



Commissioner for Children and Young People
Western Australia

All enquiries

Telephone: (08) 6213 2210
Email: Katherine.browne@ccyp.wa.gov.au
Our reference: 18/6939

Australian Human Rights Commission
GPO Box 5218
SYDNEY NSW 2001

CC: sogii@humanrights.gov.au

To the Australian Human Rights Commission

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

As Commissioner for Children and Young People in Western Australia, my role is to advocate for the best interests of all children and young people under the age of 18 in Western Australia, and to promote and monitor their wellbeing. In doing so, I must have regard for the United Nations Convention on the Rights of the Child, and prioritise the needs of Aboriginal children and young people, or children and young people who are vulnerable or disadvantaged for any reason.

Last year, my office established a portfolio area focusing on the needs and experiences of Lesbian, Gay, Bisexual, Trans, and Intersex (LGBTI) children and young people in Western Australia. All LGBTI children and young people have the right to be recognised for their gender identity, sexual orientation or intersex status, and to feel safe and respected wherever they are. Despite this, we know that many LGBTI children and young people experience issues or challenges which impact on their health, safety, wellbeing, and other areas of their life.

So far, my office's work in this space has focused primarily on the needs and experiences of children and young people with diverse gender and sexuality, and has included establishing Advisory Committees of LGBT young people and their peers, and releasing an Issues Paper outlining a broad range of recommendations to improve outcomes for LGBTI children and young people in Western Australia. I acknowledge that our work is limited so far in understanding the different experiences and needs of children and young people with variations of sex characteristics, and therefore we are not in a position to provide expert advice on some of the more technical aspects of this consultation. However, given my office's mandate to promote the wellbeing of children and young people who may be vulnerable or disadvantaged for any reason, I provide some broad statements relating to the consultation questions, with a specific focus on the rights of children and young people.

Understanding lived experiences

There is a general lack of understanding and awareness of diversity amongst the community, and little knowledge about the prevalence and nature of variations in sex characteristics. Other than a few distinct organisations and projects, there are limited information sources in Australia which detail the experiences of people born with variations in sex characteristics, and even further limited in hearing the views and experiences of children and young people. Without this understanding and visibility, communities, including individuals, parents and families, professionals and organisations are often ill-equipped to understand the diversity of variations in sex characteristics. The lack of awareness and visibility has the potential to lead to stigmatisation of people with variations in sex characteristics, an inability to access or provide the supports they require, and experiences of distress and social isolation for intersex children and young people and their families.

Consent

All children and young people should have the ability to participate in decision that affect them. Article 12 of the United Nations Convention on the Rights of the Child says that “States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.”¹ Children and young people’s feeling of being acknowledged, listened to, having their views respected and being involved in decisions that affect them has a strong link to their sense of wellbeing.²

Infants, children and young people with a variation of sex characteristics are often denied the opportunity to have their views heard or be involved in decisions being made about their bodies. This can be due to the timing of decisions being made at an early age of infancy prior to the child being able to provide consent, or due to assumptions that a child may not be able to understand the decisions being made.

Children and young people should be afforded every opportunity to participate in the decisions that are being made about their lives, including their bodies. Where there is no immediate medical risk to an infant or child, any decision making should be deferred until they are at an age where they can understand, and express their views and opinions. Parents and carers should not be able to make decisions on behalf of their child in situations where that decision could be deferred until the child is able to be involved, or where the child is expressing a view or opinion that differs from that of their parents. In situations where a child’s view may differ from that of their parents, independent support systems or representatives should be explored to support the child to have their view heard.

In situations where children and young people do have the chance to provide their views and opinions, it is vital that they are provided with sufficient information, in a manner that they understand, and support in order to be able to fully participate and provide informed consent. This would include information about the details of the variation, the potential impact on the child or young person, the options available to minimise adverse medical impacts and their

¹ United Nations General Assembly 1989, *Convention on the Rights of the Child*, United Nations Human Rights Office. Retrieved from <https://www.ohchr.org/en/professionalinterest/pages/crc.aspx>

² Commissioner for Children and Young People WA 2010, *Speaking out about wellbeing: The views of Western Australian Children and Young People*, Perth, Western Australia.

associated benefits, challenges, or other implications. The information needs to have a strong evidence base, and be based on current and up-to-date approaches and understandings of specific variations. Children and young people and their families require a specialist and multidisciplinary support to equip them with this information, and guide them through decision making processes. I am unaware of any specific protocols that address the issue of consent for children and young people in medical management of variations of sex characteristics in Western Australia.

Regulation – Clinical guidelines

Rigorous and evidence-based guidelines and protocols are required to guide decision making about any surgery on intersex infants and children, factoring any immediate medical needs or requirements, and the deferral of decisions where possible to allow the infant or child's right to provide consent to any decisions being made. Without clear guidelines, decision making will be largely dependent on the expertise and knowledge of the assessment team and family, and may be influenced by subjective factors, pressures or concerns.

Lack of data

There is a lack of data available relating to the effects and outcomes of particular types of treatments of interventions for specific variations of sex characteristics. Given the difference in the nature and impact of variations, decision making needs to be informed by accurate research and evidence. There needs to be an investment by State and Federal Governments into national and international databanks, in order to improve the diagnosis, monitoring, outcomes, and decision making relating to individual intersex conditions.

Access to support services and peer support

There are currently no specialist clinics or supports available for people with intersex variations in Western Australia, and no long-term social workers or psychological support for these children and families. My office has recommended the development and resourcing of specialist clinics and support services in Western Australia, and the provision of peer support and support from other families with lived experiences would be beneficial for children and young people and their families.

I look forward to seeing the recommendations from the Australian Human Rights Commission, and a stronger national commitment to improving outcomes for people living with variations in sex characteristics. If you would like to discuss this submission any further, please contact me, or alternatively you may contact Katherine Browne, Principal Policy Officer, on 08 6213 2210 or katherine.browne@ccyp.wa.gov.au

Yours sincerely



COLIN PETTIT

Commissioner for Children and Young People WA

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