

PROTECTING THE HUMAN RIGHTS OF PEOPLE BORN WITH VARIATIONS IN SEX CHARACTERISTICS

REGULATING INTERVENTIONS

Current medical practice in the management of people born with variations in sex characteristics is varied. The experiences of individuals largely depend upon which individual medical professionals or hospitals are managing their healthcare.

Whether practices should be regulated, in what way, and the degree to which this is done is contentious.

International practice

Internationally, regulatory practices vary. Interventions, particularly on children, have been regulated through legislative bans or judicial decisions which have narrowed the circumstances under which interventions can be undertaken. For example, Malta has enacted a law to ban deferrable surgeries on the sex characteristics of minors who cannot provide consent, and in Colombia parents cannot consent to interventions on behalf of their child if the child is over 5 years of age.

Other countries have attempted to regulate practices through guidelines or policies. For example, the Chilean government issued instructions to its Ministry of Health in 2015 to stop unnecessary 'normalising' treatment on children until they can consent, but in 2016 issued additional instructions to remove this ban in favour of guidance on when particular interventions should occur for some variations.

In Australia, no national guidelines or laws exist to regulate the medical management of people born with variations in sex characteristics.

Legal and policy prohibitions

Some intersex organisations and advocates have called for the criminalisation of non-emergency / deferrable medical interventions that alter a child's sex characteristics without their personal consent.

These advocates and organisations have drawn comparisons with female genital mutilation, which is a criminal offence in all Australian states and territories.

Clinical guidelines

Clinical guidelines can establish important principles for medical professionals to approach the care of people born with variations in sex characteristics. These guidelines may be for specific variations or may more broadly cover a number of variations.



There are currently no national clinical guidelines in Australia. However, there exist a number of international evidence-based guidelines that Australian clinicians may follow, and in 2013 the Victorian Department of Health issued decision-making principles for the care of infants, children and adolescents with intersex conditions. Victoria is the only jurisdiction in Australia to have guidelines.

Considerations

A legal prohibition on particular interventions can be seen as strict and not taking into account the circumstances of individual cases, while the flexibility of guidelines can mean they may not be closely followed or can be quickly changed. Challenges also exist in ascertaining whether practices change in line with guidelines and what enforcement options are available when guidelines are not followed.

Discussion questions:

- Should all non-emergency and/or deferrable medical interventions that alter a child's sex characteristics, where the child does not have legal capacity to consent, be prohibited by law? If so, should this prohibition be civil or criminal?
- What are the current approaches to the management of people born with variations in sex characteristics? What are these based on?
- Do any medical guidelines exist that are considered best practice in Australia or internationally, either for the general management of people born with variations in sex characteristics, or for specific variations?
- Should there be national guidelines to guide medical interventions involving people born with variations in sex characteristics?
- If so,
 - o what factors should the guidelines take into account?
 - o what should be the legal status of the guidelines?
 - what should be the process, including consultation, for drafting the guidelines?
 - what should be the oversight mechanism for decisions made under the guidelines?



This sheet forms part of the Australian Human Rights Commission's inquiry into how best to protect the rights of people born with variations in sex characteristics in the context of medical interventions. These sheets are designed to prompt thoughts and considerations for written submissions. Submissions do not need to be limited to the issues raised in this sheet.

Writing a submission? Please complete a Participant Consent Form and attach it to your submission. Submissions should be sent by email to sogii@humanrights.gov.au or by post to GPO Box 5218, Sydney NSW 2001.

Your information will be stored securely and your identity/information will be kept strictly confidential, except as required by law. Inquiry findings may be published, but you will not be individually identifiable in these publications. Submissions on behalf of organisations may be identifiable only where the organisation has given permission for the Commission to publish information attributable to that organisation.

For further information about the project, please email sogii@humanrights.gov.au or phone 02 9284 9650 or 1300 369 711.

Consultation for this project has been approved by an external, independent Human Research Ethics Committee (HREC). Any queries or concerns about ethics may be directed to the University of Sydney Human Research Ethics Committee by email to human.ethics@sydney.edu.au, citing reference 2018/338.