



Ensuring health and bodily integrity: towards a human rights approach for people born with variations in sex characteristics

Summary Report



Ensuring health and bodily integrity: towards a human rights approach for people born with variations in sex characteristics



Ensuring health towards a hu born with va

urity: n for people teristics



The Australian Human Rights Commission encourages the dissemination and exchange of information provided in this publication.

All material presented in this publication is provided under Creative Commons Attribution 3.0 Australia, with the exception of:

- the Australian Human Rights Commission logo
- photographs and images
- any content or material provided by third parties.

The details of the relevant licence conditions are available on the Creative Commons website, as is the full legal code for the CC BY 3.0 AU licence.

Material obtained from this publication is to be attributed to the Australian Human Rights Commission with the following copyright notice:

© Australian Human Rights Commission 2021.

Ensuring health and bodily integrity: towards a human rights approach for people born with variations in sex characteristics report

ISBN 978-1-925917-21-5 (Print)

ISBN 978-1-925917-22-2 (Online)

Authors: Michael Frommer, John Howell, Human Rights Commissioner, Edward Santow (term ended 28 July 2021), Dr Susan Cochrane and Bruce Alston.

Acknowledgements:

- Australian Human Rights Commission President, Emeritus Professor Rosalind Croucher AM, National Children's Commissioner Anne Hollonds and Sex Discrimination Commissioner Kate Jenkins
- Australian Human Rights Commission staff: Senior Policy Executive Darren Dick, Deputy General Counsel/ Acting General Counsel Graeme Edgerton, SOGII Specialist Adviser Daniel Nguyen, Project Support Officer Stephanie Lum, SOGII Adviser Laura Sweeney, Senior Policy Officer Susan Newell, Media Adviser Georgia Waters, Web Manager Leon Wild, Graphic Design and Publications Officer Candy Luan.
- Support with hosting consultations from King & Wood Mallesons, the Victorian Equal Opportunity and Human Rights Commission, and the WA Equal Opportunity Commission.
- Research support from Allens.

Electronic format

This publication can be found in electronic format on the website of the Australian Human Rights Commission: <http://www.humanrights.gov.au/about/publications/>.

CONTENTS

Terms of Reference	4
Executive Summary	6
Towards a human rights approach for people born with variations in sex characteristics	6
(a) Consent and decision making	7
(b) Medical necessity	8
(c) Clinical practice and new National Guidelines	8
(d) Oversight of medical interventions	8
(e) Enforcement	9
(f) Support, health records and data collection	9
Developments around Australia	10
Methodology	11
(a) Objects	11
(b) Expert reference group	11
(c) Consultation process	11
(d) Human Research Ethics Committee process	12
(e) Terminology	13
Population	13
Outcomes	13
Recommendations	15

TERMS OF REFERENCE

1 Project subject matter

1.1 The Australian Human Rights Commission (the Commission) will inquire into, and report on, how best to protect the human rights of people born with variations in sex characteristics in the context of medical interventions, including surgical and non-surgical interventions.

1.2 As part of this project, the Commission should:

- a) document and analyse existing approaches to medical interventions involving people born with variations in sex characteristics in Australia and overseas
- b) identify changes that should be made to these existing approaches, to ensure that decisions and processes regarding medical interventions involving people born with variations in sex characteristics respect and protect the human rights of those affected.

2 Project process

2.1 The Commission should undertake this project by:

- a) adopting an open, consultative approach – especially by consulting with people and organisations with lived experience and expertise of the practical issues involved, including people born with variations in sex characteristics, their parents, carers and families, medical practitioners and state, territory and federal governments in Australia

b) referring to, and acting in accordance with, international human rights principles and agreements

c) complying with all applicable ethical requirements

d) adopting a practical, evidence-based approach to any advice or recommendations proposed

e) considering relevant research and analysis, commentary, policies and law in Australia and overseas, including the 2013 report of the Senate Standing Committee on Community Affairs on involuntary or coerced sterilisation of intersex people and 2015 Government response; the Victorian Decision-Making Principles for the Care of Infants, Children and Adolescents with Intersex Conditions; the 2017 Darlington Statement by Australian and New Zealand intersex organisations and independent advocates; and relevant decisions of the Family Court of Australia.

f) publishing a consultation paper and soliciting the views of stakeholders through submissions and in meetings

g) publishing a report of its findings and recommendations.

3 Expert Reference Group

3.1 The Commission will convene an Expert Reference Group to advise the Commission on matters relevant to this project. The Expert Reference Group will be expected to:

- a) make their best endeavours to participate in three formal meetings – either in person or by teleconference
- b) provide input to the Commission on draft documents produced in the project
- c) advise the Commission as appropriate on the conduct of the project
- d) maintain strict confidentiality in respect of the meetings and deliberations of the Expert Reference Group
- e) otherwise act in accordance with these Terms of Reference.

4 Importance of privacy, confidentiality and autonomy

- 4.1 The Commission and Expert Reference Group acknowledge that some of the matters raised by participants in this project will be particularly sensitive. In undertaking the work of this project, Commission staff and Expert Reference Group members must:
- a) respect the privacy of project participants, especially in regard to the disclosure of sensitive personal information
 - b) take all necessary steps to protect confidential information from being disclosed externally
 - c) where practicable, respect the autonomy of project participants to share their experience in a manner of their choosing.

5 Appropriate language

- 5.1 The Commission notes that terminology in this area is contested, and inappropriate language use can have harmful consequences. The

Commission is committed to consulting on this issue, with a view to adopting the most appropriate terminology in this project.

- 5.2 The Commission's use of the term 'people born with variations in sex characteristics' is intended to refer compendiously to the people whose human rights are the focus of this project. Other terms are also used in this context, and the Commission remains committed to further consultation on terminology, in accordance with clause 0 above.

6 Responsibility for this project

- 6.1 Primary responsibility for this project within the Commission will rest with the Human Rights Commissioner. The Human Rights Commissioner will solicit input internally and externally as appropriate. The Commission will be responsible for the content of any documentation it publishes in connection with this project, including the proposed consultation paper and report.

EXECUTIVE SUMMARY

Towards a human rights approach for people born with variations in sex characteristics

“The effects of having the realisation that my body was at the whim of others is a realisation of the gross indifference in power and this has led to me being diagnosed with Post Traumatic Stress Disorder and impacts on my ability to form relationships and gel with society”.¹

People born with variations in sex characteristics in Australia have increasingly raised concerns with the Australian Human Rights Commission (the Commission), the Australian Government and the United Nations, about human rights violations in relation to medical interventions conducted without the full and informed consent of the person involved. These violations are of particular concern in relation to infants and children.²

This Report provides recommendations for how Australia should protect and promote the human rights of people born with variations in sex characteristics in the context of medical interventions to modify these characteristics.

These recommendations are framed by principles derived from international human rights law.

Applying a human rights analysis to medical interventions in relation to people born with variations in sex characteristics has three principal benefits:

- it promotes compliance with international and domestic law

- the human rights framework provides a near-universal set of norms by which to answer questions regarding medical interventions in relation to people born with variations in sex characteristics
- it provides a framework to consider the claimed benefits of performing these medical interventions without a person’s personal consent, against any impingement on human rights.

These principles are set out in Chapter 2:

- *Bodily integrity principle:* All people have the right to autonomy and bodily integrity. Medical interventions on people without their personal consent have the potential to seriously infringe these rights.
- *Children’s agency principle:* Children and young people have the right to express their views in relation to decisions that affect them, and those views must be given due weight in accordance with their age and maturity. The ability of children to consent to medical interventions generally increases as they grow older. Children and young people who are able to understand fully the nature and consequences of proposed medical interventions should be able to make their own decisions about whether those interventions proceed.
- *Precautionary principle:* Where safe to do so, medical interventions to modify the sex characteristics of a child born with variations in sex characteristics should be

deferred until a time when the child is able to make their own decisions about what happens to their body.

- *Medical necessity principle:* In some cases, to protect the child's rights to life or health, it may be medically necessary for a medical intervention to modify the sex characteristics of a child born with variations in sex characteristics to occur, before a child can make their own decision. An intervention will be medically necessary if it is required urgently to avoid serious harm to the child.
- *Independent oversight principle:* Given the risk of making a wrong decision, decisions about whether a medical intervention to modify the sex characteristics of a child born with variations in sex characteristics is medically necessary should be subject to effective independent oversight.

The Commission recommends new legislative protections, guidance and oversight processes when there is consideration of medical interventions for people under the age of 18 years born with variations in sex characteristics. Legislation should enforce a general requirement that medical interventions take place only with the prior, informed, personal consent of the person concerned – subject to an exception in the case of medical necessity.

The Commission is Australia's national human rights institution. The Commission is independent and impartial. It aims to promote and protect human rights in Australia. The Commission has previously highlighted some of the human rights issues experienced by people born with variations in sex characteristics, in reports,³ discussion papers,⁴ and submissions to government and the UN.⁵

The recommendations in this Report are informed by the Commission's expertise, our research and

extensive public consultation with people born with variations in sex characteristics, peer-support and advocacy organisations, medical professionals, civil society organisations and representatives from federal, state and territory governments.

All views are the Commission's, and the Commission is responsible for this Report and other Project outputs and statements.

(a) Consent and decision making

Under international human rights law, a medical intervention may only take place without the individual's personal consent where this is a medical necessity or medical emergency. The Commission recommends that this approach be taken in relation to medical interventions for people under the age of 18 years who are born with variations in sex characteristics. This general legal rule reflects a person's rights of autonomy and agency over their body.

A range of practical problems regarding obtaining consent to medical interventions are considered in Chapter 4. To address these problems, the Commission recommends the development of new guidance setting out what is required to obtain informed consent from people under the age of 18 years before performing a medical intervention for a person born with variations in sex characteristics. This guidance should ensure that

- medical interventions are proposed only when medically necessary
- consent in all cases is fully informed, and
- children and younger people are empowered to participate in decision making in a manner consistent with their evolving capacities.

Questions raised in this report regarding adequacy of current oversight mechanisms are not intended to suggest parents or doctors are not acting in good faith. Stakeholder submissions indicate quite the

opposite. However, as the High Court observed in Marion’s case, good intentions may not be enough to protect children.

(b) Medical necessity

The Commission recommends that medical interventions in relation to a person under the age of 18 without their personal consent should only take place where the intervention is required urgently to avoid serious harm to the person concerned (the ‘medical necessity’ principle). An intervention is ‘required urgently’ if it cannot be deferred without a significant risk of serious harm.

The Commission notes (in more detail at 2.3 Applicable human rights), the various UN treaty body committee comments to Australia to limit intervention without personal consent to circumstances of medical necessity.

Chapter 5 considers the different rationales put forward for medical interventions in relation to children born with variations in sex characteristics and concludes that such medical interventions should only be permissible if all of the following factors are present:

- the medical intervention is required urgently to avoid serious harm
- the risk of harm cannot be mitigated in another less intrusive way, and intervention cannot be further delayed
- the risk of harm outweighs the significant limitation on human rights that is occasioned by medical intervention without personal consent.

Chapter 5 applies the principle of medical necessity to the situation of medical interventions for people born with variations in sex characteristics. The Commission concludes that some rationales used to justify medical interventions are not consistent

with this principle including, for example, psychosocial rationales based on ‘normalising’ genitalia.

(c) Clinical practice and new National Guidelines

The Commission recommends the development of new National Guidelines to guide decision-making processes to ensure that medical interventions modifying sex characteristics are not undertaken unless intervention is a medical necessity. These are considered in Chapter 6.

The recommended National Guidelines should include guidance on

- obtaining informed consent and ensuring affected children and younger people are involved in decisions (see Chapter 4)
- the application of human rights principles in determining whether a medical intervention is a medical necessity (see Chapter 5)
- requirements for independent authorisation of certain medical interventions (see Chapter 7).

The Commission recommends that the National Guidelines be developed by a national multidisciplinary expert group convened by the Australian Government and should complement legislative reforms recommended in Chapter 7.

The National Guidelines should also promote the best standards of clinical care generally. The national multidisciplinary expert group should develop clinical guidelines and best practice and treatment protocols, including in relation to the provision of psychological and peer support.

(d) Oversight of medical interventions

The Commission recommends the establishment of Independent Panels to provide appropriate

oversight of medical interventions in relation to children born with variations in sex characteristics, through the application of a human rights framework. Chapter 7 discusses how a human rights framework for decision making about medical interventions should be incorporated into Australian domestic law and policy, and what independent oversight mechanisms should be established.

Oversight, in this context, refers to mechanisms by which an independent decision maker determines whether a medical intervention may be carried out on a person under the age of 18 without personal consent.

The Commission recommends reform of oversight mechanisms by legislation by

- establishing Independent Panels with responsibility to decide whether to authorise medical interventions in respect of people born with variations in sex characteristics
- defining the circumstances in which interventions without personal consent may be authorised, which should be limited to circumstances of medical necessity
- recognising that in emergency situations there should be an expedited authorisation process or, where this still does not provide time to deal with the emergency, a requirement for subsequent notification of the Independent Panel.

(e) Enforcement

The Commission recommends legislation to prohibit medical interventions in relation to people under the age of 18 years born with variations in sex characteristics otherwise than in accordance with the medical necessity principle. Additionally, there should be appropriate criminal penalties for carrying out a relevant intervention

without authorisation from an Independent Panel. Chapter 8 discusses how obligations placed on health practitioners and others to apply to an Independent Panel prior to performing medical interventions might be enforced in practice, under criminal law, and through regulation of health professionals.

(f) Support, health records and data collection

People affected by medical interventions modifying sex characteristics need adequate support. Stakeholders raised concerns about records having been destroyed, failure to appropriately share records between treating health professionals, and inadequate record security.

The Commission recommends in Chapter 9 that governments provide sufficient public funding for peer support organisations, comprehensive psychological and psychiatric health services, and comprehensive and up-to-date consumer resources for people born with variations, and their parents or guardians. While support for individuals born with variations is central, supports for parents or guardians is also crucial to enable families to best understand all the considerations in caring for a child born with a variation. Australian governments should also consult on establishing and funding coordinator positions to integrate care across multiple specialties and institutions.

The Commission considers that there is a need for long-term, longitudinal data on past and current practices to better understand the health and psychosocial effects of different interventions.

The Commission therefore recommends the Australian Government facilitate the establishment of a national databank to assist research on the frequency of variations in sex characteristics and the effects of medical interventions and non-intervention. The Australian Government and state and territory governments should also fund and facilitate collaborative medical, psychological,

health and wellbeing research, and socio-economic research to tackle stigma and disadvantage as relates to exclusion in schooling and employment.

Developments around Australia

In 2013, the Senate Community Affairs References Committee (Senate Committee) conducted an inquiry into the involuntary or coerced sterilisation of intersex people in Australia (Senate Committee Inquiry). In its final report, the Senate Committee made a number of recommendations to better protect the human rights of intersex people.⁶

In its formal response in May 2015, the Australian Government welcomed the report and recognised the harm experienced by many people subjected to forced sterilisation. It committed to raising with the states and territories the Senate Committee's recommendations regarding the legal framework regulating sterilisation for people with disability, with a view to promoting consistency between Australian jurisdictions.

In respect of 'involuntary or coerced sterilisation of intersex people', the Government acknowledged the report's main recommendations and specifically noted the benefit of further research on the desirability of 'bringing the medical treatment of intersex variations into the jurisdiction of guardianship tribunals' and/or the Family Court of Australia, but did not support amending the Family Law Act 1975 (Cth) to expand the Family Court's role at that time.⁷ Broadly speaking, the Australian Government has emphasised the responsibility of the states and territories and has not committed to the implementation of particular reform in this area.⁸

During the Commission's inquiry, state governments had also been considering how to better protect the rights of people born with

variations in sex characteristics and provide better support to them and their families.

In July 2021, the Victorian Government committed to prohibiting deferrable medical interventions on intersex people without personal consent, and introducing an oversight panel to ensure compliance with the prohibition. The Commission welcomes this commitment.

In July 2021, the report *(i) Am Equal: Future Directions for Victoria's Intersex community*, outlined a collaborative approach that importantly includes people born with variations in sex characteristics and their advocacy and peer support organisations.⁹

Its three main focus areas – Future Intersex Resourcing, Future Intersex Health and Wellbeing Centre, and Improving Future Treatment – are consistent with the Commission's views reflected in this Report. The proposals to develop: a mechanism to prohibit deferrable medical interventions modifying a person's sex characteristics without personal consent; an oversight panel to ensure compliance with the prohibition; provisions which ensure the collection of data and transparency over what treatments are being performed and support for the development of National Guidelines, are welcome and consistent with key recommendations in this Report.

The Commission also welcomes the ACT Government's work to protect the rights of people born with variations in sex characteristics and provide better support to them and their families. In October 2019, the ACT Government committed to developing a plan for managing deferrable medical interventions for people born with variations in sex characteristics. This has involved consulting with intersex people and experts in the field; reviewing the existing literature and initiatives in other countries; and testing key issues with stakeholder individuals and organisations.

The Commission has engaged with the ACT's efforts to formulate a proposal to develop such protections. There is congruence in the approach proposed by the ACT Government and that of the Commission's, as articulated in this report.

Methodology

(a) Objects

The Project was undertaken to evaluate the current approaches taken to medical interventions in Australia and other jurisdictions using a human rights-based framework, and to develop recommendations for a nationally consistent human-rights based approach to decision making about medical interventions.

This project aimed to

1. identify key issues and obtain perspectives on current practice by consulting with various stakeholders, including individuals born with variations in sex characteristics, advocacy groups, medical professionals and representatives from federal, state and territory governments
2. evaluate the current approaches taken to medical interventions in Australia and other jurisdictions using a human rights-based framework
3. develop recommendations for a nationally consistent human-rights based approach to decision-making about medical interventions.

(b) Expert reference group

The Commission convened an expert reference group to help guide the consultation process. The Expert Reference Group, was constituted of a range of human rights, clinical and peer support and advocacy groups. The Commission greatly appreciates the significant time and intellectual

contribution of group members, including Tony Briffa and Morgan Carpenter from Intersex Human Rights Australia, Bonnie Hart from the Androgen Insensitivity Syndrome Support Group Australia (AISSGA) – now Intersex Peer Support Australia, and Anna Brown from Equality Australia.

(c) Consultation process

The Commission released a Consultation Paper in 2018,¹⁰ received written submissions, and conducted roundtable consultations and individual interviews with people with lived experience of variations in sex characteristics.

The Commission received 48 written submissions. Organisational submissions which consented to be identified, have been cited.¹¹ All other organisational and individual submissions that were provided in confidence are not identified. The Commission conducted roundtable consultations in Sydney, Melbourne, Brisbane and Perth with people with lived experience, medical specialists, and government, academic and civil society stakeholders. The Commission conducted 17 individual interviews with people with lived experience;¹³ with people born with variations in sex characteristics, and four with parents and partners. The Commission received four submissions made by people born with variations in sex characteristics, four from parents, and received four submissions from support groups which collated the experience of their members.

The Commission has been careful to de-identify information from these contributors presented in this report, particularly in Chapter 3 – Lived experience.

The Commission notes the lack of comprehensive data collection, as discussed in Chapter 9, including on the life-long effects of interventions. The Commission did not hear contemporaneous accounts from children about their experiences. Rather, many of the people born with variations

in sex characteristics, who are now adults, shared experiences relating to when they were children. The Commission understands the sensitivity involved in people under the age of 18 sharing their experiences, within a context of varying family backgrounds.

The accounts of people with lived experience of variations in sex characteristics, have helped inform the Commission's conclusions and recommendations. The Commission acknowledges the courage of those who shared their personal, often intimate lived experience with us, and that reliving this experience can come at a significant personal cost.

While individuals' experiences varied widely, there were common themes concerning distress at physical and psychological consequences, stigma, lack of social and personal support, and challenging interactions with the health system.

Many people with lived experience told the Commission that medical interventions that had occurred in both childhood and adulthood had a variety of negative consequences on their physical and mental wellbeing. They also emphasised how feelings of isolation further exacerbated poor mental health, reinforcing a sense of being somehow 'abnormal'. Isolation was often accompanied by feelings of stigmatisation. These elements combined to create challenges in terms of self-identity and knowledge and in formation of relationships with family, friends, and peers.

The Commission is mindful of the risk of selection bias in the demographic profile of people or organisations providing submissions and/or participating in face-to-face consultations. The Commission has sought to mitigate this risk in several ways, including

- a broad call for participation in consultation to a wide range of groups with an interest, including individuals, parents and carers,

medical professionals, government, advocates and other experts

- focusing on qualitative and thematic aspects and peoples' lived experiences rather than a purely data or quantitative analysis of submissions
- consideration of advice from the project's Expert Reference Group and other knowledge in the community.

Where the Commission has made findings about past and current practice, it has done so where those findings are supported by the evidence provided by a broad range of submitters including clinical bodies, and by current guidance materials.

The Commission was mindful of the impact of consultation and the risk of re-traumatisation, especially among people born with variations in sex characteristics. Where feasible, the Commission made on-site counselling available to individuals during consultation. In other instances, the Commission referred individuals to counselling services with appropriate capacity to assist people born with variations in sex characteristics.

(d) Human Research Ethics Committee process

This project received ethics approval from the Human Research Ethics Committee at the University of Sydney. The Ethics Committee assessed the project and supporting materials against various ethical guidelines and policies, including the National Statement on Ethical Conduct in Human Research, and the Australian Code for the Responsible Conduct of Research.¹²

Ethics approval is not a requirement in advance of Commission projects or inquiries under the *Australian Human Rights Commission Act 1986* (Cth). However, the Commission decided to seek ethics approval to ensure rigour in the project's design

and processes and due to the sensitive nature of the research and consultations.

(e) Terminology

In this Report, the Commission has used the phrase ‘people born with variations in sex characteristics’. This term refers to people born with any sex characteristics that do not conform to medical norms for female or male bodies.¹³

During consultations, this terminology was broadly endorsed for the purposes of this project. Some people born with variations in sex characteristics noted that they did not use this phrase to refer to themselves in daily life, and some clinicians observed that they preferred to use different terms depending on the context, such as the language of particular medical diagnoses.

One key observation made by people born with variations in sex characteristics is that many do not identify with labels applied to them in medical contexts, and that each individual will have their own preferences for terminology when discussing their own experiences. Submissions from clinical practitioners indicate that there is some increasing awareness of this fact. However, submissions from people born with variations and civil society indicate that further progress is needed in this regard.

Population

The scope of focus for this report is on practices involving medical interventions to modify the shape, appearance – including removal of tissues/organs in some cases - and/or function of genitals and secondary sexual characteristics, largely of infants and children who cannot consent for themselves. Indeed, the vast majority of contributions received by the Commission have focused on this group.

The size of the population who may be affected is not clear. As discussed in Chapter 9, there is a lack of data collection on population size and on frequency and types of interventions that have occurred.

Around 1.7% of the population is estimated to have some variation in sex characteristics, though there is some contention about the accuracy of this figure.¹⁴ This figure includes populations, such as those with Turner’s and Klinefelter Syndromes, that some stakeholders do not consider as having a variation in sex characteristic.¹⁵

One hospital multidisciplinary team observed that there is no consensus about what variations have been included and excluded in past estimates.¹⁶ Further, while people with variations in sex characteristics may be observed at or soon after birth, and sometimes in utero, some may not be observed until puberty, when trying to conceive, randomly in adult life or, indeed, never at all.¹⁷

Outcomes

The overall effect of this Report will be to foster a deeper understanding of the human rights implications of medical interventions on children born with variations in sex characteristics. By adopting the proposed human rights approach, only interventions that conform with the medical necessity principle, that cannot be deferred, will occur, thus protecting the rights of children who are not able to provide personal consent.

The specific outcomes of this report include

- a better understanding of the lived experience of people born with variation in sex characteristics, which for some has been traumatic and caused significant ongoing health issues
- a better understanding of the range of medical interventions that have occurred

- an appreciation of the range of human rights issues raised by interventions that are performed without personal consent
 - a better understanding/appreciation of children's right to participate in decisions that affect their lives
- a template for reform that will ensure fundamental human rights such as bodily integrity, while also allowing for interventions that are needed to avoid immediate and serious harm to health.

RECOMMENDATIONS

Recommendation 1:

Laws and practices concerning medical interventions to modify the sex characteristics of people born with variations in sex characteristics should be guided by a human rights framework based on the following principles.

1. *Bodily integrity principle:* All people have the right to autonomy and bodily integrity. Medical interventions on people without their personal consent have the potential to seriously infringe these rights.
2. *Children's agency principle:* Children and young people have the right to express their views in relation to decisions that affect them, and those views must be given due weight in accordance with their age and maturity. The ability of children to consent to medical interventions generally increases as they grow older. Children and young people who are able to understand fully the nature and consequences of proposed medical interventions should be able to make their own decisions about whether those interventions proceed.
3. *Precautionary principle:* Where safe to do so, medical interventions to modify the sex characteristics of a child born with variations in sex characteristics should be deferred until a time when the child is able to make their own decisions about what happens to their body.
4. *Medical necessity principle:* In some cases, to protect the child's rights to life or health, it may be medically necessary for a medical intervention to modify the

sex characteristics of a child born with variations in sex characteristics to occur before a child can make their own decision. An intervention will be medically necessary if it is required urgently to avoid serious harm to the child.

5. *Independent oversight principle:* Given the risk of making a wrong decision, decisions about whether a medical intervention to modify the sex characteristics of a child born with variations in sex characteristics is medically necessary should be subject to effective independent oversight.

Recommendation 2:

The development of new resources to increase awareness of variations of sex characteristics in the community, educational, service and employment settings, and to reduce the associated stigma.

To undertake this, the Australian Government and state and territory governments should fund community organisations led by people born with variations in sex characteristics to .

Recommendation 3:

New National Guidelines on medical interventions for people born with variations in sex characteristics (see Recommendation 6) should set out what is required to obtain informed consent before performing a medical intervention for a person born with variations in sex characteristics. This guidance should require that:

- (a) Treating practitioners provide accurate, up-to-date, evidence-based medical information including about:

- (i) the variation in question
 - (ii) the exact nature of any proposed intervention, why it is medically necessary, and the degree of any risk from the intervention
 - (iii) what alternatives exist, including other medical interventions or delaying or deferring the proposed intervention
 - (iv) the likely long-term effects and outcomes if the proposed intervention is carried out immediately, at a later time, or if the intervention is not carried out
 - (v) what uncertainty, if any, exists in relation to the current state of medical knowledge underpinning any recommended intervention
 - (vi) any diversity of medical opinion about the proposed intervention
 - (vii) the benefits of peer support, and contact information for relevant groups.
- (b) Treating practitioners document fully the information provided, how they have included children in decision-making processes and the steps they have taken to effectively communicate the information, taking into account the age, decision-making ability or other characteristics of the person.
- (c) people born with variations in sex characteristics and, where they are children, their parents and other family members, are provided information in clear, accessible, non-technical language that they can understand
- (d) Treating practitioners refer people born with variations in sex characteristics, and where relevant their parents and other family members, to peer support and advocacy organisations, and services such as psychologists and social workers, who can provide further information to help inform their decision-making.
 - (e) children are included in decision making in an age-appropriate way, including by being given support to understand any medical advice and to express their views, with due weight being given to those views according to their age and capacity. Where a child has sufficient understanding, the child's informed consent should be sought. Where the view is formed that the child does not have sufficient understanding for their consent to be sought, the reasons and evidence for this should be documented along with a description of any attempts made to seek the views of the child
 - (f) people with variations in sex characteristics and, where they are children, their parents and other family members, are provided with adequate time to make treatment decisions, with access to necessary support, to ensure they do not feel undue pressure to consent.

Recommendation 4:

Medical interventions modifying sex characteristics of children may be conducted without personal consent only in circumstances of medical necessity. Circumstances of medical necessity exist only where all of the following factors are present:

- (a) the medical intervention is required urgently to avoid serious harm
- (b) the risk of harm cannot be mitigated in another less intrusive way, and intervention cannot be further delayed

- (c) the risk of harm outweighs the significant limitation on human rights that is occasioned by medical intervention without personal consent.

Recommendation 5:

All people born with variations in sex characteristics should have access to comprehensive, appropriately qualified multidisciplinary care, with input from mental health and other key professionals, and other people with variations. Care should be available across their lifespan and regardless of where they live.

Recommendation 6:

- (a) The Australian Government should convene and fund a national multidisciplinary expert group to develop National Guidelines on medical interventions for people born with variations of sex characteristics (National Guidelines), with input from specialist clinicians and health professional bodies, people with lived experience and their parents and carers, advocacy and peer-support groups, and human rights organisations.
- (b) The National Guidelines should reflect human rights principles including in relation to medical necessity (see Recommendation 4) and the provision of adequate information for informed consent (see Recommendation 3), as well as include best practice and treatment protocols for the management of different variations in sex characteristics and reviews of existing and emerging evidence-based research.
- (c) The National Guidelines should be reviewed periodically, to ensure guidance is based on the best available data and evidence.

Recommendation 7:

- (a) The Australian Government and state and

territory governments should legislate to establish one or more independent panels with responsibility to decide whether to authorise medical interventions modifying sex characteristics of people under the age of 18 years born with variations (Independent Panels).

- (b) Whenever a clinician or clinical treatment team intends to make such a medical intervention, they should be required to apply to an Independent Panel prior to performing the intervention.
- (c) Independent Panels should be constituted by members with expertise that includes relevant clinical expertise, lived experience of being born with variations in sex characteristics, and human rights.

Recommendation 8:

- (a) An Independent Panel should only authorise a medical intervention for a person under the age of 18 years where it is satisfied that the person concerned either:
 - (i) has the ability to provide personal consent and has provided such consent, or
 - (ii) is not able to provide personal consent and the intervention is a medical necessity.
- (b) In rare emergency situations, where there would be a real risk of serious and irreparable harm to the person if the intervention were not carried out immediately, the Independent Panel should have an expedited process to consider the request for authorisation. Only where this still does not provide enough time to address the emergency, should an intervention proceed without authorisation. In those circumstances the relevant Independent Panel must be notified promptly following

the conduct of the medical intervention.

- (c) Independent Panels, in determining whether a medical intervention is authorised, should be informed by the National Guidelines on medical interventions for people born with variations of sex characteristics.

Recommendation 9:

The Australian Government and state and territory governments should legislate to prohibit medical interventions for people born with variations in sex characteristics otherwise than in accordance with Recommendations 7 and 8. There should be appropriate criminal penalties for breaching this legislative prohibition.

Recommendation 10:

The Australian Government and state and territory governments should provide sufficient public funding for:

- (a) sustainable operation of advocacy and peer support organisations led by people born with variations of sex characteristics
- (b) comprehensive psychological and psychiatric health services, for people born with variations of sex characteristics, their parents and other family members
- (c) improved access to peer support and health services, including online and by telephone
- (d) comprehensive and up-to-date consumer resources for people born with variations in sex characteristics, their parents and other family members informed by clinical, peer support and human rights experts.

The Australian Government and state and territory governments should also consult on establishing and funding coordinator positions to integrate care across multiple specialties and institutions.

Recommendation 11:

The Australian Government should facilitate the establishment of a national databank to assist research on:

- (a) the frequency of variations in sex characteristics, including specific variations
- (b) the short-, medium- and long-term effects of medical interventions and non-intervention.

Recommendation 12:

The Australian Government and state and territory governments should fund and facilitate collaborative research, co-designed by community organisations led by people born with variations of sex characteristics, including:

- (a) medical, psychological, health and wellbeing research, across the lifespan, that affirms human rights norms and helps people born with variations of sex characteristics to flourish
- (b) socio-economic factors that put people born with variations in sex characteristics at risk leading to stigma and disadvantage, including emerging issues such as social exclusion in schooling and employment.
- (c) any research that investigates the circumstances and needs of all sexual and gender minorities should disaggregate data on people born with variations of sex characteristics.

Endnotes

- 1 Submission 57, Intersex Inquiry.
- 2 Black et al, *Darlington Statement* (10 March 2017) <<https://darlington.org.au/statement>>.
- 3 Australian Human Rights Commission, *Resilient Individuals: Sexual Orientation, Gender Identity & Intersex Rights* (2015) <https://www.humanrights.gov.au/sites/default/files/document/publication/SOGII%20Rights%20Report%202015_Web_Version.pdf>.
- 4 Australian Human Rights Commission, *Surgery on Intersex Infants and Human Rights* (July 2009) <<https://www.humanrights.gov.au/surgery-intersex-infants-and-human-rights-2009>>.
- 5 See, for example, Australian Human Rights Commission, *Information for List of Issues – Australia*, Submission to UN Committee on Economic, Social and Cultural Rights (29 August 2016) <https://rightstalk.humanrights.gov.au/sites/default/files/AHRC_ICESCR_LOI_2016.pdf>.
- 6 Senate Community Affairs References Committee, Parliament of Australia, *Involuntary or coerced sterilisation of intersex people in Australia* (2013) <http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/~/_media/Committees/Senate/committee/clac_ctte/involuntary_sterilisation/second_report/report.ashx>.
- 7 Commonwealth, *Parliamentary Debates*, Senate, 17 June 2015, 3755-3769 (Senator Fifield). At <<http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22chamber%2Fhansards%2Fb72114df-d068-4aeb-8fd0-833d5a01f955%2F0164%22;src1=sm1>>.
- 8 Commonwealth, *Parliamentary Debates*, Senate, 17 June 2015, 3755-3769 (Senator Fifield). At <<http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22chamber%2Fhansards%2Fb72114df-d068-4aeb-8fd0-833d5a01f955%2F0164%22;src1=sm1>>.
- 9 <<https://www2.health.vic.gov.au/about/publications/Factsheets/i-am-equal>>
- 10 Australian Human Rights Commission, *Consultation Paper on Protecting the Human Rights of People Born with Variations in Sex Characteristics in the context of Medical Interventions* (2018) <<https://humanrights.gov.au/our-work/lgbti/projects/protecting-human-rights-people-born-variations-sex-characteristics-context>>.
- 11 The shorthand form of 'Intersex Inquiry' is used in the notes to refer to these submissions and to interviews conducted.
- 12 National Health and Medical Research Council, *National Statement on Ethical Conduct in Human Research, and the Australian Code for the Responsible Conduct of Research, National Statement on Ethical Conduct in Human Research*, E72, 2007 (Updated 2018) <www.nhmrc.gov.au/guidelines/publications/e72>.
- 13 Male circumcision does not fall within this as it is not an intervention addressing a sex characteristic that departs from medical norms of female or male bodies.
- 14 Submission 45, *Intersex Inquiry*, 3.

- 15 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*; Submission 35, *Intersex Inquiry*, 4, which refers to some of the limitation of the approach taken to collecting data on sex and gender by the Australian Bureau of Statistics, as described at <<http://www.abs.gov.au/websitedbs/D3310114.nsf/home/ABS+Response+to+Sex+and+Gender+Guidelines>>.
- 16 Submission 68, *Intersex Inquiry*, 1-2.
- 17 Submission 68, *Intersex Inquiry*, 5; Submission 61, *Intersex Inquiry*, 5.

FURTHER INFORMATION

Australian Human Rights Commission

GPO Box 5218 SYDNEY NSW 2001

Telephone: (02) 9284 9600

Complaints Infoline: 1300 656 419

General enquiries and publications: 1300 369 711

TTY: 1800 620 241

Fax: (02) 9284 9611

Website: www.humanrights.gov.au.

For detailed and up to date information about the Australian Human Rights Commission visit our website at: www.humanrights.gov.au. To order more publications from the Australian Human Rights Commission, download a Publication Order Form at: www.humanrights.gov.au/our-work/publications, call: (02) 9284 9600, fax: (02) 9284 9611 or email: sogii@humanrights.gov.au.

Australian Human Rights Commission

www.humanrights.gov.au