand intersex ageing and the experiences and needs of older intersex people. A lack of knowledge can lead to unhelpful assumptions or discrimination. Intersex specific education needs to be undertaken by service providers at all levels (carers, nurses, administration, management, and frontline staff). This is important whether or not you are aware of an intersex client, or a client’s intersex status.

Understanding the importance of respect

One of the fundamental ways to promote intersex inclusive care is to respect the diversity of human variation. We are not all the same and intersex people have the same right to respect as everyone else. This means not asking questions that are invasive or unrelated to the service you are providing. It also means not making assumptions about anyone’s gender, intersex status or sexual orientation.

Recognising history

Most older intersex people will have experienced forced or coerced medical interventions (such as gonad removal, genital reconstructive surgeries, or hormonal therapies). This profoundly impacts their perceptions of and relationships with service providers. Service providers who recognise these historical experiences and their impacts, including the cost to older intersex people of a lifetime of self-advocacy, are well-placed to provide appropriate care.

Providing a message of welcome

Intersex people may not disclose their intersex status. They may feel it is irrelevant or they may fear prejudicial treatment if it were known. This means creating a welcoming environment specifically for intersex people is necessary for all services. This can be done by making it clear services will respect intersex people. One way to do this is to include ‘intersex status _____’ as a fill-in option on intake forms.

Pat’s story

In my opinion, trans and intersex people have a lot in common. There are some differences, but there are some really strong commonalities. For instance, intersex people, if they're obviously intersex, are most likely to be mistaken as trans, and treated as a trans person, because people don't know much about intersex, they don't know that intersex people exist. But trans has a much higher public perception. So it's very common for the immediate prejudice that we're subjected to, to be transphobia.

Virilisation is how they like to describe my differences. Deep voice, big hands, strong muscles, all that stuff. I don't think that's a problem. I don't mind it, but a lot of people around me do. It makes them think I'm a transgender person, and they like to express their prejudices about transgender to me. But I see myself as having one of a variety of natural differences. I rail against ideas of appropriate female or male bodies. I rail against the whole business about gender and maleness and femaleness. My experience of those things has been it's a damn lie, and it's a hurtful damn lie.

When I was born, the chemical that they used to manage salt-wasting, really wasn't available in Australia and if my salt-wasting had've been extreme salt-wasting, I would've died. Luckily I don't have chronic salt-wasting. When the chemicals became available to manage salt-wasting I was amongst the first users. God knows what a lifetime's use of those things works out. I don't think I will be the worst affected because I don't have to take a lot of them. But I don't know how that's going to play out; does that mean my life will be fore-shortened? Does that mean I will have different medical problems? I don't know. And then as an old person in care or an old person receiving services, how on earth does all that play out when it comes to explaining myself to geriatric doctors and aged care people coming into the house and all that, how does all that play out? I've got no idea.

My difference is caused by a problem in the adrenal gland. The adrenal gland produces three, maybe four hormones. It produces cortisol, which you need in your response to stress, physical stress and some emotional stress also uses cortisol as well. It also produces another thing called aldosterone, and aldosterone is a hormone you use to metabolise salt. So if you don't have aldosterone, the salt just goes straight through you and you can't metabolise salt. If you can't metabolise salt you can't metabolise sugar. So you go into a thing which is very much like insulin shock.

I have to have an injection of cortisol with me all the time in case I'm in an accident or something like that. I have to have a wristband, which I hate wearing. And I from time to time have to take a thing called fluorinate, which is a mineral that helps metabolise salt, it stops the salt-wasting. I've had a few adrenal crises in my life. I'm very, very hyper-aware of the feeling that happens when that starts to come on. It's pretty scary.

There are no long-term studies into intersex differences. There is no information on how that plays out as we age - particularly how the interventions that we were subjected to play out as we age. We need this information so that we can be given appropriate care as older people. I really worry about it. I ask health professionals should I continue on with the stuff that they've been giving me all my life? Is this good for me? Is this bad for me? And they don't know or don't say.

Discussion questions for Pat’s story:

1. What do you think Pat means by the ‘idea of appropriate female or male bodies’?
2. How does Pat describe being mistaken as trans? How would you take this into account in your service?
3. What do you think it would be like to be ageing without any evidence to inform the care you receive?
4. Discuss what responses Pat would receive accessing your service to the question:
“As an old person in care or an old person receiving services, how on earth does all that play out when it comes to explaining myself to geriatric doctors and aged care people coming into the house and all that, how does all that play out?”

Robert’s story

I was mis-diagnosed back in my early 20s as just having an endocrinal deficiency but there were things going badly before I was diagnosed, and so they actually did another test and then said, "Well actually, no, you've got XXY". It means basically the body not producing its own testosterone and the horrible things that can happen from that. Additionally, I have mild androgen resistance which means that they pump me full of testosterone and I only get about 10 per cent of the benefits from it.

Prior to being diagnosed intersex, when I started hormone therapy for the mis-diagnosis of an endocrinal deficiency, there was an assumption that you started therapy and you basically start living as a male and function as a male and all that kind of stuff. And I find it – found it actually quite traumatic– because don't forget that, an XY male at the age of 12 or 13 they'll start to go through puberty – they're contained within a culture where that's just par for the course. Now, you get somebody who's 30 years old who physically looks like they're 13 who has never experienced all those sexual desires and drives and stuff like that – has got the body of a 13 year old, and you start pumping them full of testosterone, well, I started just going right off the tree. Also it turns out for me I can't function as a conventional male. So a conventional male will be able to get an erection and enjoy penile stimulation and then have an orgasm and then ejaculate. Well, I can't do that. And even pumped full of testosterone, I can't do that. And I kind of experience very, very strong sexual desires, but the inability to kind of follow through and have the peak. And I found that very, very traumatic and – when I mentioned that to my doctors, well they said, "Oh, it's probably your imagination". And then he said to me, "Oh well, all boys go through this kind of process so you're just going to have to put up with it". This is me 30 years old, so I'm out of the social context of somebody going through puberty and I ended up having a nervous breakdown. They never investigated why my body wasn't behaving like an XY male would when given testosterone.

And I can tell you taking testosterone was the biggest mistake I've ever made in my life. If I had known about intersex stuff then and my rights, I would never have started the hormone therapy because it just turned me into somebody that I'm not. And once you start, the body becomes addicted to the bloody stuff and it can't stop. So now, I've tried to stop, I start getting fatigue, my body starts seizing up and that’s pretty brutal. Now I have stopped taking testosterone actually.

But like I said, I regret it because I would have preferred to live as an androgynous person, sure I was impotent but I'm still not able to enjoy sex and stuff like that. And most people consider sex to be a pleasurable experience, but for me it's always been quite a horrific, humiliating experience, so I don't engage in it any more. But I kind of fall through the cracks because for men who want to have sex with men, I don't qualify, so that's some of my humiliating experiences. Men are very, very intolerant, especially when it comes to sexual stuff. On a few occasions when I have been with males and they discover firstly, I don't look like a male when I don't have any clothes on, and I can't function like a male, then they can get rather hostile and also accuse me of being a transsexual and lying to them and deceiving them. A lot of XXY males identify as heterosexual. I don't identify as gay because I don't identify as male because I don't have the life experience of a male, as a sexual experience, and so I describe myself as a variant male. But a lot of people with XXY have wonderful effects from the hormones, it makes them sexually functional, it makes them normal – if you like, whatever that means – and they love it. And that's fine, that's fine for them, but for someone like me, it doesn't work.

Discussion questions for Robert’s story:

1. What does intersex mean? There are many different kinds of intersex variations. Robert has a chromosomal variation (XXY), do you know of any others?
2. How does Robert describe his relationship to various identities (intersex, male, gay)?
3. How do social expectations act in Robert’s story?
4. What does Robert’s history with medical practitioners reveal about medicine’s investment in binary sex (being male or female)?
5. How might this history affect his care?
6. How would you approach Robert’s care, if you knew this history and his intersex status?