

# INCLUSION GUIDE TO RESPECTING PEOPLE WITH INTERSEX VARIATIONS

## WHO ARE INTERSEX PEOPLE?

Intersex people have innate variations of sex characteristics that differ from medical and social norms for female or male bodies. Intersex is an umbrella term for a diverse range of different traits that can be determined prenatally, at birth, during puberty and at other times. These traits include androgen insensitivity, congenital adrenal hyperplasia, 17-beta hydroxysteroid dehydrogenase 3 deficiency, and many more.

Because their bodies are perceived as different, intersex people are at risk of stigmatisation, violence and harmful practices, including forced or coercive medical interventions intended to make their bodies more typically female or male.

## USEFUL TERMS

**Sex characteristics:** physical features relating to sex, including genitalia and other sexual and reproductive anatomy, chromosomes, hormones, and secondary physical features emerging from puberty.<sup>1</sup>

**Sex:** legal or social status initially based on sex characteristics observed at birth. In some cases, infants with intersex variations may undergo a series of examinations and tests to establish sex. In such cases, attempts will be made to determine the infant's intersex variation and likely future gender identity. Normative ideas about how children's bodies should look play a significant role in sex assignment.<sup>2</sup> Many – perhaps most – intersex traits only become evident after sex assignment.

**Disorders of sex development:** a pejorative term for intersex traits introduced following an invite-only clinical workshop in 2005. Some individuals prefer the ameliorative term '**differences of sex development**'.

**Endosex:** a word meaning "non-intersex". This can be helpful in acknowledging that intersex persons old enough to freely express an identity may be heterosexual and may identify with sex assigned at birth (commonly termed cisgender).





## WHAT IS INCLUSION?

Inclusion occurs when a group of people feel welcomed and respected, has access to resources and opportunities, and can contribute meaningfully. Inclusion goes beyond the use of inclusive terminology, such as the addition of an 'I' to LGBT, to consider how to meaningfully respond to the needs and circumstances of the included population.

Inclusion means *not* assuming that intersex people are or should be the same as other populations, including LGBT populations. It also means respecting the diversity of the intersex population, using language appropriately, and keeping up to date with good information and good sources.



## RESPECTING THE LANGUAGE CHOICES OF INDIVIDUALS

A majority of people born with atypical sex characteristics in a 2015 Australian sociological study use the term intersex, including people who are intersex and people who have an intersex variation or condition.<sup>3</sup> Respondents also use a wide range of other terms.

The terms used by intersex people often reflect terms they are taught by parents or clinicians, but also personal responses to misconceptions and stigma. These include misconceptions such as ideas that intersex people have a particular kind of body or a particular identity. In reality, the population is exceptionally diverse, including in sexes assigned at birth, identification or non-identification with sex assigned at birth, sexual orientations and other intersecting characteristics.

Whether or not people with intersex variations use the term intersex, or medicalised language, personal choices must be respected.



## HOW CAN INTERSEX INCLUSION BE MEASURED?

A range of different terms for people of diverse sex characteristics, sexual orientation and gender identity exist, such as 'LGBTI', 'LGBT' or 'sexuality or gender diverse'. Some of these include an 'I' for intersex, and others don't. Sometimes this is deliberate, but at other times language reflects a house style, or presumptions are made about inclusivity. This means that the terminology used by organisations or individuals does not provide an indication of whether or not intersex people are actually included.

Better means of measuring intersex inclusion focus on attention to the specific needs and circumstances of the intersex population. As with other populations encapsulated within the LGBTI acronym, this requires institutions working on or for LGBTI health issues to do meaningful research, and consult intersex-led organisations as centres of expertise on intersex health and human rights issues.

The Darlington Statement is a definitive source of information on the demands of the intersex movement in Australia and Aotearoa/New Zealand.<sup>4</sup> Intersex Human Rights Australia and Intersex Peer Support Australia provide high quality resources. There are more examples in our guide "Raising the bar, how to be an intersex ally".

## WHAT LANGUAGE IS RIGHT FOR YOUR TASK?

### BAD PRACTICE

Often, LGBTI, LGBT, LGBT+ and LGBTQ are treated as synonymous, with an impact on the legibility of the term to people with intersex variations. Even more concerningly, these terms are frequently used when material is not relevant, not *made* relevant, or is inappropriate for people with intersex variations. This is a problem when material about 'LGBTI' people assumes that individuals are non-heterosexual, non-cisgender, or both non-heterosexual and non-cisgender. It is also a problem when assumptions about sexuality or gender identities imply an experience of identity, or an age or agency to freely express an identity. There are more examples in our guide "Raising the bar, how to be an intersex ally".

### GOOD PRACTICE

Pay attention to the specific circumstances and needs of intersex populations in the same way that attention is given to the circumstances and needs of same sex attracted and gender diverse populations. This also means paying attention to the specific needs and circumstances of people with different kinds of intersex variations.



*The Intersex flag was created in July 2013 by Morgan Carpenter of Intersex Human Rights Australia (IHRA)*



### CHECKLIST ON USING APPROPRIATE TERMINOLOGY

Consider addressing the following issues when considering the language that is appropriate to describe your service, clients or work:

- What are the populations that you are representing or including?
- What are the known issues and characteristics of those populations, and knowledge gaps?
- What populations are missing and what are their issues and characteristics, and knowledge gaps?
- Are you able to demonstrate an understanding of the populations you seek to represent or include?
- If you are reporting on a study, did you provide respectful methods for each population to record themselves? Do you have statistically valid samples for each population?
- Is there a good fit between the claimed populations and their representation or inclusion, or is there a mismatch?
- Does this case demonstrate any systemic issues? Is it part of any pattern of misrepresentation, exclusion or incomprehension?



## INTAKE FORMS AND RESEARCH

In all situations, and as with endosex people, it is essential to respect intersex people's sex assigned at birth, unless and until an individual advises otherwise. This means that it is not appropriate or respectful to ask about an intersex variation within a question on sex or gender.

Asking about someone's intersex variation is asking for sensitive information, and the low frequency of many intersex variations also raises questions about ease of identification of individuals in research studies.

Intersex Human Rights Australia maintains resources on including intersex people in forms (<https://ihra.org.au/forms>) and in research studies (<https://ihra.org.au/research>).

## ENDNOTES

- 1 This definition is based on: Yogyakarta Principles. 2017. The Yogyakarta Principles Plus 10: Additional Principles and State Obligations on the Application of International Human Rights Law in Relation to Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics, to Complement the Yogyakarta Principles. <http://www.yogyakartaprinciples.org/principles-en/yp10/>
- 2 While early cosmetic surgeries are now regarded as human rights violations, assignment may still reflect ideas that it is easier to construct normative female genitals than normative male genitals; see, for example, Carpenter, Morgan. 2018. 'Intersex Variations, Human Rights, and the International Classification of Diseases'. *Health and Human Rights* 20 (2): 205–14. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6293350/>. Assignment may also reflect normative ideas about reproductive role, capacity for heterosexual sex, and cultural norms associated with, for example, girls sitting and boys standing to urinate.
- 3 Intersex Human Rights Australia. 2016. 'Demographics'. <https://ihra.org.au/demographics/>
- 4 AIS Support Group Australia, Intersex Trust Aotearoa New Zealand, Organisation Intersex International Australia, Eve Black, Kylie Bond, Tony Briffa, Morgan Carpenter, et al. 2017. 'Darlington Statement'. <https://darlington.org.au/statement>

