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Commission

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



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

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

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CONTENTS

Foreword	8
Terms of reference	10
Recommendations	12
1 Executive Summary	16
1.1 Towards a human rights approach for people born with variations in sex characteristics	16
(a) Consent and decision making	17
(b) Medical necessity	18
(c) Clinical practice and new National Guidelines	18
(d) Oversight of medical interventions	19
(e) Enforcement	19
(f) Support, health records and data collection	19
1.2 Developments around Australia	20
1.3 Methodology	21
(a) Objects	21
(b) Expert reference group	21
(c) Consultation process	21
(d) Human Research Ethics Committee process	23
(e) Terminology	23
1.4 Population	24
1.5 Outcomes	24
2 Human Rights	25
2.1 Towards a human rights framework	25
2.2 What are human rights?	26
2.3 Applicable human rights	26
(a) Bodily integrity and autonomy	27

(b) Children's rights, including to participate in decisions that affect them	29
(c) Torture or cruel, inhuman or degrading treatment	31
(d) The right to health	32
(e) The Yogyakarta Principles	33
(f) Other laws	34
2.4 Applying a human rights framework	34
3 Lived experience	36
3.1 Which medical interventions have occurred?	36
3.2 Impacts of medical interventions	38
(a) Physical consequences	38
(b) Stigma and isolation	38
(c) Invasive practices	40
(d) Autonomy, identity, personal history	41
(e) Relationships	41
(f) Mental health	42
(g) Other experiences	42
3.3 Experience of parents and carers	42
3.4 Addressing stigma	43
4 Consent and decision making	46
4.1 Consent and decision making – under Australian law	47
(a) The current legal framework	47
(b) Children	49
(c) Special medical procedures	50
4.2 Informed consent under international human rights law	52
(a) Children's right to participate in decision making	52
4.3 Clinical guidance on informed consent for people born with variations in sex characteristics	53
4.4 Giving and obtaining consent: past and current practice	55
(a) Clinical stakeholders	55
(b) Experience of people born with variations in sex characteristics	57

(c) Experience of legal guardians and families	60
(d) Providing adequate information to ensure informed consent	61
4.5 Emerging themes	62
(a) What is required for informed consent	62
(b) Barriers to informed consent	64
4.6 Ensuring consent is informed	65
5 Medical necessity of interventions	68
5.1 Justifying medical intervention	68
5.2 Consent and medical necessity	69
5.3 Rationales and circumstances claimed to justify medical interventions	70
(a) Situations where urgent treatment is required	70
(b) Protecting physical health	71
(c) Risk of cancer	72
(d) Interventions to 'normalise' genitalia and other psychosocial rationales	78
5.4 At what point of time is an intervention necessary?	85
(a) Support for early interventions	85
(b) Opposition to early interventions	85
(c) Timing of interventions	86
5.5 Human rights approach	87
6 Clinical practice and new National Guidelines	89
6.1 Clinical practice	89
(a) Multidisciplinary treatment teams	90
(b) Problems with MDT management and care	93
(c) Other problems with management and care	94
6.2 Principles that inform clinical practice	96
(a) Best practice approaches to clinical management and care	96
6.3 Better access to multidisciplinary care	98
6.4 Current clinical guidance	99
(a) The 2006 Consensus Statement and 2016 Update	99

(b) The 2013 Victorian Decision-Making Principles	101
(c) Non-binding nature of existing guidelines	102
6.5 Need for clinical guidance	103
(a) Stakeholder views on new guidance	103
(b) Possible content of new guidelines	103
6.6 New National Guidelines	105
(a) Best practice and treatment protocols	106
6.7 Should the National Guidelines be binding?	106
(a) Status of guidelines	106
(b) Stakeholder views on binding guidelines	107
(c) The binding nature of the National Guidelines	107
6.8 Development, funding, and review of the new National Guidelines	108
(a) Stakeholder views on the development of guidelines	108
(b) Developing the National Guidelines	109
(c) Review of the National Guidelines	110
7 Oversight of medical interventions	111
7.1 Current oversight mechanisms	111
(a) Review of Family Court cases	112
(b) Observations on Family Court oversight	115
7.2 Concerns about current oversight mechanisms	118
(a) Stakeholder perspectives about Family Court oversight	118
(b) A need for alternative oversight	120
7.3 Options for independent oversight	121
(a) Stakeholder views on new expert panels and tribunals	122
7.4 Authorisation by Independent Panels	123
(a) The obligation to seek authorisation	124
(b) Circumstances in which interventions may be authorised	124
(c) Independent Panels	125
(d) Implementation in policy	126
(e) Role of the National Guidelines	126

(f) Reform of court processes	126
8 Enforcement	128
8.1 Enforcement	128
8.2 Support for new regulation	128
(a) Creation of criminal offences	129
(b) Civil liability	129
(c) Disciplinary action	129
8.3 Opposition to new regulation	130
(a) Legislative prohibition is morally unjustified	130
(b) Regulation is an unnecessarily complicated response	130
(c) Regulation would breach children’s rights	130
8.4 New criminal penalties	131
9 Support, health records and data collection	133
9.1 Support for affected individuals	133
(a) Provision of information and education	133
(b) Provision of support services	136
(c) Better service and information provision	138
9.2 Access to and control of health records	139
(a) Access to health records	139
(b) Privacy	141
(c) Sharing health records	141
(d) The importance of access to records	141
9.3 Data collection	142
(a) Lack of data	143
(b) Disagreement in the absence of data	144
(c) Data collection to support optimal practice	144
(d) Barriers to data collection	145
(e) Who should be responsible for data collection?	146
(f) Towards better data	146
9.4 Responding to those harmed by past practices 208	147

FOREWORD

The Australian Human Rights Commission's report, *Ensuring health and bodily integrity: towards a human rights approach for people born with variations in sex characteristics*, seeks to provide a pathway forward to address a challenging set of human rights issues that can have significant personal impacts if not addressed. Past consideration of the issues in this Report has not resulted in the introduction of adequate protections, despite the significance of the issues.

On behalf of the Commission, I want to express my deep gratitude to those people directly affected by this issue who shared their experiences with us – people who have had interventions as children to vary their sex characteristics, and their parents. It can be both confronting and daunting to recount past experiences and I express my sincere thanks to you for participating. Your experiences and insights have helped inform the findings and recommendations in this Report.

The Commission also had the benefit of input from key clinicians, including paediatricians, endocrinologists and psychiatrists, as well as from legal, human rights and government agencies. Medical practitioners in particular were very open about the difficult decisions that they need to make, and considered they have always acted in the best interests of their patients. The Commission's recommended actions in this Report will bolster this commitment, by improving the decision-making processes for medical practitioners, as well as for parents, and assist them in navigating these complex circumstances.

The Commission thanks everyone who participated in our consultation processes: people born with variation in sex characteristics, family members, peer-support and advocacy organisations, clinicians, legal and human rights

entities, academia and government. This input has been crucial in identifying problems and solutions.

Ultimately, this report is about putting into place better protections for children who do not have the legal capacity to make life altering decisions for themselves.

Many of the most controversial and contested interventions have occurred when individuals were infants, or as children too young to be able to provide their own consent. Decisions about these procedures have often been made based on prevailing social attitudes and the available research base – both of which have changed in important ways over recent years.

In this Report, the Commission proposes better oversight and approval mechanisms, requirements for ensuring informed decision making for parents and children, a limiting of the circumstances in which an intervention may occur without the consent of the person affected, and stronger consequences where these requirements are not met.

Australia's obligations under international human rights treaties have been central to the Commission's approach in how to better protect individuals' rights. Informed by these commitments, the Commission's

proposals for reform are underpinned by a human rights framework expressed in five fundamental human rights principles.

The recommendations in this Report propose a substantial change from the current framework. While this will no doubt have its challenges, the Commission considers that adopting this approach will best guarantee the human rights to health and bodily integrity of people born with variations in sex characteristics.

This project was led by the former Human Rights Commissioner, Edward Santow, and I thank him and his team for their efforts in conducting the project on the Commission's behalf. I also appreciate the advice and input from Sex Discrimination Commissioner Kate Jenkins and National Children's Commissioner Anne Hollonds and her team.



Emeritus Professor Rosalind Croucher AM

President, Australian Human Rights Commission

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.

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.

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.

1.1 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 interventions 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 and civil 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. This includes people born with variations and their parents or guardians. 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.

1.2 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.

1.3 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.

1.4 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

1.5 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.

2

HUMAN RIGHTS

2.1 Towards a human rights framework

This chapter considers the human rights implications of medical interventions in respect of people born with variations in sex characteristics, with a particular focus on the experience of infants and children. The chapter concludes by setting out the human rights framework, with five key human rights principles that should guide reform of applicable laws, policies and practices.

International human rights law requires the Australian Government and state and territory governments to take steps to ensure its population has appropriate access to health care. Most medical interventions, including those for people born with variations in sex characteristics, are aimed at saving life or promoting the health of the affected person. Medical treatment reasonably directed to these goals can promote and protect human rights, particularly the right to life and the right to the highest attainable standard of health.

Medical interventions can also have the effect of engaging, and sometimes limiting, other human rights.

Informed consent is crucial in upholding the human rights of an individual in this context. Where a medical intervention is undertaken without the informed consent of the individual affected, it necessarily intrudes on the individual's bodily integrity and autonomy. It can also limit other rights, such as the individual's right to privacy and the right to security of the person.

Under Australian law, consent is often provided by parents and other adults on behalf of a child

who is unable to give consent. This is the reason this Report uses the term 'personal consent' to distinguish between consent given by parents and consent given by the individual concerned.

Several UN human rights treaty bodies have addressed the issue of medical interventions performed on children born with variations in sex characteristics. They have affirmed the general requirement for the individual's express and informed consent before any such intervention is performed. They have also recognised that, in exceptional cases, this consent may not be required where the intervention is *a medical necessity* in the individual's particular circumstances.

Under international human rights law, therefore, the standard of medical necessity is central to any medical intervention in respect of a child who is too young to provide personal consent.

Later chapters in this report set out what actions should be taken to embed appropriate human rights protections for people born with variations in sex characteristics.



2.2 What are human rights?

We are all entitled to enjoy our human rights for one simple reason – that we are human. We possess human rights regardless of our background, age, gender, sexual orientation, political opinion, religious belief or other status. Human rights are centred on the inherent dignity and value of each person, and they recognise humans' ability to make free choices about how to live.

Australia is a signatory to seven core human rights treaties, covering civil and political rights, as well as economic, social and cultural rights. Accordingly, Australia has voluntarily agreed to comply with human rights standards and to incorporate them into domestic law, policy and practice.

Human rights are universal, meaning that they apply to everyone. They are indivisible, meaning that all human rights have equal status. They are interdependent and interrelated, meaning the improvement of one human right can facilitate the advancement of others. Likewise, the deprivation of one right can also negatively affect other human rights. While there are sometimes complex inter-relationships between different rights, governments must ensure everyone's human rights are protected. Australia's human rights obligations require governments to respect, protect and fulfil human rights. In particular

- the obligation to respect means that governments themselves must not breach human rights
- the obligation to protect means that a country's laws and other processes must protect against breaches of human rights by others, including non-state actors
- the obligation to fulfil means that States Parties must take positive action to facilitate the enjoyment of human rights. There are some human rights that are 'absolute' and so can never be limited or

restricted. These include the right to be free from torture, freedom from slavery and servitude, and the right to recognition before the law.¹⁸

As the majority of human rights are not absolute, international law has developed principles for how a human right may be limited or restricted.

Generally speaking, a limitation on a human right can be contemplated only if this limitation arises in pursuit of a legitimate aim, such as protection of public health. The limitation must be necessary, reasonable and proportionate in pursuing that legitimate aim.¹⁹ It must involve the least restrictive limitation on another human right that is possible.

2.3 Applicable human rights

Consideration of the human rights of people born with variations in sex characteristics has typically, although not exclusively, arisen by reference to one or more of the following human rights areas:

1. bodily integrity and autonomy
2. the right of children to participate in decisions that affect them
3. the right to be free from torture and cruel, inhuman or degrading treatment
4. the right to health.

Other human rights can also be engaged in this area, including:

- a. non-discrimination and equality before the law²⁰
- b. the right to be free from violence²¹
- c. the right to privacy²²
- d. the right to found a family²³
- e. the obligation on States to eliminate harmful social or cultural practices that perpetuate gender stereotypes.²⁴

The Office of the High Commissioner for Human Rights has also summarised States' key human rights obligations in this area as including the need to prohibit the 'performance of surgical or other medical treatment on intersex children unless such procedures constitute an absolute medical necessity'.²⁵

(a) Bodily integrity and autonomy

Everyone, including adults and children, has the right to autonomy and self-determination over their own body. The only person with the right to make a decision about an individual's body is the individual themselves – no-one else. This is the principle of bodily integrity, which upholds everyone's right to be free from acts against their body which they did not consent to.²⁶

Bodily integrity is explicitly identified as a right in the *Convention on the Rights of Persons with Disabilities* (CRPD). Article 17 provides that every person with disabilities has a right to respect for their physical and mental integrity on an equal basis with others.²⁷

While the *International Covenant on Civil and Political Rights* (ICCPR) does not include an express right to physical or bodily integrity, the UN Human Rights Committee has affirmed that the rights to privacy (Art 17) and security of the person (Art 9) in the ICCPR include bodily integrity and autonomy.²⁸

The Committee on the Rights of the Child under the *Convention on the Rights of the Child*, the Committee on Economic, Social and Cultural Rights under the *International Covenant on Economic, Social and Cultural Rights*, the Committee on the Elimination of Discrimination Against Women under the *Convention on the Elimination of All Forms of Discrimination Against Women*, and the Committee Against Torture under the *Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment* (CAT), have also identified the right to bodily integrity and autonomy as a component of various rights covered under these treaties.

These United Nations treaty bodies have recommended that States implement measures to guarantee the bodily integrity and autonomy of people with intersex variations, with the common theme of avoiding unnecessary interventions.²⁹



UN Treaty Body recommendations to Australia on medical interventions on people born with variations in sex characteristics

UN Committee on the Rights of Persons with Disabilities (2019)

In relation to Australia meeting its obligations in respect of article 17, the UN Committee on the Rights of Persons with Disabilities in September 2019 stated that Australia should

adopt clear legislative provisions that explicitly prohibit the performance of unnecessary, invasive and irreversible medical interventions including surgical, hormonal or other medical procedures on intersex children before they reach the legal age of consent; also provide adequate counselling and support for the families of intersex children and redress to intersex persons having undergone such medical procedures.³⁰

UN Committee on the Rights of the Child (2019)

In September 2019, in its concluding observations on Australia, the Committee on the Rights of the Child stated that Australia should

enact legislation explicitly prohibiting coerced sterilisation or unnecessary medical or surgical treatment, guaranteeing bodily integrity and autonomy to intersex children as well as adequate support and counselling to families of intersex children.³¹

UN Committee on the Elimination of Discrimination Against Women (2018)

The Committee expressed its concern at

the conduct of medically unnecessary procedures on intersex infants and children before they reach an age when they are able to provide their free, prior and informed consent, as well as inadequate support and counselling for families of intersex children and inadequate remedies for victims.³²

It recommended that Australia

adopt clear legislative provisions that explicitly prohibit the performance of unnecessary surgical or other medical procedures on intersex children before they reach the legal age of consent, implement the recommendations made by the Senate in 2013 on the basis of its inquiry into the involuntary or coerced sterilization of intersex persons, provide adequate counselling and support for the families of intersex children and provide redress to intersex persons having undergone such medical procedures.³³

UN Human Rights Committee (2017)

In its review of Australia in 2017, the Committee stated:

The Committee is concerned that infants and children born with intersex variations are sometimes subject to irreversible and invasive medical interventions for purposes of gender assignment, which are often based on stereotyped gender roles and are performed before they are able to provide fully informed and free consent (arts. 3, 7, 9, 17, 24 and 26). ... [Australia] should give due consideration to the recommendations made by the Senate Standing Committee on Community Affairs in its 2013 inquiry report on involuntary or coerced sterilisation of intersex people, and move to end irreversible medical treatment, especially surgery, of intersex infants and children, who are not yet able to provide fully informed and free consent, unless such procedures constitute an absolute medical necessity.³⁴

UN Committee on Economic, Social and Cultural Rights (2017)

This Committee has similarly expressed concern 'that children born with intersex variations are subject to early surgeries and medical interventions before they are able to provide full and informed consent (art. 12).³⁵

(b) Children’s rights, including to participate in decisions that affect them

It is common for an intervention on a person born with a variation in sex characteristics to be proposed during infancy or early childhood. A child cannot provide personal consent for a proposed medical intervention, unless they are deemed ‘Gillick competent’. *Gillick* competence is discussed in Chapter 4 – Consent and decision making.

Nevertheless, the *Convention on the Rights of the Child* (CRC) requires consideration of the child’s views as a ‘high priority and not just one of several considerations’. Article 12(1) provides that every child who is capable of forming their own views has 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.³⁶

The Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard to physical and mental health has noted the importance of this right in health decisions about children:

The Convention on the Rights of the Child demands respect for the child’s evolving capacities and due weight to be given to the child’s views according to age and maturity. Risks and benefits of medical interventions must be adequately conveyed to the child, and, **given sufficient maturity, the child’s informed consent should be sought.**³⁷ (emphasis added)

The CRC also contains a number of additional human rights protections relevant to children born with variations in sex characteristics in medical settings. These include obligations on States Parties to

- ensure the best interests of the child is a primary consideration in all actions concerning children (art 3(1))
- respect the responsibilities, rights and duties of parents or, where applicable, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the Convention (art 5)
- ensure the survival and development of the child (art 6(2))
- respect the right of the child to preserve their identity (art 8(1))
- take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation (art 19(1))
- take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children (art 24(3))
- recognise the right of the child to the enjoyment of the highest attainable standard of health (art 24(1)).³⁸

The Committee on the Rights of the Child has repeatedly called on States Parties to better protect the human rights of children with variations in sex characteristics in the context of medical interventions. In its General Comment No. 20, on the rights of the child during adolescence, it stated:

The Committee emphasizes the rights of all adolescents to freedom of expression and respect for their physical and psychological

integrity, gender identity and emerging autonomy. It condemns the imposition of so-called ‘treatments’ to try to change sexual orientation and forced surgeries or treatments on intersex adolescents. It urges States to eliminate such practices.³⁹

UN treaty bodies have increasingly considered human rights violations in respect of people born with variations in sex characteristics in relation to medical interventions by reference to ‘harmful practices’.⁴⁰ The Committee on the Rights of the Child has previously affirmed that ‘harmful practices’ fall within the scope of ‘all forms of physical and mental violence’ in article 19 of the CRC.⁴¹

The Committee on the Rights of the Child in its General Comment No. 14, on the right of the child to have their best interests taken as a primary consideration (art 3, para 1), provides some direction on how to interpret the right in the context of the child’s right to health (article 24). The Committee explains the intersection between the best interests principle and the principle of participation, in a health context, as follows:

The child’s right to health (art 24) and his or her health condition are central in assessing the child’s best interest. However, if there is more than one possible treatment for a health condition or if the outcome of a treatment is uncertain, the advantages of all possible treatments must be weighed against all possible risks and side effects, and the views of the child must also be given due weight based on his or her age and maturity. In this respect, children should be provided with adequate and appropriate information in order to understand the situation and all the relevant aspects in relation to their interests, and be allowed,

when possible, to give their consent in an informed manner.⁴²

It also explains that what may be in the child’s best interests may not be in the interest of others, such as their legal guardian. In the event of conflict, a larger weight must be attached to what serves the child best.⁴³

The Committee also explains the need for meaningful participation of the child to realise the obligation of acting in the child’s best interests, stating:

A vital element of the process is communicating with children to facilitate meaningful child participation and identify their best interests. Such communication should include informing children about the process and possible sustainable solutions and services, as well as collecting information from children and seeking their views.⁴⁴

Commenting on article 12 of the CRC, the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health called for the deferral of all interventions which are not medical emergencies until the child is old enough to consent, stating:

Health-care providers should strive to postpone non-emergency invasive and irreversible interventions until the child is sufficiently mature to provide informed consent. Safeguards should be in place to protect children from parents withholding consent for a necessary emergency procedure. Even where laws are supportive, appropriate training of health workers is necessary to avoid continued denial of services to adolescents without parental

consent. Additional efforts must be made to ensure that information and services are child-friendly and age-accessible through appropriate opening hours, staff training and sensitization, and special considerations for information sources and presentation, such as peer health approaches.⁴⁵

A previous Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health concluded:

On the basis of international human right law and standards, States should prohibit unnecessary medical or surgical treatment during infancy or early childhood in order to guarantee the bodily integrity, autonomy and self-determination of the children concerned.⁴⁶

(c) Torture or cruel, inhuman or degrading treatment

The right to be free from torture or cruel, inhuman or degrading treatment is an absolute right under international law, recognised in the CAT and the ICCPR, among other instruments.

The UN Committee Against Torture has repeatedly expressed concerns about non-urgent medical interventions involving people born with variations in sex characteristics by reference to the obligations on States Parties to take effective legislative, administrative, judicial or other measures to prevent torture (art 2(1)) and prevent other acts of cruel, inhuman or degrading treatment (art 16).⁴⁷

In 2013, the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment called on States Parties to repeal all laws that permit intrusive and irreversible medical

interventions when enforced without the free and informed consent of the person concerned.⁴⁸ In 2016, the Special Rapporteur repeated this point and also specifically noted that children born with atypical sex characteristics are often subject to sterilisation procedures and surgeries, which are performed without their informed consent or that of their parents.⁴⁹

Further, in a joint statement in May 2015, a number of UN and international human rights experts noted that medically unnecessary medical interventions involving intersex children and young people may constitute torture or ill-treatment.⁵⁰

In its 2016 review of Australia, the Committee Against Torture called on that government to

- take the legislative, administrative and other measures necessary to guarantee the respect for the physical integrity and autonomy of intersex persons and to ensure that no one is subjected during infancy or childhood to non-urgent medical or surgical procedures intended to decide the sex of the child
- guarantee impartial counselling services for all intersex children and their parents, so as to inform them of the consequences of unnecessary and non-urgent surgery and other medical treatment to decide on the sex of the child and the possibility of postponing any decision on such treatment or surgery until the persons concerned can decide by themselves
- guarantee that full, free and informed consent is ensured in connection with medical and surgical treatments for intersex persons and that non-urgent, irreversible medical interventions are

postponed until a child is sufficiently mature to participate in decision-making and give effective consent

- undertake investigation of instances of surgical interventions or other medical procedures performed on intersex persons without effective consent and ensure that the persons concerned are adequately compensated.⁵¹

In January 2017, the Committee asked Australia to provide it with information about

- whether non-urgent and irreversible medical or surgical treatment aimed at determining the sex of a child is permitted and performed on children
- how [Australia] guarantees that the full, free and informed consent of the persons concerned is ensured
- what action has been taken to implement the recommendations of the 2013 Senate Committee Inquiry
- what criminal or civil remedies are available for people who underwent involuntary sterilisation or unnecessary and irreversible medical or surgical treatment aimed at determining their sex when they were children.⁵²

(d) The right to health

Article 12 of the *International Covenant on Economic, Social and Cultural Rights* requires States Parties to recognise the right of everyone to the highest attainable standard of physical and mental health.⁵³ Article 24 of the CRC similarly requires States Parties to recognise the right of children to the enjoyment of the highest attainable standard of physical and mental health.⁵⁴

In addition, article 25 of the CRPD requires health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent.⁵⁵ Medical interventions on people born with variations in sex characteristics may affect the realisation of the right to physical and mental health in a number of ways, including by: saving life and or enhancing health; impairing physical function now or in the future; causing pain due to invasive surgeries, sometimes requiring lifelong surgeries; causing loss of fertility; or causing serious negative psychological consequences.

Article 6 of the *Universal Declaration on Bioethics and Human Rights* states:

Any preventive, diagnostic and therapeutic medical intervention is only to be carried out with the prior, free and informed consent of the person concerned, based on adequate information. The consent should, where appropriate, be express and may be withdrawn by the person concerned at any time and for any reason without disadvantage or prejudice.⁵⁶

The UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health has observed that informed consent 'requires disclosure of the associated benefits, risks and alternatives to a medical procedure'.⁵⁷ Due to inherent inequalities between healthcare providers and individuals, there is a need for

counselling services and community involvement supporting adequate comprehension and decision-making. Health information needs to be of the highest quality, freely available on a non-discriminatory basis, accessible to the individual's particular communication needs (including special physical or cultural

circumstances), and presented in a manner culturally and otherwise acceptable to the person consenting. Communication should be cognizant of varying levels of comprehension and not be too technical, complex, hasty, or in a language, manner or context that the patient does not understand.⁵⁸

(e) The Yogyakarta Principles

The *Yogyakarta Principles*, adopted in 2007, provide the most comprehensive statement of how international human rights law applies in respect of sexual orientation, gender identity, gender expression and sex characteristics.⁵⁹ This includes consideration of the human rights of people born with variations in sex characteristics, in particular the right to bodily and mental integrity.⁶⁰

Australia introduced legislative protections for SOGII groups in 2013 with the passage of the *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013* (Cth). This Act amended the Sex Discrimination Act to include new protected attributes of sexual orientation, gender identity and 'intersex status'. With the passage of this amendment, it became unlawful to discriminate against a person on the basis of sexual orientation, gender identity and intersex status under federal law.⁶¹

While the original *Yogyakarta Principles* do not explicitly refer to people born with variations in sex characteristics, Principle 18 does state that States Parties shall, among other things

- Take all necessary legislative, administrative and other measures to ensure full protection against harmful medical practices based on sexual orientation or gender identity, including on the basis of stereotypes, whether derived from culture or otherwise, regarding conduct, physical

appearance or perceived gender norms (Principle 18(a));

- Take all necessary legislative, administrative and other measures to ensure that no child's body is irreversibly altered by medical procedures in an attempt to impose a gender identity without the full, free and informed consent of the child in accordance with the age and maturity of the child and guided by the principle that, in all actions concerning children, the best interests of the child shall be a primary consideration (Principle 18(b)).

In November 2017, the *Yogyakarta Principles plus 10* were adopted. They provide further elaboration on the rights of people born with variations in sex characteristics.⁶² Principle 32, 'The Right to Bodily and Mental Integrity', states:

Everyone has the right to bodily and mental integrity, autonomy and self-determination irrespective of sexual orientation, gender identity, gender expression or sex characteristics. Everyone has the right to be free from torture and cruel, inhuman and degrading treatment or punishment on the basis of sexual orientation, gender identity, gender expression and sex characteristics. No one shall be subjected to invasive or irreversible medical procedures that modify sex characteristics without their free, prior and informed consent, unless necessary to avoid serious, urgent and irreparable harm to the concerned person.

Specifically, it calls on States Parties to

- guarantee and protect the rights of everyone, including all children, to bodily and mental integrity, autonomy and self-determination (Principle 32(A))

- ensure that legislation protects everyone, including all children, from all forms of forced, coercive or otherwise involuntary modification of their sex characteristics (Principle 32(B))
- take measures to address stigma, discrimination and stereotypes based on sex and gender, and combat the use of such stereotypes, as well as marriage prospects and other social, religious and cultural rationales, to justify modifications to sex characteristics, including of children (Principle 32(C))
- bearing in mind the child's right to life, non-discrimination, the best interests of the child, and respect for the child's views, ensure that children are fully consulted and informed regarding any modifications to their sex characteristics necessary to avoid or remedy proven, serious physical harm, and ensure that any such modifications are consented to by the child concerned in a manner consistent with the child's evolving capacity (Principle 32(D))
- ensure that the concept of the best interest of the child is not manipulated to justify practices that conflict with the child's right to bodily integrity (Principle 32(E))
- provide adequate, independent counselling and support to victims of violations, their families and communities, to enable victims to exercise and affirm rights to bodily and mental integrity, autonomy and self-determination (Principle 32(F)).

(f) Other laws

The Commission acknowledges that there are a range of other laws that may be relevant, including

those that address sexual assault, privacy and discrimination, such as provisions relating to intersex people in the Sex Discrimination Act 1984. These are not explored in further detail, as they are beyond the scope of the terms of reference of this report.

2.4 Applying a human rights framework

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.

Recommendation 1:

Reform of 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.

- *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.

3

LIVED EXPERIENCE

Listening to the accounts of people with lived experience has been central to the Commission's assessment of the human rights implications of medical interventions on people born with variations in sex characteristics. This chapter summarises this element of the Commission's research.⁶³

While individuals' experiences varied widely, there were common themes. These included ongoing 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. A lack of access to records about past experiences and interventions has compounded the challenge of processing their past, and thus held back improvements to their health in adulthood.

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. This has provided important information about many of the matters discussed in this Report and it has helped inform the Commission's conclusions and recommendations.

3.1 Which medical interventions have occurred?

Glossary of medical terms

Clitoridectomy (or clitorectomy):

Surgery to reduce the size of the clitoris.

Clitoral recession:

Surgery to hide clitoral shaft under a fold of skin so only the glans remains visible.

Gonadectomy:

Surgery to remove the gonads.

Hypospadias:

Where the exit of the urethra is not at the tip of the penis.

Hypogonadism:

Diminished gonad activity.

Labiaplasty:

Surgery to reduce the size or changing the shape of the labia minora.

Micropenis (microphallus):

Smaller than typical male genitalia.

Vaginoplasty:

Surgery to create a vagina.

Vulvoplasty:

Surgery to modify external female genitalia.

The Commission heard from people who had experienced a range of medical interventions without their consent. These include: surgical interventions intended to 'normalise' the appearance of genitalia, such as surgeries to reduce the size of the clitoris (known as clitoridectomy or clitorectomy); other surgeries to modify female genitalia such as reducing the size or modifying the shape of the labia minora (labiaplasty); surgery on external female genitals, generally reducing the size or addressing the asymmetry of the labia minora (vulvoplasty),⁶⁴ and surgery on an infant born with smaller than usual male genitalia (micropenis) to create the appearance of a female child by the construction of a vagina (vaginoplasty). The Commission was also told that people have been put on hormone treatment, to facilitate typical male or female sex development.⁶⁵

Peer support and advocacy groups who collated lived experiences, reported that medical photography has also occurred without informed consent.⁶⁶

Amnesty International reported that surgical interventions remain part of current medical practice in Australia. It has documented the following interventions:

- operations to hide an enlarged clitoris, which carries a risk of nerve damage, scarring and pain
- vaginal surgery, or vaginoplasty, which may involve multiple surgeries over time on young children to create or enlarge a vaginal opening
- gonadectomies – the removal of the gonads (including ovarian or testicular tissue) – which are irreversible and result in a need for lifelong hormone treatment
- hypospadias operations – surgeries to reposition the urethra to the tip of the

penis, which is done to create a penis that is considered functionally and cosmetically typical

- hormone treatment, which includes hormone replacement therapy (HRT), induction of puberty when hypogonadism (diminished gonad activity) is present and, in certain cases, suppression of puberty.⁶⁷

Clinicians observed that evolving knowledge has led to treatments that are less invasive than in previous times, and clinicians being less inclined to view surgical intervention as the presumed course of action.⁶⁸ Some clinicians compared this trend to a contemporary trend away from routine performance of male infant circumcision.⁶⁹

Clinicians stated that the following interventions continue to occur: hypospadias surgery;⁷⁰ gonadectomies;⁷¹ clitoral recession;⁷² and hormone treatment. Clinicians described the circumstances in which hormone treatment occurs. This includes HRT, induction of puberty when hypogonadism (diminished gonad activity) is present and, in certain cases, suppression of puberty. Individuals for whom hormonal treatment is prescribed include individuals born with variations in which sufficient hormones are not produced, or are not sufficiently responded to, in a way that supports 'typical' development of sex characteristics.⁷³ Clinicians advised that the possibility of gender fluidity or diversity, and the development of gender dysphoria, are taken into account before hormone therapy is commenced.⁷⁴

More specifically, clinicians told the Commission that treatments provided to individuals with a diagnosed X and Y chromosome variation can include the administration of early testosterone boosters in infants. Clinicians stated that hormones may be administered when pubertal age approaches, and to stimulate onset of puberty and hormonal treatment in adults.⁷⁵

The Australasian Paediatric Endocrine Group (APEG) stated that the harmfulness of practices, including unauthorised photography and examination by multiple people, is now well known and these practices are no longer considered acceptable. However, APEG noted that photography can have value in minimising the need for physical examination by multiple clinicians, and promoting useful, informed discussion of treatment plans.⁷⁶ The 2006 Consensus Statement acknowledges that photography can be 'deeply shaming', but also notes the value of photographs in record keeping, and recommends photography under anaesthetic for certain groups of patients, including adolescents.⁷⁷

3.2 Impacts of medical interventions

Seventeen people who had been subject to medical interventions as infants, in adolescence and adulthood, shared their experiences. Additionally, the Commission received four submissions from peer-support groups which collated the experience of their members. Some of these interventions occurred many years ago and some occurred comparatively recently, though not all participants disclosed the exact timing of their experiences.

These people described their experiences resulting from societal attitudes, the medical interventions performed on them, and their interactions with medical professionals. These experiences have had profound effects.

(a) Physical consequences

Those who had experienced medical interventions reported a variety of immediate and long-term consequences for their physical health.

Some reported that early treatment without personal informed consent necessitated future treatment and procedures throughout their lives

(eg, repeated surgical interventions).⁷⁸ Others reported physical scarring from interventions.⁷⁹ One individual was administered vaginal dilation from the age of 13 years, and described the experience as a 'painful, bloody and completely unsupervised practice aimed at allowing me to successfully accommodate a future fictitious husband and hence make me a more normal female'.⁸⁰

Other physical consequences related to loss of fertility from interventions,⁸¹ and urinary tract issues, including incontinence, arising from interventions.⁸² Some people reported loss or diminution of sexual function, sensitivity and/or capacity to experience sexual pleasure.⁸³

One person receiving hormone treatment reported big swings in mood and behaviour affecting their day-to-day life. They noted the apparent lack of understanding or empathy of these impacts from their prescribing practitioners.⁸⁴ In describing the severe effects on their body, the individual stated:

The HRT tended to make me extremely aggro, and to the point of where I got expelled from my private school because I turned over a desk during an exam. The HRT actually caused cervical damage to the point that I needed cervical surgery in 2015, and it almost killed me. It [HRT] was definitely not suited to my body, to the point where I had all sorts of things, liked severe depression, double cycles, I went through hell in a handbasket and no-one could explain to me what was going on. And I could not see through the black cloud enough to ask for help ...

I'm now a lot calmer ... I can self-calm now, which couldn't do before when I was on hormones.⁸⁵

(b) Stigma and isolation

Although innate variations in sex characteristics

are not uncommon in the general population, many individuals reported widespread stigma, discrimination, ill-treatment and misunderstanding.

This stigma resulted in shame and silence for these individuals and their families, leading to withdrawal from public facets of life and ongoing impacts on mental and physical health.

Many individuals reported that although the source of such stigma is public misunderstanding of variations in sex characteristics, it is most clearly manifested in a medical context, where decisions permanently affecting their bodies are made.

Some people told the Commission that treating medical teams had given families advice to adopt behaviours that reinforced isolation, stigma and shame—for example, advising them not to tell anyone about their variation.⁸⁶ One person with a variation in sex characteristics reported their experience of isolation:

I just thought ... that I was the only person who it had happened to ... that I really shouldn't talk about it to too many people, and then me not knowing that my parents had been told not to talk about it even to me, I felt incredibly isolated.⁸⁷

Others stated that their families received advice from treating teams that each individual was so unique that there were no other or alternative sources of help (eg peer groups), and that reinforced a sense of shame and sometimes self-imposed isolation.⁸⁸

One person reflected on their feelings of shame:

My parents weren't given any advice on how to talk about it or what would be healthy to talk about. I was basically told that it was really shameful and I should never talk about it and that I was fixed basically like so I didn't have to talk about.⁸⁹



Another person reported their experience of secrecy:

I originally was with a gynaecologist who gave me the diagnosis and she told me that it was very unlikely that I'd meet someone else like me and encouraged me to keep things relatively quiet and not discuss my diagnosis with anyone. There was no counselling or support services offered.⁹⁰

Another person, speaking about the fact that doctors had not referred them to any support networks, said that 'I got told there was no support network, I got told that there were no other people nearby'.⁹¹

Similarly, one person, whose variation is anonymised here, described their experience receiving a diagnosis:

She [a clinician] gave me everything in 5 minutes, and also threw in: 'of course because you don't have (. . .) chromosomes you will not be allowed to compete in the Olympic games', and that was actually information I received in my medical notes last year.⁹²

This person stated that within this five-minute timeframe, they were given information about the state of development of their gonads and the associated risk of cancer, and told that they were atypical chromosomally. The individual said:

[My] parents were told by my GP without my knowledge that they should never talk to me about having (. . .) they told their friends they risked me being ostracised by the local community.⁹³

One person reported how their parents were encouraged to keep secret from them information about their bodies and treatments that had occurred before they were old enough to understand and participate.⁹⁴ One peer support organisation cited the experience of members,

stating that 'many older people are unaware of their variation as families hid this information for fear of shame and stigma'.⁹⁵

According to this peer support organisation, this lack of awareness, knowledge and understanding deprives people of affirming language to describe themselves and their bodies.⁹⁶ This organisation said that it also makes it harder for people to ask for, or even be aware of, available support and services.⁹⁷

The Commission was told about broader, community-wide lack of awareness, knowledge and understanding of variations in sex characteristics.⁹⁸ A peak body representing mental health professionals cited research that indicated that this makes it harder for people to identify as having variations in sex characteristics, should they wish to do so.⁹⁹

The Commissioner for Children and Young People, Western Australia, observed that the broader lack of visibility and knowledge about variations in sex characteristics can have wider practical effects, in deterring communities from acknowledging the need for specific services and responding to people with variations in informed and respectful ways.¹⁰⁰

(c) Invasive practices

An aspect of medical treatment that has caused particular distress for some people born with variations in sex characteristics, has been the significant physical invasions of privacy experienced during treatment and examinations, and the lack of sensitivity shown to them at those times.

Some of the interventions that have occurred have themselves been extremely invasive and had a significant effect on those who experienced them. An example cited was vaginal dilation.¹⁰¹

A number of people told the Commission that they had experienced repeated invasive examinations,

sometimes for student training and sometimes in front of several people (concurrently or sequentially), displaying a lack of sensitivity.¹⁰² For instance, one individual described how 'lots of men would look between my legs, put their fingers in my vagina, and talk about how abnormal I was'.¹⁰³ Another, in describing their experience of being examined, stated:

All of a sudden the room is full of doctors and trainee doctors looking at me down there, forgetting about me as a person, just looking at this phenomenon, and they're talking around me and as an adult, even now, I find that incredibly offensive. And they're the times when I feel as a child I felt like, I felt like I was sexually raped because I was just made of meat—and examinations that happened in front of numerous doctors—I knew what was going to happen but it didn't stop the internal emotional pain. And I had to come to grips with that much later in my life.¹⁰⁴

The consequences of these repeated invasive experiences can be profound. One US-based advocacy group has stated that such experiences can and have led to 'levels of Post Traumatic Stress Disorder equivalent to the experience of childhood sexual abuse'.¹⁰⁵

(d) Autonomy, identity, personal history

People with lived experience of variations in sex characteristics reported a range of consequences of medical treatment without personal consent that related to their formation of identity and sense of self. They reported long-lasting, even lifelong, consequences.

Some described how they can never know the truth of what happened to them as infants or children and that this is experienced by them as a fundamental deprivation.¹⁰⁶ This was particularly the case for older people who have been unable

to access reliable documentation or other information.

One person said that their realisation in adulthood that their 'body was at the whim of others' negatively affected their sense of self.¹⁰⁷

Another commented:

Many older intersex people have little or no records of surgery as a child and live a life of limbo in relation to their bodies adding to mental health issues and the inability to ever gain bodily autonomy and of course never bodily integrity.¹⁰⁸

Contributors born with variations in sex characteristics expressed distress at their lack of access to records about interventions which had been undertaken and the decision-making processes that had accompanied them.

As discussed in Chapter 9 – Data and Health Records Access, practices concerning the retention and destruction of medical records were seen as disempowering people from taking full agency in management of their health and well-being and detracting from people's sense of identity and safety.¹⁰⁹

(e) Relationships

People with lived experience of variations in sex characteristics reported negative impacts on personal relationships, flowing from medical interventions. They described adverse effects, regardless of whether early intervention was undertaken or not.¹¹⁰ These effects included estrangement and stresses in relationships with parents and other family members, arising sometimes from their parents having authorised treatment that they would not themselves have chosen to consent to. One person with lived experience said that the adult realisation of their lack of autonomy 'impacts on my ability to form relationships and gel with society'.¹¹¹

A community health organisation asserted that experiences of medically unnecessary interventions had led to difficulties for individuals in negotiating intimate relationships.¹¹²

(f) Mental health

People born with variations in sex characteristics reported a range of negative physical and mental outcomes.

A number of stakeholders, including specialist psychological organisations, emphasised that people experienced poor mental health arising not from variations in sex characteristics of themselves, but from how others characterise their variation as problematic.¹¹³ This was reported regardless of whether diagnosis of variations occurred at an early age and regardless of whether there was early intervention. Poor mental health was reported as being compounded where intervention was carried out without personal consent.¹¹⁴

One specialist psychological organisation cited research that indicated that people born with variations in sex characteristics reported attempts at self-harm,¹¹⁵ suicidality, including suicidal ideation, linked to negative responses from those around them or their sense of isolation, and being 'othered'.¹¹⁶ An individual with lived experience stated that people with variations in sex characteristics are reluctant to seek medical and other kinds of help, due to 'being burdened by shame and stigma'.¹¹⁷

People born with variations in sex characteristics also described the stress and lifelong burden of educating a series of health care providers.¹¹⁸ Where healthcare professionals did seek to inform themselves, that was welcomed and appreciated by individuals with variations.¹¹⁹

Some people described the distress associated with gender dysphoria, where sex of rearing did not align with gender identity as it developed.¹²⁰ Others identified experiencing PTSD consequent

to medical interventions, based on a sense that their 'body was at the whim of others'.¹²¹

(g) Other experiences

People born with variations in sex characteristics reported that the medical interventions had affected their lives in other ways.

Some described negative effects on their educational and economic prospects. These effects included poor educational outcomes and related economic hardship, due to stress consequent to medical interventions without personal consent.¹²²

Some people also noted that harms they have experienced have been compounded by other characteristics such as race, age, disability, sexual orientation and gender identity.¹²³

3.3 Experience of parents and legal guardians

For most parents, carers and family, the hospital room or the doctor's office is the first time they have ever encountered the phenomenon of people born with variations in sex characteristics.

Their experiences reflect a significant information asymmetry between individuals born with variations in sex characteristics, their parents, carers and families on the one hand, and the health professionals charged with their care and wellbeing on the other.

Many parents noted feeling 'overloaded' following the birth of their child due to a combination of new and complex information and advice provided and the emotional impact and general pressures. Nevertheless, some parents also reported overall satisfaction with the information provided by healthcare professionals and the advice for treatment and care. Parents' experiences of the provision of information and medical advice are discussed in more detail in Chapter 4 – Consent and decision making.



Some parents noted that there are geographic barriers to obtaining medical care for families based in regional and rural Australia. For example, it was reported that healthcare professionals in rural and remote areas often lacked experience dealing with people born with variations in sex characteristics.¹²⁴ Geographic barriers to timely and appropriate supports also influenced parental decisions to proceed with early intervention, rather than deferring treatment.¹²⁵ These concerns are also discussed in Chapter 9 – Support, health records and data collection.

3.4 Addressing stigma

Recommendation 2:

The development of 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.

People born with variations in sex characteristics, and their parents and carers, reported a diverse range of experiences. However, it is clear that many people who discussed their experiences with the Commission have experienced significant physical and psychological harm as a result of social attitudes and the medical interventions performed on them.

In particular, many people with variations in sex characteristics reported experiences of stigma and isolation, invasive practices, and the lifelong repercussions of medical interventions experienced in childhood. These have had profound effects on them.

Stigma has resulted in part from prevailing social and cultural attitudes, which in part flow from ignorance and prejudice. This stigma has driven further harms, including motivating doctors to recommend medical interventions, and parents to consent to them. In turn, advice from some medical practitioners has reinforced and perpetuated stigma about variations in sex characteristics. Interventions have been experienced as reinforcing a cycle of stigma,

where variations in sex characteristics are treated as a 'problem' that needs to be 'fixed'. As the 2013 Senate Inquiry report observed:

Normalising appearance goes hand in hand with the stigmatisation of difference. Care needs to be exercised that medical treatment of intersex is not premised on, and contributing to, the stigma and perceived undesirability of people appearing different from one another.¹²⁶

The Commission notes that experiences of stigma may lead to unlawful discrimination under the Sex Discrimination Act.¹²⁷ Many people with variations in sex characteristics have reported isolation resulting from an environment in which their bodies are treated as 'abnormal', shameful, and to be hidden, and from difficulties in identifying sources of peer support. They have also reported significant invasions of privacy in medical examinations, which have in some cases been conducted with insufficient regard for their dignity.

The consequences of medical interventions undertaken in childhood have been significant. Some people have reported ongoing physical consequences, requiring a lifetime of medical treatment. Others have described how the fact that interventions were performed on them in childhood, along with poor record keeping, has made it impossible to learn exactly what was done to them, affecting their sense of identity.

These observations reflect the experiences of those who shared their experiences with the Commission. The Commission does not claim that they are a representative account of the experiences of all people born with variations in sex characteristics. The Commission, nevertheless, considers that an understanding of these experiences helps inform a view of the range and nature of impacts of medical interventions. These accounts also elucidate some of the practices that are concerning for human rights.

Particularly, they indicate that there have been interventions that were not medically necessary and where minimum standards of informed consent were not met.

Some medical practitioners stated during consultations that medical practices have changed over the years and claimed that, while past practices may not have been ideal, doctors are now aware of the need for sensitivity in providing advice and conducting examinations. They argued that experiences of harms resulting from past practice consequently have little relevance to current practice. In addition, some practitioners argued that the number of people born with variations who have reported negative experiences to the Commission is too small to allow any conclusions to be drawn.

The Commission notes, however, that several of the experiences reported to the Commission relate to interventions performed relatively recently.

As discussed in later chapters, at least some practitioners have indicated that they perform early medical interventions on children to avoid cosmetic 'abnormality', so that children will 'fit in'. The case of *Re Carla* before the Family Court in 2016 referred to surgery that had occurred prior to the hearing to 'enhance the appearance' of Carla's genitalia.

Moreover, international and domestic intersex clinical guidance explicitly endorses rationales for medical intervention based on appearance and parental or cultural concerns.

The Commission considers that the 17 first-person accounts, plus four submissions from support groups which collated the experience of their members, provides a clear indication of shortcomings experienced in medical care. The experiences recorded in this chapter speak to the significant consequences that have flowed from children receiving medical interventions, some

of which were not medically necessary, at an age where they were unable to provide personal consent. The impacts of receiving poor quality of care and of being inadequately supported through these procedures are profound, regardless of how widespread such practices are.

The material discussed in this chapter informs the Commission's conclusions on a range of issues. In particular, some people's lived experience indicates that medical practice is not uniformly 'best practice' by

- failing to address real or perceived stigma through means other than medical interventions
- failing to provide parents with information so that they understand that concerns they have regarding stigma may be dealt with by means other than medical interventions
- approaching the provision of medical advice and conduct of examinations in appropriately sensitive or sympathetic ways

- referring children and their families to sources of peer support.

Even if poor practice is experienced by a minority, the profound consequences requires a response to ensure a good standard of practice. This suggests that standardised guidance for medical practitioners in relation to these matters would be useful.

Peer support was widely recognised to be vital for people born with variations in sex characteristics and their families as an essential means of support and assistance, but is not always straightforward to access. Better support for these groups and better referral pathways are needed.

Some of these matters are returned to in later chapters of this report.¹²⁸

More broadly, social attitudes to people born with variations in sex characteristics are ill-informed. This should be addressed by improved public education about variation in sex characteristics.

4

CONSENT AND DECISION MAKING

As a general principle, an individual must give informed consent before medical treatment can be carried out lawfully on them. This general legal rule reflects an individual's autonomy over their body and the human rights principle, the Bodily integrity principle, that all people have the right to autonomy and bodily integrity.

This chapter examines the role of consent in decision making regarding medical treatment or 'medical intervention' affecting people born with variations in sex characteristics. It focuses especially on children and young people—ie, anyone under the age of 18 years. This is because young children are not able to give consent, because many of the interventions occur in infancy and early childhood, and because adults do not always respect the evolving capacity of the child.

The chapter begins by explaining the current legal framework regarding consent. This includes how people receiving medical treatment may provide personal consent; and how, in certain circumstances, consent may be provided on an individual's behalf by parents, legal guardians, or other representatives. The chapter also considers the role of courts, and the Family Court of Australia in particular, in authorising some categories of medical intervention where the law does not allow parents, legal guardians or other representatives to provide consent. The term 'legal guardians' and 'parents' are used interchangeably in this report.

Ensuring that a medical intervention is performed only where informed consent has been given is fundamental to the recognition of bodily autonomy and integrity and to achieving the

highest attainable standard of health under international human rights law. The requirement of informed consent should be the default legal rule—and only dispensed with in exceptional circumstances where there is a strong human rights justification.

Under international human rights law, a medical intervention in respect of a child born with a variation in sex characteristics may take place without the child's personal consent only where this is medically necessary – as reflected in the Medical necessity principle. Stakeholders have reported to the Commission that this principle has not always been followed in Australia – both historically and more recently. Informed consent requires effective communication between medical practitioners and recipients of care—something recognised in both domestic and international law. The specific requirements to achieve consent can depend on the particular circumstances. The requirements can vary between individuals, and they can change over time for each person, especially in the case of children, whose capacity to participate in decisions about their own bodies evolves and generally increases as they grow older – as reflected in the Children's agency principle.

This chapter summarises some practical problems, raised during the Commission's consultation process, regarding the issue of consent in respect of medical interventions affecting people, especially children, born with variations in sex characteristics.

To address these problems, the Commission recommends the development of new human rights-compliant guidance setting out what is

required to obtain informed consent before performing a medical intervention on the sex characteristics of a person born with variation. This guidance should ensure that

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

4.1 Consent and decision making – under Australian law

(a) The current legal framework

It is generally unlawful to interfere with the body of another person without their personal consent. The term ‘personal consent’ means the consent of the individual concerned. It is distinguished from the situation where another individual, such as a parent or guardian, consents *on behalf of* the individual. The legal framework governing the provision of consent on someone’s else behalf – for example, by a parent for a child – is addressed at section 4.1(b) of this chapter.

Under Australian law, people may seek a legal remedy in tort in respect of contact to which they have not given their consent (trespass to the person), even if the contact was well-intentioned and its outcome beneficial. If a medical practitioner carries out treatment on a person without a valid consent, they may be liable in tort, and potentially could also be exposed to criminal actions for assault or battery.¹²⁹

At international law, this principle is reflected in the right to bodily integrity – as expressed in the Bodily integrity principle, set out in Chapter 2.¹³⁰

As part of their duty of care, medical practitioners must provide such information as is necessary for

the patient to decide whether to give consent to treatment, including information on all material risks. Failure of the medical practitioner to provide this information may lead to liability for an adverse outcome, even if the treatment itself was not negligent.¹³¹

Non-consensual physical contact can also be a criminal offence. In the context of medical or clinical interventions, this principle applies not only to surgery but also to other kinds of intervention, such as radiation and the administration of pharmaceuticals. There are a number of exceptions to this rule. Some of the more important exceptions, for present purposes, are set out below.

(i) *Where there is express legal authorisation*

A medical intervention without personal consent will not be unlawful under Australian law if legal authority enables the intervention (for example, an intervention giving effect to a mental health or public health order, or under child protection legislation).¹³²

(ii) *Emergency*

Under Australian law, medical intervention can be lawfully undertaken in the absence of personal consent in an emergency.¹³³ This exception applies if all of the following conditions are met:

- a person lacks decision-making capacity and is unlikely to attain it while the emergency persists (for example, the person is unconscious)
- without immediate intervention, loss of life or function is imminent
- there is no appointed or statutory¹³⁴ substitute decision maker reasonably available to make a decision on the patient’s behalf, and
- there is no reasonably accessible information about the affected person’s wishes.¹³⁵



In such cases, the intervention is legally permissible under the doctrine of necessity.

(iii) *Impaired cognition*

In some cases, a person with impaired decision-making ability may not be able to provide personal consent to all medical treatment under Australian law. In those cases, decision-making authority may rest with someone previously appointed by the person (when they had legal capacity) such as their enduring guardian,¹³⁶ or with a Tribunal or someone appointed as a guardian by a Tribunal for a person who has impaired decision-making ability.¹³⁷ A person who has legal capacity may also make an advance care directive which provides directions to medical practitioners about the treatments that a person wants to have or to refuse in certain circumstances if they lose legal capacity in the future.¹³⁸

Currently, in exercising their powers, these authorised decision makers are required to adopt one of two tests (or a combination of both tests in some jurisdictions) in reaching their decision on behalf of the person with impaired decision-making ability. One is the 'best interests

test', which requires a balancing of the benefit to the patient against the risks of the proposed treatment. The other test is the 'substituted judgment test', which requires a decision that is consistent with what the person would have decided if they had the capacity to do so.¹³⁹

There is some legal authority that the extent of a person's decision-making ability may vary by reference to the particular type of medical procedure in question. For example, an individual might be able to give legally-effective consent to a procedure to set a broken arm, or to donate regenerative tissue for the benefit of a third party, but the same individual might not have been able to consent to an invasive and irreversible medical intervention that would result in sterilisation.¹⁴⁰

This is consistent with more contemporary understandings, influenced by international human rights law,¹⁴¹ that a person with apparently impaired cognition should not be assumed to lack decision-making ability in respect of all potential medical interventions at all times, and that such ability as they have should be supported and maximised.¹⁴²

(b) Children

Special rules apply to medical treatment given to children. In most states and territories, the age of consent to medical treatment is 18 years and the common law principles in *Gillick* and *Marion's Case* would apply. In South Australia, legislation provides that children who are at least 16 years of age may consent to treatment on their own behalf.¹⁴³ Where medical treatment is contemplated for a child, and a statutory rule of that nature does not apply, the general rule at common law is that, where a child is mature enough to understand fully the nature and consequences of proposed treatment, they may make their own decisions about treatment.

Where the child is not mature enough to understand fully the nature and consequences of proposed treatment, in most cases their legal guardian or guardians can provide consent on their behalf.¹⁴⁴ In cases where legal guardians provide consent on behalf of a child, they are obliged to undertake this role only in the best interests of the child.¹⁴⁵

There are some limits to the rights of legal guardians in this regard. Since the leading UK case of *Gillick v West Norfolk AHA*,¹⁴⁶ Australian courts have followed those of the UK in recognising that children's capacity evolves with age, and that when they reach a level of maturity where they are capable of providing consent themselves, the rights of their legal guardians to consent for them ends. The test of 'Gillick competency' is as follows:

the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed.¹⁴⁷

In *Marion's case*, the majority of the High Court cited *Gillick* in deciding:

Parental rights ... do not wholly disappear until the age of majority ... But the common law has never treated such rights as sovereign or beyond review and control. Nor has our law ever treated the child as other than a person with capacities and rights recognised by law. The principle of the law ... is that parental rights are derived from parental duty and exist only so long as they are needed for the protection of the person and the property of the child.¹⁴⁸

Even when children are not legally competent to make medical decisions for themselves, they have a right to be involved in medical decision making. In *Re W (a minor) (medical treatment)*,¹⁴⁹ Lord Donaldson MR held that the lack of *Gillick* competence, while reducing the weight that ought to be given to a young person's views and wishes, did not mean that those views and wishes should be disregarded. The Full Court of the UK Family Court endorsed this view in 1995.¹⁵⁰

The *Family Law Act 1975* (Cth) provides a range of ways in which children's voices can be heard in matters affecting them. The Family Court hears and relies on evidence from children, whether directly or through an intermediary such as a family report writer or independent children's lawyer (ICL), appointed under the Act.¹⁵¹

These common law and statutory principles may also be seen to reflect Principle 2, that 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. 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. Circumstances in which they are unable to do so are discussed in Chapter 5.

(c) Special medical procedures

There are decisions about medical interventions for children which have been held to fall outside the scope of parental responsibility.¹⁵² Such interventions are known as ‘special medical procedures’.¹⁵³

It is not lawful for a special medical procedure to be performed on a child without express authorisation from a court of competent jurisdiction. The role of common law courts in authorising this type of procedure is part of what is known as the *parens patriae* jurisdiction.¹⁵⁴

The leading Australian case on special medical procedures is *Marion’s case*. In that case, the High Court considered whether the parents as legal guardians of a child with an intellectual disability were legally empowered to consent to her medical sterilisation. The Court held that, even where the parents had consented to this intervention, that parental consent was not enough on its own to authorise the intervention. In addition, it was necessary first to obtain authorisation from a competent court. The court identified the factors which led it to that conclusion:

- the proposed treatment involved a major intervention (in that case, surgical) that was invasive and irreversible¹⁵⁵
- there was a ‘significant risk of making the wrong decision, either as to a child’s present or future capacity to consent or about what are the best interests of a child who cannot consent’¹⁵⁶
- the ‘consequences of a wrong decision [were] particularly grave’.¹⁵⁷

The Court identified a number of factors which led to the significant risk of making the wrong decision in that case. The first of these was that the medical profession cannot be assumed always to behave properly. A majority of the Court stated:

The medical profession very often plays a central role in the decision to sterilise as well as in the procedure itself. Indeed the question has been ‘medicalised’ to a great degree. Two concerns emerge from this. It is hard to share the view of Cook J in *Re a Teenager* that absolute faith in the integrity of all medical practitioners is warranted. We agree with Nicholson CJ in *Re Jane* that, as with all professions, there are those who act with impropriety as well as those who act bona fide but within a limited frame of reference. And the situation with which they are concerned is one in which incorrect assessments may be made.¹⁵⁸

The second factor they identified was that doctors had at the time of the decision come to assume a very significant role in decision making about sterilisations, despite the fact that the factors relevant to that decision were not purely medical. The same joint majority judgment said:

The second concern is that the decision to sterilise, at least where it is to be carried out for contraceptive purposes, and especially now when technology and expertise make the procedure relatively safe, is not merely a medical issue. This is also reflected in the concern raised in several of the cases reviewed, that the consequences of sterilisation are not merely biological but also social and psychological. The requirement of a court authorisation ensures a hearing from those experienced in different ways in the care of those with intellectual disability and from those with experience of the long term social and psychological effects of sterilisation.¹⁵⁹

Further, the Court observed that the decision could lead to conflicts between the best interests of the child, and the interests of parents or other family members. The majority held:

Subject to the overriding criterion of the child's welfare, the interests of other family members, particularly primary care-givers, are relevant to a court's decision whether to authorise sterilisation. However, court involvement ensures, in the case of conflict, that the child's interests prevail.¹⁶⁰

The Court identified the following factors that meant that the consequences of making the wrong decision were particularly grave:

The gravity of the consequences of wrongly authorizing a sterilization flows both from the resulting inability to reproduce and from the fact of being acted upon contrary to one's wishes or best interests. The fact of violation is likely to have social and psychological implications concerning the person's sense of identity, social place and self-esteem. As the Court said in *In re Grady*, a decision to sterilize involves serious questions of a person's 'social and biological identity' ...

The far-reaching consequences of a general rule of law allowing guardians to consent to all kinds of medical treatment, as well as the consequences of a wrong decision in any particular case, are also relevant. As Nicholson CJ pointed out in *Re Jane ...* such a rule may be used to justify other procedures such as a clitoridectomy or the removal of a healthy organ for transplant to another child.¹⁶¹

While the facts in *Marion's case* related to a procedure intended to cause the sterilisation of a child, the principles in the case have more general application. For example, these principles have been applied by the Family Court in decisions relating to the authorisation of medical interventions in the context of children with gender dysphoria.¹⁶²

Following the High Court's decision in *Marion's case*,¹⁶³ s 67ZC was inserted into the *Family Law Act 1975* (Cth), conferring on the Family Court

a welfare power.¹⁶⁴ That provision gives the Family Court jurisdiction to authorise special medical procedures. Applications under s 67ZC are regulated by the *Family Law Rules 2004* (Cth), which require applicants to file evidence from expert witnesses about the following matters:

- (a) the exact nature and purpose of the proposed medical procedure;
- (b) the particular condition of the child for which the procedure is required;
- (c) the likely long-term physical, social and psychological effects on the child:
 - (i) if the procedure is carried out; and
 - (ii) if the procedure is not carried out;
- (d) the nature and degree of any risk to the child from the procedure;
- (e) if alternative and less invasive treatment is available--the reason the procedure is recommended instead of the alternative treatments;
- (f) that the procedure is necessary for the welfare of the child;
- (g) if the child is capable of making an informed decision about the procedure whether the child agrees to the procedure;
- (h) if the child is incapable of making an informed decision about the procedure--that the child:
 - (i) is currently incapable of making an informed decision; and
 - (ii) is unlikely to develop sufficiently to be able to make an informed decision within the time in which the procedure should be carried out, or within the foreseeable future;

- (i) whether the child’s parents or carer agree to the procedure.¹⁶⁵

The Family Court has heard a small number of applications under s 67ZC for the authorisation of medical procedures on people under 18 years of age born with variations in sex characteristics.

Most of these applications have involved proposed gonadectomies, resulting in sterilisation. In some cases, the Court has held that the proposed procedures were special medical procedures requiring judicial authorisation. In other cases, the court has taken the opposite view. Some of these cases are discussed in more detail in Chapter 7 – Oversight of medical interventions.

4.2 Informed consent under international human rights law

The UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health has observed that informed consent ‘requires disclosure of the associated benefits, risks and alternatives to a medical procedure’.¹⁶⁶

The Special Rapporteur went on to state that, due to inherent inequalities between healthcare providers and individuals, there is a need for

counselling services and community involvement supporting adequate comprehension and decision-making. Health information needs to be of the highest quality, freely available on a non-discriminatory basis, accessible to the individual’s particular communication needs (including special physical or cultural circumstances), and presented in a manner culturally and otherwise acceptable to the person consenting. Communication should be cognizant of varying levels of comprehension and not be too technical,

complex, hasty, or in a language, manner or context that the patient does not understand.¹⁶⁷

This makes clear that informed consent is predicated on the provision of all relevant information, in a manner that it is understandable to the affected person. Avoiding technical, complex language with the affected individual and/or their legal guardian is crucial. It is important also to provide sufficient time for the individual to participate effectively in the decision-making process.

(a) Children’s right to participate in decision making

Article 24 of the CRC requires States Parties to recognise

the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.¹⁶⁸

Article 12 also requires States Parties to

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.

In discussing the right generally to the highest attainable standard of health, the Special Rapporteur stated that ‘certain groups deserve special consideration regarding protection of informed consent as a result of vulnerabilities stemming from economic, social and economic circumstances’.¹⁶⁹

In respect of children, the Special Rapporteur noted that the CRC

demands respect for the child's evolving capacities and due weight to be given to the child's views according to age and maturity. Risks and benefits of medical interventions must be adequately conveyed to the child, and, given sufficient maturity, the child's informed consent should be sought.¹⁷⁰

Children need additional support in relation to medical decision making that concerns them. As a result, the UN Committee on the Rights of the Child has stated:

States Parties need to introduce legislation or regulations to ensure that children have access to confidential medical counselling and advice without parental consent, irrespective of the child's age, where this is needed for the child's safety or well-being ... The right to counselling and advice is distinct from the right to give medical consent and should not be subject to any age limit.¹⁷¹

4.3 Clinical guidance on informed consent for people born with variations in sex characteristics

The current framework for consent includes guidelines and protocols developed by clinical professional bodies and government health agencies. The Commission's research and consultation revealed only limited high-level guidance applicable to consent in relation to medical interventions for people born with variations in sex characteristics.

Clinical bodies identified a number of documents that provide some level of guidance on the issue of consent. These documents are the 2006 Consensus Statement,¹⁷² the 2016 Consensus Statement Update,¹⁷³ and the 2013 Victorian Decision-Making Principles.¹⁷⁴

One clinical body observed that the 2016 Consensus Statement Update

suggest[s] that informed consent is achieved through shared decision making, involving education, sharing of risks/benefits, articulating uncertainties in the care and outcomes of people born with variations in sex characteristics, and providing time for the patient and family to articulate back the risks and benefits of each option.¹⁷⁵

Stakeholders did not identify other specific guidance material about consent and people born with variations in sex characteristics.

The 2006 Consensus Statement does not address the issue of obtaining consent, except for some information in an appendix outlining the legal requirements for disclosure of information to patients under US, UK and Colombian law.¹⁷⁶

The 2016 Consensus Statement Update states that parents are responsible for providing consent to medical interventions, on the basis of available evidence, and in the best interests of their child.¹⁷⁷ It goes on to note that a parent's 'right' to provide this consent has been questioned:

Physicians working with these families should be aware that the trend in recent years has been for legal and human rights bodies to increasingly emphasize preserving patient autonomy.¹⁷⁸

However, it does not express any concluded views about this topic nor provide practitioners with any concrete guidance.

The 2013 Victorian Decision-Making Principles provide some guidance for clinicians on obtaining consent. They state that Victorian hospitals providing care to people born with variations in sex characteristics should provide

- honest and complete disclosure of the diagnosis, risks, options, issues and treatments

- sufficient time and opportunity for discussion of all options for healthcare and a balanced review of risks and benefits
- intensive support, education and counselling during the decision-making phase
- standardised, age-appropriate resources for parents, children and adolescents that provide education about sex and gender diversity
- information about, and referral to, support groups for both parents/families, and the patient
- assistance for parents with informing their child in stages about their condition, and with seeking their child's consent for any medical or surgical intervention
- ongoing follow up and referral to psychological support for patients and their parents throughout the patient's life.¹⁷⁹

These high-level principles are explained further in an appendix to the 2013 Victorian Decision-Making Principles.¹⁸⁰ In relation to supporting parents in decision making, they state:

Those responsible for providing information to parents should assist them to manage these initial reactions, and create an environment of calm and careful decision making. It is important to note, and to emphasise to patients and parents, that a diagnosis of an intersex condition does not mean that a decision about treatment is necessarily urgent.¹⁸¹

The appendix to the 2013 Victorian Decision-Making Principles notes that in some cases it may be possible to defer treatment until a person under 18 years of age is able to participate

in decision making but stops short of saying this course should or must be followed.¹⁸² The appendix also emphasises how important are both the content of medical advice given to parents, and the manner in which that advice is given:

Those responsible for the care for the patient should emphasise that intersex conditions are not shameful and focus on the potential for positive long-term outcomes. In particular, initial contacts with patients and parents during this period are crucial, because the response of clinical staff to the situation can leave a lasting impression.¹⁸³

While the current guidance documents (in particular, the 2013 Victorian Decision-Making Principles) describe some general principles that should be applied by clinicians when providing care to a person born with a variation in sex characteristics, they do not provide comprehensive guidance about consent and decision making.

Some stakeholders (including clinicians from Victoria) expressed concern about the lack of standards to support informed decision-making including how to obtain consent, and indicated support for clinical guidelines, as well as standardised information being made available to decision makers.¹⁸⁴ One multidisciplinary team stated:

At present there are no standardised safeguards to ensure a process of informed consent occurs, apart from clinical best practice. ... [We] support the development of clinical guidelines and standardised material to assist with documentation of informed consent in decision making.¹⁸⁵

4.4 Giving and obtaining consent: past and current practice

The legal framework for consent to medical treatment was generally well understood by stakeholders. That is, stakeholders who addressed the issue generally acknowledged that at present

- medical interventions may not be performed without consent
- doctors play a crucial role in providing relevant information to allow consent to be meaningfully given
- in the case of children, the ordinary rule is that legal guardians can provide consent for ‘therapeutic’ treatment for their children
- in a small subset of cases, court authorisation of medical interventions involving children must be sought before treatment proceeds.

There were widely divergent views about how well this framework works in practice, and how well it protects the right of children not to undergo medically unnecessary interventions without providing personal consent.

Clinical stakeholders provided some information about their current practices in providing information to patients and obtaining consent. Many people with variations in sex characteristics expressed dissatisfaction with decision-making processes in their own cases.

(a) Clinical stakeholders

Clinical stakeholders who participated in the Commission’s consultations generally suggested that current practices on obtaining consent are satisfactory, and ensure that adequate

information is provided to decision makers. In the case of children, they submitted that current practices in obtaining consent from legal guardians are appropriate.¹⁸⁶

Some clinical stakeholders recognised that there had been concerns about past decision-making practices, with one stating that practices had evolved in response to those concerns.¹⁸⁷

(i) *Current practice in obtaining consent for children*

Some clinician stakeholders indicated that for children born with variations in sex characteristics, consent to medical interventions is given by legal guardians.¹⁸⁸ The Australasian Paediatric Endocrine Group stated:

The process for obtaining consent for children and adolescents from their legal guardians is no different to any medical or surgical procedure, ensuring the best interests (survival, age appropriate development and wellbeing and limitation of harm) of the child is a primary consideration in all actions.¹⁸⁹

Modern decision-making practices were said to be inclusive and to emphasise shared models of decision making by legal guardians and clinicians.¹⁹⁰ One clinical stakeholder stated that there has been a ‘significant shift towards dialogue and shared decision-making between parents and a multidisciplinary medical team’.¹⁹¹

The Endocrine Society of Australia stated that ‘consent/decisions should be made in the context of an expert multidisciplinary team in conjunction with the child’s parents/carer’ in respect of children who are not yet *Gillick* competent, with recourse to litigation in the event of disagreement between parents and clinicians who may not have reached consensus about whether to intervene.¹⁹²

Clinician stakeholders argued that developmentally-appropriate participation by

children and young people is encouraged, and that early intervention is not the default starting position for clinicians when caring for a person born with variations in sex characteristics.¹⁹³ The Australasian Paediatric Endocrine Group stated that the process of shared decision making

incorporates the expert knowledge of a health care provider, the right of an individual or their surrogate (parent/legal guardian in paediatrics) to make health care decisions with full information and the developing capacity of the child or adolescent over time.¹⁹⁴

Clinicians indicated that decision making in relation to variations in sex characteristics can be complex, involves extensive input from a wide range of medical (and sometimes other) experts to support decision making, and that this input can be required over an extended period of time to ensure consent remains informed.¹⁹⁵ They stated that when agreement cannot be reached between members of the team or between the team and the legal guardians, the case is either brought to the hospital clinical ethics committee for guidance or referred to a highly specialised centre.

(ii) *Documenting consent*

There seems to be variable practice for the documentation of consent. One specialist multidisciplinary team confirmed that they obtain consent from guardians in writing before interventions proceed,¹⁹⁶ while another noted that there is no accepted, standardised process for documenting consent. The second team stated that they 'support the development of clinical guidelines and standardised material to assist with documentation of informed consent in decision making'.¹⁹⁷

The Commission did not receive enough submissions to say whether obtaining written consent is standard practice in respect of people

born with variations in sex characteristics.

According to the Australian Commission on Safety and Quality in Health Care, there is no general legal requirement for consent to be written. It must only be written where 'required by law or by the policies of the state, territory or healthcare organisation where the person is receiving care and treatment'.¹⁹⁸

(iii) *Provision of information and hearing the views of children*

Clinician stakeholders stated that they provide a variety of information to support legal guardians when making decisions affecting their children. Contemporary practice was said to include explaining the particular variation, its health implications, as well as potential risks and benefits associated with all treatment options (including undertaking no intervention).¹⁹⁹ These explanations include information about what is medically known and what is currently unknown about diagnoses, intervention options and their respective risks and benefits, and the risks and benefits of deferring interventions and the expected consequences if no treatment is provided.²⁰⁰

One hospital multi-disciplinary team reported that it provides legal guardians with available medical literature and educational materials, as well as contact details for support groups.²⁰¹

Doctors also indicated that they recognise the need to involve children in decision making that affects them, and that they provide age-appropriate information to children.²⁰²

The information doctors provide will vary depending on the variation and the proposed intervention. In the context of proposed surgery, the Western Australian Multidisciplinary DSD Team, remarked:

The indication for any surgical treatment is carefully discussed by all members of the

DSD Multidisciplinary team and the child (if of an appropriate age of understanding), and parents.²⁰³

It also stated:

If the child is older at diagnosis, and able to understand the underlying problem and possible treatments, the young person's views, gender identity and wishes are an integral part of the decision-making process.²⁰⁴

APEG described how information is provided in the context of proposed hormone treatment:

The proposed hormonal treatment/reasons for recommending hormone replacement therapy and its anticipated effects are also described in age appropriate terms to the young person and their understanding of this assessed. Written/picture-based resources may also assist in aiding understanding. Pubertal hormone therapies are prescribed in many forms which involve the young person's active involvement (and hence ongoing assent) in the process (eg swallowing tablets/applying patches/attending for intramuscular injections). Typically young people on hormone therapies have regular medical reviews to allow monitoring of effects and wellbeing, further discussions/adjustments and at any stage a young person is free to opt to discontinue therapy or discuss alternative options with their treating team.²⁰⁵

In recognition of the importance of children participating in making decisions that affect them, some clinicians expressed support for delaying surgical intervention in instances where it is not medically necessary.²⁰⁶ The NHMRC Funded Program stated that there is a growing awareness that some issues present no immediate medical concern, so any intervention can be deferred until the child's development is clearer and the

child can participate in decision making about potential interventions.²⁰⁷ The issue of delaying non-essential interventions is discussed further in Chapter 5 – Medical necessity of interventions.

(b) Experience of people born with variations in sex characteristics

In submissions, several people born with variations in sex characteristics expressed dissatisfaction with information provision and the decision-making processes relating to their bodies, both as children and adults.

Consultation participants reported a lack of information provided about their variation by healthcare workers. Some of these concerns related to their receiving insufficient explanation and information at the time an intervention was performed on them, meaning that they were not meaningfully able to provide consent or, as children, participate in decision making.²⁰⁸ Others reported a lack of explanation and information at times after an intervention, leading to them lacking knowledge about their body and what may have been done to it.²⁰⁹

Of the experiences reported to the Commission about a lack of information, and lack of meaningful participation in decision making, most related to interventions performed on stakeholders as children.²¹⁰ The ongoing impacts of not feeling that they were informed or included and that things were 'done to them' can be quite profound.

(i) Exclusion of children from discussion

Some people born with variations in sex characteristics reported that they were excluded from medical discussions when they were under 18 years and were not involved in making decisions about their treatment. For example, one person reported:

my doctor talking to my parents and I would be in the other room and it would be like, oh James [name changed], could you just

go out of the room for a bit sort of thing ... I dunno they would always do this sort of thing when I was 15 or 14 or whatever.²¹¹

Another described their similar experience of exclusion:

There was zero psychosocial support, or even counselling, there was no discussion, I was a minor, as far they were concerned, my parents and the doctor made the decision. Even though when I finished being in his care, I was 16 or 17, he could easily have spoken to me, he did not speak one single word to me when I was in his office on my own.²¹²

Similarly, one person said:

As a teenager I experienced no consent. Consent was only apparently required via my father and stepmother. I was not included in anything during my [doctor's] appointments.²¹³

Another person born with a variation in sex characteristics stated:

I was not at all in touch with the decisions that were being made on behalf of me and I wasn't aware, I just had no awareness of anything like that. You know this is the way it has to happen and this is the way it has to be.²¹⁴

(ii) *Pressure to consent*

Some people born with variations in sex characteristics stated that they had some involvement in decision making as children, but they had felt coerced or pressured to assent to medical treatment. One person stated:

I felt pressured to consent to my irreversible surgery. Withdrawal did not feel like an option. This was because I was a child and children don't have the ability to speak their mind fully or understand all the implications.²¹⁵

Another individual described the pressure they felt to consent to an intervention as an adult in these terms:

when I reached adulthood and was told of my situation, I felt that I was under some pressure to make a decision, this led to me making a decision based on my chromosomes and my past history with Oestrogen at age 13. I honestly probably would've preferred to move between hormones or to never have hormones.²¹⁶

(iii) *Inadequate information about exact nature of treatment*

One matter about which people with lived experience of variations in sex characteristics was the exact nature of, or need for, the treatment that doctors proposed to administer to them.²¹⁷ Related to this, an LGBTI community organisation said that individuals were sometimes not informed of what particular examinations, inspections, tests or other medical practices were proposed to be undertaken in relation to a to a proposed intervention.²¹⁸

One example was provided by a state/territory anti-discrimination body, which reported that it had recently been made aware of a case where a 16-year-old 'underwent a gonadectomy, yet she was not told the truth about her procedure. This had serious ramifications upon her psychologically'.²¹⁹

In some instances, people felt misled by the conflation of multiple treatments as being necessary and interdependent. A Gender Agenda, a peer support organisation, submitted that doctors have in some cases recommended multiple interventions to individuals, without disclosing that these were not interdependent, with individuals consenting to all the interventions, as a result.²²⁰

(iv) *Lack of information on alternatives to intervention*

People born with variations in sex characteristics told the Commission that they did not receive information about the ability for people born with variations in sex characteristics to live, in the absence of intervention, healthy and happy lives, to celebrate their diversity, and to form strong social, romantic and sexual relationships.²²¹

The provision of this kind of information is particularly important for these people and their legal guardians, given the risk that psychosocial factors may be relied on by some legal guardians when consenting to interventions for their children, and by some doctors in advising legal guardians and children.²²²

(v) *Lack of information about long-term effects and outcomes*

Some people with variations in sex characteristics, or their legal guardians, reported receiving inadequate information about all the consequences of proposed medical interventions, including possible long-term effects.²²³

Several intersex peer and advocacy organisations said that individuals with variations in sex characteristics have reported that they have not been provided with information in relation to the consequences of intrusive procedures.²²⁴

One advocacy and peer-support group collated the experiences of a number of people born with variations in sex characteristics, who described not receiving enough information about long-term effects and outcomes of interventions.²²⁵ For instance, one person reported:

I did say yes to the surgery I received as a teenager, but I had no idea about the impact it would have on my body and my life, and the lifelong follow ups and treatment the surgery brought about. That information didn't get discussed, or only in a very cursory manner. If I had of known all the facts, I would have said no.²²⁶

Another said:

I kind of consented, as an adult, but it wasn't an informed consent. I was isolated, had no support and no idea what the long term consequences of medical interventions were, and really wasn't able to make good decisions. They had big consequences not only for my physical health, but also for my mental health.²²⁷

(vi) *Inadequate information about lack of medical consensus*

Several civil society organisations claimed that health professionals have not always fully disclosed to people born with variations in sex characteristics or their legal guardians that there is a lack of clinical knowledge or consensus about the best approach to providing medical care for some individuals or variations. Specifically, these organisations claimed that doctors do not always provide information about: what is known and what is not yet known about the variation in question; potential complications from proposed treatment; and the efficacy and risks of the proposed treatment.²²⁸

(vii) *Lack of referrals to peer support*

People born with variations in sex characteristics stated that doctors or medical teams have not always provided them with referrals to peer support groups. They argued that connection to peer support at the time of diagnosis can provide crucial input to help individuals when weighing up whether to proceed with interventions or not.²²⁹ Such input can relate to

- Lived experience of others who have the same variation. These people, who may or may not have had medical interventions, can provide valuable information about long-term outcomes in their own cases, and how this has affected them. Such a range of experiences can help inform individuals of potential different future

scenarios. Access to this experience was said to be particularly important in light of the fact that there is very little long-term outcome data in the medical literature to guide individual decision making.²³⁰

- Psycho-emotional support at a stressful time from those who can best understand and relate, because they have similar experiences.²³¹

Both these kinds of input can support a person in deciding whether or not to consent to a proposed medical intervention.

These stakeholders suggested that provision of peer support at the time of diagnosis can establish a strong, healthy and affirming foundation for ongoing engagement with all parts of the treating team, and could remove from the clinicians the responsibility of providing psychosocial support.²³²

One individual born with variations in sex characteristics stated:

Consent is more than what happens on the way into an operating theatre. It's about exposure to information, to peers, to different perspectives, and especially to affirmative perspectives that can help tackle shame and secrecy in constructive ways.²³³

A peer support and advocacy organisation submitted:

The time of diagnosis for an individual or parent can be intensely stressful and uncertain ... the range of information ... can be overwhelming. Individuals or parents in this situation may also be navigating social difficulties, understanding or talking about the variation as a result of the stigma associated with their variations. Making contact with an unknown person or organisation at this stage may

be increasingly difficult. Any tension between medical and social models of intersex may also be difficult to navigate, particularly if the benefits of peers [sic] support are not explained by clinicians and recommendations for psychosocial support made as a first tier intervention.²³⁴

The concern was that, in assisting legal guardians or people born with variations in sex characteristics, medical teams provide inadequate or inappropriate referrals to peer support groups; it was not suggested that these referrals were never made by medical teams. This organisation submitted that whatever referral mechanisms may be in place are not currently working, and that it was not 'aware of a single referral to our support group from any Australian hospital in the past decade'.²³⁵ There was support from parent support groups for referrals to peer support organisations.²³⁶

(c) Experience of parents and legal guardians

Some parents who had provided consent to interventions on behalf of their children expressed satisfaction with decision-making processes, including the information made available by clinicians.²³⁷ They expressed the view that parents are the appropriate decision makers about medical treatment for children, including interventions for children born with variations in sex characteristics.

They argued that parents have their children's best interests at heart. One parent, in explaining their decision to consent to an intervention on behalf of their child, said that 'as parents all you want is for your child to fit in and be happy and healthy'.²³⁸ The parent continued that '[w]e do not make decisions too quickly or without thinking of the full extent the decision would have on the child later in life' and argued that applying a human rights framework risked curtailing the

legitimate exercise of parents' rights to make decisions in their child's best interests.²³⁹

(i) Age-appropriate engagement

Several parents stated that information was provided to allow for the age-appropriate participation of children.²⁴⁰ Specifically, one parent expressed satisfaction with how their child was engaged with by clinicians in relation to proposed treatment in the following terms:

My 13 year old daughter gave informed consent and we as parents also consented. Information was provided by one specialist, age appropriate for my 13 year old, psychological assessment was conducted to ensure she was not coerced, etc.²⁴¹

(ii) Inadequate information provision

Some parents indicated that doctors did not provide enough information, and as a result they needed to do a lot of their own research to understand both what treatment options were available for their children, and the merits or otherwise of each option. One frustrated parent said, 'you need a lot more support at that than you actually get'.²⁴²

In describing her ability to ensure that her daughter, who has congenital adrenal hyperplasia, was provided with the appropriate medical care, she continued:

what makes me so upset about this scenario is I had the means to gain access and to do it [obtain condition-related information] on my own but I don't think everybody does you know, we're not all created equal in that scenario. And that's where I would say, I was dissatisfied with that. Well, I had to go out and do it all on my own to find out what I wanted to do for my daughter. There wasn't access coming to me.²⁴³

An intersex peer and advocacy organisation said that parents reported to them that information

about alternative treatment options was not provided to them.²⁴⁴ In some instances doctors have not provided all relevant information without significant prompting by parents.²⁴⁵

(d) Providing adequate information to ensure informed consent

Stakeholders agreed that people born with variations in sex characteristics and their legal guardians should be provided with adequate relevant information to ensure informed consent. Stakeholder views about what information should be provided, and how, are discussed below.

(i) What information should be provided

Stakeholders submitted that decision makers need to receive information that is accurate, up-to-date and evidence based. Information should be provided from multiple perspectives, including that of mental health specialists and people with lived experience of variations in sex characteristics, and should address proposed treatments, potential alternatives, and the associated risks and benefits of all options, including the risks and benefits of opting for no treatment.²⁴⁶ Decision makers should also be informed about whether proposed interventions are reversible.²⁴⁷

People born with variations in sex characteristics called for clear articulation by treating professionals of the purpose or purposes of proposed treatment. In particular, it should be made clear whether factors said to weigh in favour of an intervention relate to physical matters such as function, pain or discomfort, or to psychosocial or other matters (for example, addressing concerns about bullying). People born with variations in sex characteristics also called for access to information about social understandings of 'intersex'.²⁴⁸

Clinician stakeholders supported the dissemination of results of research and studies in an accessible format.²⁴⁹ There is currently

a lack of long-term outcome data relating to interventions for people born with variations in sex characteristics, as discussed in Chapter 9 – Support, health records and data collection. The Endocrine Society of Australia stated that availability of long-term outcome data ‘would enhance the capacity of people born with variations in sex characteristics to provide full and informed consent’.²⁵⁰

(ii) How information should be provided

The Endocrine Society of Australia said the provision of information should be open and clear, with space and time made for ongoing discussion before a decision is made, at least in the absence of an emergency.²⁵¹ Some parents and clinicians emphasised the need for families to be given time to consider information properly before being asked to provide consent because, at the time of diagnosis, the information can be overwhelming.²⁵²

The Endocrine Society of Australia highlighted that the 2016 Consensus Statement Update recommends that doctors ensure time is provided those providing consent to ‘articulate back’ the information and advice provided, and the implications of proposed treatment.²⁵³ This can ensure that decision makers fully understand these matters.

Information and educational materials should be developed with guidance from people with lived experience of variations in sex characteristics.²⁵⁴ The Australasian Paediatric Endocrine Group suggested that these materials should be developed in a range of media and formats, to help children better understand their bodies and participate in decision-making.²⁵⁵

The Western Australian Multidisciplinary DSD Team stated that the provision of ‘consent’ is often an ongoing discussion, rather than a single, point-in-time decision.²⁵⁶ Some medical interventions occur in stages or over an extended period of

time. The Australasian Paediatric Endocrine Group cited the example of the need for ongoing assent when pubertal hormone therapies are undertaken.²⁵⁷

One multidisciplinary team noted that there are ‘no standardised safeguards to ensure a process of informed consent occurs, apart from clinical best practice’.²⁵⁸ This team was in favour of ‘the development of guidelines and standardised material to assist with documentation of informed consent in decision making’.²⁵⁹ The need for new guidelines more generally is explored in Chapter 6 – Clinical practice and new National Guidelines.

4.5 Emerging themes

Two significant and related themes about consent have emerged. The first is the central importance of ensuring that consent to medical interventions for people born with variations in sex characteristics is fully informed. The second is the need to ensure that any person who is not able to provide personal consent, such as a child who is not Gillick competent, is empowered to participate meaningfully in relevant decision making and have their views heard, consistent with the principle of supported decision making.

Both of these are requirements under international human rights law. Both received wide acceptance from all stakeholder groups. However, there is inevitably some divergence of views about the degree to which these requirements are being met in practice. It also appears that there is some disagreement about precisely what these requirements entail.

(a) What is required for informed consent

International human rights law requires that for personal consent to be effective, the person giving it must have sufficient understanding of all the factors relevant to their circumstances, and



enough time and support to arrive at a decision.

The principal source of information for people about medical decisions will necessarily be doctors and other health professionals, who therefore have a special responsibility to their patients to support their decision making. These requirements are explained in detail in the 2009 report of the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.²⁶⁰

People considering medical treatment for themselves or those in their care require comprehensive information about the benefits and risks of any proposed treatment, and any alternative options. That includes information about the risks and benefits of other treatments, of delaying treatment, or not undergoing any treatment. It also includes information about any relevant uncertainties about the state of medical knowledge, and consequently about assessing whether the proposed treatment is necessary.

This information must be provided to those providing consent in a way that is appropriate

and accessible to the individual concerned, without being too technical or complex for their understanding. It is vital that people are provided with adequate time to consider advice, and to ask questions to clarify it. People should not be pressured or rushed in their decision making, in the absence of a medical emergency.

Further factors apply in the case of people may not legally be able to provide their own consent, such as children and adolescents, where there may be a role for someone, such as a guardian, to consent on their behalf. The mere fact that a person is under 18 years of age cannot be taken as establishing that they lack legal capacity to make decisions for themselves. Where they do have decision making ability, they should be supported to participate in a way that is consistent with their ability, and allowed to express their views. In all cases where consent is provided on behalf of a younger child, decisions must be made in the best interests of the child. Critically, in the context of proposed medical interventions for children born with variations of sex characteristics, non-consensual interventions should be performed only where medically necessary.

There was general agreement on these requirements from stakeholders, although there was a broader range of views about the concept and role of medical necessity in decision making. That is discussed separately in Chapter 2 – Human rights.

In particular, some clinical stakeholders recognised the need to support decision makers in providing informed consent, and to include children in decision making. How well those principles are applied in practice is discussed below.

(b) Barriers to informed consent

In the Commission's view, where medical interventions were made on people born with variations of sex characteristics in the past, the broadly accepted requirements for informed consent under Australian domestic law or international human rights law have not always been met. Further, there is a real risk that these requirements may not always be met in current practice. The areas of concern in this regard are discussed below.

(i) Provision of information

The Commission received powerful accounts from some people born with variations in sex characteristics that they were not provided with sufficient information to allow them to provide fully informed consent or participate fully in decision making, even where medical intervention occurred when they were of an age to be capable of full participation. As noted above, clinicians generally reported to the Commission that affected people were provided with sufficient information to provide fully informed consent and to participate fully in decision making. The Commission is concerned by the reports it received that some people born with variations of sex characteristics received inadequate information about the exact nature of, or need for, the treatment that doctors proposed to administer to them.

Some people born with variations of sex characteristics report not receiving adequate explanations of the potential long-term consequences of medical interventions before consenting to treatment. In some cases, this may be due to the lack of scientific data about these consequences. In any event, that lack of data is itself something that should be explained to people before they are asked to consent to medical treatment.

Some legal guardians reported not receiving enough information from treating doctors about potential alternatives to recommended medical interventions. Legal guardians can prompt doctors to provide more information; or they can conduct their own research to address gaps. However, these options cannot be assumed to be open to all legal guardians, and cannot replace the provision of relevant information and advice at first instance by medical practitioners.

(ii) Exclusion of children from discussion, and failure to defer non-urgent interventions

Some clinical bodies consider that current practice involves children in decision making in an age-appropriate way. While there are some suggestions in submissions and current guidance documents that it may be appropriate to defer some treatments until children can participate in decision making, this does not appear to be a principle that is given a high priority.

Some people born with variations in sex characteristics reported that as children, they had some involvement in decision making, but did not feel that involvement was adequate. However, some reported being ignored by doctors, even in adolescence, and that doctors had spoken exclusively to their legal guardians about proposed treatments on their own bodies. While some reports related to experiences that occurred some time ago, others were recent. The Commission is concerned that, in some cases, children are today not fully involved in decision

making in a way appropriate for their developing ability, and there is a risk that will continue to be the case.

At the same time, there are legal guardians who strongly consider that they should be able to make unfettered decisions on behalf of their children, including in circumstances where there is no immediate threat to life or physical health. Under the current medical framework, there is a significant risk that legal guardians will not choose to defer intervention until children can meaningfully participate in the decisions, or decide for themselves.

Together, these factors indicate that the principle of ensuring that children have the maximum possible opportunity to participate in decision making is not consistently prioritised in obtaining consent to medical interventions directed toward variations in sex characteristics.

(iii) Inadequate time for decision making and pressure to consent

People born with variations in sex characteristics can feel pressured, or rushed, to assent to treatment recommended to them as children.

Legal guardians can feel overwhelmed when they first receive a diagnosis for their child relating to a variation of sex characteristics, and it is essential that enough time be given for them to make reflective, informed decisions.

While these problems may not be pervasive, there is a real risk that legal guardians and children may not be given sufficient time to consider medical advice in at least some non-urgent cases.

(iv) Inadequate referrals to peer support

While some legal guardians and children are referred by clinicians to peer support groups, evidence from those support groups and people with lived experience suggests that these referrals are not routinely made. That deprives legal

guardians and, as they mature, children, from a valuable source of information, particularly regarding experiences of interventions and alternatives, as well as psycho-emotional support.

(v) Lack of standardised procedures and materials

There appear to be no standardised guidelines to regulate the provision of information and advice by doctors to people born with variations in sex characteristics and their legal guardians. Nor are there guidelines standardising the obtaining and documenting of consent. These matters are therefore left to clinical practice, which is unlikely to be uniform, and makes departures from best practice more likely.

4.6 Ensuring consent is informed

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 of 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, and if 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 communicate effectively the information taking into account the age, disability 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 the 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, be provided with adequate time to make treatment decisions, with access to necessary support, to ensure they do not feel undue pressure to consent.

Medical decision making in respect of people born with variations in sex characteristics can be particularly complex. Medical practitioners referred to the need for decision making to be informed by specialist expertise from a number of disciplines in the context of multi-disciplinary teams.

Medical knowledge is both incomplete and evolving in significant ways with respect to many variations in sex characteristics. Doctors agreed that data about long-term outcomes is not adequate to inform accurate assessments of the risks to health associated with some variations, and to understand whole of life consequences of some interventions. This evolving state of knowledge increases the risk that new research will not be immediately communicated to all treating professionals, or included in materials provided to people born with variations in sex characteristics or their legal guardians.

The Commission considers that there is credible evidence that best practice in obtaining informed consent has not always been adhered to in medical interventions directed toward variations in sex characteristics. This is so in a context in which there

is no specific standard outlining best practice for providing information and obtaining consent.

The Commission recommends that comprehensive standards regulating the provision of medical advice and the obtaining of consent in cases concerning variations in sex characteristics should be developed, as part of the new *National Guidelines on medical interventions for people born*

with variations of sex characteristics, recommended in Chapter 6. These should require the documentation of informed consent processes by treating medical teams. Documentation of these matters would help ensure that best practices are followed, and would improve the records available in later life to people who are subject to medical interventions in childhood.

MEDICAL NECESSITY OF INTERVENTIONS

5.1 Justifying medical intervention

As a general rule, all people have the right to either provide their free and fully informed consent, or to refuse their consent, to any medical intervention modifying their sex characteristics.

International human rights law recognises a limited and narrowly defined exception to this general rule, where it is permissible to perform medical interventions without the consent of the affected individual.

This exception relates to medical necessity – as expressed in the Medical necessity principle. It is permissible to carry out a medical intervention on a person without their personal consent only where the intervention is required urgently to avoid serious harm to the person affected (the ‘medical necessity’ principle). In this context, an intervention is ‘required urgently’ if it cannot be deferred without a significant risk of serious harm.

The Commission considers that legal principles, including those derived from and reflect international human rights law, as reflected in Chapter 2, mean that medical interventions on children with variations in sex characteristics, where such interventions modify their sex characteristics, should be permissible only 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.

This chapter applies this legal principle of medical necessity to the situation of medical interventions in respect of people born with variations in sex characteristics. It explores the elements of the principle by considering

- particular situations where urgent treatment is required to address an unacceptable risk of serious harm
- other claimed needs to intervene to protect physical health
- the situation where intervention is proposed to address a risk of cancer
- psychosocial rationales for intervention, including to ‘normalise’ genitalia.

The Commission concludes that, while some of these rationales may have been relied on in the past to justify medical interventions, not all are consistent with the Medical necessity principle. In later chapters, the Commission makes recommendations for new guidance on how to determine whether a medical intervention modifying sex characteristics is a medical necessity and can be carried out without personal consent, if authorised by an independent panel (see Recommendation 8).

5.2 Consent and medical necessity

The requirement for consent to medical interventions at international law derives from the right to bodily integrity, which is an aspect of the right to security of the person – expressed in the Bodily integrity principle set out in Chapter 2.²⁶¹ More recently, it has been reaffirmed in the World Health Organization’s *Amsterdam Declaration on Patients’ Rights*, which requires informed consent as a prerequisite for any medical intervention and guarantees the right to refuse or halt medical interventions.²⁶²

International law also recognises the autonomy and agency of children to influence decisions that will have an impact on them – expressed in the Children’s Agency Principle. Children are rights bearers and not merely objects of protection.²⁶³ Decisions about children must have their best interests as a primary consideration,²⁶⁴ and in addition children have a right to express their own views about decisions that affect them and their views must be given due weight in accordance with their age and maturity.²⁶⁵

As discussed in Chapter 4, there is a recognition in Australian law that children’s ability to understand medical procedures, and consent to them, generally increases with age.²⁶⁶

What this means in combination is that if a child is legally unable to give fully informed consent to a proposed medical intervention now, and the intervention can be safely deferred, the child’s ability to make a fully informed decision about what happens to their own body will be enhanced.

Children also have the right to enjoy the highest-attainable standard of health.²⁶⁷ In order to secure this right, there may be situations where it is necessary for a medical intervention to be carried out urgently without the fully informed personal consent of the child. Because an intervention of this kind impinges on the affected child’s rights

to autonomy and agency, the two sets of rights need to be accommodated. The usual way that international human rights deals with a situation like this is by weighing the respective rights in a proportionality analysis.²⁶⁸

The rationale for interfering with the child’s autonomy and agency is that it is necessary to protect the child’s health. In this chapter, the Commission refers to that rationale as one of ‘medical necessity’. It is an exception that allows some limitation to the right to bodily integrity. As an exception, it must be narrowly construed so that medical interventions – and particularly intrusive interventions like surgery – do not take place where they are not necessary or when they could be deferred to allow fully-informed decision making by the child – as reflected in the Precautionary principle.

The parameters of the exception to personal consent have both a temporal element (the intervention must be urgent, that is, unable to be deferred) and a materiality element (the intervention must be necessary to address a serious medical issue, with no less restrictive alternatives available). The *Amsterdam Declaration on Patients’ Rights* provides for an exception to personal consent where intervention is ‘urgently needed’.²⁶⁹ The *Yogyakarta Principles Plus 10* give specific consideration to this issue in the context of medical treatment for people born with variations in sex characteristics. They provide that medical interventions modifying sex characteristics should not be performed without free, prior and informed consent, ‘unless necessary to avoid serious, urgent and irreparable harm’.²⁷⁰

The former Special Rapporteur on the right to health, Mr Anand Grover, recognised a similar exception to the need for personal consent. In relation to medical interventions on children, he said:

Health-care providers should strive to postpone non-emergency invasive and irrevers-

ible interventions until the child is sufficiently mature to provide informed consent.²⁷¹

He noted that proposed interventions on children with variations in sex characteristics need to be particularly scrutinised.²⁷²

5.3 Rationales and circumstances claimed to justify medical interventions

Under international human rights law, medical necessity is the only scenario in which a medical intervention on people with variations in sex characteristics may occur without their personal consent – as expressed in the Medical necessity principle. However, not all stakeholders explicitly endorsed the standard of medical necessity and, where stakeholders used the term, it was given a range of meanings.

Whether a particular intervention complies with this legal principle can be complex. Often, multiple factors must be taken into account.²⁷³

Stakeholders reported a broad range of experiences regarding the circumstances in which medical interventions have been conducted without personal consent, both historically and in current clinical practice. Stakeholders also expressed divergent views on when such interventions should be permitted.²⁷⁴

Some people born with variations in sex characteristics and some civil society organisations stated that, in their experience, permissible and impermissible considerations are currently considered together in deciding whether an intervention should be conducted.²⁷⁵

(a) Situations where urgent treatment is required

A small number of variations in sex characteristics

are associated with life-threatening risk if not treated promptly.

All stakeholders agreed that immediate intervention is permissible in situations where treatment is medically necessary and especially urgent.²⁷⁶

One example of a variation associated with a serious risk to health or even a threat to life is congenital adrenal hyperplasia (CAH). There are several types of CAH, of which the most serious is 'salt-wasting' CAH, in which

the adrenal glands make too little of the hormone aldosterone, causing the body to be unable to retain enough sodium (salt). ... If undiagnosed, symptoms of classic salt-wasting CAH appear within days or weeks of birth and, in some cases, death occurs.²⁷⁷

Clinicians stated that a diagnosis of salt-wasting CAH requires the immediate provision of glucocorticoids (a type of hormone).²⁷⁸ Clinical stakeholders made clear that this treatment is routinely administered where salt-wasting CAH is diagnosed.²⁷⁹

As discussed later in this chapter, some stakeholders also cited variations associated with an increased risk of cancer as justifying prompt treatment to protect life. These were the only specific variations explicitly cited by stakeholders as involving a threat to life.

Situations of medical emergency clearly fall within the concept of medical necessity described above. Where a person's life is in imminent danger, their right to life and to health must be prioritised over their right to make decisions about their bodily integrity.

A critical consideration in determining when to proceed without personal consent is the timing of the decision required. If a variation in sex characteristics is associated with a risk to life

or significant physical health that is unlikely to manifest until a long time after it is identified by doctors, it may not be necessary to intervene immediately—and consistently with the Precautionary principle.

In that scenario, the decision to intervene may be able to be deferred until the risk becomes more proximate. If that can be done safely, it would increase the likelihood that the affected person will be able to participate meaningfully in decision making.

(b) Protecting physical health

Some variations in sex characteristics are associated with serious risk to physical health. While not having the same level of urgency as CAH, some stakeholders argued that these variations also justified an intervention, without personal consent, to address the serious risk to physical health. The language used to describe this rationale for intervention varied, but the Commission considers that interventions in such circumstances would need to be assessed against the elements of the test for medical necessity, to be consistent with Medical necessity principle.

Stakeholders identified the following categories of intervention necessary to protect physical health:

- to 'provide therapy for issues that are associated with morbidity'²⁸⁰
- where 'necessary to avoid serious, urgent and irreparable harm to the patient'²⁸¹
- where 'the intervention is serving a serious medical need at the time re the health of the person'²⁸²
- where needed for 'preservation of organ function'²⁸³
- where needed to assist bodily or 'biological' functions such as bladder or bowel

function, or the flow of menses²⁸⁴

- in relation to the administration of hormones, 'to assist in increasing muscle tone, language development ... and to assist in decreasing anxiety'.²⁸⁵

Intervention relating to protecting physical health was said to include where an organ or bodily function is, or is at serious risk of, being impaired or compromised. All categories of stakeholders agreed that medical interventions should be permitted on children in circumstances where there is a significant risk of an organ or bodily function being impaired, and intervention cannot safely be deferred until the child can provide personal consent.²⁸⁶ Some clinicians also described these circumstances as amounting to a 'medical necessity'. Stakeholders generally agreed that parental consent must be sought as a prerequisite for undertaking such interventions.

Some stakeholders included the preservation or assistance of sexual functions within the rationale of protecting physical health. This perspective is strongly contested by stakeholders from the clinical disciplines of psychiatry and psychology and most people born with variations in sex characteristics who contributed to this project. This rationale for medical interventions is addressed in detail later in this chapter (Interventions to 'normalise' genitalia and address other psychosocial rationales).

(i) Current clinical guidance

Current clinical guidance documents support undertaking medical interventions on children where needed to treat serious physical health issues. The *Victorian Decision-making principles for the care of infants, children and adolescents with intersex conditions* (2013 Victorian Decision-Making Principles) include the need to 'minimise physical risk to child'.²⁸⁷ The document states:

This principle relates to the risk of physical

harm to the child (both short and long term) that is directly attributable to their intersex condition, for example, urinary passage obstruction. Any treatments proposed in the management plan should be proportionate to the level of physical risk resulting from the patient's particular condition.²⁸⁸

The need to ensure urinary function is also cited in the *Consensus statement on management of intersex disorders* (2006 Consensus Statement) as an example of a rationale justifying early intervention.²⁸⁹ These guidance documents do not, however, provide significant further detail about what kinds of intervention might be needed to protect the health of people born with variations in sex characteristics.

(ii) *Protecting physical health and medical necessity*

Performing a medical intervention on a child without obtaining their personal consent can be justified only where the intervention is a medical necessity. That includes where the intervention is necessary to protect them from serious physical harm.²⁹⁰ It would have to relate to a significant health issue that poses a serious risk to the person's physical health; that requires action within a timeframe where they are not able to provide consent, and the intervention must be proportionate in the sense that it is the least intrusive necessary to address the threat of serious harm to the individual's physical health.²⁹¹

The proposed intervention should be limited to what is strictly required to address the medical issue. This would include ensuring that the measures to be undertaken are proportionate and the least-intrusive effective options available.

Consultations commonly cited situations where organ or bodily function were at risk of being impaired or compromised in relation to urinary function.

Existing guidance in the 2006 Consensus Statement and the 2013 Victorian Decision-

Making Principles identify interventions relating to urinary function as being necessary.²⁹²

However, there are other situations that may arise from time to time where medical intervention may also be considered to be necessary.

The Commission considers there is a need to clarify the existing guidance for any interventions premised on risk to organ or biological function.

This guidance should identify the obligation under the *Convention on the Rights of the Child* (CRC) to protect the child's right to health and the right to life. Accordingly, where robust evidence supports a proposed intervention and there is no less rights-intrusive option available, it would be permissible to intervene where organ or bodily function is at risk of impairment. Such circumstances would fall within the concept of 'medical necessity'.

Deferral of treatment, where safe to do so, should occur because the child might be able to make a decision about treatment before it becomes necessary – consistent with the Precautionary principle. In the meantime, it is necessary for treating clinicians to allow child to express views/ be heard, consistent with child rights under the CRC – reflecting the Children's agency principle.

(c) Risk of cancer

One of the most frequently cited rationales for performing early medical interventions, where personal consent cannot be obtained, is to address or mitigate the risk of cancer.

Most clinical submitters stated that risk of malignancy may justify surgery on young children. This view is underpinned by the evidence over many years that some variations have high risk of malignancy that may result in death. An organisation advocating for the rights of people born with variations in sex characteristics supported interventions where there is a high cancer risk.²⁹³

However, there were also concerns raised about the medical evidence for the magnitude of those risks, the timeframes within which surgery is required to mitigate them, its conflation with other social rationales, and the circumstances in which alternatives to immediate surgery should be considered.

This rationale is particularly controversial because, in the case of people born with variations of sex characteristics, the tissue which is at increased risk of malignancy is gonadal tissue. The associated interventions generally involve the removal of gonadal tissue, which can result in infertility. Also of concern are the hormonal consequences that can result from removal of gonadal tissue, with some individuals requiring lifelong hormone replacement.

Interventions to address malignancies, such as surgeries, must be based on robust evidence of unacceptable risk of serious harm. Where such evidence suggests that the malignancy risk is so high that it cannot be deferred until the individual can consent – that is, where the risk cannot be effectively monitored until the individual has legal capacity to make the decision themselves – more invasive intervention may be considered a medical necessity. On the other hand, where effective monitoring is possible, invasive surgery would not meet the standard of medical necessity and thus would not be permissible in the absence of personal consent – consistent with the Precautionary principle.

(i) Past and present practice

Some clinicians and people born with variations in sex characteristics told the Commission that preventing the development of cancer has long been accepted as a justifiable basis for early intervention; in particular, to remove tissue located in body areas that are difficult to monitor.²⁹⁴

A submission from a hospital multi-disciplinary team indicated that some gonadectomies are

proceeding where no risk of cancer was ultimately found. This stakeholder provided results of an audit of recent cases conducted over period of several years. In three quarters of cases where gonadectomy was conducted, there was evidence of uni/bilateral gonadoblastoma.²⁹⁵ Gonadoblastoma is a rare benign tumour that has the potential for malignant transformation.²⁹⁶ The inference, therefore, is that in one quarter of cases, there was no risk of cancer found.

This submission also indicated that some gonadectomies are being deferred where they are considered low risk. The most common referrals to the Differences of Sex Development (DSD) forum were for timing and need for gonadectomy for non-functioning gonads with malignant potential and hypospadias surgery for boys with complex hypospadias associated with other genital variations (eg, undescended testes).

Surgery was recommended to be deferred until the individual was old enough to consent in about 20% of cases, for reasons including mild virilisation and low tumour risk. Legal advice was sought by the hospital multi-disciplinary team from the state health legal adviser for one patient and the decision was made to defer surgery for a few months until the individual turned 16 years old.²⁹⁷

Some people with lived experience of variations in sex characteristics expressed concern about cancer risks being conflated with other rationales for intervention.²⁹⁸ The peer-support and advocacy organisation, Intersex Human Rights Australia (IHRA), stated that ‘documentation suggests that such issues [malignancy risk] are intertwined with non-therapeutic rationales’. It cites the case of Re Carla (see Chapter 7) as exemplifying how cancer risk can be conflated with other factors.²⁹⁹

(ii) Robustness of evidence and risk assessment

Some of the contention about cancer being used as a basis to perform interventions such as gonadectomies relates to the robustness of risk assessment.

It is established that some variations are associated with increased cancer risk, but that the extent of that risk depends on a number of factors. In teasing out some of the variables, the Australasian Paediatric Endocrine Group (APEG) cited the example of Androgen Insensitivity Syndrome (AIS). They stated that the risk varies depending on: whether the insensitivity is complete or partial; the position of the gonads (lowest risk if in labio-scrotal position; highest if intra-abdominal); and with advancing age.³⁰⁰

The degree of risk of cancer developing for any person born with variations in sex characteristics is informed by a number of variables. Further, the ability to effectively monitor any risk varies too.³⁰¹ Thus, whether an intervention such as a gonadectomy, with attendant significant consequences, is necessary to preserve life or ensure organ or bodily function, should be informed by relevant medical opinion based on the degree of individualised cancer risk and the ability to effectively monitor that risk.

To demonstrate how early a malignancy risk can manifest, APEG stated that in children with 46XY complete gonadal dysgenesis who underwent a gonadectomy, 'malignant changes have been found in gonads removed from girls younger than 1 year old in this instance'.³⁰²

Assessment of cancer risk is complex. Improved guidance and support for clinicians and others on this issue may be needed.

There were a range of views about how well-evidenced cancer risks are. A hospital multi-disciplinary team told the Commission about problems with the data relied upon to assess risk, and with the quality of the evidence base relied upon to justify interventions without personal consent.³⁰³ The team stated that guidance for intervention was often very broad, with specific evidence pertaining to any given DSD variation frequently based on results of un-pooled data, small sample sizes and centre experience rather

than on systematic review or meta-analysis of high-quality data.

APEG described the evolution in understanding of malignancy risk. It referred to the example of Androgen Insensitivity Syndrome (AIS), for which it was once standard to remove gonads, based on published evidence that reported gonadal malignancy in approximately one third of cases. APEG stated that it is now known from further studies in the last 10–20 years that the risk varies depending on whether the insensitivity is complete or partial and on the position of the gonads.³⁰⁴

The case of *Re Carla* was cited with concern by many people with variations in sex characteristics. One area of concern in this case was related to the out-of-date information relied upon by the Court to assess whether a gonadectomy was an appropriate intervention to deal with Carla's malignancy risk. Some critics argue that the accepted intervention for someone with Carla's actual cancer risk at the time of the case, was to monitor her gonads, rather than the gonadectomy that was recommended by the treating clinicians.³⁰⁵

One of Carla's treating clinicians cited the 2006 Consensus Statement to describe the risk of malignancy. It was their evidence that the Consensus Statement rated Carla's risk as an 'intermediate level' of risk, cited as 28%, and that surgery was thus recommended.³⁰⁶ However, this recommendation does not conform to the Consensus Statement, which states that in the case of 17 β -HSD3, the gonads should be monitored, not removed,³⁰⁷ and that the risk based on an individual assessment of the child may be significantly lower than the quoted rate.³⁰⁸ Additionally, the version of the Consensus Statement relied upon by the experts in *Re Carla* was outdated, particularly with regard to data on malignancy rates for children with 17 β -HSD3. More recent research, which was quoted in the 2013 Senate Report and so presumably would have been available to Carla's doctors, placed the risk of cancer for children

with 17 β -HSD3 at 17%.³⁰⁹ Further, diagnostic techniques allow an individualised risk assessment to be carried out, based on observation of specific immunohistochemical markers, rather than assuming that every child with 17 β -HSD3 has a 17% risk of cancer.³¹⁰

Specialist medical submitters stated that interventions to address malignancy risks are justified, with APEG stating that ‘leaving an abnormal gonad in situ might result in harm to the patient, such as developing a malignant tumour in the retained gonad which can result in death’ and that ‘Gonadal removal related to malignancy risk is deemed by most to be a medical necessity.’³¹¹ A parent-support group also expressed its view that risk of cancer is a reasonable basis for intervention.³¹²

IHRA stated that there is ‘no wish to reduce the timeliness of urgent or emergency medical interventions’, noting that ‘management of high cancer risks and urinary issues should not be controversial’.³¹³ However, speaking on behalf of people born with variations in sex characteristics, IHRA strongly rejected rationales for interventions that conflated legitimate medical concerns about malignancy with psychosocial rationales.³¹⁴ The Senate Committee Report also stated its concern that other matters such as ‘sex of rearing’ or ‘likelihood of gender dysphoria’ are interpolated into the discussion of cancer risk.³¹⁵

(iii) *Guidance materials and Senate Committee report*

A detailed exposition of interventions performed to manage cancer risks was considered in the 2013 Senate Community Affairs References Committee Report, *Involuntary or coerced sterilisation of intersex people in Australia* (the Senate Committee Report).

The Senate Committee Report stated that whether someone with a variation in sex characteristics is considered fertile depends on the type of variation a person has, as well as the specifics of their case.

Removal of gonads in some cases would not be sterilising, because the person would not be fertile in the first place. In other cases, however, gonads may be fertile, or may contain tissue that could allow fertility as a result of future advances in medicine. The Senate Committee Report observed that, as some decisions to remove gonads are made shortly after birth, this means removal occurs 20 to 40 years before the person might seek to have children—a very long period over which to predict what advances in medicine might occur.³¹⁶

The 2006 Consensus Statement supports interventions in some cases to mitigate cancer risks and gives some detail about the nature and magnitude of those risks across different variations and recommendations for appropriate treatment.³¹⁷ Treatments range from doing nothing, to monitoring, through to gonadectomy for the majority of variations. For a few, the recommendation is listed as ‘unresolved’.

The Commission notes that recommendations for action have changed between the 2006 Consensus Statement and the 2016 update. For example, the 2006 version recommends gonadectomy for partial androgen insensitivity syndrome (PAIS) non-scrotal, while in the 2016 update, monitoring is recommended.³¹⁸ Monitoring is more consistent with the Precautionary principle.

(iv) *Risk of cancer and medical interventions modifying sex characteristics*

For an intervention to be characterised as necessary to address a serious risk to physical health, the intervention must be

- needed to address a serious risk to the individual’s physical health
- needed before the person is old enough to consent (or otherwise in a position to consent)
- a proportionate intervention, including being the least intrusive option.

It is not controversial that surgical intervention may be required to mitigate the risk of cancer developing, where the risk of cancer is high and the development is imminent. However, there are other cases where the risk of cancer can be managed through less intrusive means, such as by careful monitoring of the situation. Invasive, irreversible intervention, such as gonadectomy, to address risk of malignancy in these circumstances is more controversial. Aside from concerns about whether the surgery is needed, intervention is contested as it frequently involves gonadectomy, thus foreclosing future fertility.

Assessing whether a medical intervention to prevent malignancy warrants removal of gonadal tissue should be informed by the magnitude of the risk of development of cancerous tissue. That is, whether there is a serious risk to the individual's physical health. Understanding of malignancy risk has evolved, as cited by APEG in relation to approaches to gonadectomies for Androgen Insensitivity Syndrome. Likewise, APEG stated that the approach to dealing with children with 17 beta HSD raised as females, has evolved with the

leaving of gonads in situ, rather than performing gonadectomies.³¹⁹

The Commission acknowledges the guidance provided in the 2006 Consensus Statement and the evolution of recommendations around appropriate interventions between then and the 2016 update. However, there remains a need for better data to underpin cancer risk assessments. Guidance should include more explicit discussion of the limitations of current data and associated clinical recommendations. Oversight of all recommendations for interventions may be warranted, given the grave and irreversible nature of some interventions, resulting in infertility.

The Commission notes the call for personalised risk assessment based on individualised immunohistological investigations to ensure that the risk assessment is as accurate as possible. Revised guidelines could highlight the need for such investigations prior to formation of any recommendations.

The Commission considers that decisions to undertake interventions such as gonadectomies



should be premised on robust evidence of preventing unacceptable risk to health.

Interventions to address malignancy may involve gonadectomy, which may have serious human rights implications. Whether a person with a variation in sex characteristics is fertile or not depends on the type of variation, and other specifics of their case. Removal of gonads in some cases would not be sterilising, because they would not be fertile in the first place. In other cases, however, gonads may be fertile, or may contain tissue that could allow fertility as a result of future advances in medicine. Thus, the consequences of gonadectomy for some is serious.

Another factor relevant to the assessment of risk is when the potential malignancy may manifest itself, and therefore whether the intervention is needed before the person is old enough to consent, (or otherwise in a position to consent). In some cases, significant risk is present from an early age, while in others it is unlikely to manifest until puberty.

Where the risk is unlikely to arise until later infancy or puberty, the Commission considers there are strong grounds to defer any intervention to preserve the possibility of fertility – consistent with the Precautionary principle. Deferral where safe to do so is consistent with human rights obligations so that children are in a better position to make decisions for themselves or actively contribute to those decisions about serious medical interventions on their bodies – consistent with the Children’s agency principle.

To be characterised as an intervention necessary to address a serious risk to physical health, the intervention must be proportionate, including being the least intrusive intervention. The 2006 Consensus Statement provides information on the variability of malignancy risk across different variations and recommendations for appropriate treatment.³²⁰ Treatments range from doing

nothing, to, in other cases, monitoring. The most frequent recommendation is for gonadectomy.

Where the option to effectively monitor the gonads exists, that should be preferred to early gonadectomy. From a human rights stance, the less invasive option, that allows for the maximum enjoyment of human rights (including retaining the potential for fertility and for informed personal decision making), is always preferred. Monitoring still allows for gonadectomy to occur at a future time where the risk can no longer be safely monitored. It also allows for exploration of alternatives to gonadectomy that may develop in the meantime.

The Senate Committee Report expressed concern about the risk of gender-based rationales ‘being interpolated into risk of cancer’ to justify interventions.³²¹ This echoes views expressed by people born with variations in sex characteristics.

Any intervention should be based on medical necessity, and not on another psychological or gender-based rationale.

Some variations in sex characteristics carry a risk of cancer. Decisions to intervene, such as with the performance of a gonadectomy, must be based on robust evidence of unacceptable risk of serious harm. Where such evidence suggests the risk of malignancy is so high that intervention cannot be deferred, nor effectively monitored, more invasive intervention may be considered a medical necessity.

Intervention in these circumstances achieves the goal of preserving life or promoting health, and thus would meet the standard of medical necessity – as reflected in the Medical necessity principle. Where, however, effective monitoring is possible, the Commission does not consider that invasive surgery would meet the standard of medical necessity and would not be permissible in the absence of personal consent.

(d) Interventions to ‘normalise’ genitalia and other psychosocial rationales

The Commission heard from a range of submitters that interventions occur for psychosocial reasons. A ‘psychosocial rationale’ refers to where an intervention is undertaken to make an individual’s body look and function in a ‘typically’ male or female way. These rationales often reflect a presumption that an individual’s womanhood or manhood would be challenged by having genitalia that did not match what is expected of that sex.

Some interventions have been based on psychosocial reasons, to address concerns from clinicians and/or parents that the child has ‘ambiguous’ sex characteristics. Sex characteristics that are perceived by some as ‘ambiguous’ or atypical are perceived to cause problems that do not relate to the individual’s physical health. Interventions in this instance are sought to create more ‘typical’ sex characteristics and facilitate binary sex assignment and consequent gender rearing.

Other interventions have occurred not in relation to ambiguous sex assignment, but rather sex characteristics that are considered to adhere to certain traditional notions of how male or female genitals should appear. An example would be a clitoris that is considered too large, such as with some girls with CAH.

Arguments in support of such rationales advanced the view that children who did not have interventions to make their sex characteristics more typical were at risk of potential familial rejection and bullying-isolation among their peers.

These arguments were strongly opposed by people with lived experience of variations in sex characteristics and stakeholders in psychology and psychiatry who called for less rights-

intrusive responses to manifestations of these variations, such as psychological support and community education. They argued that non-intervention enables individuals to avoid the risks of surgery including, among other things, psychological damage, repeated surgeries, and sexual satisfaction issues, following surgical and hormonal interventions.

Psychosocial rationales do not rise to the standard of medical necessity to avoid serious harm, given that less intrusive options exist that should be preferred, and that psychological and psychiatric experts do not believe that there is any robust scientific evidence to support the assertion that interventions in the circumstances are in the individual’s best interests.

(i) Past/present practice

Stakeholders expressed differing views about whether interventions have been and continue to be undertaken for psychosocial reasons.

One hospital multi-disciplinary team stated that decisions about past interventions were

made by the individual themselves, parents, and professionals ... based on the available information and contemporaneous socio-cultural values in the context of a perceived optimal gender framework prioritising the best interests of the child within the family unit.³²²

Many human rights groups and people born with variations in sex characteristics reported that interventions they have experienced were based on traditional binary views of gender identity and sexual orientation. These include interventions to modify sex characteristics based on assumptions about gender identity, and binary, heteronormative expectations of children.³²³ They argue that interventions

are based on heteronormative ideals about what women and men's genitals are supposed to look like, how they are supposed to be used, and who they are supposed to be used with. They make a lot of assumptions that people are going to be straight and into having "normal" sex.³²⁴

The term 'binary expectations of sex characteristics' refers to community expectations that an individual should have sex characteristics that conform to either traditional medical view of male or female bodily parts. The term 'heteronormative expectations of sex characteristics' means community expectations of sexual performance that conform to traditional male with female sexual activity or intercourse.

Some people born with variations in sex characteristics also reported experiencing pressure to take hormonal treatments to support and maintain ongoing alignment between their bodies and assigned sex.³²⁵ A parent framed their reason for agreeing to a particular surgery for their child with a variation in sex characteristics as being to avoid teasing/bullying of their child from other children for looking like an atypical girl.³²⁶ In respect of hormone therapy, a parent peer-support group said that early low dose boosters are administered, among other things, to allay parental anxiety about their child's micropenis.³²⁷

One person born with a variation in sex characteristics described the vaginoplasty they experienced as a child as 'allowing me to successfully accommodate a future fictitious husband and hence make me a more normal female'.³²⁸

This justification links sex assignment with technical surgical outcomes and relies on the idea that children need sex characteristics that match their assigned sex.³²⁹ In the Family Court decision of *Re Carla*, feminising surgery was partially justified on

the basis that it would align Carla's genitalia with gender-identity, as perceived by the parents and the treating paediatric psychiatrist.³³⁰

Some clinicians stated that they take steps to alleviate pressure to make decisions about gender assignment. One group of clinicians referred to their use of armbands. They stated that they use white, rather than pink or blue armbands on infants; and notations may be made to the effect that the child is born 'intersex' or of 'indeterminate' sex, with the intention of reducing pressure (perceived or actual) to assign a sex as a matter of urgency.³³¹

Concerns about dissatisfaction with gender assignments were nevertheless raised. A government agency with relevant expertise submitted that studies have found rates of gender assignment rejection among intersex children ranging from 5 to 40%, depending on the condition, and thus it preferred deferral of such interventions.³³² For example, in the 2006 Consensus Statement, a rate of 25% is cited for dissatisfaction with sex of rearing among individuals with PAIS, androgen biosynthetic defects, and incomplete gonadal dysgenesis.³³³

Hypospadias surgeries are a type of 'normalising' surgery usually undertaken on individuals when they are children. According to the submission from a hospital multidisciplinary team

Hypospadias surgery is routinely offered to boys, on the basis that surgery in infancy or early childhood carries better urological outcomes and minimises psychological harm.³³⁴

The evidence from this submitter indicates that they do happen. However, given the lack of systematic data collection, it is unclear to what extent interventions on hypospadias persist.

Current medical guidance explicitly contemplates conducting normalising interventions for psychosocial reasons. For example, the 2006 Consensus Statement advises clinicians that factors that influence gender assignment include ‘the diagnosis, genital appearance, surgical options, need for life-long replacement therapy, the potential for fertility, views of the family and sometimes, circumstances relating to cultural practices’.³³⁵

The statement later explains that what is surgically possible is a relevant factor to consider to inform sex of rearing:

The decision on sex of rearing in ovotesticular DSD should consider the potential for fertility based on gonadal differentiation and genital development, and assuming the genitalia are, or can be made, consistent with the chosen sex.³³⁶

Along the same lines, it states:

The magnitude and complexity of phalloplasty in adulthood should be taken into account during the initial counselling period if successful gender assignment is dependent on this procedure. At times this may affect the balance of gender assignment.³³⁷

It addresses the view that early intervention is preferable for psychosocial reasons:

It is generally felt that surgery that is carried out for cosmetic reasons in the first year of life relieves parental distress and improves attachment between the child and the parents. The systematic evidence for this belief is lacking.³³⁸

In the 2013 Victorian Decision-Making Principles, there is a cataloguing of factors relevant to ‘Minimise psychosocial risk to child’.³³⁹ It states, for example, that ‘the risk of embarrassment about genital appearance and related stigma should not be given undue weight in the decision-making process at the expense of other human rights’.

It guides clinicians on factors to consider, relevant to ‘Leave options open for the future’. Three of the four factors relate to familial and social acceptance, which are the

- risk that the child will not be accepted by parents in the chosen sex of rearing, leading to impaired bonding and associated negative consequences
- risk of social or cultural disadvantage to the child, for example, reduced opportunities for intimate relationships, or reduced opportunity for meaningful employment and capacity to earn an income
- risk of social isolation, restrictions or difficulties, for example, caused by embarrassment or social stigma associated with having genitalia that does not match the gender in which the person lives.³⁴⁰

Medical guidance materials issued in relation to specific variations also indicate that psychosocial rationales are used to justify interventions. For instance, draft guidance issued by the World Health Organization in relation to a variation referred to as 17 β -HSD3 states:

If the diagnosis is made at birth, gender assignment must be discussed, depending on the expected results of masculinizing genitoplasty. If female assignment is selected, feminizing genitoplasty and gonadectomy must be performed.³⁴¹

Information provided by clinicians and people with lived experience of variations in sex characteristics seems to confirm that interventions have been carried out, at least partly, for psychosocial reasons. The 2013 Victorian Decision-Making Principles and the World Health Organization’s ICD-11 beta draft classification for 17 β -HSD3 consider psychosocial reasons as a relevant rationale for medical intervention.

(ii) *Perspectives on intervention for psychosocial reasons*

Clinicians expressed a range of views about whether interventions on infants based on 'normalisation' should be allowed in future.

Some clinicians from outside the fields of psychology and psychiatry considered psychosocial rationales to be relevant to determining whether a proposed intervention is justified.³⁴² One specialist clinical organisation stated that current recommended medical practice does not see surgery aimed at aligning the genital appearance with the chosen sex-of-rearing as a default option.³⁴³ At the same time, it stated that one reason to intervene is to preserve individuals' capacity for satisfying sexual function'.

Some clinicians from outside the fields of psychology and psychiatry and some parents considered that interventions should be allowed to occur where genitalia depart from the medical, binary notions of typical genital appearance. They argued that such interventions can

- promote and support a child's integration in family, community and culture³⁴⁴
- pre-empt potential bullying or stigmatisation, thus promoting their overall wellbeing.³⁴⁵

Clinical experts from specialist bodies in psychiatry and psychology rejected the notion that it is necessary to 'normalise' sex characteristics for mental health reasons. One specialist body in psychology stated:

Having an intersex variation is not a mental health issue in itself, but mental health issues may arise due to perceived conflicts with social and cultural ideas about sex. Additional mental health issues can emerge as a result of surgeries and hormone treatments that may be imposed on infants and young people throughout childhood and adolescence.³⁴⁶

In rejecting psychosocial reasons as grounds for intervention, it continued:

decisions and processes regarding medical intervention need to focus primarily on the individual's wellbeing, over and above a concern for social integration which often means normalisation.³⁴⁷

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) disputed the assertion of positive mental health outcomes following interventions:

There is little evidence for sex assignment therapies leading to positive or negative mental health outcomes. Accordingly, claims that sex assignment therapies are 'necessary' or 'therapeutic' are dubious. In the absence of such evidence, decisions should be made with the understanding that the patient's wishes are absolutely paramount.

The family's belief regarding the psychosocial impacts of intervention or non-intervention are unlikely to be based on medical evidence, and therefore reliance on such beliefs may result in inappropriate decisions being made for individuals whose wishes may ultimately prove counter to their families. In such cases, enforced sex assignment therapies may produce more harm than good. The RANZCP supports a cautious approach to decision making where there is no physical necessity for intervention.

In relation to predicting future health and wellbeing, the RANZCP stated that

decisions should be made taking into account the paramountcy of informed consent and the importance of leaving options open for the future, particularly regarding an individual's choices with regard to gender identity, fertility and sexual relations which may each prove critical to a person's life and therefore mental health.³⁴⁸

The RANZCP also expressed concern that

sex reassignment decisions may be made within an overly narrow frame. *Primum non nocere* – do no harm – is central to medical ethics and [carries] with it powerful and longitudinal meaning for this group. Therefore, the RANZCP supports the deferral of sex assignment treatment decisions which have irreversible consequences until the person can provide informed consent, [except] in case of medical necessity.³⁴⁹

People born with variations in sex characteristics did not support normalising interventions on children who were not yet *Gillick* competent. They considered that such interventions are not medically necessary and as a result infringe human rights. They expressed the view that only interventions that are medically necessary should be permitted without personal consent.³⁵⁰

Some people born with variations in sex characteristics questioned the capacities of non-psychological/psychiatric clinicians to assess the psychosocial impacts of intervention. They contended that this is due to the dominant biomedical framework in which key clinician specialities such as paediatrics and surgery work and their overall lack of understanding of all of the psychosocial dimensions that are engaged in interventions that affect sex characteristics.³⁵¹

Discussions in treating teams benefit from the input of professionals, such as psychologists and psychiatrists, who have expertise in the psychosocial dimensions of any potential intervention. However, treating teams often do not contain psychologists or psychiatrists.³⁵² According to IHRA, even where psychologists and psychiatrists are present, their ability to contribute to treatment recommendations is limited, as argue that the power structures of treating teams privilege surgeons' opinions and advice to parents.³⁵³

Some clinicians expressed a view that variations in sex characteristics, if not 'normalised' through medical intervention, can disrupt parent/child attachment.³⁵⁴

Other clinicians expressed willingness to regard parental urgings for intervention as determinative of, or at least relevant to, the question whether and when to intervene.³⁵⁵ This is based on regarding the autonomy of young children as purely relational to a child's family and culture. On this view, from early childhood and progressively lessening overtime, a child's developing autonomy can only be given substance by reference to the family, community and cultural context in which they are being raised. In this context, some clinicians regarded religious, cultural and community beliefs about variations in sex characteristics, gender identity and expression, and sexuality as relevant to decision making about interventions.³⁵⁶

Some stakeholders from LGBTI community organisations expressed concern that psychosocial justifications privilege parental, family or community wellbeing and the avoidance of potential discomfort of parents, family, and the community with diverse body shapes.³⁵⁷

Parents and clinicians often explained decisions to intervene with reference to how the child might be treated by others, and preventing poor treatment, such as stigmatisation or bullying, by 'normalising' the child's sex characteristics.

In this context, hypospadias surgeries are routinely offered during infancy as it produces 'better urological outcomes and minimises psychological harm'.³⁵⁸ A hospital multi-disciplinary team observed that the 'evidence for this is incomplete; however so is the evidence to support deferring surgery'.³⁵⁹ The NHMRC funded research program stated that 'hypospadias surgery [is] almost universally acknowledged to be beneficial'.³⁶⁰ Clinicians who supported conducting hypospadias surgery did not articulate the reasoning for why such surgery is considered medically necessary.

A parent provided an insight into why they wanted their son to have a hypospadias surgery:

My son's severe hypospadias[s] repair requires several surgeries. In non-medical terms, he [was] born with a hole in the middle of his scrotum. ... He has had two surgeries so far and will need another one when he is 5 or 6 years old depending on a number of different medical factors. However having completed the two surgeries, I know we've made the right decision. He was younger when he had them and does not remember them. He is now at the age where he is becoming increasingly aware of his penis and its purpose, potty training is just around the corner. He now pees through the hole on the head of his penis as opposed to from the hole located underneath his scrotum. ... It also meant that if the repair was not done, the functioning of his genitals would not work in a normal way and cause his peers to look at him when the time came, differently. It also would have meant he would not be able to stand and urinate as other males and he would always need to sit and urinate.³⁶¹

This objective to enable a boy to stand to urinate is commonly cited, among other reasons, in the medical literature.³⁶²

One specialist body in psychology rejected the assumption that hypospadias surgeries are medically necessary. It stated:

Importantly, some surgeries are often treated as medically necessary – such as for hypospadias – when in fact perceived complications may self-correct as the child matures. 'Self-correct' does not necessarily mean that the issue will go away; rather

it means that in many cases the person finds ways to happily live with the variation – an option that is denied if unnecessary treatment occurs.³⁶³

Some people born with variations in sex characteristics disputed that such interventions are medically necessary.³⁶⁴ They argued against medical interventions as a response to anticipated bullying and stigmatisation. They rejected the view that parents and clinicians are well-placed to predict what a child will need to attain psychosocial health and wellbeing.³⁶⁵

These stakeholders expressed a view that intervention in the absence of personal consent on these grounds perpetuates stigma and discrimination by

- pathologising variations in sex characteristics
- 'normalising' sex characteristics through intervention
- erasing diversity of bodies
- not encouraging greater community and professional knowledge and understanding of bodily diversity, including variations in sex characteristics.³⁶⁶

Some of these stakeholders argued for 'a social model of intersex', and for community education about bodily diversity, to remedy what they perceive as medical erasure of diversity in sex characteristics.³⁶⁷ They described the social model of intersex as seeking

to provide social pathways that enable intersex people and their families to be accepted, protected, self-determining, empowered, resilient, visible, and represented at all levels of society - to share

a deep sense pride and belonging in our bodies and community.³⁶⁸

They argued for more education, information, and counselling.

(iii) *Psychosocial rationales and medical interventions modifying sex characteristics*

Interventions on people born with variations in sex characteristics for psychosocial reasons was contested by a range of stakeholders, with most clinicians and some parents arguing that it is a relevant rationale. Clinicians from specialist bodies in psychiatry and psychology stated that there is no evidence that interventions on this basis provide better psychosocial outcomes. They argued that such interventions can in fact cause psychological problems. People born with variations in sex characteristics, regulators, and legal and human rights organisations, all opposed surgical or hormonal interventions based on psychosocial rationales. People born with variations in sex characteristics who had interventions on this basis did not report good psychological outcomes. Nevertheless, various other clinicians argued that ‘normalisation’ can be justified, at least partially, based on mental health benefits. The Commission has not been presented with compelling evidence to support this justification. The 2006 Consensus Statement says that there is no systematic evidence to support the assertion that early surgical interventions are more effective.³⁶⁹

Making a decision about the gender or sex characteristics of another person, without their consent, is a significant intrusion on their right to bodily autonomy and integrity.

The Commission notes that surgeries and other interventions that occur for psychosocial reasons are generally intended to erase visible signs of variation in sex characteristics and acknowledges the part of parents in urging such interventions.³⁷⁰ However there is the potential to mix considerations about the child’s health and wellbeing with considerations that relate more to

those people around the child, such as parents and other caregivers.

As discussed in Chapter 3 – Lived experience, people born with variations in sex characteristics reported experiences of stigma and discrimination associated with interventions. ‘Normalising’ interventions have been understood by both people born with variations in sex characteristics and those around them as meaning that their bodies are undesirable or problematic. This can fuel stigma and shame.

The Commission agrees that ‘normalising’ interventions appear to exacerbate a cycle of stigma about bodily diversity, thereby being used to justify further medical interventions. Some people born with variations in sex characteristics considered that repeated early medical intervention to prevent bullying and isolation, led to them becoming adults who feel that they have been deprived of agency over their bodies and their health. They reported poor mental health related to this deprivation of agency (and to other aspects of their variation).

While human rights law permits parents to consent to certain medical interventions on behalf of their children, this is not an open-ended right to consent to any intervention whatsoever. In cases of medical intervention to modify a child’s sex characteristics, the child’s autonomy can be limited only where the proposed intervention meets the standard of medical necessity.

Intervention based on psychosocial grounds frequently involves giving undue weight to factors such as the preferences of parents or the wider family. Those factors alone cannot justify non-consensual intervention.

It was argued by some clinicians that interventions are needed to protect psychological health. The Commission is not persuaded that interventions without personal consent are needed to protect psychological health for the following reasons:

- interventions can lead and have led to psychological harm and mental anguish related to feelings of stigma and shame
- there is mixed evidence about whether interventions prevent harm to the individual in a way that is proportionate to the harm that the interventions may cause
- expert medical opinion before the Commission (from psychologists and psychiatrists) is that the interventions are not needed to prevent these claimed harms
- evidence from people with lived experience indicates the variations themselves do not lead to these harms – parental, clinical, and social attitudes do
- there are other, less human rights intrusive ways to address these harms (especially education, counselling and peer support).

Thus, the Commission considers that interventions based on notions of normalising sex characteristics and other psychosocial rationales do not meet the standard of medical necessity.

5.4 At what point of time is an intervention necessary?

A critical element of the concept of medical necessity is understanding the justification for the timing of an intervention. For example, can the condition be monitored until a child is at a later age or reaches an age where they can provide their personal consent? Is it feasible that less intrusive medical options may be possible if interventions are left until a future time? Alternatively, does earlier surgical intervention reduce the complexity of the surgery or increase the chance of optional functioning?

There was a divergence of views on the weight that should be placed on early interventions to prevent serious consequences at some time in the future.

(a) Support for early interventions

Most parents and clinicians supported ‘early’ interventions, in circumstances where they believed that it would be less complex to achieve the desired outcome. Support for early interventions was based on the belief that this was in the child’s best interests.

Parents told the Commission that authorising such interventions fulfils their parental responsibilities by protecting their children’s rights to attain the highest possible standard of health and wellbeing.³⁷¹

One clinician cited the example of performing hypospadias surgery, stating that it

is routinely offered to boys, on the basis that surgery in infancy or early childhood carries better urological outcomes and minimises psychological harm. The evidence for this is incomplete; however so is the evidence to support deferring surgery.³⁷²

This clinician goes on to say that ‘there is little evidence to support the long term psychological effect of early or delayed surgery’.³⁷³

Some parents and clinicians supported early intervention based on the assertion that it is better as a child cannot remember the interventions.³⁷⁴

One parent clarified that having her son’s hypospadias surgery early was of benefit as they believed their child doesn’t remember ‘the surgery or pain’.³⁷⁵

(b) Opposition to early interventions

Opposition to early interventions was based on the view that only interventions that are medically necessary at the present moment should occur

without personal consent. They also argued that parents and clinicians are not in a position to evaluate what would be in the child's best interests at some future point.

Specialist bodies in psychiatry and psychology, including RANZCP, opposed early intervention for 'sex assignment' surgeries, arguing that they should not be undertaken before the person is considered Gillick competent.³⁷⁶ People born with variations in sex characteristics consistently rejected arguments in support of early intervention based on interventions being less complex or being more likely to yield optimal functional outcomes.³⁷⁷ They advocated for deferral until a child is old enough to define and voice their own understanding of their rights and interests.³⁷⁸

Human rights groups rejected the argument about the 'benefit' of not being able to recall surgical or other painful interventions. They felt that individuals' developing sense of self was impaired by early intervention, and that this was compounded where they did not receive timely, developmentally appropriate information about interventions that had previously been undertaken.³⁷⁹

(c) Timing of interventions

The 2016 update to the Consensus Statement makes clear that timing of interventions is not settled, stating:

There is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery ... Timing, choice of the individual and irreversibility of surgical procedures are sources of concerns.³⁸⁰

One specialist body in psychology cited *Intersex: Stories and statistics from Australia*, which states:

People with intersex variations may experience mental health concerns arising from the effects of early surgeries undertaken when they were infants that affect them throughout their life (e.g., in terms of sexual functioning, fertility, continence) ... Young people with intersex variations may also be given hormones to impose physical characteristics expected of the sex they were assigned. Unnecessary hormone treatments can also have negative impacts on people with intersex variations throughout life.³⁸¹

Fagerholm and others argue that differences in mental wellbeing outcomes between people born with and without intersex variations may only become apparent as people grow older. Their research indicates that the impact of early surgeries on overall mental health, quality of life, and health-related quality of life was good for most participants, but for a significant minority there were concerns relating to unhappiness with the outcome of their surgery or current poor sexual function.³⁸²

The divergence of views about the timing of interventions stems partially from how a child's current and future rights and interests are understood.

Parents and many clinicians argue that early intervention is justifiable on the basis that parents are acting in the best interests of their children, understood through the prism of family and community relationships, norms and expectations.³⁸³ From this stems a view that they are in a unique position to make decisions about timing of interventions, premised on assertions that early interventions achieve more optimal outcomes for infants.

People born with variation in sex characteristics dispute this characterisation of more optimal outcomes, citing, for example, research indicating that early interventions do not always have the positive outcomes claimed.³⁸⁴

Significantly, as cited earlier, the evidence that procedures such as hypospadias surgeries result in better urological outcomes and minimise psychological harm is incomplete (as is the evidence to support deferring surgery). In respect of data relating to optimal timing of surgical interventions generally, the 2016 Consensus Statement update states:

Timing, choice of the individual and irreversibility of surgical procedures are sources of concerns. There is no evidence regarding the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization.³⁸⁵

This echoes the position expressed in the 2006 Consensus Statement.³⁸⁶

The Commission notes that, since the High Court's decision in *Marion's case*, it has been accepted as part of Australian law that the interests of a child are not necessarily fully congruent with the interests of other family members, or the family as a whole.

The Commission is cautious about arguments about better 'psychological outcomes' from early interventions, given what the Commission heard of the experiences of people born with variations in sex characteristics that the results of early interventions have not been universally optimal.

Caution also stems from the fact that even those clinicians who support early interventions as producing better outcomes concede that evidence

is incomplete. A human rights-based approach, reflected in the Precautionary principle, would be to defer interventions where safe to do so until the individual concerned can engage in the decision-making process.

5.5 Human rights approach

Recommendation 4:

Medical interventions modifying sex characteristics of children born with variations 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.

International human rights law recognises that there will be some limited and narrowly defined situations where it is permissible to perform medical interventions without the consent of the affected individual—under the Medical necessity principle.

In the Commission's view, this relates to the situation of *medical necessity*—that is, where medical intervention is required urgently to avoid serious harm to the person concerned. In this context, an intervention is 'required urgently' if it cannot be deferred without a significant risk of serious harm.

Evidence of current and past practice suggests that medical interventions have been undertaken on people born with variation in sex characteristics in circumstances that do not always constitute medical necessity.

Current clinical guidelines permit such medical interventions on children without personal consent in circumstances where these interventions do not constitute a medical necessity.

New *National Guidelines on medical interventions for people born with variations in sex characteristics* (see Recommendation 6) are needed to explain the application of the Medical necessity principle in complex decision-making environments. This would include explanation and guidance on concepts like proportionality, and the need to adopt the least intrusive intervention.

These guidelines should, for example, explain that psychosocial rationales are not a permissible basis

for intervention without personal consent and highlight where there is incomplete evidence—for example, in respect of certain cancer risks.

These guidelines should also emphasise the need for robust evidence that any proposed intrusion on rights is rational and can be expected to be effective in realising the legitimate purpose of promoting health.

Independent scrutiny is also needed to ensure proposals for intervention meet the standard of medical necessity—particularly in areas of ambiguity such as risk of impairment to organ or biological function, or cancer risk. Such independent scrutiny would manage the significant risk of making a decision about the ‘best interests’ of a child where the child is not yet able to consent, and where, given the nature of many of these interventions, the consequences of making a wrong decision are particularly serious.

CLINICAL PRACTICE AND NEW NATIONAL GUIDELINES

This chapter discusses how clinical care is provided to people born with variations in sex characteristics, and how decisions about medical interventions are made. A variety of clinical management practices were identified by stakeholders as being significant in this context. Multidisciplinary care is the preferred model of care, although the extent to which it is available varies across the country.

At present, clinical management occurs within a framework of non-binding international and jurisdiction-specific guidelines. In the Commission's view, these guidelines should be augmented by new National Guidelines informed by the human rights framework in this report.

The National Guidelines should guide decision-making processes to ensure that medical interventions modifying sex characteristics are not undertaken unless intervention is a medical necessity. The recommended National Guidelines should include guidance on

- obtaining informed consent and ensuring affected children and younger people are involved in decisions – consistent with the Children's agency principle (see Chapter 4)
- the application of human rights principles in determining whether a medical intervention is a medical necessity – as expressed in the Medical necessity principle (see Chapter 5), and
- requirements for independent authorisation of certain medical interventions – consistent

with the Independent oversight principle (see Chapter 7).

The Commission recommends that the National Guidelines be developed by a national multidisciplinary expert group convened by the Australian Government (see Recommendation 6) and they should complement legislative reforms recommended in Chapter 7.

These latter reforms would require that certain medical interventions modifying variations in sex characteristics must be subject to authorisation by an Independent Panel. Decisions about which medical interventions require authorisation would be informed by the National Guidelines.

The recommended 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.

6.1 Clinical practice

Clinical management practices vary considerably across Australia. In large tertiary centres, clinical care is often provided in multidisciplinary treatment teams (MDTs), especially for children.

The following section discusses MDTs and how they are constituted and operate, and some problems identified with current MDT management and care. The section then highlights a range of broader

concerns about medical management and care for people born with variations in sex characteristics.

(a) Multidisciplinary treatment teams

MDTs comprise clinicians with a range of specialist skills, as well as other relevant qualifications. In some centres, MDTs are constituted at least partly of clinicians who are not part of the treating team. In other locations, multidisciplinary care is not necessarily available. MDTs are widely considered to be the best model for providing medical care to people born with variations in sex characteristics, although there was some divergence of views about the best composition of those teams.

(i) *Benefits of multidisciplinary teams*

Stakeholders said that MDTs provide diverse input from an array of relevant disciplines to inform the discussions about care and treatment for individuals born with variations in sex characteristics. A hospital MDT in a major tertiary centre said that:

[With] every case, current knowledge and latest developments in practice are applied to decision-making. Ongoing review and feedback from both clinicians and families suggest this process is useful.³⁸⁷

Clinicians involved in established MDTs stated that these teams can provide a holistic approach and evidence for and against all treatment options, including surgery. In each individual situation they can guide and support the parents and guardians in reaching informed choices. These clinicians expressed the view that external legal oversight is generally ill-equipped to address these questions, with matters usually referred back to expert clinicians.³⁸⁸

(ii) *Access to MDTs*

There are MDTs in Sydney at The Children's Hospital, Westmead and Sydney Children's Hospital,

Randwick; in Melbourne at the Royal Children's Hospital and Monash Children's Hospital; and in Perth, at Perth Children's Hospital.³⁸⁹ There is also an informal inter-disciplinary body in Brisbane at the Queensland Children's hospital.³⁹⁰ Many children who are not born or being treated at these locations will need to be referred to an MDT, either by a clinician or by their own or their parents' or guardians' volition.

The Australasian Paediatric Endocrine Group (APEG) noted the importance of the role of the clinician in centres away from the major cities, emphasising that

awareness of the need to refer to such teams lies with clinicians in smaller centres and recognition of a DSD [Differences of sex development]/variation in sex development in the first instance (which is not always straightforward).³⁹¹

A specialist at a medical roundtable observed that it is a challenge to ensure care where a child is born in a smaller town.³⁹² Where possible, that multidisciplinary team tries to see the family with their child shortly after birth, keeping the local paediatrician involved.³⁹³ Children are predominantly referred to their MDT from within their network, but children and adolescents seen by clinicians outside the network can also be referred for discussion.³⁹⁴

(iii) *Composition of MDTs*

APEG stated that MDTs are constituted by 'paediatric endocrinologists, urologists, gynaecologists, geneticists, ethicists, psychologists, hospital executives and medico-legal representatives'.³⁹⁵

MDTs were described as varying in relation to the 'criteria of cases requiring discussion, geographic set-ups (national versus regional centre MDTs), and the regular participant specialties who attend meetings'.³⁹⁶

The Western Australian Multidisciplinary DSD Team stated that its team is constituted by an endocrinologist, and paediatric surgeon/urologist, with a social worker involved at diagnosis.³⁹⁷ However, it noted there was a 'lack of mental health professionals with expertise and training, to provide both initial help and long-term follow-up'.³⁹⁸ Clinicians at the Perth medical roundtable confirmed the need for 'more psychological help'.³⁹⁹

A clinical specialist at the Melbourne medical roundtable described the Royal Melbourne Children's Hospital MDT as being constituted by about 15 different types of clinicians, including clinical ethicists.

One MDT in a major tertiary centre drew on

the professional experience of up to 25 clinicians including endocrinologists, urologists, gynaecologists, geneticists, a psychologist and ethicists (whose collective experience exceeds 300 years) is directed towards each individual case.⁴⁰⁰

(iv) *Which cases are seen by MDTs?*

MDTs are autonomous and independent of one another, and the people they see differ in their characteristics. Some clinical stakeholders stated that they do not see people with certain specific variations or those with 'simple' hypospadias. It was suggested that MDT review is generally for those characterised as more complex cases.

Clinicians at the Perth roundtable said they see about 20–30 individuals a year with a 'real ambiguity at birth, who have a defined and significant variation of DSD, or certain specified syndromes like AIS (Androgen Insensitivity Syndrome)'.⁴⁰¹ This cohort does not include individuals with Turner's syndrome, whom they do not regard as intersex, nor does it include boys with Klinefelter Syndrome. Rather, these two groups are treated by general endocrinologists.

Specialist clinicians from Royal Children's Hospital in Melbourne said that the cohort they see includes complex hypospadias, babies where prenatal non-invasive pre-natal screening (NIPS) indicates



genetics are inconsistent with phenotype, as well as any variation that has atypical appearance.⁴⁰² They stated that characteristics such as micropenis may not be reviewed by their MDT. They indicated that they do not review cases of Klinefelter Syndrome or Turner's Syndrome, as these are managed largely with hormonal treatment. They see people across age groups, as variations are not always picked up at birth.

Clinicians at the Sydney medical roundtable said that their MDT sees anyone up to 18 or 20 years of age, for whom medical, surgical, ethical decisions need to be made. 90% are under one year of age, although they might come back several years later when another decision needs to be made. This MDT tends to see people with more complicated problems that may be more controversial. They stated:

An audit of the cases presented at the meeting from August 2012 to August 2018 identified 48 new referrals and 14 follow up discussions. The most common referrals to the DSD forum were for timing/need for gonadectomy for non-functioning gonads with malignant potential and hypospadias repair for boys with complex hypospadias associated with other genital variations (eg undescended testes).

This MDT does not see people with regular hypospadias or standard Turner's Syndrome.

Clinicians at the Brisbane medical roundtable said they do not have a formally constituted MDT. However, there is a monthly, in-person, state-wide audit of cases, with the participation of specialists from a range of locations.

(v) *MDT decision making about proposed medical interventions*

The WA MDT described how clinicians approach surgical treatment, stating:

The indication for any surgical treatment is carefully discussed by all members of the DSD Multidisciplinary team and the child (if of an appropriate age of understanding), and parents ... Decision for surgery is a consensus decision, and always with the aim of long-term medical benefit to the child as the primary goal. The need for reconstructive or excisional surgery, appropriate timing for surgery, risks and benefits, and the choice of not having surgery (where this is safe) are discussed. Surgery is undertaken with informed written consent from parents or carers, after this team process is undertaken, and with consensus from the entire DSD Multidisciplinary team.⁴⁰³

Specialist clinicians from the Royal Children's Hospital, Melbourne, described the sorts of cases considered as complex, and thus requiring multidisciplinary review. These included circumstances where there may be a management issue, differences of opinion, and lack of clear evidence over the benefits of one option over another.⁴⁰⁴ At such meetings they always have a clinical ethicist attend to tease out the ethical considerations. If there is no unanimous agreement, they then take the issue to a clinical ethics meeting. This consists of clinicians, ethicists and lay people, although not necessarily any person born with variations in sex characteristics.

(vi) *Summary*

Clinical stakeholders stated that the MDT system improves treatment decision making because it brings together extensive medical expertise from a range of relevant specialities. This is qualified by the recognition that access to such care is not universally available.

The Commission recognises the benefits of this current model, where multiple areas of expertise

inform care for individuals born with variations in sex characteristics.

However, the Commission's consultations indicate some concerns with the current structure of MDTs, and the delivery of care to people born with variations in sex characteristics more generally. These are discussed below.

(b) Problems with MDT management and care

Stakeholders identified problems with current clinical management and care in relation to MDTs. These included issues relating to the composition, availability and funding of MDTs and, in particular, the relative lack of mental health professionals and care coordinators. There were also suggestions that people with lived experience of variations in sex characteristics should be included in MDTs.

A range of stakeholders agreed that mental health services to support individuals born with variations in sex characteristics and their families are inadequate. The WA Children's Hospital MDT identified a

need for following an individual's course, analysing emerging gender identity, supporting a family through very challenging situations at school and in the community and gradually educating a child and young person about their condition, thereby ensuring ongoing informed consent, [this] is time-consuming and cannot be over-emphasized and currently is not being met. This would need dedicated funding for a psychologist with interest and skills in this field as well as funded time for medical interviews, usually much longer than the normal appointments, as well as time for meetings of the wider DSD team. The need for psychological and social worker would be as great, or perhaps more important, if surgery was delayed to age of consent.⁴⁰⁵

Some clinical stakeholders identified the lack of care coordinators as detrimental to the provision of clinical care. APEG called for adequate funding for MDTs, specifically for 'psychological support and a dedicated MDT liaison/care coordinator'.⁴⁰⁶

A clinician at the Perth medical roundtable stated that having a dedicated care coordinator to run a dedicated DSD clinic would be very beneficial.

Some stakeholders proposed that people with lived experience should be included in MDTs. One clinician from a major tertiary hospital stated that the perspectives of people with lived experience of the specific variation being examined by MDTs would enhance their deliberations.⁴⁰⁷

Intersex advocacy and support groups also called for their inclusion in MDTs. One stated that they 'have been calling for greater access to psychological services and the integration of peer support within multidisciplinary clinical teams for 15 years'.⁴⁰⁸

As discussed above, there is a great variability in the management of multidisciplinary teams. One MDT member called for 'the development of a properly funded and formally constituted national DSD MDT which would allow for external consultation from all paediatric care providers in Australia'.⁴⁰⁹

Another MDT member acknowledged the challenge in identifying all individuals with variations in sex characteristics and providing universal and equitable access to appropriate multidisciplinary care. They stated:

We strongly recommend and call for the injection of funds to adequately resource these multidisciplinary services Australia-wide and for the education of clinicians in regional and remote areas outside of major centres in the access to and availability of these resources.⁴¹⁰

Clinicians said that the initiation and conduct of existing MDTs is only possible because clinicians are willing to meet out of hours, in their own time. There is no funding allocation to support the use of a team-based approach.⁴¹¹

(c) Other problems with management and care

Stakeholders identified other problems with current clinical management and care relating to care outside of the MDT framework. These included inconsistent clinical practice, lack of access to mental health services, and lack of referral and continuity of care.

(i) Inconsistent clinical practice

Some people born with variations in sex characteristics stated that they were aware of individuals who had inconsistent treatment recommendations, despite having the same variation.⁴¹² In one instance, it was claimed that the same treating clinician recommended surgical intervention for one individual, but not another, despite similar clinical presentations.⁴¹³

Another person born with a variation in sex characteristics expressed the view that people experienced sub-standard treatment due to variable skills or particular institutional practices and ethos.⁴¹⁴ An MDT also said that different institutions have biases for or against some of the most contentious treatments.⁴¹⁵

The Senate Community Affairs References Committee (Senate Committee) report on the involuntary or coerced sterilisation of intersex people in Australia also made observations about variability in clinical approaches.⁴¹⁶

The Senate Committee referred to a study undertaken by Jaqueline Hewitt for APEG. The survey asked a question about when surgery should be conducted on females with congenital adrenal hyperplasia who show different degrees of virilisation of their genitals, based on the Prader

Scale.⁴¹⁷ It demonstrated a great diversity of opinions among doctors about when intervention would be considered appropriate, and some extreme geographical variation in medical practice. For instance

those favouring surgery at less than 6 months were all from New Zealand, Queensland or outside the region, while those at the other extreme, recommending no infant surgery in any circumstances, were all from New South Wales.⁴¹⁸

Evidence in the Senate Committee Report supported the view that there are variable treatment standards, depending on different individual and institutional approaches. To prevent further medically unnecessary interventions, the Commission considers that the existing clinical practice framework needs reform.

(ii) Access to mental health services

Many stakeholders pointed to a lack of counselling and psycho-social support.⁴¹⁹ Clinicians at the Perth medical roundtable said there is an 'acute intervention service, but long term follow up, we don't have psychological help'.⁴²⁰ Another clinical specialist at this roundtable said that it would be beneficial to have more psychological capacity –

to provide more ongoing support for young children and their families, and also as they exit the paediatric space which doesn't have any public provision at the moment. There is no paid public service; cost is a significant factor for accessing psychological support in the private sector.

APEG concurred, and stated:

Although clinical practice guidelines and advocacy groups universally recommend psychological support for children with variations of sex development and their families, this is not routinely offered at all tertiary paediatric centres due to a lack of dedicated resources.⁴²¹

A peer support and advocacy organisation for people born with variations in sex characteristics stated that the current medical frameworks 'do not provide adequate psychosocial support services for our community'.⁴²² Similarly, a parent-support group submitted that 'for those without the capacity, resources, finances or access to [these] allied professionals, individuals are not afforded the care they need and deserve'.⁴²³

(iii) Lack of referral and continuity of care

There can be challenges in initially accessing appropriate care, and continuity of care is of particular concern during the transition from childhood to adulthood.

Some clinicians stated that there is no systematic way that children born with variations in sex characteristics get appropriate multidisciplinary care. As outlined earlier, if they encounter the medical system outside the few capital city institutions with MDTs, it is up to the individual treating clinician to refer them to a major centre. One clinician at a medical roundtable stated that without systematic data collection of people born with variations in sex characteristics, individuals located outside of major metropolitan services miss out on expert care.⁴²⁴

Several clinical and peer-support organisations told the Commission that there is not adequate integration between paediatric and adult care.⁴²⁵ The Commission understands that healthcare needs of people born with variations in sex characteristics are often identified in childhood. Paediatric centres sometimes have MDTs, but even where that is not the case, there are still sometimes mechanisms to share information and expertise to provide whole of patient care. When people turn 18 or thereabouts, they often lose access to these specialist services, with no equivalent adult tertiary, inter-disciplinary service model.

The Endocrine Society of Australia (ESA) said that the 'current lack of transition services has significant impact on the health and well-being of individuals with these complex and chronic conditions as they move into young adulthood'.⁴²⁶

At the Perth medical roundtable, a clinician stated that while there is need for specialist, adult care, the numbers are not big enough to have an actual adult clinic, so they tend to get lost amongst GPs and other practitioners.

One person born with a variation in sex characteristics described their experience of not being supported in their transition from paediatric to adult care:

The paediatrician wasn't very helpful. He wasn't like 'oh you should see this endocrinologist', it was more like 'you know I can't see you anymore because you're not a child so, you know, now you have to find like a GP', or something. And I don't really remember any help with that.

A range of stakeholders pointed to a gap in the provision of lifelong, ongoing and accessible counselling and psycho-social support.⁴²⁷ APEG stated that psychological support

should equally continue to be offered as routine care intermittently over an individual's lifecourse at various developmental stages. Ensuring clinicians providing psychological support are an integral part of the team and well informed about variations of sex development and supporting families in their decisions will also help to overcome the perception of 'they won't understand' that can be a barrier as children are older.⁴²⁸

6.2 Principles that inform clinical practice

This section discusses the principles and approaches that inform clinical practice and interventions for people born with variations in sex characteristics.

A participant in the Brisbane medical roundtable identified acting in the interests of the child as a key principle. An MDT stated that clinical management is guided by principles such as beneficence and non-maleficence, autonomy and justice (both procedural and distributive).⁴²⁹ This stakeholder also identified relevant ethical principles for the management of infants with disorders of sex development to guide clinical management, derived from a resolution of the Fifth World Congress on Family Law and Children's Rights.⁴³⁰ The seven key ethical principles are:

- minimising physical risk to child
- minimising psychosocial risk to child
- preserving potential for fertility
- preserving or promoting capacity to have satisfying sexual relations
- leaving options open for the future
- respecting the parents' wishes and beliefs
- taking into account the views and wishes of children and adolescents who are capable of contributing to decision making about their healthcare.⁴³¹

The extent to which these principles have guided medical practice is unclear. Stakeholders at the Melbourne medical roundtable identified these principles as guiding their processes.⁴³² These ethical principles were significantly informed by the 2013 *Ethical Principles for the Management of Infants with Disorders of Sex Development* (2013 Victorian Decision-Making Principles).⁴³³

(a) Best practice approaches to clinical management and care

There is international clinical consensus that best practice clinical management is supervised and undertaken by teams of specialists.⁴³⁴ This is expressed in the 2006 *Consensus statement on management of intersex disorders* (2006 Consensus Statement),⁴³⁵ and in its update in 2016, *Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care* (2016 Consensus Statement Update).⁴³⁶ The 2016 Consensus Statement Update says that to provide optimal care, a thorough prenatal history should be taken, particularly in the case of infants, as well as a thorough physical examination. It also recommends management by a team of clinicians.

The 2006 Consensus Statement suggests that the composition of teams may vary 'according to DSD type, local resources, developmental context and location'. In terms of the duties of the MDT, it suggests:

The team has a responsibility to educate other health care staff in the appropriate initial management of affected newborns and their families. For new DSD patients, the team should develop a plan for clinical management with respect to diagnosis, gender assignment and treatment options before making any recommendations. Ideally, discussions with the family are conducted by one professional with appropriate communication skills.⁴³⁷

In relation to continuity of care, it states that 'Transitional care should be organized with the multidisciplinary team operating in an environment comprising specialists with experience in both paediatric and adult practice'.⁴³⁸

Most stakeholders considered that many of the shortcomings of current clinical management can be at least partly addressed through provision of comprehensive care by MDTs.

Clinician and parent stakeholders highlighted that people born with variations in sex characteristics may have complex needs that cannot be met solely within a particular institution or service discipline. Sometimes a person's needs can only be met through accessing an array of multiple institutions and service disciplines. These may include

- endocrinologists
- fertility specialists
- general practitioners
- geneticists
- gynaecologists
- occupational therapists
- paediatricians with specialist expertise in child development
- patient advocates
- peer workers
- physiotherapists
- psychiatrists and psychologists
- social workers
- specialist educational interventions
- speech pathologists
- surgeons
- urologists.⁴³⁹

Some clinicians proposed the creation of a register of all individuals born with variations in sex characteristics to ensure that all children are referred to an MDT.⁴⁴⁰ They argued that this would address the issue of people born with variations in sex characteristics living in smaller locations not being identified and therefore not receiving adequate multidisciplinary care.

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) stated its support for

a framework wherein all people born with variations in sex characteristics have access to long term support and management ... to ensure that medical decisions can be made at times in a person's life that they feel are right for them.⁴⁴¹

There was support across stakeholder groups for well-resourced multidisciplinary teams, consistent with recommended international best practice.

Some stakeholders advocated for 'cross-institutional' collaboration to ensure that multiple perspectives are considered when contemplating treatment, particularly in more complex cases. One MDT member advocated the creation of a single, national multidisciplinary team to consider cases and provide assurance as to whether proposed treatment is based on the best contemporary evidence and would be carried out with appropriate expertise.⁴⁴² Such a team should

- make and preserve systematic documentation of the matters coming before it, including rationales cited in favour of intervention and different opinions as to appropriate clinical management
- undertake regular review of ongoing future treatment, especially for complex cases
- have access to an expert reference group, along the lines being developed in New Zealand.⁴⁴³

Stakeholders said that these and other systematic practices, including adoption of formal terms of reference, are currently used by some MDTs in Australia.⁴⁴⁴

One MDT member stated that there is great benefit 'when the MDT comprises individuals who are not the immediate care providers'. They argued that the pooling of a broader range of experience, expertise and perspectives would be valuable and can assist when some of the medical diagnoses are rare and complex. However, 'the process of

seeking external consultation and peer review is difficult in centres where there are few clinicians managing patients with DSD'.⁴⁴⁵

Advocacy organisations agreed that MDTs were desirable, although they cautioned that without human rights compliant standards, MDTs alone would not guarantee human rights-compliant practice. That is, it is necessary to have human-rights compliant standards of care to complement multidisciplinary approaches.⁴⁴⁶

Parent groups also expressed support for multidisciplinary team care.⁴⁴⁷ Other clinical and parental stakeholders argued that creating or involving any entity external to the treating team or institution is 'unnecessary and impractical', on the grounds that

- some treatments are highly time-sensitive
- some treatments occur frequently, and can be addressed by minor surgery (eg, for mild hypospadias), without need for recourse to external expertise or scrutiny
- the current system, which is highly collaborative and informed by extensive expertise across a multiplicity of specialisations, provides all the oversight required.⁴⁴⁸

6.3 Better access to multidisciplinary care

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.

Comprehensive multidisciplinary care is the cornerstone of best clinical management. This is because variations in sex characteristics can be complex and require the expertise of a range of clinical specialities. The 2006 Consensus Statement and the 2016 Update call for this. Clinicians and people with lived experience of variations in sex characteristics have also expressed this view in submissions and elsewhere.

Comprehensive multidisciplinary care must include mental health professionals. Such expertise in the psychological dimensions of variations in sex characteristics is crucial. These dimensions include notions of typical and atypical bodies; family, social and cultural considerations; and concerns about social acceptance and bullying. The Commission understands that mental health professionals are currently not often included in MDTs. Access to mental health services more generally was identified as a significant concern by a range of clinical and non-clinical stakeholders.

Multidisciplinary teams should also include people with lived experience of variations in sex characteristics. In the Commission's view, this would enhance the deliberations of MDTs. It would provide important insights into the lifetime experiences of living with a variation, including from individuals who did and did not experience interventions. Such insights may be of great value, given the paucity of information about the long-term outcomes of intervention.⁴⁴⁹

Multidisciplinary care needs to be included from the first point a person and their family come in contact with the healthcare system. Multidisciplinary care needs to be available across the lifespan of the individual. Particular attention is needed to ensure no loss to care during the transition time around late adolescence when moving from paediatric to adult care. Multidisciplinary care should also be available regardless of location.

Inadequate funding seems to be partially to blame for lack of access to mental health

professionals. Similarly, the lack of comprehensive multidisciplinary healthcare across people's lifespan seems to stem partly from inadequate funding. Inequitable access to multidisciplinary care due to geography may also partly be attributed to inadequate funding for MDTs in places that people born with variations in sex characteristics are born or live.

6.4 Current clinical guidance

No national guidelines exist to inform the treatment of people born with variations in sex characteristics in Australia. One MDT referred to the absence of guidelines to inform practice, stating this is 'a complex and highly emotive area of medicine in which diverse opinions abound and evidence to guide practice is scarce'.⁴⁵⁰

However, some documents provide high-level guidance for medical practitioners. These include the 2006 Consensus Statement,⁴⁵¹ the 2016 Consensus Statement Update,⁴⁵² which are international guidance documents, and the 2013 Victorian Decision-Making Principles.⁴⁵³

Endocrinologists referred to the 2006 Consensus Statement, including its 2016 Update, as providing guidance for clinicians in Australia. APEG contributed to and endorsed the 2016 Update.

(a) The 2006 Consensus Statement and 2016 Update

The 2006 Consensus Statement was published in May 2006, following the 2005 Chicago Consensus Conference. It was developed largely by European and North American clinical experts. Working groups were created to work on discreet parts of the statement. The membership of these working groups was drawn from 50 international experts in the field. The 2016 Consensus Statement Update was published in January 2016. It was written as a collaboration of international experts from Europe and North America.

(i) Purpose of statements

The stated purpose of the 2006 Consensus Statement was to review the management of intersex disorders from a broad perspective, to review data on longer-term outcomes and to formulate proposals for future studies.⁴⁵⁴

The 2016 Consensus Statement Update was intended to address the evolution in clinical approach since the 2005 Consensus Conference, given change in knowledge and viewpoints.⁴⁵⁵

These documents are not binding. They are framed at a high level of generality, and do not discuss in detail the diagnosis or treatment approaches of all variations in sex characteristics, nor do they set out best practice in providing medical care to people born with variations in sex characteristics in all circumstances.

(ii) Scope of statements

The 2006 Consensus Statement addresses nomenclature and definitions, general concepts of care, including for example, multidisciplinary care, clinical evaluation, diagnostic evaluation, gender assignment in newborns, surgical management, sex steroid replacement, psychosocial management, outcomes, risk of gonadal tumours and cultural and social factors.

The 2016 Consensus Statement Update provides an update on the clinical evaluation of infants and older individuals with ambiguous genitalia including perceptions regarding male or female assignment. Topics include biochemical and genetic assessment, the risk of germ cell tumour development, approaches to psychosocial and psychosexual well-being and an update on support groups.

Clinicians refer to the consensus statements as providing guidance, including on protocols for multidisciplinary management of patient cohorts including neonate inpatients, neonate outpatients, and child outpatients.⁴⁵⁶



(iii) *Guidance on consent, children, medical necessity and rationales for intervention*

The 2006 Consensus Statement and the 2016 Consensus Statement Update provide limited guidance on expectations for consent and decision making in the context of infants. They contain a paragraph with high-level recommendations, including sharing information about risks and benefits, articulating uncertainties in the care and outcomes of people born with variations in sex characteristics, and providing time for the person and family to demonstrate to the clinician that they have understood the risks and benefits of each option.⁴⁵⁷

The 2006 Consensus Statement makes no reference at all to the concept of medical necessity.⁴⁵⁸ The 2016 Consensus Statement Update acknowledges that there has been questioning of the parents' 'right to consent to non-medically necessary irreversible procedures that may adversely affect the child's future sexual function and/or reproductive capacity ... particularly when such parental decisions preclude the child's ability to be involved in decision making'.⁴⁵⁹

However, neither document defines 'medical necessity'. Nor does either document suggest that 'non-medically necessary' interventions in such circumstances are inappropriate or, at the very least, to be discouraged.

The 2006 Consensus Statement and the 2016 Consensus Statement Update contemplate various rationales for intervention, including psychosocial, cancer-risk, and cultural and social reasons. The Endocrine Society of Australia stated that the 2016 Consensus Statement Update acknowledges that it is still impossible to predict gender development in an individual case with certainty, and that decisions regarding this and surgery during infancy that alters external genital anatomy or removes germ cells continue to carry risk.⁴⁶⁰

(iv) *Critiques of statements*

As noted above, these documents do not state that medical interventions should only be provided in circumstances of medical necessity or provide any guidance about when interventions are medically necessary. On the contrary, the documents clearly contemplate at least some interventions being

conducted in circumstances where that threshold is not met.

Intersex advocacy groups stated that the 2006 Consensus Statement and the 2016 update were problematic, as they imply a “consensus” on how to manage treatment of people born with variations in sex characteristics. However, the Consensus Statement says that

There is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery ... Timing, choice of the individual and irreversibility of surgical procedures are sources of concerns. There is no evidence regarding the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization. The low level of evidence for management should lead multidisciplinary expert teams to design collaborative prospective studies involving all parties and using protocols of evaluation.⁴⁶¹

(b) The 2013 Victorian Decision-Making Principles

In 2013, the Victorian Department of Health and Human Services issued the Victorian Decision-Making Principles.⁴⁶²

(i) Purpose of principles

The stated purpose of the 2013 Victorian Decision-Making Principles is to help achieve the best possible outcomes for infants, children and adolescents with intersex conditions who are cared for in Victorian hospitals. The principles are framed as current best practice, with an acknowledgment that medical management, human rights, ethical and legal considerations and standards and approaches to treatment for intersex conditions are constantly evolving.

The principles are not binding; they assist in decision making. Clinicians refer to the 2013

Victorian Decision-Making Principles as providing guidance.⁴⁶³

(ii) Scope of principles

The 2013 Victorian Decision-Making Principles cover five topics:

- principles for supporting patients and parents
- medical management principles
- human rights principles
- ethical principles
- legal principles.

(iii) Guidance on consent, decision making, medical necessity and rationales for intervention

Most of the discussion about consent relates to the legal framework in Australia. The 2013 Victorian Decision-Making Principles explain the circumstances in which individual consent must be sought, and where the person is considered *Gillick* competent. They explain when parents are not permitted to authorise interventions and court approval must be obtained, as set out in *Marion's case*.

It suggests age-appropriate educational resources should be provided for parents, children and adolescents about sex and gender diversity. It also recommends the provision of information about, and referral to, support groups for parents and families, and ongoing follow-up and referral to psychological support for patients and their parents throughout the patient's life.⁴⁶⁴

The 2013 Victorian Decision-Making Principles do not address the specific concept of medical necessity. However, they do address the related question of whether a proposed treatment would be non-therapeutic. This is framed as a question relevant to whether a proposed intervention may be authorised without Family Court approval,

under the test articulated by the High Court in *Marion's case*.

The 2013 Victorian Decision-Making Principles recommend that decision making should be guided by the need to preserve the potential for fertility, preserve or increase capacity to have satisfying sexual relations, and leave options open for the future.⁴⁶⁵ The principles address the imperative to 'minimise psychosocial risk to child', setting out four relevant factors that provide reasonable justification for intervention. Three of those factors relate to family, cultural, or social bonding issues. The four factors are:

- risk of assigning the 'wrong' sex of rearing, meaning a gender that the child will later reject or feel uncomfortable with, potentially leading to depression or other mental health problems
- risk that the child will not be accepted by parents in the chosen sex of rearing, leading to impaired bonding and associated negative consequences
- risk of social or cultural disadvantage to the child; for example, reduced opportunities for intimate relationships, or reduced opportunity for meaningful employment and capacity to earn an income
- risk of social isolation, restrictions or difficulties, for example, caused by embarrassment or social stigma associated with having genitalia that does not match the gender in which the person lives.⁴⁶⁶

(iv) *Critiques of the Victorian Decision-Making Principles*

Some intersex advocates have criticised the 2013 Victorian Decision-Making Principles as still permitting early interventions that are not medically necessary and reject them as inadequate to protect human rights.⁴⁶⁷

By contrast, an MDT member said that this document emerged from broad consultation and reflects the importance of holistic care from multidisciplinary teams, as well as a concern to limit medical treatment and prioritise the psychosocial care and welfare of these individuals and their families.⁴⁶⁸

The Commission understands that the Victorian Department of Health and Human Services will be reviewing and updating the 2013 Victorian Decision-Making Principles to ensure they reflect more contemporary understandings and approaches. At present, the 2013 Victorian Decision-Making Principles are not consistent with the Commission's views on when interventions should be able to be authorised, based on the Medical necessity principle.⁴⁶⁹

(c) Non-binding nature of existing guidelines

An MDT member observed that existing guidelines provide the framework on which their team base care management of individuals born with variations in sex characteristics.⁴⁷⁰

Some clinicians said that the non-binding nature of this guidance was a benefit as it allows for individual variability.⁴⁷¹ APEG stated:

Australian physicians and surgeons contribute to the development, endorse and follow international multidisciplinary guidelines for the management of specific conditions under the umbrella 'people born with variations in sex characteristics'. Guidelines give a framework for clinical care based on best available evidence; however they are as the name implies 'guidelines' or proposed strategies for interventions but should not be thought of as 'mandatory' as they cannot account for every individual variation.⁴⁷²

Intersex advocates stated that the non-binding nature of the existing guidelines meant they could not be considered as an effective framework to ensure human rights compliant interventions occurred.⁴⁷³ A LGBTI community organisation argued that there is no published, independent evidence to indicate that any of the guidelines affect practice. They attributed this to, among other things, their non-binding nature.⁴⁷⁴ They also argued that the guidelines were ineffective in protecting human rights given their endorsement of psycho-social rationales for intervention.

6.5 Need for clinical guidance

Most stakeholders were in favour of new guidelines. Support from people with lived experience of variations in sex characteristics was based on the view that guidelines are needed to limit interventions to circumstances of medical necessity and provide for minimum standards of care. Support for guidelines from some clinicians was based on the need for updates to best practice information. However, some clinical stakeholders questioned the usefulness of guidelines.

(a) Stakeholder views on new guidance

Many stakeholders supported new guidelines. APEG submitted that the development of new guidelines could allow for regular reviews of available evidence to update recommendations for practice, though they said that this was predicated on the provision of sufficient funding to resource a writing team.⁴⁷⁵

Intersex peer-support and advocacy organisations, people with lived experience, as well as human rights and legal organisations, were also supportive of new guidelines.⁴⁷⁶ They argued that the 2006 Consensus Statement as a non-binding document does not provide a minimum care standard nor consistency of care, as adherence to the 2006 Consensus Statement is subject to individual

clinician preference. They also considered that the content of the 2006 Consensus Statement fails to protect human rights as it does not prohibit medical interventions on psychosocial grounds.

These organisations stated that the current system has failed to adequately protect the human rights of individuals with variations in sex characteristics and so new guidelines are a necessary part of a framework to ensure human rights.⁴⁷⁷

Arguments against the development of new guidelines included that

- each case is so individual that guidelines would be of limited value⁴⁷⁸
- Australian guidelines would do no more than duplicate the existing 2006 Consensus Statement.⁴⁷⁹

(b) Possible content of new guidelines

Stakeholders made a range of suggestions about the possible content of any new guidelines, including in relation to clinical management, long-term care needs, as well as philosophical approaches to guidelines.

Legal and intersex advocacy organisations envisaged a broad scope for national standards or guidelines, covering more than just recommendations for clinical care. These stakeholders proposed National Guidelines covering both clinical care and management and decision-making processes, as summarised below.⁴⁸⁰

(i) Clinical management

New guidelines should

- prescribe standards of care, across the lifetime⁴⁸¹
- contain specific guidance on the treatment of different types of variations in sex characteristics as distinct components of the overall National Guidelines

- set out contemporary evidence of available treatments, their benefits, risks and expected outcomes in the short, medium and long-term, and identify areas which remain uncertain.⁴⁸²

(ii) *Rationales and consent*

New guidelines should

- detail rationales and procedures that should be deferred until such time as an individual can determine if or when they wish to proceed⁴⁸³
- identify psychosocial purposes that should or should not be taken into account in deciding on whether treatment is medically necessary and non-deferrable⁴⁸⁴
- provide appropriate direction for clinicians, parents, guardians and children about the circumstances in which parents can and cannot give consent to treatment for children and young people who are not *Gillick* competent⁴⁸⁵
- provide standardised materials to assist with the documentation of informed consent in decision making.

(iii) *Legal and human rights framework*

New guidelines should be consistent with the human rights principles set out in Chapter 2 and

- explain the human rights approach to weighing of rights, using the proportionality principle
- provide information for hospitals and clinical teams on the human rights affected by clinical decision making
- develop guidance on legal definitions of 'medical necessity' and 'therapeutic treatment'

- provide direction regarding the types of procedures and scenarios where judicial oversight is necessary⁴⁸⁶

- provide for redress for individuals subjected to some medical interventions without their informed consent.

(iv) *Information, data and privacy requirements*

New guidelines should

- prescribe arrangements for protecting privacy and safeguarding security of data and records⁴⁸⁷
- identify criteria and suggested content for information disclosure to parents and carers, and individuals with variations in sex characteristics.

(v) *Psychological and peer support requirements*

New guidelines should

- require dialogue to be commenced with the child by appropriately qualified medical and psychological experts to assist the child in determining an outcome⁴⁸⁸
- require provision of referral to peer support organisations and access to information for children, parents and guardians.

(vi) *Philosophical approach*

New guidelines should

- acknowledge and make specific provision to address imbalances of knowledge and power between clinicians and individuals, their parents or carers⁴⁸⁹
- reflect views of those with lived experience of variations in sex characteristics⁴⁹⁰
- affirm the value of bodily diversity⁴⁹¹

- affirm respect for bodily integrity⁴⁹²
- state that care must be predicated on the body one has, not one's sex marker or gender identity or expression.⁴⁹³

Clinical stakeholders tended to see the purpose of standards and guidelines as providing direction on questions such as clarifying terms such as 'medical necessity', 'therapeutic treatment' and guidance to assist with the documentation of informed consent in decision-making. They noted a current lack of consensus about such matters as the deferability of certain interventions.⁴⁹⁴

6.6 New National Guidelines

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 in 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.

There are currently no National Guidelines providing minimum standards of care. The existing guidelines – the 2006 Consensus Statement, the 2016 Consensus Statement Update and the 2013 Victorian Decision-Making Principles – collectively are inadequate because they

- do not fully reflect a human rights approach, contemplating interventions for reasons other than medical necessity
- leave important issues unaddressed, including any guidance on limiting intervention to circumstances of definition of medical necessity, minimum consent requirements
- are not the product of inclusive consultation
- need to be updated to take account of the most recent available research, including from psychological and peer expertise.

New National Guidelines are needed to provide guidance on decision making in the context of medical interventions modifying sex characteristics, and on clinical best practice more generally.

This conclusion is consistent with that of the Senate Committee, which called for guidelines to be issued on the treatment of common intersex conditions based on medical management, ethical, human rights and legal principles.⁴⁹⁵ The Senate Committee also recommended that 'all medical treatment of intersex people take place under guidelines that ensure treatment is managed by multidisciplinary teams within a human rights framework'.⁴⁹⁶

The Commission considers that the new National Guidelines should reflect the human rights framework and principles set out at Chapter 2 of this report in Recommendation 1.

The Commission recommends that the National Guidelines should set out what is required to obtain

informed consent before performing a medical intervention for a person born with variations in sex characteristics (see Recommendation 3).

The National Guidelines should also set out the circumstances of medical necessity in which medical interventions modifying sex characteristics can justifiably be conducted without personal consent (see Recommendation 4).

The Commission supports the development, as part of the National Guidelines, of clinical guidelines articulating best practice clinical care, including minimum practice standards.

(a) Best practice and treatment protocols

The National Guidelines should include best practice and treatment protocols for the management of different variations in sex characteristics and reviews of existing and emerging evidence-based research.

In particular, this clinical guidance should recommend that clinical management take place in the context of comprehensive multidisciplinary care, including professional psychological care.

New clinical guidance should also recommend specifically that treating practitioners refer individuals and, where relevant, their families, to peer support organisations.

There are a range of other issues, including support for affect individuals, access to and control of health records, and data collection for research purposes, that could also be addressed in clinical guidelines.⁴⁹⁷

6.7 Should the National Guidelines be binding?

(a) Status of guidelines

There are a range of models for developing and issuing medical and ethical guidelines such as the

recommended new National Guidelines.

Clinical guidelines are commonly developed by working parties of health practitioners and issued by expert bodies, such as the Royal Australian College of General Practitioners,⁴⁹⁸ or Cancer Council Australia.⁴⁹⁹

Clinical guidelines can be defined as 'evidence-based statements that include recommendations intended to optimise patient care and assist health care practitioners to make decisions about appropriate health care for specific clinical circumstances'.⁵⁰⁰ They should assist clinicians and patients in shared decision making.⁵⁰¹

In a strict sense, clinical guidelines are not legally binding on health practitioners or others and do not usually have any legislative basis but are important in defining best practice.

Clinical guidelines may be an important reference point when assessing minimum standards of care in the context of complaints made about professional standards. Breach of clinical guidelines may lead to disciplinary action by professional regulatory entities, such as the Australian Health Practitioner Regulatory Authority.

Compliance with clinical guidelines may help protect health practitioners from civil liability. For example, under the *Civil Liability Act 2002* (NSW) a professional does not incur liability in negligence if they act in a manner that is 'widely accepted in Australia by peer professional opinion as competent professional practice',⁵⁰² which can be reflected in clinical guidelines.

Some clinical and other healthcare guidelines are made binding by administrative means. For example, the National Safety and Quality Health Service Standards provide a nationally consistent statement of the level of care consumers can expect from health service organisations,⁵⁰³ and implementation of the standards is mandated in all hospitals, day procedure services and public dental services across Australia.⁵⁰⁴

Some guidelines have a legislative basis – for example, those issued by the National Health and Medical Research Council (NHMRC) under the *National Health and Medical Research Council Act 1992* (Cth). The Act enables the NHMRC to issue evidence-based guidelines in various areas relating to human health, including clinical practice.⁵⁰⁵ In addition, the NHMRC may approve guidelines developed by external bodies.⁵⁰⁶

Legislation may make guidelines binding in prescribed circumstances. For example, under the *Guardianship Act 1987* (NSW), the NSW Civil and Administrative Tribunal is empowered to give consent to medical treatment, including ‘special treatment’, a term that includes any new treatment that has not yet gained the support of a substantial number of medical practitioners. The legislation provides that the Tribunal may only give consent to new treatment if satisfied that any relevant NHMRC guidelines have been or will be complied with as regards the patient.⁵⁰⁷

(b) Stakeholder views on binding guidelines

There were differences of opinion about whether any new guidelines should be binding – that is to say, with stricter legal obligations attached than is presently the case – on clinicians and others making decisions about medical interventions.

Clinical stakeholders were divided on this question, while parent groups opposed binding guidelines. Intersex advocacy, health and human rights organisations were unanimous in support.⁵⁰⁸ By ‘binding’, stakeholders understood that compliance would be legally required, and departures from the guidelines subject to more direct legal remedies or sanctions.

Several clinical organisations opposed the making of binding guidelines because they would fetter nuanced medical decision making. They argued that the large number of variations, and the unique aspects of individual cases, defied comprehensive regulation.

APEG argued that guidelines ‘cannot account for every individual variation’.⁵⁰⁹ Several clinical stakeholders were strongly opposed to new guidelines being binding, because guidelines should only ever be a guide to practice and should not limit the clinician’s role to propose any intervention they deem appropriate. One clinician stated that ‘guidelines should not be legally binding but act as a tool to facilitate shared decision making in an individualised, patient focussed manner’.⁵¹⁰

In arguing that guidelines should be binding, human rights and community stakeholders observed that medically unnecessary interventions continue to occur and that legal guidelines are needed to address this. A human rights organisation recommended

A rights-based healthcare protocol, with binding guidelines for healthcare professionals, should be implemented for individuals with variations of sex characteristics to guarantee their bodily integrity, autonomy and self-determination and to ensure that no child is subjected to non-emergency, invasive and irreversible surgery or treatment.⁵¹¹

(c) The binding nature of the National Guidelines

The Commission considers that the National Guidelines need to help ensure that medical interventions do not infringe the human rights of people born with variations in sex characteristics.

It is clear from people’s lived experience⁵¹² that many medical interventions have occurred for reasons other than medical necessity. These interventions have sometimes been carried out in the absence of evidence on effectiveness and long-term outcome data. At the same time, documents guiding clinical management of variations in Australia contemplate interventions on bases other than medical necessity.

This is of great concern. Binding guidelines are essential to support a change of current practice to one that fully complies with human rights obligations. That is, to ensure that interventions occur within a context of medical necessity, are consistent with best evidence-based understandings, and that consent is informed based on provision of adequate information and other minimum decision-making standards.

In Chapters 7 and 8, the Commission recommends the enactment of legislation effectively prohibiting medical interventions for children with a variation in sex characteristics without their personal consent except in cases of medical necessity (see Recommendations 7, 8, and 9).

The National Guidelines would, in effect, be binding to the extent that they are consistent with these legislative reforms. Further, the Commission recommends that Independent Panels, in determining whether a medical intervention is authorised, should be informed by the National Guidelines (see Recommendation 8).

Even in the absence of this legislative backing, there are other mechanisms by which the National Guidelines could be given some binding effect, including administratively, through government health department and public and private hospital policies and procedures. Also, in the context of complaints made about professional standards, the National Guidelines may have a binding effect, as breach of clinical guidelines may lead to disciplinary action by professional regulatory entities.

The Commission considers that the recommended content of the National Guidelines would not unduly fetter the ability of clinicians to form treatment recommendations according to individual circumstances.

The purely clinical components would provide recommendations and treatment protocols for specific variations, and reviews of variation-specific

existing and emerging evidence-based research. A range of different stakeholders, including clinicians, have argued that such guidance would provide useful support for clinical decision making.

Guidance in relation to recommended treatment and relevant research should not be binding but support expert clinician deliberation that appropriately accounts for circumstances of an individual case.

6.8 Development, funding, and review of the new National Guidelines

The Commission considers that the National Guidelines should be developed by a national multidisciplinary expert group convened by the Australian Government and facilitated by the NHMRC. There needs to be adequate funding for development and review of the new guidelines.

(a) Stakeholder views on the development of guidelines

Stakeholders suggested specific bodies that might develop new guidelines. These included

- the National Health and Medical Research Council⁵¹³
- the Australasian Paediatric Endocrine Group⁵¹⁴
- some new entity created for the purpose, such as a 'special medical procedures advisory body'.

In relation to the latter suggestion, the Senate Committee recommended that a special medical procedures advisory committee (SMPAC) should draft 'guidelines for the treatment of common intersex conditions based on medical management, ethical, human rights and legal principles'.⁵¹⁵ The Senate Committee argued that the need for the

SMPAC stemmed from the range and variation of diagnoses associated with intersex conditions, and as well as drafting guidelines it would help ensure a consistent approach in the health care management of people born with variations in sex characteristics.⁵¹⁶

Intersex advocacy and support groups referred to the Senate Committee's recommendation that a SMPAC draft new guidelines.⁵¹⁷

Stakeholders emphasised that any entity responsible for developing guidelines should include a wide range of expertise, including from people with lived experience and civil society organisations, to ensure that people whose rights guidelines are intended to protect can inform their development.⁵¹⁸

Many stakeholders agreed that the development of guidelines would require a range of expertise and could not successfully be developed by health practitioners or medical scientists alone.

It was suggested that guidelines be developed by a process of co-design. This would mean that clinicians from a range of relevant specialties would collaborate with intersex-led community organisations and others, or that widespread consultation would be conducted regardless of which entity prepared the guidelines.⁵¹⁹ Input would be required from people with lived experience, their parents/carers, peer-support groups, specialist clinicians and health practitioner and human rights organisations.⁵²⁰

(b) Developing the National Guidelines

The National Guidelines should be developed by a national multidisciplinary expert group. It is clear that the National Guidelines need input from a range of relevant specialties, along with intersex-led community organisations and human rights experts, through a process of co-design.

It was suggested that guidelines be developed by a process of co-design. This would mean that clinicians from a range of relevant specialties would collaborate with intersex-led community organisations and others, or that widespread consultation would be conducted regardless of which entity prepared the guidelines.⁵²¹ Input would be required from people with lived experience, their parents/carers, peer-support groups, specialist clinicians and health practitioner and human rights organisations.⁵²²

The key areas of focus should include outlining human rights obligations and limiting the rationales for medical interventions to that of medical necessity, clarifying consent processes and the provision of information and outlining best practice clinical management, including through multidisciplinary care.

The first two areas would require expertise in human rights, informed by input from clinicians and people with lived experience. The last area would require clinical expertise, including in psychology and psychiatry. At the same time, this should be informed by lived experience and human rights expertise. This mix of contributors should ensure that human rights concerns are addressed, and community and clinical expectations are met.

The NHMRC would be a suitable Australian Government entity to facilitate the development of the National Guidelines. The NHMRC itself develops guidelines related to health, and supports others to do so, including by helping guideline developers produce high quality guidelines that meet the NHMRC's Standards for Guidelines.⁵²³ Importantly, the NHMRC requires the development of guidelines to involve consumers as members of the guideline development group and throughout the process.⁵²⁴

In final form, the National Guidelines could be approved by the NHMRC under the *National*

Health and Medical Research Council Act 1992 (Cth), indicating that the guidelines are of high quality, based on the best available scientific evidence, and have been developed to rigorous standards.⁵²⁵

Adequate public funding should be made available to support the development of the National Guidelines by the national multidisciplinary expert group, and the role of the NHMRC, including dedicated funding for drafting and community participation.

(c) Review of the National Guidelines

Stakeholders agreed that any new guidelines should be regularly reviewed, to ensure they remain up to date with emerging research, are fit for purpose, and continue to receive ongoing community support.⁵²⁶

Stakeholders confirmed that medical knowledge about variations in sex characteristics continues to evolve and will continue to do so with better data collection, research, and experience. In particular, understanding of the risks to health associated with some variations is likely to continue to improve, allowing better informed decisions about whether specific interventions meet the standard of medical necessity.

It is therefore essential that the National Guidelines are subject to regular review, to ensure that the best standard of human rights-compliant care is provided to all people born with variations in sex characteristics. This will require that the standards be developed by a standing entity, and that adequate ongoing funding is available to support its work.

OVERSIGHT OF MEDICAL INTERVENTIONS

This chapter discusses how the human rights framework for decision making about medical interventions for people born with variations in sex characteristics, discussed in previous chapters, should be incorporated in 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 should be carried out without an individual's personal consent. The Commission recommends reform of oversight mechanisms by

- establishing Independent Panels with responsibility to decide whether to authorise medical interventions in respect of people born with variations in sex characteristics (Recommendation 7)
- defining the circumstances in which interventions for people under the age of 18 years without personal consent may be authorised, which should be limited to circumstances of medical necessity (Recommendation 7)
- 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 (Recommendation 8).

Court processes alone are not well suited to provide effective oversight of medical interventions modifying sex characteristics. This conclusion is

based on the Commission's review of Family Court decision making in this area and informed by the experience of stakeholders.

7.1 Current oversight mechanisms

Children born with variations in sex characteristics can be engaged in the family law system when family and medical professionals seek authorisation from the court for surgical interventions to physically modify their bodies. The Family Court currently has a role of oversight of these procedures through its *parens patriae* or welfare jurisdiction.

As discussed in Chapter 4, under Australian law, there are certain kinds of medical interventions in relation to which parents or guardians cannot provide consent on behalf of children. In the case of these 'special medical procedures', interventions can only proceed if they have been authorised by a court.

The legal criteria limiting the scope of parental or guardian authority to provide consent for what are known as 'special medical procedures' are derived from *Marion's case*.⁵²⁷

In *Marion's case*, the majority of the High Court pointed tentatively to whether or not a procedure was 'therapeutic' when determining whether it was the kind of procedure that required court authorisation.⁵²⁸ Justice Brennan considered the concept of a 'therapeutic' treatment in more detail and said that it involved a treatment that not only was administered for a therapeutic purpose, but was 'appropriate for and proportionate to the purpose for which it is administered'.⁵²⁹ Justice

Brennan’s discussion involved a proportionality assessment.⁵³⁰

In *Marion’s case*, among other things, such special medical procedures were also characterised also as being invasive and irreversible, carrying a significant risk of making the wrong decision about either the child’s present or future capacity to consent or what was in the child’s best interests, and giving rise to particularly grave consequences if a wrong decision were made.⁵³¹ While *Marion’s case* dealt specifically with the case of sterilisation of a girl with an intellectual disability, subsequent cases have recognised other procedures as also being ‘special medical procedures’ that require court authorisation. Certain other categories of procedure are specifically defined in state and territory legislation as also requiring court or tribunal authorisation, including sterilisation⁵³² and novel treatments.⁵³³

There have only been a small number of cases where the Family Court of Australia (Family Court) has been asked to authorise medical interventions for people born with variations in sex characteristics, on the basis that they amounted to special medical procedures. As discussed below by reference to these cases, the law under which

the Family Court and other courts operate is not designed to ensure that such medical interventions are carried out only where medically necessary, or that the best evidence is available to the court.

This chapter recommends instead a role for one or more Independent Panels, informed by the *National Guidelines on medical interventions for people born with variations in sex characteristics* (National Guidelines), in providing oversight of decisions about medical interventions in relation to people under the age of 18 years.

(a) Review of Family Court cases

The case most often used to illustrate the Family Court’s approach in this area is *Re Carla (Medical Procedure)*.⁵³⁴ Seven other cases have been identified where the Family Court has been asked to authorise medical interventions for children born with variations in sex characteristics. In all but one of these cases, the children were not *Gillick* competent⁵³⁵ to consent to treatment on their own behalf. These cases are discussed below.

The cases invoke the limits on parental authority to approve of interventions in relation to their children, the scope of the agency of the child to express their own views, and ideas of ‘best



interests', and the role of the court in the *parens patriae* jurisdiction.

(i) *Re Carla (Medical Procedure)*

Carla was born with 17 beta hydroxysteroid dehydrogenase 3 deficiency (17 β -HSD3), a genetic variation in sex characteristics. As a result, at birth Carla had XY chromosomes but was, in the words of the Court, 'markedly under-virilised for a genetic male'. That is, Carla had XY chromosomes but had external sex characteristics that resembled those associated with girls. Carla had male gonads, but these were located internally in the intra-abdominal cavity. Carla was raised as a girl, 'with the understanding that her gender identity would be assessed when it was developmentally appropriate to do so'.⁵³⁶

When she⁵³⁷ was five, Carla's parents applied to the Family Court, asking it to authorise a gonadectomy, as well as 'such further or other necessary and consequential procedures to give effect to her treatment, as may be recommended by Carla's treating medical practitioners'.⁵³⁸ The Director-General of the 'Relevant Government Department' appeared as *amicus curiae*.⁵³⁹ Carla's parents were the applicants and were represented, but no independent children's lawyer was appointed.

The Court considered the principles in *Marion's case*. It held that the treatment proposed for Carla was 'therapeutic', and therefore that her parents could consent to it without authorisation from the court. Two reasons were given for the finding that the treatment was therapeutic:

- the Court was satisfied the procedure was necessary to mitigate an intermediate risk of cancer, based on a risk of germ cell malignancy of 28%⁵⁴⁰
- the proposed interventions would affirm the gender of rearing and prevent virilisation of Carla's body⁵⁴¹ and would minimise risk of mental health problems,

including 'serious confusion about her gender identity'.⁵⁴²

In making these findings, the Court relied on evidence from Carla's parents and three medical practitioners: Carla's treating paediatric surgeon, Carla's treating paediatric endocrinologist, and Carla's treating paediatric psychiatrist.

In assessing the risk of cancer, the Court relied on evidence from the expert endocrinologist, who cited the 2006 *Consensus statement on management of intersex disorders* (2006 Consensus Statement).⁵⁴³ The Court said that there was 'a risk of malignancy occurring in the short, medium and long term', but included no discussion of whether the risk of malignancy was equally high within those timeframes.⁵⁴⁴

The Court referred to the possibility of deferring surgery, but found that that was not advisable because Carla's gonads were placed in the intra-abdominal cavity, and the expert surgical witness gave evidence that this placement meant it would have been 'virtually impossible' to 'regularly monitor' them for malignancy. The Court found that the gonads could have been 'moved external to the abdominal cavity but that, of course, would be likely to have quite adverse psychological consequences for Carla'.⁵⁴⁵ The Court's reasoning for this conclusion was not explained.

The Court also found that, if surgery were deferred, Carla would, at puberty, undergo irreversible virilisation because of hormonal changes, leading to mental distress, unless hormone blocking drugs were to be administered. This would require regular injections and mean Carla did not go through puberty at the same time as her peers.

Criticisms have been made of the decision in *Re Carla*. The first is that, in assessing the risk of cancer, the Court was directed to and relied on apparently outdated data.⁵⁴⁶ The Court relied on data contained in the 2006 Consensus Statement, but evidence from 2010, cited in the Senate

Community Affairs References Committee report, *Involuntary or coerced sterilisation of intersex people in Australia* (Senate Committee Report), cited a lower risk of cancer – 17% rather than 28%.⁵⁴⁷

A second criticism is that the 2006 Consensus Statement advises that in cases of 17 β -HSD3, the recommended course of action is to ‘monitor’ for cancer, rather than perform immediate gonadectomy.⁵⁴⁸

Another criticism is that the Court did not adequately consider deferring surgical treatment for Carla and did not properly weigh the arguments in favour of and those against deferring surgery.⁵⁴⁹ The Court referred to the fact that in the absence of surgery, Carla would undergo hormonal changes at puberty. That was still some years away in Carla’s case, and the Court did not say whether a delay of several years would better allow Carla to express a view about her preferences, including about whether to receive puberty-blocking drugs.

Similarly, the Court did not discuss in detail the potential impact that the loss of fertility resulting from the proposed surgery could have on Carla and does not appear to have given that impact appropriate weight in assessing whether the surgery should proceed. The impact on fertility was at least a significant relevant factor that should have been weighed against any supposed psychological harm that Carla may have suffered if her gonads had been surgically relocated rather than immediately removed.

Stakeholders also criticised the evidence put before the Court to establish that Carla had a female gender identity that was unlikely to change in the future.⁵⁵⁰ The Court accepted the evidence of Carla’s treating psychiatrist, but some of this evidence has been criticised as of limited value, including observations about Carla having ‘stereotypically female’ interests, such as toys and favourite colours.⁵⁵¹

A final observation about the decision is that the Court referred to the fact that Carla had, when four years old and prior to the application to the Court being made, undergone surgery including clitoral recession and a labiaplasty to ‘feminise Carla’s external appearance’.⁵⁵² These procedures were evidently performed without court authorisation, a matter which passed without comment from the Court in *Re Carla*.

The Commission considers that some of these concerns may illustrate problems that arise when a limited range of expert evidence is put before the Court, and there is no contradictor to test that evidence through cross-examination or calling additional expert witnesses. While three expert witnesses were called in *Re Carla*, each had a different specialty and was a current treating practitioner for Carla. There was no diversity of medical opinion independent of the treating team. As Carla was not independently represented, and the Director-General did not oppose the application, there was no-one to test or challenge the evidence led before the Court.

(ii) *Other decisions of the Family Court*

In *Re Welfare of a Child A*,⁵⁵³ the Court authorised surgical procedures to remove female sex characteristics and create male genitalia for a 14-year-old child, ‘A’, finding that they were ‘overwhelmingly in A’s interests’.⁵⁵⁴ A was born with congenital adrenal hyperplasia. Shortly after birth, A had undergone surgeries to feminise A’s genitalia, and was administered hormones to prevent masculinisation. The dosage administered did not have that effect, and ‘recurrent masculinisation’ of A’s genitalia occurred. The Court held that the proposed surgeries required court authorisation.⁵⁵⁵ It held that they were in A’s interests because of the risk to A’s mental health, identity and self-esteem if the procedures were not performed. The Court found that A was not *Gillick* competent in respect of the proposed intervention, although the judge took A’s views into account in support of the application.

In *Re Lesley*,⁵⁵⁶ the Court held that a gonadectomy for four-year-old Lesley, who was born with 17 β -HSD3 deficiency, was in Lesley's best interests. This was because it would prevent the risk of virilisation and negative serious psychological and social consequences.⁵⁵⁷ The fact that it would address an increased risk of cancer developing was considered 'a further important factor'.⁵⁵⁸ In making this finding, the Court relied on evidence from three doctors, who testified that Lesley identified as female, and that she was likely to continue to do so for the rest of her life. The Court held that the interventions proposed fell 'squarely within the principles enunciated in Marion's case', and that judicial authorisation was therefore necessary.⁵⁵⁹

In *Re Sally*,⁵⁶⁰ the Court held that a gonadectomy for 14-year-old Sally, who was born with 5-alpha reductase deficiency, was in her best interests given the significant psychological risks associated with postponing the surgery, including Sally's schooling, ability to form and maintain relationships, self-esteem and behaviour. Sally was not considered by the Court to be *Gillick* competent, though she supported the procedures and the Court took her views into account. The Court considered that the alternative of waiting until Sally turned 18 involved significant risks, particularly to her mental health.

In *Re Sean and Russell*,⁵⁶¹ the Court held that gonadectomies for 18-month-old Russell and three-and-a-half-year-old Sean were in their best interests. Both children had Denys-Drash Syndrome, which the Court found was associated with a significant risk of cancer. The Court held that judicial authorisation was not required, as the procedures fell within the scope of parental powers. Nevertheless, the Court had jurisdiction to deal with the applications and made declarations that the parents were authorised to consent to the proposed treatment.

In *Re Dylan*,⁵⁶² the Court held that Stage 2 cross-sex hormone treatment for 15-year-old Dylan, who

was born with 11 beta-hydroxylase deficiency, was in his best interests because of the potential for significant psychological and social damage to Dylan if treatment was not undertaken. The Court found that judicial authorisation was required for Dylan's intervention (intermuscular administration of testosterone), notably because of the 'very significant risks' associated with it, and the fact that the intervention would have irreversible effects.

In *Re Sarah*,⁵⁶³ the Court held that a gonadectomy for 16-year-old Sarah, who was born with 45X/46XY Turner Syndrome, was in her best interests. The Court heard that the procedure would address a 10–15% chance of cancer developing, and that it was necessary to allow Sarah to have hormone therapy so that she would undergo puberty.⁵⁶⁴ The Court held that the intervention did not require court authorisation as it was 'therapeutic' treatment that was not for the purpose of sterilisation. The Court also described the surgery as 'relatively minor and non-invasive'.⁵⁶⁵

Several expert witnesses testified that Sarah was *Gillick* competent to consent to the treatment on her own behalf. However, the Court declined to make a declaration of *Gillick* competence on the ground that Sarah's parents were legally allowed to consent to the treatment for her. While Sarah's clinical psychologist provided some evidence to the Court of Sarah's views,⁵⁶⁶ the Court did not receive any evidence directly from Sarah about her views on the intervention.

In *Re Kaitlin*,⁵⁶⁷ the Court held that Stage 2 cross-sex hormone treatment for 16-year-old Kaitlin, who was born with hypopituitarism, was in her best interests. The Court found that Kaitlin was *Gillick* competent to consent to taking oestrogen. It followed that court authorisation was not required.

(b) Observations on Family Court oversight

Since *Marion's case*, courts have often sought to determine whether a proposed treatment

was ‘therapeutic’ by looking only to the stated purpose of the treatment, without conducting the required proportionality assessment. In cases involving proposed treatment on children with variations in sex characteristics, the ability to conduct a proportionality assessment has often been limited by the lack of a contradictor or independent children’s lawyer to test the evidence put forward in favour of the proposed treatment and, in the absence of such evidence, by the lack of independent medical expertise by judges of the Family Court.

The result has been that treatments have been labelled as ‘therapeutic’ in circumstances where such a conclusion may be contestable. The distinction between therapeutic and non-therapeutic is problematic in the context of interventions modifying sex characteristics, as there may be therapeutic arguments that can be made for or against a particular intervention that need to be properly tested.

Only a limited number of applications are made to the Family Court

Only eight applications seeking authorisation for medical interventions in relation to people born with variations in sex characteristics appear to have been decided by the Family Court between 1993 and 2017. This implies that medical interventions of this kind are generally being performed without judicial oversight.

Six of the eight applications that have been decided by the Court have involved the removal of gonadal tissue, and consequently the loss of fertility. The restricted range of these cases may have been influenced by the fact that, in *Marion’s case*, a sterilising procedure was proposed to be performed on a person without legal capacity to consent.

A corollary of these observations is that court authorisations are not being sought for other

interventions, such as the administration of hormones (where it appears there have been only two relevant cases), or cosmetic procedures aimed at ‘normalising’ the appearance of genitalia. Indeed, some of the Family Court cases refer to other interventions that had been previously performed, evidently without court authorisation. For example, the judgment in *Re Carla* refers to a past clitoral recession and labioplasty performed on Carla.⁵⁶⁸ In *Welfare of a Child A*, the Court referred to feminising surgeries conducted in the post-natal period and the subsequent administration of hormones.⁵⁶⁹ In *Re Kaitlin*, the Court referred to hormones administered without court authorisation.⁵⁷⁰

Inconsistent approach to the need for court authorisation

The Court has not taken a consistent approach to the question as to whether medical interventions in relation to people born with variations in sex characteristics require court authorisation. For example, *Re Lesley* and *Re Carla* both considered whether a gonadectomy for a person with 17β-HSD3 was ‘therapeutic’ or required court authorisation. The Court arrived at a different conclusion in each case.

Lack of independent representation for children and limited expert evidence

There has been no active contradictor in any of the cases brought to the Family Court, and all applications have been granted. An independent children’s lawyer was appointed in only one of the cases (*Re Sarah*). In that case, the independent children’s lawyer was appointed on the Friday prior to the final hearing the following Monday and did not file or seek to rely on any evidence.⁵⁷¹ In one case (*Re Lesley*), the Court was urged but declined to appoint an independent children’s lawyer, holding that it would not be assisted by the appointment.⁵⁷² In a further three cases (*Re Sean* and *Russell*, *Re Dylan* and *Re Sally*), the

Court considered whether it should appoint an independent children's lawyer and decided it was not necessary.

In the cases brought to the Family Court to date, all the medical evidence has been called by parties supporting the interventions. While a variety of medical experts have been called, in each case only one witness from each relevant medical specialisation has given evidence. Frequently, it appears that some of these have been members of the treating team that has proposed the intervention.

The lack of a contradictor or independent children's lawyer has meant that there has been no-one to identify or call other expert witnesses who might express contrary views, no-one to cross-examine the witnesses before the court, and no-one to make independent submissions about the best interests of the child. In *Re Welfare of a Child A*, the judge observed:

A difficulty which I have faced in this matter has been that I have not had the benefit of anybody to put the contrary view to the court. ...

While it is reasonable to infer that the apparent non-existence of a person to argue against the granting of the relief sought by the mother leads to the conclusion that the case for the relief is strong, I must comment that it would have been most helpful to hear a contrary argument put.⁵⁷³

Inadequate consideration of future possibilities

In some cases, inadequate consideration appears to have been given to options to preserve future fertility, or the different possibilities for adult sexuality, gender identity and relationships.

For example, in *Re Carla*, the judgment considered the fact that gonadectomy would remove any chance of fertility for Carla but rejected the option of relocating Carla's gonads outside the abdominal

cavity due to potential 'adverse psychological consequences'. The ramifications of this approach on future possibilities were not discussed.

In *Re Carla* and *Re Lesley*, the reasons of the Court appear to have been based in part on an unspoken assumption that the child in question would, or should, be heterosexual. In *Re Carla*, for example, the Court speculated that Carla may require other surgery in the future 'to enable her vaginal cavity to have adequate capacity for sexual intercourse'.⁵⁷⁴ The Court also observed that if the surgical procedure were not undertaken, by leaving the gonads 'in situ', while preserving the potential of fertility with male gametes, this raised 'other significant social and emotional complexities', because 'Carla identifies as a female and is likely to continue to do so'.⁵⁷⁵

Authorisation inconsistent with precautionary principle

Importantly, it seems that the Court may have authorised medical interventions where intervention has not been a matter of medical necessity nor where a precautionary approach might have suggested deferring the intervention. In particular, the Court has given significant weight to psychosocial factors in making a 'best interests' assessment. For example, in *Re Carla*, the judge considered the fact that the child's pubertal development would have been delayed compared to her peers was relevant to the need for intervention.⁵⁷⁶

In *Re Carla* and *Re Lesley*, the judgments rely heavily on the assertion of each child's future identity as a female, leading to a view that interventions to create female genitalia were justified.⁵⁷⁷ In some cases, these factors have been intermixed with other factors that more clearly go to the assessment of the child's best interests viewed through a lens of medical necessity (such as a risk of cancer). These factors are sometimes conflated to a degree that it is difficult to determine whether the Court would have found that an intervention was warranted if

only the factors supported by a robust evidence base were considered. In *Re Carla* and *Re Lesley*, for example, it is unclear to what degree the Court's reasoning was based on the need to manage a risk of cancer, and to what degree it was based on the perceived risks of future psychological distress.⁵⁷⁸

Leaving aside the complication of the 'therapeutic/non-therapeutic' threshold, many medical interventions modifying sex characteristics involve factors suggesting they share characteristics with special medical procedures. Applying the reasoning in *Marion's case*:

- Many such interventions are invasive and frequently irreversible.
- In most cases, the interventions are proposed in relation to infants who are not able to give consent and so there is a significant risk of making the wrong decision about whether the procedure is one that the child would consent to, if able.
- Making the wrong decision carries significant risks. There is a real lack of data about many variations, and the long-term consequences of various interventions.
- The consequences of a wrong decision can be particularly serious, such as the loss of future fertility, chronic pain and severe mental distress. People with lived experience of interventions said they had suffered significant physical and mental impacts from surgical and hormonal interventions.⁵⁷⁹
- Decision making in this context is highly medicalised. Doctors are intimately involved in presenting the available options to parents, which circumscribe the possible decisions. Decision making sometimes takes place within multidisciplinary teams, but these are

largely composed of clinicians. However, decisions are not based only on strictly medical factors but are also influenced by cultural and psychosocial factors.

These factors suggest medical interventions modifying variations in sex characteristics should generally be subject to some form of independent oversight or authorisation and with the human rights framework of principles embedded.

7.2 Concerns about current oversight mechanisms

This section discusses more general problems with current oversight of medical interventions for people born with variations in sex characteristics. An underlying concern is that current law allows parental consent or court authorisation for interventions that are not medically necessary under international human rights law. Options and recommendations for law reform to address this problem are discussed later in this chapter.

(a) Stakeholder perspectives about Family Court oversight

In general, medical practitioners and parents supported the current oversight framework, although some practitioners indicated that, for at least some interventions, improved oversight would be beneficial.

People with lived experience, and civil society organisations, provided powerful accounts of the impacts that interventions under the current framework have had on their lives, and advocated for a new model of independent oversight to ensure interventions are conducted only where medically necessary.

Such an approach reflects the medical necessity principle.

Parents and medical practitioners emphasised their concern to make decisions that are in the best

interests of children. The Commission recognises the good intentions of all stakeholders.

People with lived experience, support groups, advocates and some clinicians considered that the Family Court has not provided effective oversight of medical interventions, in light of decisions to date regarding intersex infants, and they expressed concern that the Court is not suited to play this role.⁵⁸⁰ A range of reasons were given, many of which are consistent with the Commission's observations on Family Court cases.

Lack of appropriate expertise

A hospital multi-disciplinary team stated that the Family Court does not have the relevant expertise to independently interrogate and assess the medical evidence adduced before it. The team said that the Court tended to simply endorse the medical evidence brought before it.⁵⁸¹

A clinical stakeholder argued that the Court is not suited to assessing optimal clinical management based on written reports or affidavits:

The court relies heavily on the information provided to it, which may differ in different instances. Specialist multi-disciplinary teams may vary in their opinion as to what constitutes optimal management, hence what is recommended to the court.⁵⁸²

They stated that, as a result, the decisions of the Court have resulted in different outcomes in similar clinical scenarios.

Others also argued that the Court is not suited to dealing with complex and sensitive matters involving children's medical care.⁵⁸³ One legal academic with expertise in family law argued that there should be independent oversight over clinical decisions, but not in the form of Family Court authorisation. They stated that Family Court judges may 'lack knowledge necessary to assess these cases and may be inclined to defer to doctors'.⁵⁸⁴

A person born with variations in sex characteristics said that they believed the Family Court is

not equipped to handle the complexity of intersex children and infants, nor do they have the knowledge and expertise to make a decision, given that the medical establishment can hold far more weight than what intersex support groups have.⁵⁸⁵

Absence of contradictor or independent children's lawyer

Stakeholders observed that almost all relevant Family Court cases to date have proceeded with the consent of the parties and without a contradictor or independent children's lawyer.⁵⁸⁶ This means that submissions in favour of intervention may not adequately be interrogated or challenged, and that there is frequently no-one to advocate independently for the best interests of the child, particularly as viewed through the medical necessity and precautionary principles.

Absence of clinical consensus

The Australasian Paediatric Endocrine Group said that evidence of optimal management for some variations is too sparse or of insufficient probative value to be tendered in evidence before a Court. They stated that optimal management in a significant number of cases is complex and difficult to distil in a court report or affidavit to offer comprehensive advice to the Court. This stakeholder did not suggest that this lack of evidence led to clinicians being unable to form opinions about the best course of treatment.⁵⁸⁷

Lack of community confidence

Civil society organisations and people born with variations in sex characteristics indicated they did not have confidence that the Family Court will make decisions consistent with human rights. Some stakeholders with lived experience expressed strong views that the Court has let down people born with variations in sex characteristics.⁵⁸⁸ Stakeholders said that this was partly due to the

Court's reliance on medical evidence and the lack of reference to other sources of expertise.⁵⁸⁹

Courts ignore non-traditional ideas

Stakeholders argued that the Family Court defers to clinical notions of binary, heteronormative models of human bodies, gender identity and expression, and sexual orientation. It was said that this leads it to give weight when considering applications to matters that should be irrelevant and, in particular, to authorise interventions for psychosocial reasons.⁵⁹⁰

For example, some cases indicate that the Family Court has understood certain types of behaviours as only pertaining to girls, such as playing with dolls.⁵⁹¹ This could suggest that particular assumptions about gender may have influenced the judge's decision in *Re Carla*.⁵⁹²

Lack of accessibility

Stakeholders characterised the Family Court process as expensive, time-consuming, emotionally exhausting and adversarial, and reliant on evidence brought before it by interested parties.⁵⁹³ One legal academic with expertise in family law stated that applications to the Family Court are 'expensive, lengthy and intimidating'.⁵⁹⁴

(b) A need for alternative oversight

The experiences of people born with variations in sex characteristics confirm that the current system has allowed interventions that are not medically necessary. Family Court cases indicate that interventions without personal consent have been justified, at least in part, by reference to psychosocial reasons. Interventions on such a basis do not fall within the Commission's definition of medical necessity (see Recommendation 4).

In the Commission's view, these interventions are inconsistent with human rights law, as reflected in particular through the principles set out in Chapter 2, and may have severe and lifelong consequences for people, as evidenced by their lived experience (see Chapter 3 – Lived experience).

The experiences of people born with variations in sex characteristics indicate that interventions based on reasons other than medical necessity have also occurred outside of the oversight of the court (see Chapter 3). The observation in *Re Carla*, that an earlier medical intervention to enhance 'the appearance of her female genitalia' had not gone before any court for authorisation, is also consistent with this conclusion.⁵⁹⁵

There is real risk that, without changes to oversight mechanisms, interventions will continue to be made that are not medically necessary and which could have been deferred under a precautionary approach. Current practice has included interventions that are based on psychosocial rationales, such as gender-conforming treatments.

As discussed in Chapter 6, current international and Australian clinical guidance allows clinicians to take psychosocial factors, such as cultural or social pressure, into account as relevant when considering whether an intervention should be proposed.

The Commission's criticisms 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's best interests:

The anxious goodwill of the repository of the power – whether parents, guardians or courts – can generally be assumed, but there are too many factors which tend to distort a dispassionate and accurate assessment of the true interests of the child. There are some powerful if unarticulated influences affecting, albeit in good faith, the presentation of information on which a decision as to the best interests of the child is to be made and the making of that decision.⁵⁹⁶

There is a need for alternatives to Family Court oversight, which are more cost effective and a less formal process than that of the Family Court or state and territory courts. Independent Panels or tribunals provide such alternatives. Independent Panels or tribunals would also be able to be specially constituted with a range of expertise able to thoroughly scrutinise proposed medical interventions.

7.3 Options for independent oversight

The Senate Community Affairs References Committee (Senate Committee) released two reports in 2013. The first report, *Involuntary or coerced sterilisation of people with disabilities in Australia*, concerned people with disability. The second report, under amended terms of reference, was entitled *Involuntary or coerced sterilisation of intersex people in Australia* (second 2013 Senate Inquiry report).

In the second 2013 Senate Inquiry report, the Senate Committee recommended that 'all proposed intersex medical interventions for children and adults without the capacity to consent require authorisation from a civil and administrative tribunal or the Family Court'.⁵⁹⁷ It also recommended that tribunals and the Family Court be given concurrent jurisdiction to determine such authorisations.⁵⁹⁸

The Senate Committee observed that it had adopted the position, in its first report, that the 'proper jurisdiction for consideration of sterilisation cases for those unable to consent should remain with the Family Court of Australia but with improved criteria'. In its second report, the Senate Committee considered whether the Family Court remained 'the proper forum for consideration of intersex cases'.⁵⁹⁹

The Senate Committee argued that tribunals are an appropriate forum to decide on intersex

medical interventions, given the complexity of intersex cases. It stated:

Because intersex cases require consideration by an extensive number of medical, psychological and psychosocial professionals, the capacity to access that expertise is a key requirement of any forum. The multi-disciplinary composition of tribunals would assist in drawing in the required expertise.⁶⁰⁰

The other advantage of tribunals was their accessibility in terms of approach, procedures and cost:

The general consensus in the evidence received was that the procedures in tribunals were less formal, and more flexible in terms of how evidence is gathered and how parties can be represented and supported. In addition, the low or no costs for participants compared to those for applications to the Family Court enhance the case for tribunals to be the primary forum for consideration for intersex cases.⁶⁰¹

The Senate Committee concluded:

[T]ribunals are a more accessible and cost effective option to hear these cases. They will also be able to act quickly, and be more responsive to the needs of intersex people and their families.⁶⁰²

However, it also stated:

[T]here may be cases of particular legal complexity that would be properly considered in the Family Court and the committee would not wish to close this avenue of expertise. The committee therefore supports the proposal that tribunals should be given concurrent jurisdiction with the Family Court, and that participants in the case should decide which jurisdiction would best address their needs.⁶⁰³



(a) Stakeholder views on new expert panels and tribunals

Some stakeholders expressed support for new tribunals or expert decision-making panels, as a better means to review whether proposed interventions are appropriate, including in terms of being medically necessary and in the child's best interests.⁶⁰⁴

Some stakeholders argued that an independent entity with an explicit human rights mandate should be established by legislation to oversee medical treatment of people born with variations in sex characteristics.⁶⁰⁵

Other stakeholders also proposed the creation of an independent entity, either to advise parents and treating clinicians or to be a decision maker about medical interventions, with primary reference to relevant international human rights instruments and the principles contained in those instruments.⁶⁰⁶ It was suggested that such a tribunal should be a national entity, with binding rules as to composition and operating procedures.⁶⁰⁷ The involvement of the Council of Australian Governments (or its successor through the National Cabinet) in establishing such a tribunal was suggested.⁶⁰⁸

The Australasian Paediatric Endocrine Group (APEG) did not call for the creation of any new decision-making entity, despite opposing Family Court involvement in authorising interventions. Rather, APEG argued that 'cross-centre multidisciplinary team review for discussion and review of management' is sufficient.⁶⁰⁹

(i) Functions of expert panels or tribunals

Stakeholders suggested a range of potential advisory or decision-making functions and powers that should be vested in a new expert panel or tribunal. These included functions and powers to:

- develop and review decision-making or clinical guidelines,⁶¹⁰ including national guidelines with an explicit human rights basis⁶¹¹
- assist individuals, parents, carers and courts to make decisions by providing advice on clinical management or on both clinical management and human rights considerations⁶¹²
- make decisions about whether a child is *Gillick* competent⁶¹³

- make decisions for children who are not *Gillick* competent about whether proposed treatment is medically necessary.

The idea of a new decision-making expert panel or tribunal to determine whether medical interventions should be authorised, in accordance with national guidelines, was supported by many people born with variations in sex characteristics and peer-support groups, legal and human rights stakeholders and some clinician stakeholders.⁶¹⁴

One specialist community legal centre argued that an expert tribunal could scrutinise the course of action proposed by the treating clinicians and resolve disagreements about medical necessity and deferability. The same stakeholder did not favour statutory definition of these concepts because of the diverse range of presentations among people born with variations in sex characteristics.⁶¹⁵

(ii) Composition of expert panels or tribunals

Contributors indicated that any new expert panel or tribunal should be comprised of members who are:

- clinicians from relevant specialties, including paediatric endocrinologists, psychiatrists, psychologists⁶¹⁶
- ethicists, and social workers
- from intersex-led community organisations⁶¹⁷
- parent representatives⁶¹⁸
- child advocates⁶¹⁹
- human rights experts.⁶²⁰

One stakeholder suggested that a new tribunal could be convened on an ‘as needed’ basis, rather than being a standing entity, and that when convened it should include a person with the same variation as the person for which treatment is proposed.⁶²¹

It was suggested that a new entity to review non-deferrable interventions should be funded jointly by the Commonwealth, states and territories.⁶²²

7.4 Authorisation by Independent Panels

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*.

(a) The obligation to seek authorisation

In the Commission’s view, an application for authorisation should initially be required for all proposed medical interventions seeking to modify sex characteristics on people under the age of 18 years born with variations.

An advantage of initially requiring all medical interventions seeking to modify sex characteristics on people under the age of 18 years born with variations to be subject to independent authorisation is that interventions based on psychosocial rationales, such as cosmetic surgeries, would be subject to scrutiny rather than just a narrow subset of cases, such as gonadectomies.

The Independent Panel should first scrutinise whether a young person is able to provide consent to the intervention, and whether personal consent was provided on a sound, informed basis. Authorisation would not be required where consent is able to be given by the person concerned. If the young person was not able to consent to the intervention, the Independent Panel would then consider whether the intervention was

medically necessary.

For particularly common variations, it may be that the Independent Panel is also able to provide guidance about how similar cases should be dealt with, which may assist in reducing the workload of the Panel as well as providing clarity for clinicians.

Following initial experience with applications for authorisation by the Independent Panel, there may be increased clarity about the kinds of cases where treatment should be deferred, thereby reducing the need for those kinds of applications to be made.

(b) Circumstances in which interventions may be authorised

Authorisations should be assessed through the human rights principles set out in Chapter 2 – particularly the principle of medical necessity and the precautionary principle.

Authorisation should be limited to circumstances in which the person under the age of 18 is not able to provide their personal consent and the intervention is medically necessary.

Emergency situations may require some modification of process. An appropriate threshold for an emergency situation, drawing on existing state legislation dealing with circumstances where treatment may be carried out on a child or young person without their consent or that of their parent or guardian, is where treatment is medically necessary and required as a matter of urgency in order to save the child’s life or prevent serious damage to the child’s health.⁶²³

It may be that some urgent cases are still able to be dealt with by an Independent Panel if an expedited process were adopted. The Commission considers that this is an appropriate safeguard to ensure that oversight is able to be provided to the maximum extent possible. Only where this still does not provide enough time to address an emergency situation, should an intervention proceed without

authorisation. In those circumstances the Independent Panel must be notified promptly following the conduct of the medical intervention.

(c) Independent Panels

As reflected in the independent oversight principle, there are solid arguments for new mechanisms to ensure independent oversight of decisions about medical interventions for people born with variations in sex characteristics who are unable to provide personal consent. Such oversight should be independent from the medical treating team.

There is a need for a mechanism or network of mechanisms to

- be inexpensive and able to operate quickly
- have expertise about the complex medical and other considerations relevant to decision making
- be constituted in a way that ensures children's best interests are represented.

The Australian Government and state and territory governments should cooperate to establish one or more Independent Panels with responsibility to decide whether to authorise medical interventions for persons born with variations in sex characteristics.

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.

Given the psychological dimensions of peoples' experiences of sex variations, including clinicians with mental health expertise may inform discussions about the possible future psychological consequences of proposed medical interventions. Including people with variations in sex characteristics on Independent Panels may provide insights into lived experience to inform

understandings about of the possible future impact on the person concerned Independent Panels may also benefit from members with expertise in the application of human rights principles in the context of decisions about medical treatment.

These forms of expertise are not an exhaustive list. There may also be a role on Independent Panels for ethicists, social science academics, and individuals with expertise in how to apply statutory criteria in making decisions, such as existing tribunal members, or judicial officers.

In the longer term, a national Independent Panel may be the best way to decide whether to authorise medical interventions. However, enacting Commonwealth legislation to establish such a decision maker in cases involving medical interventions would be complex to implement, and may raise constitutional issues, including in relation to referral of powers and limitations on the exercise of the judicial power of the Commonwealth.

While a national approach would be preferable, there is a range of options for establishing mechanisms for independent oversight at state and territory level.

Ideally, state and territory legislation would establish and prescribe the composition of stand-alone Independent Panels. Alternatively, states and territories could establish new tribunals or provide existing tribunals, such as guardianship tribunals, with new legislative responsibilities to decide on the authorisation of medical interventions for people born with variations.

These legislative provisions might be included in state and territory child protection, guardianship,⁶²⁴ or other legislation. For example, in New South Wales, the Guardianship Division of the NSW Civil and Administrative Tribunal has power under s 175(2)(b) of the *Children and Young Persons (Care and Protection) Act 1998* (NSW) to consent to special medical treatments on behalf of people aged under 16.

In any case, the intention is that Independent Panels or tribunals would provide a more cost effective and less formal process than that of the Family Court or state and territory courts. Independent Panels or tribunals would also be able to be specially constituted with a range of expertise able to thoroughly scrutinise proposed medical interventions. There may be advantages in arrangements being entered into allowing smaller jurisdictions to refer cases to Independent Panels or tribunals in jurisdictions with more resources or expertise.

(d) Implementation in policy

While the obligation to seek independent authorisation should be enacted in legislation, in its absence, state and territory government and health professional entities may choose to implement aspects of the Commission's recommendations through policies and practices, including those applying to treatment in public hospitals.

Implementation in policies and practices would not require legislation. For example, state and territory governments, through health departments and public hospital administrations, could ensure that there is formal and independent multidisciplinary review of relevant medical interventions.

(e) Role of the National Guidelines

Whatever the eventual forums for independent oversight of medical interventions, decision making should be informed by a national approach consistent with international human rights law, as reflected in the National Guidelines.

(f) Reform of court processes

Court processes alone are not well suited to provide effective oversight of medical interventions modifying sex characteristics. This conclusion is based on the Commission's review of Family Court decision making in this area and informed by the experience of stakeholders.

A major theme of stakeholder concern is that cases brought in the Family Court may not always present all of the evidence necessary for the Court to decide what is in the 'best interests' of the child and, in the absence of this evidence, Family Court judges may lack knowledge and understanding of the complexities of intersex medical and other issues. People born with variations in sex characteristics argue that this leads to unquestioning, uncritical deference to the medical opinion of the treating team. The Court's lack of access to scientific expertise and knowledge and understanding of the socio-cultural factors in play may lead to limited scrutiny of the assertions of the treating team that a particular intervention is in the child's best interests. These characterisations are consistent with the Commission's review of the cases that have been before courts to date.

Cases involving children with variations in sex characteristics brought to the Family Court for authorisation have all proceeded on an uncontested basis. In only one case has the Family Court exercised its discretion to appoint an independent children's lawyer.

The lack of independent advocacy for the child's best interests in the applications to the Family Court is problematic, as the interests of the child, as distinct from those of their family, may not have been adequately explored. It is important for medical evidence to be properly tested and scrutinised to ensure that crucial human rights obligations, such as protection of bodily integrity, are given adequate consideration. The Commission considers that Family Court processes do not currently provide adequate oversight protecting the human rights of children born with variations in sex characteristics – particularly as expressed through the human rights framework of principles set out in Chapter 2.

In any case, given the numbers of people who are born with variations in sex characteristics, it would place a significant burden on the courts if they had

to authorise all proposed medical interventions. APEG noted that this could require the Family Court to authorise treatment for up to 1.7% of the population.⁶²⁵

This is an important practical reason for the Commission's view that authorisation should be determined primarily by Independent Panels, rather than the courts. Independent Panels may be able to develop guidance or administrative procedures that allow them to respond more easily to applications in relation to common variations.

However, courts may still be involved in some cases where authorisation is required. Some applications for court authorisation may continue under the welfare jurisdiction of the courts if they retain concurrent jurisdiction with Independent Panels. Further, parties who are dissatisfied with a decision of an Independent Panel may seek judicial review of panel decisions, although this is more likely to involve questions of legal error rather than review on the merits.

If courts continue to have a substantial role in decision making in this area, court processes may need reform to ensure judges have access to a fuller range of perspectives and expert opinion evidence.

For example, one suggested reform is the mandatory appointment of an independent children's lawyer in all cases involving children born with variations in sex characteristics. The presence of a dedicated advocate for the child's best interests may help to elucidate whether a proposed intervention is medically necessary.

There are a range of other reforms to court processes that might ensure judges have access to a fuller range of perspectives and expert opinion evidence.

The Senate Committee considered that more complex cases of medical intervention should be referred by courts or other decision makers to a 'special medical procedures advisory body' for their advice.⁶²⁶ It said:

The decision on whether a referral is required should be taken by whoever is considering the case. The committee envisages that this would normally be a tribunal, but in some complex cases could be the Family Court. In the committee's view this procedure would assist in objectivity in the decision-making process, as well as providing the opportunity to ensure that international best practice was followed.⁶²⁷

More generally, court processes might be more often assisted by the involvement of *amicus curiae* or interveners.

While the role of an *amicus curiae* is to assist the court, the role of an intervener is to represent the intervener's own legal interests or legislative responsibilities in proceedings. For example, the *Australian Human Rights Commission Act 1986* (Cth) confers an intervention function on the Australian Human Rights Commission under which the Commission, with the leave of the court, can intervene in proceedings that involve human rights issues.⁶²⁸

There could also be greater use of court-appointed expert witnesses and assessors. The Family Court may, on its own initiative, appoint expert witnesses.⁶²⁹ The Family Law Rules also provide for the appointment of assessors.⁶³⁰ Assessors perform a similar role to expert witnesses, but are not subject to cross-examination. They act in an advisory capacity to the judge.

If practicable, reform should also ensure that the National Guidelines, and expert opinion on how they should be interpreted, are able to be fully considered if relevant cases come before the federal courts.⁶³¹ This might require legislative action by the Australian Government, and reform of the legal criteria for authorisation of medical interventions by federal courts, consistent with the Commission's recommendations.

8

ENFORCEMENT

8.1 Enforcement

Under international human rights law, Australia's federal, state and territory governments must ensure that human rights are upheld in relation to medical interventions for people born with variations in sex characteristics.

In Chapter 7, the Commission recommends that the Australian Government and state and territory governments legislate to require clinicians to apply to an Independent Panel prior to performing medical interventions modifying the sex characteristics of a person born with a variation (Recommendation 7).

This chapter discusses how these obligations placed on health practitioners and others might be enforced in practice, under criminal and civil law, and through regulation of health professionals.

In the Commission's view, legislation should prohibit medical interventions without authorisation, and there should be appropriate criminal penalties attached to breaching this prohibition.

The reforms recommended by the Commission may also have implications in terms of disciplinary action against health professionals and civil liability, which are discussed briefly in this chapter.

8.2 Support for new regulation

Stakeholders expressed a range of views about how medical interventions modifying variations in sex characteristics without individual consent should be regulated.

The importance of effective regulation was highlighted by reference to a qualitative study of the relationship between intersex experience and law.⁶³² This study concluded that 'prevention of non-therapeutic medical intervention on the bodies of children was understood to be the key method of achieving equality for intersex embodied people'.⁶³³

A range of measures was suggested, including

- establishing a comprehensive legislative framework regulating a defined category of intervention⁶³⁴
- the creation of criminal offences for medical interventions modifying sex characteristics that are deferrable or not medically necessary⁶³⁵
- the creation of civil liability for medical interventions modifying sex characteristics that are deferrable or not medically necessary⁶³⁶
- removal of any limitation periods for legal action⁶³⁷
- the use of de-registration and other professional disciplinary measures.⁶³⁸

Stakeholders argued that changes in clinical practice would fail to achieve the cultural change necessary to safeguard people's human rights unless given legislative backing.⁶³⁹ One stakeholder stated, 'National guidelines are important, but they are still just guidelines which physicians could choose to ignore willy nilly'.⁶⁴⁰

(a) Creation of criminal offences

Stakeholders from peer support and human rights organisations, and people with lived experience of variations in sex characteristics, advocated for the creation of new criminal offences.⁶⁴¹

Creating new offences for some medical interventions would, it was argued, align with the *Yogyakarta Principles plus 10*,⁶⁴² the *Darlington Statement*,⁶⁴³ and the *Universal Declaration of Human Rights*.⁶⁴⁴

Stakeholders noted that there have been many calls for legislative prohibition, including via new criminal offences, in respect of non-consensual medical interventions.⁶⁴⁵ One peer support and advocacy organisation noted that since the 1990s, it has been calling for a moratorium on deferrable surgeries.⁶⁴⁶ It observed that advocacy for criminalisation has come from diverse sources, including in

- UN treaty body concluding observations
- recommendations made by Special Rapporteurs
- recommendations by independent experts
- community consensus statements⁶⁴⁷
- statements by disability organisations.⁶⁴⁸

Some stakeholders called for criminalisation in line with human rights obligations. Existing offences relating to female genital mutilation were taken as a precedent, including in relation to extra-territorial application.⁶⁴⁹ Some emphasised that criminalisation was a concern of the highest priority to them,⁶⁵⁰ and argued that a criminal prohibition would enhance the human rights of all members of the community.⁶⁵¹

Some stakeholders were adamant that nothing short of criminalisation would be adequate to promote a cultural shift, which they considered necessary to de-pathologise people born with variations in sex characteristics and de-medicalise initial responses by means of early intervention.⁶⁵² Stakeholders also considered that criminal prohibitions should be preferred to civil remedies, because civil litigation would effectively require children to bring actions against their parents.⁶⁵³

Some stakeholders expressed dismay that Australian governments have dismissed calls for new offences applying to carrying out medical interventions modifying sex characteristics.⁶⁵⁴ On the other hand, as discussed below, there was strong opposition from clinical stakeholders to any criminalisation of medical practice.

(b) Civil liability

Existing civil remedies include those in tort such as trespass to the person, which is actionable without proof of damage or causation of damage, and in negligence, including negligent nondisclosure of material risks.

Some human rights experts and people with lived experience of variations in sex characteristics advocated for improved civil remedies, including extending limitation periods.⁶⁵⁵

(c) Disciplinary action

Some stakeholders highlighted the possible role of disciplinary action by professional regulatory entities, such as the Australian Health Practitioner Regulatory Authority, in sanctioning health practitioners who carry out medical interventions modifying sex characteristics of people under the age of 18 years, in circumstances other than medical necessity.⁶⁵⁶ Disciplinary action may include de-registration, suspension from practice and supervision arrangements.

8.3 Opposition to new regulation

Clinical stakeholders and some parents of people born with variations in sex characteristics made forceful objections to legislative prohibition of medical interventions modifying sex characteristics and, in particular the creation of new criminal offences.

(a) Legislative prohibition is morally unjustified

There was a view that regulation would not be appropriate because medical interventions proposed by clinicians or agreed to by parents are aimed at improving the lives of people born with variations in sex characteristics and in accordance with medical ethics⁶⁵⁷ and the good intentions of parents.⁶⁵⁸ The introduction of prohibitions would, it was said, imply malicious intent on their part.⁶⁵⁹

Criminalisation of medical interventions was considered by some to be inappropriate and impractical.⁶⁶⁰ This was based on the notion that interventions are undertaken based on good impulses to help people, and thus criminalisation is not appropriate. It was observed that Chile rolled back its original blanket prohibition on unnecessary treatments.⁶⁶¹

(b) Regulation is an unnecessarily complicated response

Some clinician stakeholders and parents stated that a formal regulatory response to medical interventions would lead to a range of problems, including inappropriately limiting treatment choices, and causing stress to parents by frustrating their legitimate role in making decisions on behalf of their children.

A legislative response was considered inappropriate for the following reasons:

- New legislation would be cumbersome, complex, and difficult to draft,⁶⁶² especially given the evolving nature of medical science.⁶⁶³ In particular, because individuals and their needs are diverse and complex,⁶⁶⁴ it would be impractical to define the limits of permissible intervention.
- This complexity risks causing inadvertent harm to other individuals. Some legitimate medical interventions would be inadvertently captured and clinicians and parents criminalised inappropriately.⁶⁶⁵ A longer-term consequence would be more difficulties for people in obtaining necessary treatment.⁶⁶⁶
- New legislation would generally be unnecessary and impractical, would get in the way of the provision of medical care,⁶⁶⁷ and create risks for people in life-threatening situations flowing from inevitable delays in working through prescribed processes.⁶⁶⁸
- New legislation would impose unnecessary expenses on stressed and vulnerable families,⁶⁶⁹ and breach parents' rights to make decisions for their children.⁶⁷⁰

One multidisciplinary team argued that formal regulation is unnecessary as there is no evidence that early medical intervention is harmful to children born with variations in sex characteristics.⁶⁷¹

(c) Regulation would breach children's rights

Some parents and clinical stakeholders considered that any additional regulation of medical interventions for children born with variations in sex characteristics would undermine the realisation of the rights of the child. Specifically, it was stated that

- any legal hurdles to obtaining treatment would breach children's rights to attain the highest possible standard of health (understanding health in a particular socio-temporal context)⁶⁷²
- regulation would provide an incentive for well-intentioned parents to take children to other jurisdictions for desired treatments⁶⁷³
- some classes of procedure (in particular, hypospadias surgery) are 'almost universally acknowledged to be beneficial'.⁶⁷⁴

8.4 New criminal penalties

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 criminal penalties for breaching this prohibition.

Australia's human rights obligations require governments to ensure human rights are adequately observed and enforced. As discussed in Chapter 7, there is a real risk that medical interventions, other than on grounds of medical necessity, may be undertaken in the future. This position is informed by the views of a range of clinicians that psychosocial factors are justifiable considerations for medical interventions, with such justifications given weight in leading international guidance documents. Therefore, overall cultural change would be unlikely in the absence of binding directions.

While new clinical guidelines, including in the new National Guidelines, may help bring about changes in medical practice and culture, more formal regulation is necessary to prevent medical interventions that infringe human rights.

While medical interventions without personal consent may be carried out with the best of intentions, this is not a valid argument against the introduction of sanctions designed to protect people's human rights. These medical interventions do cause some people devastating and lifelong harm – and are in conflict with the principle of bodily integrity.

Some stakeholders seemed to base their opposition to any legal sanctions on the premise that all medical interventions modifying sex characteristics would be prohibited, in all circumstances.⁶⁷⁵ However, neither the Commission nor any stakeholders have advocated such a blanket prohibition.

The view that any legislative prohibition on medical interventions would breach children's rights to attain the highest possible standard of health fails to recognise the significant, ongoing harm experienced by some individuals following interventions without their consent – despite those interventions having been undertaken in the belief that they were in the child's best interests.

The Commission's recommended reforms need legislative backing and an effective means of enforcing the obligation to seek authorisation from Independent Panels.

Exactly where these legislative provisions should be located and how they will be enforced will depend on legal and policy decisions taken in each jurisdiction. However, the Commission recommends that criminal penalties be provided in relation to the carrying out of relevant medical interventions without authorisation.

One model for a criminal offence is that provided under NSW guardianship legislation relating to sterilisation procedures. This provides an offence, punishable by seven years imprisonment, for carrying out such a procedure without the consent (that is, authorisation) of the NSW Civil and Administrative Tribunal.⁶⁷⁶

The Commission does not recommend any other criminal offences, like those, for example, which apply to female genital mutilation under state and territory legislation.⁶⁷⁷ Unlike in the case of female genital mutilation, it is unlikely that the offence would be committed by anyone other than a health practitioner who, in addition to the offence recommended by the Commission, would also risk professional disciplinary action and exposure to civil liability. It would also be difficult to define the exact scope of the interventions that would be subject to criminal sanctions.

The reforms recommended by the Commission would also have implications in terms of disciplinary action against health professionals. As discussed in Chapter 6, the recommended National Guidelines could become an important reference point when assessing minimum standards of care in the context of complaints made about professional standards.⁶⁷⁸ Breach of clinical guidelines may lead

to disciplinary action by professional regulatory entities, such as the Australian Health Practitioner Regulatory Authority.

The recommended reforms may also have implications in terms of the civil liability of health practitioners who carry out medical interventions modifying sex characteristics without personal consent. For example, if carrying out a medical intervention without authorisation is a criminal offence, this conduct may also constitute a wrongful act or omission giving rise to civil liability.

On the other hand, compliance with the National Guidelines may help protect health practitioners from civil liability. For example, under the Civil Liability Act 2002 (NSW) a professional does not incur liability in negligence if they act in a manner that is 'widely accepted in Australia by peer professional opinion as competent professional practice',⁶⁷⁹ which can be reflected in clinical guidelines.



SUPPORT, HEALTH RECORDS AND DATA COLLECTION

The bulk of this report has focused on decision making that directly relates to medical interventions in respect of people born with variations in sex characteristics. This chapter considers three other related issues.

The first issue is the need for adequate support for individuals affected by medical interventions. Several stakeholders raised concerns about a lack of information about the lived experience of variations in sex characteristics and alternatives to invasive, irreversible medical interventions on children, including non-intervention. They focused on a need for better access to peer support and professional psychological and psychiatric services.

Secondly, this chapter considers the rights of affected people to access and control their health records. Concerns were raised with the Commission about records having been destroyed, failure to appropriately share records between treating health professionals, and inadequate record security.

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

9.1 Support for affected individuals

The provision of adequate support for individuals born with variations in sex characteristics is important for the realisation of their human rights. This support should include provision of relevant information about health and other related issues, as well as professional psychological and peer support.

Adequate support for families of children born with variations in sex characteristics is also important, in particular in the period following birth, when families may be facing an unknown picture and are reliant on guidance from experts.

For children, support can enable their fullest engagement in health-related decision making as they mature. This helps children to exercise autonomy, in accordance with article 12 of the CRC,⁶⁸⁰ and as expressed in the children's agency principle. Children are guaranteed access to information under article 13 on freedom of expression, and article 17 on information and media. Information provision needs to be appropriate for children, adults and parents/families.

(a) Provision of information and education

Many people born with variations in sex characteristics described their dissatisfaction with the information provided by health professionals and others in relation to their variation in sex characteristics.⁶⁸¹ The provision of information as it relates specifically to informed consent is addressed in detail in Chapter 4. More general concerns about information provision were raised by people with lived experience. These concerns focused on a lack of information about experience of variations and alternatives to invasive, irreversible interventions, including the alternative of non-intervention.

In this context, stakeholders referred to article 18(2) of the CRC:



For the purpose of guaranteeing and promoting the rights set forth in the present Convention, States Parties shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children.⁶⁸²

The Commission notes that article 18(2) is about information for parents and legal guardians, not children.

(i) *Need for information for individuals and their families*

Stakeholders expressed diverse views on whether adequate information has been provided to individuals, and where appropriate, their families.

One clinical stakeholder stated that contemporary practice involves

explaining the condition, its consequences and likely impacts, treatment or management options including non-intervention, and the potential benefits and risks associated with each option, in cases where the affected person is in a position to provide or deny consent. This situation is no different from any other area of medical practice.⁶⁸³

Some stakeholders from peer and parent advocacy and support organisations, and some health service providers, argued that the provision of information has been inadequate. One parent advocacy and support organisation stated that there are major shortfalls in available information resources. For their adult members, who have had little or no support, this lack of knowledge and information can have major negative impacts on health and mental wellbeing.⁶⁸⁴

One peer advocacy and support organisation stated that information provision remains insufficient.⁶⁸⁵ Individuals with lived experience of variations in sex characteristics observed that information provision varies considerably, dependent on location, and many people do not have a choice of information sources.⁶⁸⁶

Some stakeholders identified the need to promote understanding and awareness among health care professionals, educators, teachers and across the broader community.⁶⁸⁷

One peer-support and advocacy organisation stated that there is need for

adequate training and education about the diversity of bodies contained under the intersex umbrella, including the specific

concerns for some of the more common variations, and the human rights issues that face our community should be included in all new medical, health, psychological, sociological, social work, and community services related studies and ongoing professional development opportunities for practicing professionals should be available so that referral pathways to affirmative peer support and information is available. Additionally, sex education delivered in schools must provide at least the most basic description of intersex so that individuals are not erased in this context and discussion around intersex issues is open, non-pathologising, and supported. Peer-led intersex organisations should be consulted in the drafting of any such educational material. Individuals with lived-experience who are open and willing to speak about their experiences have often spent many years in reflection and resilience and therefore must be considered experts in intersex issues.⁶⁸⁸

A Gender Agenda suggested that, in addition to information and advice, parents and carers should be given patients' rights 'toolkits' to support people to navigate healthcare services.⁶⁸⁹

In July 2021, Intersex Human Rights Australia worked with the Victorian Government by auditing community and related resources on people with variations in sex characteristics.⁶⁹⁰ The review identified mixed messaging by health and community organisations, in relation to both medical practices affecting people with intersex variations, and the characteristics of the population.

(ii) Need for balanced information

Stakeholders disagreed about the adequacy and transparency of information coming from specific sources. For example, one clinical stakeholder had concerns about support groups and peer workers

not giving balanced information and being unduly negative about medical intervention, including in assuming that medical or clinical information is inherently biased.⁶⁹¹

In contrast, people born with variations in sex characteristics noted the pitfalls of assuming that medical practices of intervention were value-neutral and objective. Stakeholders suggested that medical practices in respect of variations in sex characteristics problematises being intersex due to societal and cultural expectations about the alignment between bodies and stereotypical gender roles.⁶⁹² One clinical stakeholder referred to a study by Jones et al (2016), which recounted numerous experiences of inadequate disclosure.⁶⁹³

(iii) Clinical education

Some stakeholders stressed the importance of ongoing education and training for professionals serving people born with variations in sex characteristics, including peer-led training.⁶⁹⁴ A peer support and advocacy organisation called for

Adequate training and education about the diversity of bodies contained under the intersex umbrella, including the specific concerns for some of the more common variations, and the human rights issues that face our community should be included in all new medical, health, psychological, sociological, social work, and community services related studies and ongoing professional development opportunities for practicing professionals.⁶⁹⁵

A hospital multi-disciplinary team observed that medical education now includes content on ethics and human rights frameworks, although content varies between institutions and courses.⁶⁹⁶ The Jones et al (2016) study identified a range of priority measures to achieve improved health for people born with variations in characteristics; 34 of the 137 responses identified as a priority providing education and training to staff on intersex variations.⁶⁹⁷

(iv) *Better information provision*

Clinicians and other health service providers should ensure that people with variations in sex characteristics and, where appropriate, their parents or guardians are provided with adequate information, at points of first contact and on an ongoing basis. Given that most interventions occur when individuals are infants and young children, provision of adequate information to parents is paramount.

Information may be needed from a range of sources, including from peer and parent support organisations; psychiatrists, paediatricians, endocrinologists and other clinical specialists; and psychologists and other allied health professionals involved in care.

In particular, the Commission considers that referral to peer support organisations is important to ensure people with variations in sex characteristics, and their parents and guardians, obtain the information they need.⁶⁹⁸ The value of peer support has been recognised in the WHO Mental Health Action Plan 2013–2020,⁶⁹⁹ and the 2016 Consensus Statement and Update.⁷⁰⁰

People with lived experience have called for improved training and education of healthcare professionals to enable them to better understand the diversity of variations in sex characteristics.

The need for better information provision is addressed in Recommendation 10 (at 9.1(c) of this report). Issues surrounding the education and training of health professionals who provide care to people with variations may be matters suitable for consideration by the multidisciplinary expert group (See Recommendation 6(a)).

(b) Provision of support services

Stakeholders expressed concern that individuals born with variations in sex characteristics do not have adequate peer support or more formal psychological services available to them and called for better access to such services.⁷⁰¹

Peer support

Peer support is important for people born with variations in sex characteristics and their families to make informed decisions about their healthcare. It can help alleviate feelings of stigma and isolation and can expose individuals to further information, options and experiences.

Adolescents and other young people can especially respond to peer support, when they feel they cannot get support from parents/families, are exploring identity issues and want to belong to others their age.

In Australia, the Senate Committee report, the Consensus Statements, the Victorian Decision-Making Principles and the Darlingtong Statement all recognise the importance of peer support for people born with variations in sex characteristics and their families and carers.

While the importance of peer support is clinically recognised, in practice referrals to support groups are inconsistent. Further, capacity and resource constraints for peer support groups and organisations in Australia remain poorly funded, with most support groups run in a voluntary capacity or with limited and short-term funding, restricting the ability of these groups to provide the support that is required.

(i) *Peer support services*

Stakeholders generally agreed that properly funded and resourced peer support workers would be of great help in supporting individuals, their families and carers.⁷⁰²

Some called for clinicians to ensure referral of individuals, and where relevant their families, to peer support organisations.⁷⁰³ A human rights organisation argued that it should be mandatory for parents and carers of infants and children to be referred to peer support groups.⁷⁰⁴

Properly resourced peer support is considered integral to a human-rights based approach.⁷⁰⁵ The Jones et al (2016) study identified a range of priority measures to achieve improved health for people born with variations in characteristics people; 20 of the 137 responses identified providing referrals to intersex support groups as a priority.⁷⁰⁶

Concerns were expressed about the need for clear and accessible referral pathways to peer support and information.⁷⁰⁷ Currently, most peer support, both to assist individuals and to undertake systemic advocacy, is provided by volunteers.⁷⁰⁸ There are significant risks of vicarious trauma and burnout.⁷⁰⁹ Stakeholders considered that funding for peer support workers should be provided at all levels of government.⁷¹⁰

Value could be added through properly funding support groups, to enable them to

- enhance the quality, timeliness and accessibility of online resources⁷¹¹
- support outreach, including to rural, regional and remote communities⁷¹²
- provide education, awareness and training to bodies such as health care services, schools and workplaces.⁷¹³

A range of LGBTI organisations called for better funding for peer support services to allow them to conduct important systemic advocacy.⁷¹⁴ A peer

support and advocacy organisation stated that there

seems to be a disconnect between medical professionals and support groups, and this results in families and individuals not receiving the best care and advice that is possible. Ultimately, the consumer suffers because those in positions of power don't hold the consumer's needs/rights/best interests as paramount.⁷¹⁵

(ii) *Mental health services*

There was a call from a range of stakeholders, including people born with variations in sex characteristics and clinicians, for psychosocial support for family members across their lifespan. This should include access to psychologists and social workers.⁷¹⁶

One stakeholder representing mental health professionals called for services tailored for young people, offering them space away from their parents to reflect on, and talk about, their experiences.⁷¹⁷ This stakeholder cited the Jones et al (2016) study, which noted:

therapy can potentially provide a space for people with an intersex variation to come to accept any physical differences they may have, work through confusion about their sex or gender identity (if any is apparent), or issues related to any enforced surgeries if relevant.⁷¹⁸

Intersex Human Rights Australia called for psychological and other psychosocial support services to support parents who may otherwise feel that surgical intervention is the only way to resolve the psychosocial issues they face in having a child with a variation in sex characteristics.⁷¹⁹ Other stakeholders also called for 'increased psychosocial interventions to address issues relating to people born with variations'⁷²⁰ and better professional psychological support.⁷²¹

Some stakeholders drew attention to significant workforce capability gaps, such as the scarcity of psychologists trained to work with people born with variations in sex characteristics and their parents or carers.⁷²² The Western Australian Multidisciplinary DSD Team, for example, drew attention to the fact that in their service, there are no positions for a dedicated psychologist for immediate and long-term follow-up.⁷²³ The Australasian Paediatric Endocrine Group noted that this currently unmet need is exacerbated for sub-groups, such as adolescents.⁷²⁴

A range of stakeholders noted that psychological support is, for the most part, completely unfunded as part of usual care provided to people born with variations, and that this needs to be addressed as part of a national strategy.⁷²⁵ The lack of expert psychological help was considered to have a negative impact on the human rights of people born with variations in sex characteristics.⁷²⁶

(iii) *Coordinated services*

Some stakeholders called for people with variations in sex characteristics to have ongoing access to advice from multidisciplinary teams of experts,⁷²⁷ who should also offer information about contemporary evidence and gaps in that evidence.⁷²⁸

The Commission recommends, in relation to clinical practice standards, that all people born with variations with sex characteristics should have access to comprehensive multidisciplinary care, including through multidisciplinary treatment teams (Recommendation 5).

Some stakeholders also called for well-planned and managed transition from paediatric to adult care and services, including through adolescence.⁷²⁹ The Western Australian Multidisciplinary DSD Team saw this as particularly important because there are currently significant attrition rates at adult clinics.⁷³⁰

Clinical stakeholders called for more funding to adequately resource multidisciplinary services Australia-wide and provide information to clinicians in regional and remote areas about the availability of these resources.⁷³¹ The Western Australian Multidisciplinary DSD Team and the Australasian Paediatric Endocrine Group called for the funding of coordinator positions, to support individuals and families to navigate services across services and to maintain follow up and monitor wellbeing.⁷³²

(iv) *People in rural, regional and remote Australia*

Stakeholders suggested that more telephone and online services could help address concerns about inferior access to information and services for people in rural, regional and remote areas.⁷³³ One parent stated that to better support individuals and their families, there was a need for

psychological support available via phone or telehealth. It is prohibitive for a lot of families, particularly living in rural and remote areas to access support for all health services.⁷³⁴

Given the limited number of peer support groups, it was suggested that governments should establish an online presence for these groups to ensure individuals can access support, especially those who live in rural and remote areas.⁷³⁵

(c) **Better service and information provision**

Recommendation 10:

The Australian Government and state and territory governments should provide sufficient, recurrent 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, co-designed and delivered 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.

Peer support plays a crucial role in helping people and their families better understand their variations and what the implications may be. The limited funding of peer support services significantly restricts service provision. Sufficient public funding for peer support organisations is essential.

There is a widespread view that the provision of professional psychological and psychiatric services is central to the wellbeing of people born with variations in sex characteristics and their families. The Commission understands that psychological and psychiatric services are not generally funded as part of the care received by people born with variations, with availability further limited for people in rural/remote locations. Funding for comprehensive psychological and psychiatric health services is also essential for optimal care.

There was general agreement across sectors about the need for improved access to online peer support and health services. The Australian Digital Inclusion Index 2018 reports that the gap between digitally included and digitally excluded Australians is substantial and is widening for some

groups.⁷³⁶ Given this 'digital divide', it is important that information and services for people with variations in sex characteristics are offered in a range of mediums.

In the Commission's view, the idea of funding coordinator positions to help support integrated care across multiple specialties and institutions has merit and should be considered further by governments.

The Commission welcomes the Victorian Government's recent work with Intersex Human Rights Australia to audit resources on the experience of people with variations in sex characteristics. The workplan to address the gaps identified in the audit would go to addressing some of the shortcomings in information provision.

9.2 Access to and control of health records

There have been widespread concerns expressed about inadequate access for individuals to their health records. Problems are said to have arisen because records have been destroyed and due to bureaucratic barriers to access. Concerns were also expressed about unauthorised access to records, inadequate record security, and inadequate sharing of individual histories with relevant healthcare professionals.⁷³⁷

(a) Access to health records

Some stakeholders who had experienced medical interventions expressed distress at their lack of access to records about interventions and associated decision-making processes. Concern was expressed about archiving and records destruction practices. The harmful consequences were said to include disempowering people from taking full agency in management of their health and well-being and detracting from people's sense of identity and safety.⁷³⁸

A Gender Agenda commented that lack of access to records means that

It is not at all uncommon for someone approaching the intersex community [at AGA] to be unsure of their intersex status. Instead they are only able to piece together surgical scars and vague memories.⁷³⁹

In relation to paediatric records, A Gender Agenda argued that, for many people

paediatric records are long lost, unrecoverable, or deliberately withheld. If there is no further information available from their family, there is no certainty and no safety.⁷⁴⁰

A person with a variation in sex characteristics commented:

As an older person I was told that my health records were destroyed, meaning that I have no record of any surgery prior to the age of 21 as I was a state ward before that

time and I was not in a position to even enquire.⁷⁴¹

Inability to access records can be experienced as a harm in its own right, and was also reported to lead to additional harms, such as impeding access to services that are contingent on a diagnostic and treatment history.⁷⁴² One stakeholder commented:

Many older intersex people have little or no records of surgery as a child and live a life of limbo in relation to their bodies adding to mental health issues and the inability to ever gain bodily autonomy and of course never bodily integrity.⁷⁴³

Stakeholders born with variations in sex characteristics called for lifelong access to records.⁷⁴⁴ One suggested that access should not be impeded by prohibitive bureaucratic obstructions or financial cost to the patient.⁷⁴⁵

A human rights agency suggested there should be a legal requirement to disclose variation-related information to children, with support from



psychologists to minimise any risk of trauma, to allow children to obtain full knowledge appropriate to their age and level of maturity.⁷⁴⁶

Several individuals with lived experiences of variations in sex characteristics reported that when they sought access to records, they were dissatisfied with what they received. One commented:

I got my medical records through a FOI application. There was so much blacked out it was almost impossible to work out who had done what. This was done to protect everyone else who made those decision[s], not my right to know the truth about what had happened to me and what the reasons were.⁷⁴⁷

(b) Privacy

People with lived experience called for improved security and privacy of records.⁷⁴⁸ A Gender Agenda argued that privacy is not adequately protected, leading to an absence of feelings of safety and security.⁷⁴⁹

A parent advocacy and support group reported records being disclosed to third parties, including researchers, without consent.⁷⁵⁰ This stakeholder also expressed concern about unauthorised, unregulated data being available to entities, such as insurers and employers, who might unlawfully discriminate against people.

(c) Sharing health records

Some individuals with lived experience expressed their distress at having to retell their history to new healthcare professionals, along with explaining to the professional the nature of the variation. One interviewee stated:

You know I have to tell them what the diagnosis was, what medications I'm on, what it means to be ... you know I have to give them an intersex 101 lesson, you know

here I am paying \$60 to see a new GP and meanwhile I'm educating them and giving them a free education. So I think there needs to be better ways of ensuring that information, while maintaining a patient's privacy, information is transferrable, so that a patient can go and see a doctor and present with an issue and see their issue resolved rather than you know, beat around the bush and have to deal with you know the ground stuff, the historical stuff around their diagnosis.⁷⁵¹

(d) The importance of access to records

Access to detailed health records for the individuals concerned is crucial to their self-understanding. The Commission has heard in its consultations how obtaining access to individuals' own health records can be problematic. To ensure that, in the future, people born with variations in sex characteristics will have access to their health records, the Commission considers that healthcare providers should generally maintain lifelong patient records for this group. However, this is not the current law. Laws and policies covering access to and retention of medical records are complex. They include health professional standards,⁷⁵² and Commonwealth, state and territory privacy and health records legislation.

For example, while the *Privacy Act 1988* (Cth) gives people a general right to request access to the health information a health service provider holds about them, state or territory laws cover health information held by public hospitals.⁷⁵³

The *Privacy Act* provides that personal information, including health information, should be destroyed or permanently de-identified once it is no longer needed for any authorised use or disclosure.⁷⁵⁴

However, legislation in NSW, Victoria and the ACT requires medical records to be retained until a child turns 25, and for adults, for seven years

from the date of the provision of the last health service.⁷⁵⁵ Health information held by government agencies, including public hospitals, may be subject to longer retention periods under public records legislation.⁷⁵⁶ These obligations override the *Privacy Act*.

It would be difficult to frame legislative provisions applying specifically to the retention of medical records of people born with variations in sex characteristics. While the Commission is not in a position to make recommendations for legislative change in this area, these issues deserve further consideration. For example, there may be no reason other states and territories should not adopt the seven-year retention rule applicable in NSW, Victoria and the ACT.

Issues concerning access to and retention of the medical records of people born with variations in sex characteristics are matters that could also be considered by the multidisciplinary expert group (Recommendation 6).

Some features of the Australian Government's My Health Record system may be of assistance to people born with variations in sex characteristics. My Health Record is an online summary of an individual's health information, accessible to any healthcare professional involved in the individual's care. Importantly, My Health Records information is retained for the life of the individual, unless they cancel their registration.⁷⁵⁷

Children younger than 14 years of age must have their My Health Record managed by their parents. From the age of 14 years, young people are deemed by the Australian Digital Health Agency to be allowed to control their record.⁷⁵⁸ This means that from this point, they can choose to prohibit their parents or guardians from accessing their record.

People born with variations in sex characteristics need to feel comfortable with, supported and proficient at, sharing relevant parts of their health

record with healthcare professionals. Repetition of medical history can be time-consuming and distressing. The My Health Record is designed to facilitate record sharing.

The improved accessibility is of particular benefit for individuals with several comorbidities who have complex care arrangements involving multiple healthcare settings, such as some people born with variations in sex characteristics. The ability to select which documents are seen by whom allows the record to be tailored to individual preferences, so people who have experienced stigma can more confidently engage with the system.

People with variations in sex characteristics, and their parents, should be supported by their healthcare providers and peer support organisations, to consider using this electronic health record as a means of sharing their health information with trusted health professionals.

9.3 Data collection

There is a significant disagreement among stakeholders on the health and psychosocial effects of medical interventions for people with variations in sex characteristics. There is also disagreement about whether problematic practices are confined to the past or continue to occur.

The collection of better long-term, longitudinal data on past and current practices may greatly assist to assess the extent of interventions that are occurring and their outcomes.

Clinicians stated that some more invasive interventions, which historically were routinely undertaken, are no longer conducted in light of evolving science.⁷⁵⁹ Some clinicians conceded that interventions have been carried out that should not have occurred, resulting in significant health issues for some individuals.⁷⁶⁰

As discussed in Chapter 3 – Lived experience, many clinicians assert that the fact some people report

negative experiences with medical interventions is not indicative of any ongoing problem in medical practice, because

- contemporary medical practice is much more cautious than in the past, so none of the problematic interventions that led to negative outcomes are still being conducted
- there is a silent 'majority' who are satisfied with their interventions.⁷⁶¹

Many people with lived experience of variations in sex characteristics and their representative organisations, on the other hand, stated that there has been no comprehensive research to provide evidence about the nature and extent of past and current medical interventions or their outcomes, including in relation to the wellbeing of people with variations in sex characteristics.⁷⁶² In the absence of such data, they argue there is no evidence to support the view that fewer medical interventions are occurring or that those which are being conducted do not have negative consequences.

(a) Lack of data

Stakeholders agreed that data about the consequences of medical interventions, including long-term outcomes, has been lacking.⁷⁶³

Some clinicians also observed the paucity of data on outcomes for individuals who do not undergo interventions.⁷⁶⁴ The Australasian Paediatric Endocrine Group stated:

We agree there is a lack of Australian and international data available on people born with variations in sex characteristics including their investigations, management and long-term outcome. There are no reliable, easily accessible Australian sources of data on contemporary medical interventions in individuals born with variations in sex development. This is a significant limitation

to both the provision of care and the development of evidence based optimal care guidelines for different variations. Studies that exist provide cross-sectional 'snapshot' insights, but have significant limitations, particularly in relation to selection bias and difficulties in recruitment of cohorts that are representative of the broader population of people with variations in sex development.⁷⁶⁵

It also stated that existing medical evidence 'is almost uniformly sparse when it comes to the rarer variations of sex characteristics'.⁷⁶⁶

A hospital multi-disciplinary team observed that there is a paucity of evidence to provide guidance for treatment:

guidance for intervention was often very broad, with specific evidence pertaining to any given DSD variation frequently based on results of un-pooled data, small sample sizes and centre experience rather than on systematic review or meta-analysis of high quality data.⁷⁶⁷

Another hospital multi-disciplinary team stated, in relation to the timing of interventions, that there is 'little evidence to support the long term psychological effect of early or delayed surgery'.⁷⁶⁸

Some people with lived experience of variations in sex characteristics and their peer-support groups also identified a systemic lack of data.⁷⁶⁹ One person with lived experience said that 'life long data is not in abundance because of hospitals refusal to share data'.⁷⁷⁰ Another stated:

No one hospital or team can say with any accuracy or knowledge what any other hospital or team is doing. There are lots of fine words about changed practices, but no evidence of those changes. Instead, we keep seeing evidence that things haven't changed.⁷⁷¹

A peer-support organisation also called for data that is community led, and focuses on non-medical aspects of the experiences of people born with variations in sex characteristics, calling for

ethical research, including clinical, sociological and psychological research, led by community input. Clinical research, including longitudinal research, requires true, non-medicalised controls.⁷⁷²

(b) Disagreement in the absence of data

The lack of relevant and robust data fuelled some of the strongest disagreements among stakeholders.

For example, those opposing early intervention pointed to a lack of data about the efficacy and long-term effects of treatments as a basis for advocating for a conservative, non-interventionist approach. The Royal Australian and New Zealand College of Psychiatrists stated that

There is little evidence for sex assignment therapies leading to positive or negative mental health outcomes. Accordingly, claims that sex assignment therapies are 'necessary' or 'therapeutic' are dubious. In the absence of such evidence, decisions should be made with the understanding that the patient's wishes are absolutely paramount.⁷⁷³

Stakeholders advocating early intervention pointed to a lack of data about the long-term effects of inaction to justify ongoing early interventions, because it cannot be asserted that deferring interventions produced better outcomes for individuals. They also argued that longitudinal research should be undertaken to monitor medium to long-term outcomes and develop an evidence base.⁷⁷⁴

Some stakeholders representing people born with variations in sex characteristics considered that a lack of data should not be relied on to obstruct

the application of a human rights-based approach prohibiting certain categories of intervention. For example, one stakeholder said

We can build on this to debunk claims by clinicians ... that more research and data is needed. What data is needed to determine that reducing the size of a baby girl's clitoris is OK? Or why is data required to know that babies should not be given hormone treatment without their consent to influence their gender identity and sexual orientation. Intersex conversion therapy needs to be prohibited.⁷⁷⁵

(c) Data collection to support optimal practice

Stakeholders from a range of sectors, including people born with variations in sex characteristics, peer support organisations, clinicians and human rights groups, agreed that there is a pressing need for data on the

- frequency of variations in sex characteristics⁷⁷⁶
- short, medium and long-term effects of intervention and non-intervention.⁷⁷⁷

Clinician stakeholders also called for the collection of data on the consequences of deferred intervention⁷⁷⁸ and to validate existing practices and guide future practices.⁷⁷⁹

The Australasian Paediatric Endocrine Group stated that it would be useful for data to be collected retrospectively, as well as prospectively.⁷⁸⁰

(i) Frequency of variations

Various sources suggest a range between 0.05% to 4.0% of births as the prevalence of individuals born with variations in sex characteristics.⁷⁸¹ However, data has not been collected consistently or systematically and, where it exists, its validity is impaired by a range of limitations.⁷⁸²

One hospital multidisciplinary team observed that there is no consensus about what variations have been included and excluded in past estimates.⁷⁸³ 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.⁷⁸⁴

(ii) *Short, medium and long-term effects of intervention and non-intervention*

Clinician stakeholders argued that access to data about long-term outcomes is crucial to informing what, if any, future treatments are appropriate.⁷⁸⁵ One clinician stakeholder stated that better long-term outcome data would also allow for linking of molecular diagnoses with informed long-term anatomical, physiological and psychological trajectories.⁷⁸⁶

Stakeholders stated that data should be collected on individuals who do not undergo early interventions, as well as those who do.⁷⁸⁷ It was suggested that long-term data collection should include

- quality of life data
- psychological outcome data
- cardiovascular outcomes
- metabolic outcomes
- bone metabolism
- malignancy risk
- sexual function
- satisfaction with genital appearance
- outcomes of alternative treatments.⁷⁸⁸

(d) Barriers to data collection

Stakeholders identified a range of barriers to better data collection in the context of medical interventions.

The Endocrine Society of Australia considered these barriers to include

- the lack of nationally consistent language, guidelines and standards of care
- ethical and privacy issues
- the differing expertise of medical and allied health professionals
- the ongoing evolution of treatment techniques and options.⁷⁸⁹

A parent support organisation observed that a lack of resources to deal properly with sensitive information constitutes a major barrier to collating, accessing and analysing data.⁷⁹⁰

Intersex Human Rights Australia argued that the primary barrier to data collection was not resourcing but rather 'lack of transparency, and unevidenced appeals to assurances of changed clinical practice'.⁷⁹¹

Another intersex peer support and advocacy organisation stated that for some individuals with lived experience of variations in sex characteristics, trauma and distrust of the medical and research establishment is likely to stymie collection of consistent, reliable data over an extended period. The organisation reported that, based on input from those with lived experience:

Many intersex people are not willing to disclose personal information for research purposes.

Disclosure is traumatic. Each time it requires revisiting harmful experiences.

Our trust in researchers and scientific or medical research has been abused time and again.⁷⁹²

The organisation stated that it

rejects research aimed at confirming the efficacy of current clinical interventions

that does not take into account, or is conducted at the expense of investigating of the true effects of past (and continuing) interventions. As such, the [organisation] ... calls for greater community based participatory research.⁷⁹³

(e) Who should be responsible for data collection?

Clinical stakeholders called for the creation of a national databank of information about individuals with variations in sex characteristics.⁷⁹⁴

Other contributors also advocated for the establishment of a national databank to collect and share data about medical interventions.⁷⁹⁵

Some stakeholders expressed a willingness to assist in the development of a databank. However, there was a general view that primary responsibility for such an initiative should rest with government and government agencies.⁷⁹⁶

A clinical stakeholder stated that the institution hosting the databank would need to be selected with care, to enjoy the trust and confidence of all stakeholders.⁷⁹⁷ Contributors across the board highlighted the need for adequate funding to support comprehensive data collection.

One peer support and advocacy organisation argued that research should be led by those with lived experience of being born with variations in sex characteristics.⁷⁹⁸

(f) Towards better data

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 that is 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 research to tackle 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 meet the above design standards and disaggregate data on people born with variations of sex characteristics.

The Senate Community Affairs References Committee's second 2013 report observed that 'there is a serious shortage of quality information, not only about medical treatment, but about the non-medical dimensions of intersex life'.⁷⁹⁹ The Senate Committee recommended that

the Commonwealth Government support the establishment of an intersex patient registry and directly fund research that includes a long-term prospective study of clinical outcomes for intersex patients.⁸⁰⁰

The need for better data collection to assist research and optimal care appears to remain. In the Commission's view, there are strong arguments that a national databank or registry should be created to record important data about the nature and outcome of medical interventions. Lack of data may also be a relevant factor in human rights analysis where considering whether medical interventions may be carried out without

individual consent. Where there is a lack of data demonstrating the health benefits of intervention, it is difficult to characterise them as being necessary and proportionate to avoid serious and irreparable harm.⁸⁰¹ This may have implications for decision making about interventions, including in future applications for authorisation.

The Commission suggests that data should be collected on, at least, the following matters:

- frequency of variations in sex characteristics, including of specific variations, associated phenotypes and their long-term outcomes
- short-, medium- and long-term effects of intervention and non-intervention
- consequences of deferred intervention
- psychosocial, sexual and general medical dimensions, to provide comprehensive evidence of whole-of-life impacts.

In order for reliable, high-quality longitudinal data to be collected, adults with lived experience of variations will need to choose to engage with and to trust in researchers and medical professionals. A great deal of preparatory work will need to be undertaken over a lengthy period by all stakeholder groups to build the kinds of relationships necessary for this to be possible. The Commission supports the development of community and clinical co-designed research to help gain trust and participation of people with lived experience.

There are many issues that would need to be addressed in order to establish a national databank. Importantly, adequate funding from government would be essential.

How such a databank should be established and where it should be located are open questions. Issues surrounding the establishment of a databank could be considered by the multidisciplinary expert group (see Recommendation 6). There may

also be a role for the National Health and Medical Research Council, as the key driver of health and medical research in Australia.

There should be robust consultation to ensure that any databank meets the expectations of people with lived experience. Such consultation should address, among other things, whether individuals should have the right to opt-out from having personal information recorded on the databank. A databank would need to have strong privacy protection and ethics approval mechanisms.

The development of such a databank should be tasked to the national multidisciplinary expert group that is responsible for the development of the *National Guidelines on medical interventions for people born with variations of sex characteristics* (see Recommendation 6).

9.4 Responding to those harmed by past practices

People born with variations in sex characteristics' experiences are outlined in Chapter 3 – Lived experience. In the submissions describing their experiences, some expressed their views on the need for redress for past harms. Other contributors, such as human rights agencies, also expressed their views on what redress they believe is needed to address past harms.

Options proposed include:

- apology from both governments and institutions⁸⁰²
- direct personal responses, such as those offered to survivors of institutional child sexual abuse, where desired⁸⁰³
- reparation, redress and life-long financial support for ongoing reparative treatment required by virtue of non-consensual intervention⁸⁰⁴

- life-long access to counselling for individuals and family members, where desired⁸⁰⁵
- no statute of limitations on civil or criminal litigation.⁸⁰⁶

These are important contributions. The Commission also notes the remarks to Australia by the UN Committee on the Rights of Persons with Disabilities (2019) and the UN Committee on the Elimination of Discrimination Against Women (2018) calling for provision of redress.⁸⁰⁷ The right to an effective remedy is also provided for in the *International Covenant on Civil and Political Rights*.⁸⁰⁸

In the Consultation Paper the Commission did not ask any questions relating to views of stakeholders

on redress measures for past harms. As a result, the Commission is not a position to have a fulsome understanding of the community's views on the need for redress, other than the few comments above. In the absence of comprehensive input across the range of stakeholders, it would be premature for the Commission to express a view on appropriate redress measures. Any model for redress would need to consider the specifics of harms caused and the most appropriate way of remedying them.

The Commission is sympathetic to an appropriate body exploring this issue, with a view to engaging all relevant stakeholders. The Australian Law Reform Commission might be such a body.

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 is it 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.
- 18 *Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, opened for signature 10 December 1984, 1465 UNTS 85 (entered into force 26 June 1987) art 2(1); ICCPR arts 6,7, 8, 11,15, 16.
- 19 United Nations Economic and Social Council, *Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights* UN Doc E/CN.4/1985/4, Annex (1985) (ICCPR); United Nations Human Rights Committee, *General Comment No. 31 [80]: The Nature of the General Legal Obligation Imposed on States Parties to the Covenant*, UN Doc CCPR/C/21/Rev.1/Add. 13 (26 May 2004) 6.
- 20 *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976) arts 2(1), 3, 24(1) and 26; *International Covenant on Economic, Social and Cultural Rights*, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976) art 2; *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) art 2(1); *Universal Declaration of Human Rights*, GA Res 217A (III), UN GAOR, 3rd sess, 183rd plen mtg, UN Doc A/810 (10 December 1948) arts 2 and 7.
- 21 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 16; *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) art 19.
- 22 *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) art 16(1); *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976) art 17(1); *Universal Declaration of Human Rights*, GA Res 217A (III), UN GAOR, 3rd sess, 183rd plen mtg, UN Doc A/810 (10 December 1948) art 12.
- 23 *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976) art 23(2); *Universal Declaration of Human Rights*, GA Res 217A (III), UN GAOR, 3rd sess, 183rd plen mtg, UN Doc A/810 (10 December 1948) art 16(1).
- 24 Article 5 of the Convention on the *Elimination of All Forms of Discrimination against Women* calls for the elimination of practices emanating from gender stereotypes. Contributors viewed this as relevant because of the justification for early intervention on the basis of making a child's body look more stereotypically feminine or more stereotypically masculine: see Submission 36, *Intersex Inquiry*; Submission 37, *Intersex Inquiry*; Submission 70, *Intersex Inquiry*, 1; Submission 33, *Intersex Inquiry*; Submission 38, *Intersex Inquiry*. Attention was drawn, in particular, to art 2 of the *Convention on the Rights of the Child*, which prohibits discrimination against children; art 3.1, which emphasises the primacy of the child's best interests; art 12, which confers on children the right to express their views and participate in decision-making; art 16, which confers on children the right to a private life; art 18.2, which requires states to support parents and guardians in fulfilling their responsibilities to their children. Article 2 of the *International Covenant on Economic, Social and Cultural Rights*, prohibiting discrimination of any kind on any ground including sex, which has been interpreted to also include 'not only physiological characteristics but also the social construction of gender stereotypes, prejudices and expected roles': cited in Submission 41, *Intersex Inquiry*, 10. Submission 56, *Intersex Inquiry*, 5, noted that non-consensual medical treatment can constitute torture or inhumane treatment within the meaning of the *Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*. Submission 32, *Intersex Inquiry*, 8, highlighted that 'the CRPD provides a critical human rights conceptualisation of "disability" that is specifically relevant to human rights conceptions of "intersex"'.
- 25 United Nations High Commissioner for Human Rights, *Background Note on Human Rights Violations against Intersex People*, 37-40<<https://www.ohchr.org/Documents/Issues/Discrimination/LGBT/BackgroundNoteHumanRightsViolationsagainstIntersexPeople.pdf>>.

- 26 Child Rights International Network, *Issues – Bodily Integrity* <<https://home.crin.org/issues/bodily-integrity>>. As discussed in the next section, it is recognised in domestic and international human rights law that parents or guardians in certain circumstances may make decisions on behalf of a child, however, this is not open-ended.
- 27 *Convention on the Rights of Persons with Disabilities (Disability Convention)*, opened for signature 13 December 2006, 2515 UNTS 3 (entered into force 3 May 2008) art 17.
- 28 See, for example, Human Rights Committee, *General Comment No 35: Article 9 (Liberty and Security of Person)*, 112th sess, UN Doc CCPR/C/GC/35 (16 December 2014) [3]; Human Rights Committee, *General Comment No 28: Article 3 (The Equality of Rights Between Men and Women)*, 68th sess, UN Doc CCPR/C/21/Rev.1/Add.10 para 20.
- 29 See, for example, Committee on the Rights of the Child, *Concluding Observations on South Africa*, UN Doc CRC/C/ZAF/CO/2 (30 September 2016) [37]–[38]; Committee on Rights of Persons with Disabilities, *Concluding observations on Italy*, UN Doc CRPD/C/ITA/CO/1 (31 August 2016) [45]–[46]; Committee on the Elimination of Discrimination against Women, *Concluding observations on Switzerland*, UN Doc CEDAW/C/CHE/CO/4-5 (18 November 2016) [25]; Committee against Torture, *Concluding observations on France*, UN Doc CAT/C/FRA/CO/7 (10 June 2016) [34]–[35]; Committee on Economic, Social and Cultural Rights, *Concluding observations on Germany*, UN Doc E/C.12/DEU/CO/5 (20 May 2011) [26].
- 30 Committee on the Rights of Persons with Disabilities, *Concluding observations on the combined second and third reports of Australia*, UN Doc CRPD/C/AUS/CO/2-3 (23 September 2019) [34b].
- 31 Committee on the Rights of the Child, *Concluding Observations on the combined fifth and sixth periodic reports of Australia*, UN Doc CRC/C/AUS/CO/5-6 (30 September 2019) [31b].
- 32 Committee on the Elimination of Discrimination Against Women, *Concluding Observations – Australia*, UN Doc: CEDAW/C/Aus/CO/8, (25 July 2018) [25].
- 33 Committee on the Elimination of Discrimination Against Women, *Concluding Observations – Australia*, UN Doc: CEDAW/C/Aus/CO/8, (25 July 2018) [26].
- 34 Human Rights Committee, *Concluding Observations on the sixth periodic report of Australia*, UN Doc: CCPR/C/AUS/CO/6 (1 December 2017) paras 25–26.
- 35 Committee on Economic, Social and Cultural Rights, *Concluding Observations- Australia*, UN Doc: E/C.12/AUS/CO/5 (11 July 2017) para 49.
- 36 *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990).
- 37 Anand Grover, *Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health* (2008-2014), UN Doc A/64/272 (10 August 2009) <<https://undocs.org/A/64/272>>.
- 38 *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990).
- 39 Committee on the Rights of the Child, *General Comment No 20 (2016) on the implementation of the rights of the child during adolescence*, UN Doc CRC/C/GC/20 (6 December 2016) para 34.
- 40 See for example, Committee on the Rights of the Child, *Concluding Observations on the Combined Fourth to Fifth Periodic Reports of Chile*, UN Doc CRC/C/CHL/CO/4-5 (29 October 2015); Committee on the Rights of the Child, *Concluding observations on the fifth periodic report of France*, UN Doc CRC/C/FRA/CO/5 (date 2016).

- 41 Committee on the Rights of the Child, *General Comment No 13: The Right of the Child to Freedom from all Forms of Violence*, UN Doc CRC/C/GC/13 (18 April 2011) para 29.
- 42 Committee on the Rights of the Child, *General comment No. 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration (art. 3, para. 1)* UN Doc CRC /C/GC/14 (29 May 2013) para 77.
- 43 Committee on the Rights of the Child, *General comment No. 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration (art. 3, para. 1)* UN Doc CRC /C/GC/14 (29 May 2013) para 39.
- 44 Committee on the Rights of the Child, *General comment No. 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration (art. 3, para. 1)* UN Doc CRC /C/GC/14 (29 May 2013) para 89.
- 45 Anand Grover, *Right of everyone to the enjoyment of the highest attainable standard of physical and mental health* UN Doc A/64/272 (10 August 2009) para 49.
- 46 Dainius Puras, *Report on the right to health in early childhood: right to survival and development*, UN doc A/70/213 (30 July 2015) para 86.
- 47 See, for example, Committee Against Torture, *Concluding Observations on Germany*, UN Doc CAT/C/DEU/CO/5 (12 December 2011) [20]; Committee Against Torture, *Concluding Observations on Switzerland*, UN Doc CAT/C/CHE/CO/7 (7 September 2015) para 20.
- 48 Juan E Méndez, *Report of the Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment*, UN Doc A/HRC/22/53 (1 February 2013) [88].
- 49 Juan E Méndez, *Report of the Special Rapportuer on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment*, 31st sess, UN Doc A/HRC/31/57 (5 January 2016) [48] and [50].
- 50 Office of the High Commissioner on Human Rights, *Discriminated and made Vulnerable: Young LGBT and Intersex People need Recognition and Protection of their Rights, International Day Against Homophobia, Biphobia and Transphobia* (13 May 2015) <<http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=15941&LangID=E>>
- 51 United Nations Committee against Torture, "Concluding Observations on the Sixth Periodic Report of Austria," CAT/C/AUT/CO/6, January 27, 2016, <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT/C/AUT/CO/6&Lang=En>.
- 52 Committee against Torture, *List of Issues Prior to Submission of the Sixth Period Report of Australia*, UN Doc CAT/C/AUS/QPR/6 (9 January 2017) [26].
- 53 *International Covenant on Economic, Social and Cultural Rights*, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976) art 12.
- 54 *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) art 24.
- 55 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 25.
- 56 United Nations Education, Scientific and Cultural Organization, *Universal Declaration on Bioethics and Human Rights*, General Conference, 33rd sess, vol 1 (3–21 October 2005) res 36, arts 6–7. <<http://unesdoc.unesco.org/images/0014/001428/142825e.pdf#page=80>>.
- 57 United Nations General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the*

- highest attainable standard of physical and mental health*, 64th sess, UN doc A/64/272 (2009), para 23 <<https://undocs.org/A/64/272>>.
- 58 United Nations General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, 64th sess, UN doc A/64/272 (2009), para 23 <<https://undocs.org/A/64/272>>.
- 59 International Commission of Jurists, *Yogyakarta Principles – Principles on the application of international human rights law in relation to sexual orientation and gender identity* (March 2007) 7, was adopted by leading experts in international laws.
- 60 The Yogyakarta Principles have since been referred to and used by a variety of international and domestic decision-making bodies and courts, evidencing a growing acceptance that they reflect international human rights obligations; see for example Michael O’Flaherty, ‘The Yogyakarta Principles at Ten’ (2015) 33(4) *Nordic Journal of Human Rights* 280, 287–294.
- 61 *Sex Discrimination Act 1984* (Cth) ss 5A–5C.
- 62 ARC International and International Service for Human Rights, *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* (November 2017).
- 63 The Commission conducted interviews with 13 people born with variations in sex characteristics, and four with parents and partners, received four submissions made by people with lived experience, four from parents, and received four submissions from support groups which collated the experience of their members.
- 64 Intersex Human Rights Australia, Submission 40, *Intersex Inquiry*, 31, citing Morgan Carpenter submission to the Religious Freedom Review (2018).
- 65 Interview 10, *Intersex Inquiry*.
- 66 A Gender Agenda, Submission 52, *Intersex Inquiry*, 9; Submission 36, *Intersex Inquiry*, 22.
- 67 Submission 41, *Intersex Inquiry*, 7.
- 68 Submission 68, *Intersex Inquiry*, 3; Submission 67, *Intersex Inquiry*, 4.
- 69 NHMRC funded research program, Submission 30, *Intersex Inquiry*, 4.
- 70 Western Australian Multidisciplinary DSD Team, Submission 23, *Intersex Inquiry*, 3; NHMRC funded research program, Submission 30, *Intersex Inquiry*, 4; Submission 68, *Intersex Inquiry*, 5.
- 71 Submission 68, *Intersex Inquiry*, 3; Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 6.
- 72 Submission 68, *Intersex Inquiry*, 3.
- 73 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 1, 4.
- 74 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 5.
- 75 Submission 55, *Intersex Inquiry*, 4.
- 76 Submission 20, *Intersex Inquiry*, 9.

- 77 I.A. Hughes et al, 'Consensus statement on management of intersex disorders' 2006 2 *Journal of Pediatric Urology*, 148
- 78 Submission 36, *Intersex Inquiry*, 11.
- 79 Submission 29, *Intersex Inquiry*, 1.
- 80 Submission 36, *Intersex Inquiry*, 8-9.
- 81 Submission 70, *Intersex Inquiry*, 1; A Gender Agenda, Submission 52, *Intersex Inquiry*, 5; Submission 29, *Intersex Inquiry*, 1.
- 82 Submission 41, *Intersex Inquiry*, 7; Submission 45, *Intersex Inquiry*, 8.
- 83 Submission 70, *Intersex Inquiry*, 1; Submission 41, *Intersex Inquiry*, 7; Submission 52, *Intersex Inquiry*, 6; Submission 29, *Intersex Inquiry*, 1; Submission 45, *Intersex Inquiry*, 8.
- 84 Interview 15, *Intersex Inquiry*.
- 85 Interview 15, *Intersex Inquiry*.
- 86 Submission 36, *Intersex Inquiry*, 1.
- 87 Interview 1, *Intersex Inquiry*.
- 88 Submission 36, *Intersex Inquiry*, 30; Submission 57, *Intersex Inquiry*, Submission 54, *Intersex Inquiry*, 3; Submission 61, *Intersex Inquiry*, 5; Submission 65, *Intersex Inquiry*, 3-4.
- 89 Interview 9, *Intersex Inquiry*.
- 90 Interview 1, *Intersex Inquiry*.
- 91 Interview 15, *Intersex Inquiry*.
- 92 Interview 1, *Intersex Inquiry*.
- 93 Interview 1, *Intersex Inquiry*.
- 94 Submission 57, *Intersex Inquiry*.
- 95 Submission 36, *Intersex Inquiry*, 23.
- 96 Submission 36, *Intersex Inquiry*, 32, citing the Darlington Statement – paragraph 51.
- 97 Submission 36, *Intersex Inquiry*, 32, citing the Darlington Statement – paragraph 51.
- 98 Submission 45, *Intersex Inquiry*, 3,5; Submission 25 *Intersex Inquiry*, 6.
- 99 Submission 45, *Intersex Inquiry*, 9 including citing Tiffany Jones et al, *Intersex: Stories and statistics from Australia*. (Open Book Publishers 2016)
- 100 Submission 43, *Intersex Inquiry*, 2.
- 101 Submission 36, *Intersex Inquiry*, 8.
- 102 Submission 41, *Intersex Inquiry*, 9; Submission 36, *Intersex Inquiry*, 26; Submission 57, *Intersex Inquiry*; A Gender

- Agenda, Submission 52, *Intersex Inquiry*, 9-10; Submission 25, *Intersex Inquiry*, 5.
- 103 Submission 36, *Intersex Inquiry*, 8.
- 104 Interview 2, *Intersex Inquiry*.
- 105 Submission 33, *Intersex Inquiry*, 1.
- 106 Submission 36, *Intersex Inquiry*, 28.
- 107 Submission 57, *Intersex Inquiry*.
- 108 Submission 36, *Intersex Inquiry*, 9.
- 109 A Gender Agenda, Submission 52, *Intersex Inquiry*, 10; Submission 36, *Intersex Inquiry*, 27.
- 110 Submission 62, *Intersex Inquiry*; Interview 1, *Intersex Inquiry*.
- 111 Submission 57, *Intersex Inquiry*.
- 112 Submission 70, *Intersex Inquiry*, 1.
- 113 Submission 45, *Intersex Inquiry*, 9; Royal Australia New Zealand College of Psychiatrists, Submission 26, *Intersex Inquiry*, 1; A Gender Agenda, Submission 52, *Intersex Inquiry*, 1. For more extensive information and discussion about this, see Jones et al, 2016.
- 114 Submission 48, *Intersex Inquiry*; Submission 57, *Intersex Inquiry*; Submission 36, *Intersex Inquiry*, 24; Submission 25, *Intersex Inquiry*, 5, which referred to data from the National LGBTI Health Alliance about elevated rates of suicidality and selfharm, as well as diagnosis of depression and anxiety.
- 115 Submission 45, *Intersex Inquiry*, 9, citing Jones et al, 2016, 123.
- 116 Submission 36, *Intersex Inquiry*, 9. See also Darlington Statement, including at paragraph 39.
- 117 Submission 36, *Intersex Inquiry*, 33.
- 118 Submission 45, *Intersex Inquiry*, 10, citing Jones et al, 2016, 123.
- 119 Submission 45, *Intersex Inquiry*, 10, citing Jones et al, 2016, 123.
- 120 Submission 45, *Intersex Inquiry*, 9, citing Jones et al, 2016, 123; Submission 41, *Intersex Inquiry*, 7.
- 121 Submission 57, *Intersex Inquiry*.
- 122 Submission 36, *Intersex Inquiry*, 30, citing the Darlington Statement, paragraph 53.
- 123 A Gender Agenda, Submission 52, *Intersex Inquiry*, 2.
- 124 Submission 21, *Intersex Inquiry*.
- 125 Submission 67, *Intersex Inquiry*.
- 126 Senate Community Affairs References Committee, *Parliament of Australia, Involuntary or coerced sterilisation of intersex people in Australia* (2013), 74 <http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/~media/Committees/Senate/committee/clac_ctte/involuntary

- 127 *Sex Discrimination Act 1984* (Cth) s 5C
- 128 See Chapter 6 (new National Guidelines), Chapter 9 (Support and health records), Chapter 4, (Informed consent), and Chapter 5 (Medical necessity of interventions).
- 129 *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218, 232–233 (Mason CJ, Dawson, Toohey & Gaudron JJ).
- 130 ICCPR, art 9; Human Rights Committee, *General Comment No. 35 Article 9 (Liberty and security of person)*, UN Doc CCPR/C/GC/35 (16 December 2014).
- 131 *Rogers v Whitaker* (1992) 175 CLR 479, 490.
- 132 For example, in NSW, medical interventions without personal consent can be authorised under the *Mental Health Act 2007* (NSW), the *Guardianship Act 1987* (NSW), the *Public Health Act 2010* (NSW) and the *Children and Young Persons (Care and Protection) Act 1998* (NSW).
- 133 *Rogers v Whitaker* (1992) 175 CLR 479, 487; *Mercy Hospitals Victoria v D1 & Anor* [2018] VSC 519, paragraph 66, citing the *Medical Treatment Planning and Decisions Act 2016* (Vic). For discussion of the emergency exception in common law, see *Wilson v Pringle* [1987] 1 QB 237, 252 (CroomJohnson LJ); *Marshall v Curry* [1933] 3 DLR 260; *Murray v McMurchy* [1949] 2 DLR 442. See also *Re A (children) (conjoined twins: surgical separation)* [2000] 4 All ER 961.
- 134 Some legislation recognises a statutory hierarchy of alternative decision makers: see, eg, s 55 of the *Medical Treatment Planning and Decisions Act 2016* (Vic).
- 135 Such information might include a ‘do not resuscitate’ notation on the person’s records or a card identifying the patient as a Jehovah’s Witness and indicating that blood products should not be administered: see *Malette v Shulman* 67 DLR (4th) 321 (1990). *Malette v Shulman* was cited with approval in the 2013 Court of Appeal decision in *X v Sydney Children’s Hospital Network* (2013) 85 NSWLR 294 (which presented the novel feature of the young person’s refusal extending to refusal of transfusion with his own blood products: see paragraph 4). See also *Re F (a mental patient: sterilisation)* [1990] 2 AC 1.
- 136 Eg, *Guardianship Act 1987* (NSW), Part 2.
- 137 Eg *Guardianship Act 1987* (NSW), *Guardianship and Administration Act 2019* (Vic), *Guardianship and Administration Act 2000* (Qld).
- 138 *Hunter New England Area Health Service v A* [2009] NSWSC 761.
- 139 Australian Government, Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, (ALRC Report 124, November 2014), [10.50].
- 140 See eg *Gillick v West Norfolk and Wisbech Health Authority* [1986] AC 112, 169B-E.
- 141 See eg, CRPD art 12.
- 142 Australian Government, Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, (ALRC Report 124, November 2014). See also Australian Government, Australian Law Reform Commission Report, *Elder Abuse: A National Legal Response*, (ALRC Report 131 June 2017), which made recommendations to support the integrity and value of enduring documents. See also J Chesterman, ‘Prioritising Patients’ Preferences: Victoria’s New Advance Planning and Medical Consent Legislation’ (2017) 25 *Journal of Law and Medicine* 46, noting ‘a general

international trend towards enabling patients and consumers of health services to have greater control over the treatment they receive.’ (at 46)

143 *Consent to Medical Treatment and Palliative Care Act 1995* (SA) s 6.

144 *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218, 235 (Mason CJ, Dawson, Toohey & Gaudron JJ),

145 *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218, 295. See also the joint judgment at 239–240

146 *Gillick v West Norfolk AHA* [1986] AC 112.

147 *Gillick v West Norfolk AHA* [1986] AC 112, 188–189.

148 *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218, 237 (Mason CJ, Dawson, Toohey & Gaudron JJ), quoting Lord Scarman in *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112, 183–184 (emphasis added).

149 *Re W (a minor) (medical treatment)* [1992] 4 All ER 627.

150 *In the Matter Of: H Appellant/Husband and W Respondent/Wife Appeal* [1995] FamCA 30, paragraph 58, having noted such recognition in other jurisdictions, including the United Kingdom, citing (for example) Butler-Sloss LJ in *Re P (A Minor) (Education)* (1992) 1 FLR 316 at 321. In *Marion's case* (1992) 175 CLR 281, the majority accepted that the *parens patriae* jurisdiction (in all respects but for the power to make a child a ward of the state, as noted in *Fountain & Anor v Alexander & Anor* [1982] HCA 16 per Gibbs CJ and Mason J) had been vested in the Family Court by amendments in 1983 (see p 257).

151 A range of constraints have impaired the efficacy of ICLs (eg the concern has often been expressed that independent children’s lawyers, because of timing constraints, do not have sufficient – or indeed any – opportunity to talk directly to children themselves: see Kaspiw et al, *Independent Children’s Lawyers Study*, Final Report, 2nd edition, 2014). The importance, to children’s healthy development, of being heard in matters affecting them has recently been the subject of a major research project by the Australian Institute of Family Studies: see Carson et al, *Children and young people in separated families: Family law system experiences and needs*, 2018.

152 *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218.

153 This is the term employed in the *Family Law Act 1975* (Cth): s 67ZC.

154 *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218, 246 (joint judgment quoting *In re F* [1990] 2 AC 1, 56 (Lord Brandon)), 249–52 (joint judgment), 296, 303 (Deane J), 320–321 (McHugh J). In *Re Sean & Russell* [2010] FamCA 948, Murphy J expressed the view that this is also recognised in the Family Law Act: [70].

155 *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218, 250 (Mason CJ, Dawson, Toohey and Gaudron JJ).

156 *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218, 250 (Mason CJ, Dawson, Toohey and Gaudron JJ)

157 *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218, 250 (Mason CJ, Dawson, Toohey and Gaudron JJ).

158 *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218, 251 (Mason CJ, Dawson, Toohey and Gaudron JJ) (citations omitted).

- 159 *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218, 251 (Mason CJ, Dawson, Toohey and Gaudron JJ) (citations omitted).
- 160 *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218, 252 (Mason CJ, Dawson, Toohey and Gaudron JJ) (citations omitted).
- 161 *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218, 252 (Mason CJ, Dawson, Toohey and Gaudron JJ) (citations omitted).
- 162 *Re Jamie* [2013] FamCAFC 110, *Re Kelvin* [2017] FamCAFC.
- 163 Other responses to *Marion's case* included the insertion of Order 23B in the Family Law Rules and protocols developed by the Family Court, the Office of the Public Advocate (Vic) and Victoria Legal Aid.
- 164 See *Re Sean and Russell (Special Medical Procedures)* [2010] FamCA 948, per Murphy J, [44]. For a discussion of the limits of s 67ZC (in particular, that there be an attachment to a 'matter' within the application of Part VII of the Family Law Act), see also Murphy J in *Re Shane (Gender Dysphoria)* [2013] FamCA 864, [6]. The *Family Court Act 1997* (WA) confers a similar welfare jurisdiction on the Family Court of Western Australia: see section 162. For consideration of the operation of that provision, see for example, *Director Clinical Services, Child & Adolescent Health Services and Kiszko & Anor* [2016] FCWA 75, especially [63]ff.
- 165 Family Law Rules 2004, Rule 4.09.
- 166 United Nations General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, 64th sess, UN doc A/64/272 (2009), para 23 <<https://undocs.org/A/64/272>>.
- 167 United Nations General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, 64th sess, UN doc A/64/272 (2009), para 23 <<https://undocs.org/A/64/272>>.
- 168 *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 171 (entered into force 2 September 1990).
- 169 United Nations General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, 64th sess, UN doc A/64/272 (2009), para 46 <<https://undocs.org/A/64/272>>.
- 170 United Nations General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, 64th sess, UN doc A/64/272 (2009), para 47 <<https://undocs.org/A/64/272>>.
- 171 UN Committee on the Rights of the Child, *General comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health (art. 24)**, 62nd sess, UN Doc CRC/C/GC/15 (17 April 2013) 5 <https://www2.ohchr.org/english/bodies/crc/docs/GC/CRC-C-GC-15_en.doc>
- 172 I.A. Hughes et al, 'Consensus statement on management of intersex disorders' (2006) 2 *Journal of Pediatric Urology*, 148.
- 173 Peter A. Lee et al, 'Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care' (2016) 85 *Hormone Research in Paediatrics* 158.
- 174 Victorian Government (Department of Health), 'Decision-making principles for the care of infants, children and adolescents with intersex conditions' (February 2013) <<https://www2.health.vic.gov.au/about/populations/lgbti->

[health/rainbow-equality/working-with-specific-groups/infants-children-adolescents-with-intersex-conditions](https://www2.health.vic.gov.au/about/populations/lgbti-health/rainbow-equality/working-with-specific-groups/infants-children-adolescents-with-intersex-conditions)>.

- 175 The Endocrine Society of Australia, Submission No 39, 2.
- 176 IA Hughes et al, 'Consensus statement on management of intersex disorders' (2006) 2 *Journal of Pediatric Urology*, Appendix 2.
- 177 Peter A Lee et al, 'Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care' (2016) 85 *Hormone Research in Paediatrics* 158, 176.
- 178 Peter A Lee et al, 'Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care' (2016) 85 *Hormone Research in Paediatrics* 158, 177.
- 179 Victorian Government (Department of Health), 'Decision-making principles for the care of infants, children and adolescents with intersex conditions' (February 2013) p 4. <<https://www2.health.vic.gov.au/about/populations/lgbti-health/rainbow-equality/working-with-specific-groups/infants-children-adolescents-with-intersex-conditions>>
- 180 Victorian Government (Department of Health), 'Decision-making principles for the care of infants, children and adolescents with intersex conditions' (February 2013) Appendix 1, p 12. <<https://www2.health.vic.gov.au/about/populations/lgbti-health/rainbow-equality/working-with-specific-groups/infants-children-adolescents-with-intersex-conditions>>
- 181 Victorian Government (Department of Health), 'Decision-making principles for the care of infants, children and adolescents with intersex conditions' (February 2013) Appendix 1, p 12. <<https://www2.health.vic.gov.au/about/populations/lgbti-health/rainbow-equality/working-with-specific-groups/infants-children-adolescents-with-intersex-conditions>>
- 182 Victorian Government (Department of Health), 'Decision-making principles for the care of infants, children and adolescents with intersex conditions' (February 2013) Appendix 1, p 13. <<https://www2.health.vic.gov.au/about/populations/lgbti-health/rainbow-equality/working-with-specific-groups/infants-children-adolescents-with-intersex-conditions>>
- 183 Victorian Government (Department of Health), 'Decision-making principles for the care of infants, children and adolescents with intersex conditions' (February 2013) Appendix 1, 14. <<https://www2.health.vic.gov.au/about/populations/lgbti-health/rainbow-equality/working-with-specific-groups/infants-children-adolescents-with-intersex-conditions>>.
- 184 Submission 21, *Intersex Inquiry*; Submission 36, *Intersex Inquiry*; Submission 35, *Intersex Inquiry*; Submission 50, *Intersex Inquiry*, 2; NHMRC Funded Program, Submission 30, *Intersex Inquiry*, 5; Endocrine Society of Australia, Submission 39, *Intersex Inquiry*, 3.
- 185 Submission 50, *Intersex Inquiry*, 2.
- 186 NHMRC Funded Program, Submission 30, *Intersex Inquiry*, 3; Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 3.
- 187 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 3.
- 188 Western Australian Multidisciplinary DSD Team, Submission 23, *Intersex Inquiry*, 2; NHMRC Funded Program, Submission 30, *Intersex Inquiry*, 3; Submission 50, *Intersex Inquiry*, 2.
- 189 Submission 20, *Intersex Inquiry*, 5.

- 190 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 1; NHRMC Funded Program, Submission 30, *Intersex Inquiry*, 4.
- 191 NHRMC Funded Program, Submission 30, *Intersex Inquiry*, 4.
- 192 Submission 39, *Intersex Inquiry*, 2.
- 193 Submission 68, *Intersex Inquiry*, 4, remarking that while there is little evidence to support deferral of treatment, clinicians hold diverse views on management and bring to bear extensive collective experience and insight. Submission 68 further said that the existing system ensures that decisions are informed not only by this breadth of experience, but also the most contemporary research-findings.
- 194 Submission 20, *Intersex Inquiry*, 1.
- 195 Western Australian Multidisciplinary DSD Team, Submission 23, *Intersex Inquiry*, 2; APEG, Submission 20, *Intersex Inquiry*, 1; Endocrine Society of Australia, Submission 39, *Intersex Inquiry*, (2) & (2); NHRMC Funded Program, Submission 30, *Intersex Inquiry*, 3; Submission 50, *Intersex Inquiry*, 2.
- 196 Western Australian Multidisciplinary DSD Team, Submission 23, *Intersex Inquiry*, 2.
- 197 Submission 50, *Intersex Inquiry*, 2.
- 198 Australian Commission on Safety and Quality in Health Care, *Fact Sheet: Informed consent in health care*, 2 <https://www.safetyandquality.gov.au/sites/default/files/2020-09/sq20-030_-_fact_sheet_-_informed_consent_-_nsqhs-8.9a.pdf>.
- 199 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 9; NHRMC Funded Program Submission 30, *Intersex Inquiry*, 2; Endocrine Society of Australia, Submission 39, *Intersex Inquiry*, 2.
- 200 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 5.
- 201 Submission 68, *Intersex Inquiry*, 4.
- 202 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 2.
- 203 Submission 23, *Intersex Inquiry*, 2.
- 204 Submission 23, *Intersex Inquiry*, 2.
- 205 Submission 20, *Intersex Inquiry*, 5.
- 206 Submission 68, *Intersex Inquiry*, 4; Submission 65, *Intersex Inquiry*, 2, referring to APEG sources.
- 207 Submission 30, *Intersex Inquiry*, 2.
- 208 Submission 36, *Intersex Inquiry*, 12; Submission 57, *Intersex Inquiry*.
- 209 Submission 70, *Intersex Inquiry*, 1; Submission 61, *Intersex Inquiry*, 5; Submission 25, *Intersex Inquiry*, 3. For example, the Commission heard that some individuals born with variations in sex characteristics were told that they had cancer when they did not, in preference to being told that they were born with a variations in sex characteristics. Further, when these individuals did discover the truth, the secrecy that had been imposed was a further source of trauma, and internalised shame. The Commission also heard that, on diagnosis as a young person or adult, some people had been discouraged from seeking peer support on the basis that they had no peers (eg Submission 36, *Intersex Inquiry*, 30; Submission 67, *Intersex Inquiry*).

- 210 One person reported receiving inadequate information in relation to medical interventions as adults, Submission 36, *Intersex Inquiry*, 11.
- 211 Interview 10, *Intersex Inquiry*.
- 212 Interview 15, *Intersex Inquiry*.
- 213 Cited in Submission 36, 12, a submission from an advocacy and peer-support group that collated the experiences of a number of individuals born with variations in sex characteristics.
- 214 Interview 10, *Intersex Inquiry*.
- 215 Cited in Submission 36, *Intersex Inquiry*, 14, a submission from an advocacy and peer-support group that collated the experiences of a number of individuals born with variations in sex characteristics.
- 216 Submission 63, *Intersex Inquiry*.
- 217 Submission 38, *Intersex Inquiry*. A peer advocacy and support organisation cited individuals who reported that the possibility (and implications) of not undergoing treatment was never identified or explained to them (eg Submission 36, *Intersex Inquiry*, 12)
- 218 Submission 54, *Intersex Inquiry*, 9.
- 219 Submission 25, *Intersex Inquiry*, 4.
- 220 Submission 52, *Intersex Inquiry*, 5-6.
- 221 Submission 36, *Intersex Inquiry*, 11.
- 222 There is further discussion about this risk in Chapter 5 – Rationales for Intervention.
- 223 Submission 56, *Intersex Inquiry*, 5.
- 224 A Gender Agenda, Submission 52, *Intersex Inquiry*, 4; Intersex Human Rights Australia, Submission 40, *Intersex Inquiry*, 8, 11.
- 225 Submission 36, *Intersex Inquiry*.
- 226 Submission 36, *Intersex Inquiry*, 11–12.
- 227 Submission 36, *Intersex Inquiry*, 11.
- 228 Submission 41, *Intersex Inquiry*, 9; Submission 56, *Intersex Inquiry*, 5–6, 8; Submission 36, *Intersex Inquiry*.
- 229 Submission 36, *Intersex Inquiry*, 32; Submission 63, *Intersex Inquiry*; Submission 67, *Intersex Inquiry*.
- 230 Submission 70, *Intersex Inquiry*, 2.
- 231 Submission 67, *Intersex Inquiry*.
- 232 Submission 21, *Intersex Inquiry*; Submission 36, *Intersex Inquiry*, 34; Submission 60, *Intersex Inquiry*.
- 233 Cited in Submission 36, *Intersex Inquiry*, 13, a submission from an advocacy and peer-support group that collated the experiences of a number of individuals born with variations in sex characteristics.

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- 235 Submission 36, *Intersex Inquiry*, 32.
- 236 Submission 21, *Intersex Inquiry*; Submission 55, *Intersex Inquiry*, 12.
- 237 Submission 67, *Intersex Inquiry*; Submission 55, *Intersex Inquiry*, 6; Submission 21, *Intersex Inquiry*.
- 238 Submission 19, *Intersex Inquiry*.
- 239 Submission 19, *Intersex Inquiry*.
- 240 Submission 55, *Intersex Inquiry*, 6.
- 241 Cited in Submission 36, *Intersex Inquiry*, 11, a submission from an advocacy and peer-support group that collated the experiences of a number of individuals born with variations in sex characteristics.
- 242 Interview 5, *Intersex Inquiry*.
- 243 Interview 5, *Intersex Inquiry*.
- 244 Submission 52, *Intersex Inquiry*, 3.
- 245 Submission 52, *Intersex Inquiry*, 3.
- 246 Royal Australian and New Zealand College of Psychiatrists, Submission 26, *Intersex Inquiry*, 2; Submission 36, *Intersex Inquiry*; A Gender Agenda, Submission 52, *Intersex Inquiry*; Submission 55, *Intersex Inquiry*, 4; WA Commissioner for Children and Young People, Submission 43, *Intersex Inquiry*, 3; Submission 67, *Intersex Inquiry*.
- 247 Submission 70, *Intersex Inquiry*, 2.
- 248 Submission 36, *Intersex Inquiry*, 15.
- 249 NHMRC Funded Program 30, 2. The Darlington Statement also calls for 'regular public disclosure of accurate summary data on all medical interventions to modify the sex characteristics of children, and disclosure of historical data' (paragraph 29).
- 250 Submission 39, *Intersex Inquiry*, 2.
- 251 Submission 39, *Intersex Inquiry*, 2.
- 252 Submission 21, *Intersex Inquiry*; Endocrine Society of Australia, Submission 39, *Intersex Inquiry*, 2.
- 253 Submission 39, *Intersex Inquiry*, 2.
- 254 Submission 25, *Intersex Inquiry*, 3; Submission 36, *Intersex Inquiry*, 30.
- 255 Submission 20, *Intersex Inquiry*, 5.
- 256 Submission 23, *Intersex Inquiry*, 3.
- 257 Submission 20, *Intersex Inquiry*, 3.
- 258 Submission 50, *Intersex Inquiry*, 2.

- 259 Submission 50, *Intersex Inquiry*, 2.
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- 261 ICCPR, art 9; Human Rights Committee, General Comment No. 35 Article 9 (*Liberty and security of person*), UN Doc CCPR/C/GC/35 (16 December 2014).
- 262 World Health Organization, *A declaration on the promotion of patients' rights in Europe*, ICP/HLE 121 (1994), arts 3.1 and 3.2.
- 263 *Juridical Condition and Human Rights of the Child (Advisory Opinion)* [2002] Inter-American Court of Human Rights (Ser A) No 17, p 79 at [1].
- 264 CRC, art 3.
- 265 CRC, art 12.
- 266 *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218, 237 (Mason CJ, Dawson, Toohey & Gaudron JJ), quoting Lord Scarman in *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112, 183–184.
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- 269 World Health Organization, *A declaration on the promotion of patients' rights in Europe*, ICP/HLE 121 (1994), art 3.3.
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- 271 Anand Grover, Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (2008–2014), UN Doc A/64/272 (10 August 2009), paragraph 49.
- 272 Anand Grover, Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (2008–2014), UN Doc A/64/272 (10 August 2009), footnote 67.
- 273 Western Australian Multidisciplinary DSD Team, Submission 23, *Intersex Inquiry*, 4; Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 7.
- 274 This was in response to Question 13 of the consultation paper which asked *What are the permissible rationales/ considerations that should be taken into account when determining whether or not to undertake a medical intervention on behalf of those who lack the capacity to consent?*
- 275 Intersex Human Rights Australia, Submission 40, *Intersex Inquiry*, 61; A Gender Agenda, Submission 52, *Intersex Inquiry*, 6.
- 276 Submission 54, *Intersex Inquiry*, 1; A Gender Agenda, Submission 52, *Intersex Inquiry*, 7; Endocrine Society of

Australia, Submission 39, *Intersex Inquiry*, 2.

277 National Institutes of Health, 'What are the symptoms of congenital adrenal hyperplasia (CAH)?' <<https://www.nichd.nih.gov/health/topics/cah/conditioninfo/symptoms>>.

278 Endocrine Society of Australia, Submission 39, *Intersex Inquiry*, 2; Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 1.

279 Melbourne medical roundtable, Brisbane medical roundtable.

280 Endocrine Society of Australia, Submission 39, *Intersex Inquiry*, 2.

281 Submission 54, *Intersex Inquiry*, 9.

282 Submission 36, *Intersex Inquiry*, 13.

283 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 7.

284 Submission 45, *Intersex Inquiry*, 7; Submission 70, *Intersex Inquiry*, 2; Submission 68, *Intersex Inquiry*, 5. For example, one clinical organisation noted that in some cases urological surgery may be needed to prevent recurrent urinary tract infections.

285 Submission 55, *Intersex Inquiry*, 4.

286 Submission 45, *Intersex Inquiry*, 7; Endocrine Society of Australia, Submission 39, *Intersex Inquiry*, 2; Submission 67, *Intersex Inquiry*; Submission 70, *Intersex Inquiry*, 2; Submission 36, *Intersex Inquiry*, 17; Submission 40, *Intersex Inquiry*, 61.

287 Victorian Government (Department of Health), *Decision-making principles for the care of infants, children and adolescents with intersex conditions* (February 2013) 5 <<https://www2.health.vic.gov.au/about/populations/lgbti-health/rainbow-equality/working-with-specific-groups/infants-children-adolescents-with-intersex-conditions>>.

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289 IA Hughes et al, 'Consensus statement on management of intersex disorders' (2006) 2 *Journal of Pediatric Urology*, Appendix 2, 153

290 ARC International and International Service for Human Rights, *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* (November 2017) art 32, which states that medical interventions that modify sex characteristics should not be performed without personal consent unless 'necessary to avoid serious, urgent and irreparable harm to the concerned person'.

291 United Nations Economic and Social Council, *Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights* UN Doc E/CN.4/1985/4, Annex (1985) (ICCPR); United Nations Human Rights Committee, *General Comment No. 31 [80]: The Nature of the General Legal Obligation Imposed on States Parties to the Covenant*, UN Doc CCPR/C/21/Rev.1/Add. 13 (26 May 2004) 6.

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- 293 Intersex Human Rights Australia, Submission 40, *Intersex Inquiry*, 61.
- 294 Submission 68, *Intersex Inquiry*, 3, 5; Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 6; Intersex Human Rights Australia Submission 40, *Intersex Inquiry*, 61.
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- 297 Submission 68, *Intersex Inquiry*, 3.
- 298 Submission 40, *Intersex Inquiry*, 61.
- 299 Submission 40, *Intersex Inquiry*, 62.
- 300 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 6.
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- 302 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 4.
- 303 Submission 50, *Intersex Inquiry*, 3.
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- 312 Submission 55, *Intersex Inquiry*, 2.
- 313 Intersex Human Rights Australian, Submission 40, *Intersex Inquiry*, 61–62.
- 314 Intersex Human Rights Australian, Submission 40, *Intersex Inquiry*, 61.
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- 323 Submission 36, *Intersex Inquiry*, 2; Submission 60, *Intersex Inquiry*; Submission 38, *Intersex Inquiry*; Submission 56, *Intersex Inquiry*, 7; Submission 41, *Intersex Inquiry*, 7–8; Submission 45, *Intersex Inquiry*, 3; Submission 59, *Intersex Inquiry*, 1; Submission 70, *Intersex Inquiry*, 1; Submission 33, *Intersex Inquiry*.
- 324 Submission 36, *Intersex Inquiry*, 19; Submission 67, *Intersex Inquiry*.
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- 342 NHMRC funded research program, Submission 30, *Intersex Inquiry*, 5.
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- 345 Submission 67, *Intersex Inquiry*.
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- 354 Western Australian Multidisciplinary DSD Team, Submission 23, *Intersex Inquiry*, 3.
- 355 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 6.
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- 357 Intersex Human Rights Australia, Submission 40, *Intersex Inquiry*, 6; Submission 33, *Intersex Inquiry*, 1.
- 358 Submission 68, *Intersex Inquiry*, 5.
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- 361 Submission 19, *Intersex Inquiry*.
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- 363 Submission 45, *Intersex Inquiry*, 7.
- 364 Intersex Human Rights Australia, Submission 40, *Intersex Inquiry*, 67; Submission 36, *Intersex Inquiry*, 14.
- 365 Intersex Human Rights Australia, Submission 40, *Intersex Inquiry*, 65.
- 366 Submission 32, *Intersex Inquiry*, 9.
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- 373 Submission 68, *Intersex Inquiry*, 5.
- 374 Submission 19, *Intersex Inquiry*; Submission 68, *Intersex Inquiry*, 5.
- 375 Submission 19, *Intersex Inquiry*.
- 376 Submission 26, *Intersex Inquiry*, 2; Submission 45, *Intersex Inquiry*, 7.
- 377 Intersex Human Rights Australia, Submission 40, *Intersex Inquiry*, 76.
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- 390 Brisbane medical roundtable.
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- 396 Submission 50, *Intersex Inquiry*, 2.
- 397 Submission 23, *Intersex Inquiry*, 3.
- 398 Submission 23, *Intersex Inquiry*, 3
- 399 Perth medical roundtable.
- 400 Submission 68, *Intersex Inquiry*, 3.
- 401 Perth medical roundtable.
- 402 Melbourne medical roundtable 2.
- 403 Submission 50, *Intersex Inquiry*, 4.
- 404 Melbourne medical roundtable 2.
- 405 Western Australian Multidisciplinary DSD Team, Submission 23, *Intersex Inquiry*, 3.
- 406 Submission 20, *Intersex Inquiry*, 9.
- 407 Clinician contribution, at Melbourne clinical roundtable.
- 408 Submission 36, *Intersex Inquiry*, 3.
- 409 Submission 50, *Intersex Inquiry*, 3.

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- 440 Brisbane medical roundtable, Sydney medical roundtable.
- 441 Submission 26, *Intersex Inquiry*, 1.
- 442 Submission 50, *Intersex Inquiry*, 3.
- 443 Submission 20, *Intersex Inquiry*, 7-8.
- 444 Submission 68, *Intersex Inquiry*, 2.
- 445 Submission 50, *Intersex Inquiry*, 3.
- 446 Submission 36, *Intersex Inquiry*.
- 447 Submission 55, *Intersex Inquiry*, 13; Submission 21, *Intersex Inquiry*.
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- 449 See Chapter 9 – Data and health record access.
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- 458 IA Hughes et al, 'Consensus statement on management of intersex disorders' (2006) 2 *Journal of Pediatric Urology* 148, 159. It provides a passing reference to limitations in the United States to the rights of parents to consent to interventions on their children, in the context of a discussion on medical negligence.
- 459 Peter A Lee et al, 'Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care' (2016) 85 *Hormone Research in Paediatrics* 158, 176.
- 460 Submission 39, *Intersex Inquiry*, 3.
- 461 Peter A. Lee et al, 'Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care' (2016) 85 *Hormone Research in Paediatrics* 158, 176.
- 462 Victorian Government (Department of Health), 'Decision-making principles for the care of infants, children and adolescents with intersex conditions' (February 2013) <<https://www2.health.vic.gov.au/about/populations/lgbti-health/rainbow-equality/working-with-specific-groups/infants-children-adolescents-with-intersex-conditions>>.
- 463 Submission 65, *Intersex Inquiry*, 2–3; Endocrine Society of Australia Submission 39, *Intersex Inquiry*, 3; Submission 68, *Intersex Inquiry*, 2.
- 464 Victorian Government (Department of Health), 'Decision-making principles for the care of infants, children and adolescents with intersex conditions' (February 2013) 4, <<https://www2.health.vic.gov.au/about/populations/lgbti-health/rainbow-equality/working-with-specific-groups/infants-children-adolescents-with-intersex-conditions>>.
- 465 Victorian Government (Department of Health), 'Decision-making principles for the care of infants, children and adolescents with intersex conditions' (February 2013) 4, <<https://www2.health.vic.gov.au/about/populations/lgbti-health/rainbow-equality/working-with-specific-groups/infants-children-adolescents-with-intersex-conditions>>.
- 466 Victorian Government (Department of Health), 'Decision-making principles for the care of infants, children and adolescents with intersex conditions' (February 2013) 19, <<https://www2.health.vic.gov.au/about/populations/lgbti>>.

- 467 Intersex Human Rights Australia, Submission 40, *Intersex Inquiry*, 72.
- 468 Submission 68, *Intersex Inquiry*, 2.
- 469 See Chapter 7 – Oversight of Medical Interventions, Recommendation 8.
- 470 Submission 68, *Intersex Inquiry*, 2.
- 471 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 8.
- 472 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 8.
- 473 Intersex Human Rights Australia, Submission 40, *Intersex Inquiry*, 13, 79.
- 474 Submission 56, *Intersex Inquiry*, 8.
- 475 Submission 20, *Intersex Inquiry*, 8.
- 476 Intersex Human Rights Australia, Submission 40, *Intersex Inquiry*, 80; Submission 36, *Intersex Inquiry*, 20; Submission 56, *Intersex Inquiry*, 8; Submission 41, *Intersex Inquiry*, 8.
- 477 See Chapter 3 – Lived experience.
- 478 Submission 55, *Intersex Inquiry*, 10; Submission 65, *Intersex Inquiry*, 3–4. This latter submission suggested that this problem could be countered by ensuring that guidelines were ‘readily adaptable’.
- 479 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 8; Submission 23, *Intersex Inquiry*, 4.
- 480 Submission 41, *Intersex Inquiry*, 8; Submission 54, *Intersex Inquiry*, 7; Submission 50, *Intersex Inquiry*, 2.
- 481 Submission 36, *Intersex Inquiry*, 31, also citing the recommendation in the Darlington Statement, [21].
- 482 Submission 54, *Intersex Inquiry*, 7.
- 483 Intersex Human Rights Australia, Submission 40, *Intersex Inquiry*, 81.
- 484 Submission 45, *Intersex Inquiry*, 8; Submission 54, *Intersex Inquiry*, 4.
- 485 Submission 56, *Intersex Inquiry*, 8.
- 486 The Human Rights Law Centre, Submission 71, *Intersex Inquiry*, 19, citing the recommendations of the Senate Committee.
- 487 Submission 55, *Intersex Inquiry*, 11; Submission 25, *Intersex Inquiry*, 5–6; Submission 35, *Intersex Inquiry*, 4. Note some clinician stakeholders also stressed the importance of safeguarding privacy – submission 50, *Intersex Inquiry*, 4–5; some stakeholders indicated that this was not an issue unique to people born with variations in sex characteristics - Submission 20, *Intersex Inquiry*, 9.
- 488 Submission 72, *Intersex Inquiry*, 13.
- 489 Submission 54, *Intersex Inquiry*, 9; Endocrine Society of Australia, Submission 39, *Intersex Inquiry*, 3; A Gender Agenda, Submission 52, *Intersex Inquiry*, 8.

- 490 Endocrine Society of Australia, Submission 39, *Intersex Inquiry*, 3.
- 491 Submission 36, *Intersex Inquiry*, 22.
- 492 Submission 36, *Intersex Inquiry*, 22.
- 493 Darlington Statement, paragraph 24.
- 494 For example, there were indications that some clinicians would consider deferring treatment, and using puberty blockers, until an individual possessed *Gillick* competence: Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 6.
- 495 Recommendation 8.
- 496 Senate Standing Committee on Community Affairs, Parliament of Australia, *Involuntary or Coerced Sterilisation of Intersex People in Australia*, (Second Report, 25 October 2013), xiv.
- 497 See Chapter 9 – Support, health records and data collection.
- 498 <<https://www.racgp.org.au/clinical-resources/clinical-guidelines/key-racgp-guidelines/view-all-racgp-guidelines/female-genital-cosmetic-surgery>>.
- 499 See eg, Cancer Council Australia Surveillance Colonoscopy Guidelines Working Party. Clinical practice guidelines for surveillance colonoscopy. Sydney: Cancer Council Australia, <https://wiki.cancer.org.au/australia/Guidelines:Colorectal_cancer/Colonoscopy_surveillance>.
- 500 <<https://www.clinicalguidelines.gov.au/portal>>.
- 501 <<https://www.clinicalguidelines.gov.au/portal>>.
- 502 *Civil Liability Act 2002* (NSW) s 50.
- 503 <<https://www.safetyandquality.gov.au/standards/nsqhs-standards>>.
- 504 Australian Commission on Safety and Quality in Health Care, *Implementation of the NSQHS Standards* <<https://www.safetyandquality.gov.au/standards/nsqhs-standards/implementation-nsqhs-standards#the-nsqhs-standards>>.
- 505 For example, guidelines for best clinical care of people with borderline personality disorder National Health and Medical Research Council, Guidelines, <<https://www.nhmrc.gov.au/guidelines>>.
- 506 National Health and Medical Research Council, Guidelines, (Web Page) <<https://www.nhmrc.gov.au/guidelines>>, provided for at *National Health and Medical Research Council Act 1992* (Cth) s 14A.
- 507 *Guardianship Act 1987* (NSW) ss 33, 45.
- 508 Submission 41, *Intersex Inquiry*, 3, 8; Submission 56, *Intersex Inquiry*, 8; Submission 32, *Intersex Inquiry*, 8; Submission 36, *Intersex Inquiry*, 17; A Gender Agenda, Submission 52, *Intersex Inquiry*, 5.
- 509 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 8.
- 510 Endocrine Society of Australia, Submission 39, *Intersex Inquiry*, 3.
- 511 Submission 41, *Intersex Inquiry*, paragraph 4.10.

- 512 See Chapter 3 – Lived experience.
- 513 Submission 50, *Intersex Inquiry*, 4–5.
- 514 Submission 65, *Intersex Inquiry*, 3–4.
- 515 Senate Community Affairs References Committee, Parliament of Australia, *Involuntary or coerced sterilisation of intersex people in Australia* (2013) Rec 9.
- 516 Senate Community Affairs References Committee, Parliament of Australia, *Involuntary or coerced sterilisation of intersex people in Australia* (2013) 101.
- 517 Intersex Human Rights Australia, Submission 40, *Intersex Inquiry*, 11; Submission 36, *Intersex Inquiry*, 4.
- 518 Submission 36, *Intersex Inquiry*, 23; Submission 54, *Intersex Inquiry*, 7; Submission 65, *Intersex Inquiry*, 3–4.
- 519 Submission 36, *Intersex Inquiry*, 23; Submission 32, *Intersex Inquiry*, 9; Submission 54, *Intersex Inquiry*, 7; Submission 65, *Intersex Inquiry*, 3–4.
- 520 Submission 36, *Intersex Inquiry*, 22; Submission 25, *Intersex Inquiry*, 4; Human Rights Law Centre Submission 71, *Intersex Inquiry*, 14.
- 521 Submission 36, *Intersex Inquiry*, 23; Submission 32, 9; Submission 54, *Intersex Inquiry*, 7; Submission 65, *Intersex Inquiry*, 3–4.
- 522 Submission 36, *Intersex Inquiry*, 22; Submission 25, *Intersex Inquiry*, 4; Human Rights Law Centre Submission 71, *Intersex Inquiry*, 14.
- 523 National Medical Health and Research Council, 2016 *NHMRC Standards for Guidelines*, <<https://www.nhmrc.gov.au/guidelinesforguidelines/standards>>.
- 524 National Medical Health and Research Council, Consumer involvement <<https://www.nhmrc.gov.au/guidelinesforguidelines/plan/consumer-involvement>>.
- 525 National Health and Medical Research Council, Guidelines, <<https://www.nhmrc.gov.au/guidelines>>.
- 526 Submission 36, *Intersex Inquiry*, 22; Submission 68, *Intersex Inquiry*, 2.
- 527 *Department of Health and Community Services (NT) v JWB and SMB (Marion's case)* (1992) 175 CLR 218.
- 528 *Marion's Case* at 250 (Mason CJ, Dawson, Toohey and Gaudron JJ).
- 529 *Marion's Case* at 269 (Brennan J).
- 530 *Re Kelvin* [2017] FamCAFC 258 at [132]–[136].
- 531 *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218, 250 (Mason CJ, Dawson, Toohey and Gaudron JJ).
- 532 Some medical interventions for people born with variations in sex characteristics may fall within these state and territory laws.
- 533 See, eg, *Guardianship Act 1987* (NSW) s 33, definition of ‘special treatment’; ss 44, 45.

- 534 *Re Carla (Medical Procedure)* [2016] FamCA 7.
- 535 The concept of *Gillick* competence is discussed in Chapter 4 – Consent and decision making.
- 536 *Re Carla (Medical Procedure)* [2016] FamCA 7, [13].
- 537 The Commission uses female pronouns for Carla to match those used by the Court.
- 538 *Re Carla (Medical Procedure)* [2016] FamCA 7, [3].
- 539 The role of an amicus curiae ('friend of the court') is to assist the court 'by drawing attention to some aspect of the case which might otherwise be overlooked': *Bropho v Tickner* (1993) 40 FCR 165, 172 (Wilcox J).
- 540 *Re Carla (Medical Procedure)* [2016] FamCA 7, [19].
- 541 *Re Carla (Medical Procedure)* [2016] FamCA 7, [22].
- 542 *Re Carla (Medical Procedure)* [2016] FamCA 7, [24]–[25].
- 543 IA Hughes et al, 'Consensus statement on management of intersex disorders' (2006) 2 *Journal of Pediatric Urology* 148.
- 544 *Re Carla (Medical Procedure)* [2016] FamCA 7, [19].
- 545 *Re Carla (Medical Procedure)* [2016] FamCA 7, [20].
- 546 Fiona Kelly and Malcolm K Smith, 'Should court authorization be required for surgery on intersex children? A critique of the Family Court decision in *Re Carla*' (2016) 31(2) *Australian Journal of Family Law* 118, 122.
- 547 J Pleskacova et al, 'Tumor Risk in Disorders of Sex Development' (2010) 4(4–5) *Sexual Development* 7, cited by Senate Community Affairs References Committee, Parliament of Australia, *Involuntary or Coerced Sterilisation of Intersex People in Australia* (2013) 84, <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>
- 548 Fiona Kelly and Malcolm K Smith, 'Should court authorization be required for surgery on intersex children? A critique of the Family Court decision in *Re Carla*' (2016) 31(2) *Australian Journal of Family Law* 118, 123; IA Hughes et al, 'Consensus statement on management of intersex disorders' (2006) 2 *Journal of Pediatric Urology* 148, 155.
- 549 Fiona Kelly and Malcolm K Smith, 'Should court authorization be required for surgery on intersex children? A critique of the Family Court decision in *Re Carla*' (2016) 31(2) *Australian Journal of Family Law* 118, 124.
- 550 Fiona Kelly and Malcolm K Smith, 'Should court authorization be required for surgery on intersex children? A critique of the Family Court decision in *Re Carla*' (2016) 31(2) *Australian Journal of Family Law* 118, 126.
- 551 *Re Carla (Medical Procedure)* [2016] FamCA 7, [15]. See also submissions from Intersex Human Rights Australia, submission 40, *Intersex Inquiry*, 63, and the Human Rights Law Centre, submission 71, *Intersex Inquiry*, 10.
- 552 *Re Carla (Medical Procedure)* [2016] FamCA 7, [16].
- 553 (1993) 16 Fam LR 715, [30].
- 554 (1993) 16 Fam LR 715, [29].

555 (1993) 16 Fam LR 715, [20].

556 [2008] FamCA 1226.

557 [2008] FamCA 1226, [20], [24] – ‘adverse’, ‘detrimental’, respectively.

558 [2008] FamCA 1226, [29].

559 [2008] FamCA 1226, [38].

560 [2010] FamCA 237.

561 (2010) 44 Fam LR 210.

562 [2014] FamCA 969.

563 [2014] FamCA 208.

564 [2014] FamCA 208, [23].

565 [2014] FamCA 208, [26].

566 [2014] FamCA 208, [46].

567 [2017] FamCA 83.

568 [2016] FamCA 7, [16].

569 (1993) 16 Fam LR 715, [10].

570 [2017] FamCA 83, [4], [6] and [19].

571 [2014] FamCA 208, [17].

572 [2008] FamCA 1226, [43]-[45].

573 *Re A* (1993) 16 Fam LR 75, [21]-[22].

574 *Re Carla (Medical Procedure)* [2016] FamCA 7, [18].

575 *Re Carla (Medical Procedure)* [2016] FamCA 7, [28]. The implication seems to be that either Carla would not be comfortable as a female having male gametes and/or would not want to have a child with a woman. This scenario was assumed to be undesirable and to be avoided.

576 *Re Carla (Medical Procedure)* [2016] FamCA 7, [24].

577 *Re Carla (Medical Procedure)* [2016] FamCA 7; *Re Lesley (Special Medical Procedure)* [2008] FamCA 1226.

578 *Re Lesley (Special Medical Procedure)* [2008] FamCA 1226, [29], *Re Carla (Medical procedure)* [2016] FamCA 7, [24].

579 Interview 15, *Intersex Inquiry*; Interview 1, *Intersex Inquiry*; Submission 36, *Intersex Inquiry*, 8–9; Submission 29, *Intersex Inquiry*, 1; Submission 70, *Intersex Inquiry*, 1; A Gender Agenda, Submission 52, *Intersex Inquiry*, 5.

580 Submission 56, *Intersex Inquiry*, 7; Submission 41, *Intersex Inquiry*, 8; Submission 61, *Intersex Inquiry*, 6; Submission 32, *Intersex Inquiry*, 3; Intersex Human Rights Australia, Submission 40, *Intersex Inquiry*, 3; Submission 29 *Intersex Inquiry*;

- NHMRC funded research program, Submission 30 *Intersex Inquiry*.
- 581 Submission 50, *Intersex Inquiry*, 3.
- 582 Submission 20, *Intersex Inquiry*, 6.
- 583 Submission 20, *Intersex Inquiry*, 6; Western Australian Multidisciplinary DSD Team, Submission 23, *Intersex Inquiry*, 4; Submission 68, *Intersex Inquiry*, 6; Submission 57, *Intersex Inquiry*.
- 584 Submission 29, *Intersex Inquiry*, 2.
- 585 Submission 57, *Intersex Inquiry*.
- 586 Submission 50, *Intersex Inquiry*, 3; Submission 29, *Intersex Inquiry*.
- 587 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 6.
- 588 Submission 36, *Intersex Inquiry*, 15.
- 589 Submission 35, *Intersex Inquiry*, 2; Submission 56, *Intersex Inquiry*, 7; Submission 41, *Intersex Inquiry*, 8; Submission 61, *Intersex Inquiry*, 6; Submission 57, *Intersex Inquiry*; Submission 54, *Intersex Inquiry*, 5; see also paragraph 16(b) of the Darlington Statement. For example, there has been a noticeable absence of independent advocates for the child or other contradictors.
- 590 Submission 57, *Intersex Inquiry*.
- 591 Submission 57, *Intersex Inquiry*.
- 592 Submission 29, *Intersex Inquiry*, 2. See *Re Carla*, [15].
- 593 Submission 19, *Intersex Inquiry*; Submission 56, *Intersex Inquiry*, 7; Submission 55, *Intersex Inquiry*, 8; Western Australian Multidisciplinary DSD Team, Submission 23, *Intersex Inquiry*, 4; Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 6.
- 594 Submission 29, *Intersex Inquiry*, 2.
- 595 *Re Carla (Medical Procedure)* [2016] FamCA 7, [2].
- 596 *Department of Health and Community Services (NT) v JWB and SMB ('Re Marion')* (1992) 175 CLR 218, 272 (Brennan J).
- 597 Senate Community Affairs References Committee, Parliament of Australia, *Involuntary or Coerced Sterilisation of Intersex People in Australia* (2013) 99, Rec 6, <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>.
- 598 Second 2013 Senate Inquiry report, Rec 7.
- 599 Senate Community Affairs References Committee, Parliament of Australia, *Involuntary or Coerced Sterilisation of Intersex People in Australia* (2013) 93, <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>.
- 600 Senate Community Affairs References Committee, Parliament of Australia, *Involuntary or Coerced Sterilisation of Intersex People in Australia* (2013) 99, <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](http://www.Aph.Gov.Au/Parliamentary_Business/Committees/Senate/Committee/Clac_ctte/Involuntary_sterilisation/Second_report/Report.Ashx).

601 Senate Community Affairs References Committee, Parliament of Australia, *Involuntary or Coerced Sterilisation of Intersex People in Australia* (2013) 98, <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>.

602 Senate Community Affairs References Committee, Parliament of Australia, *Involuntary or Coerced Sterilisation of Intersex People in Australia* (2013) 99, <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>.

603 Senate Community Affairs References Committee, Parliament of Australia, *Involuntary or Coerced Sterilisation of Intersex People in Australia* (2013) 99, <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>.

604 Submission 54, *Intersex Inquiry*, 5; A Gender Agenda, Submission 52, *Intersex Inquiry*, 6; Royal Australia New Zealand College of Psychiatrists, Submission 26, *Intersex Inquiry*, 2.

605 Submission 25, *Intersex Inquiry*, 2; Submission 32, *Intersex Inquiry*, 14; Submission 52, *Intersex Inquiry*, 6; Submission 54, *Intersex Inquiry*, 4; Submission 50, *Intersex Inquiry*, 3; Submission 60, *Intersex Inquiry*; Submission 29, *Intersex Inquiry*; Submission 36, *Intersex Inquiry*, 15-16, drawing attention to the Darlingston Statement, Principle 22.

606 Submission 25, *Intersex Inquiry*, 2.

607 Submission 61, *Intersex Inquiry*, 6.

608 Submission 61, *Intersex Inquiry*, 6.

609 Submission 20, *Intersex Inquiry*, 7.

610 Submission 56, *Intersex Inquiry*, 8.

611 Submission 25, *Intersex Inquiry*.

612 Royal Australian and New Zealand College of Psychiatrists, Submission 26, *Intersex Inquiry*, 2.

613 Submission 54, *Intersex Inquiry*, 5.

614 Royal Australian and New Zealand College of Psychiatrists, Submission 26, *Intersex Inquiry*, 2; Submission 36, *Intersex Inquiry*, 15; Submission 56, *Intersex Inquiry*, 3; Submission 32, *Intersex Inquiry*, 14; Submission 60, *Intersex Inquiry*; Submission 61, *Intersex Inquiry*, 7.

615 Submission 35, *Intersex Inquiry*, 3.

616 Royal Australia and New Zealand College of Psychiatrists, Submission 26, *Intersex Inquiry*, 2; Submission 60, *Intersex Inquiry*.

617 Submission 56, *Intersex Inquiry*, 8; Intersex Human Rights Australia, Submission 40, *Intersex Inquiry*, 55; Royal Australia and New Zealand College of Psychiatrists, Submission 26, *Intersex Inquiry*, 2; Submission 60, *Intersex Inquiry*; Submission 36, *Intersex Inquiry*, 23.

- 618 Submission 36, *Intersex Inquiry*, 23.
- 619 Submission 60, *Intersex Inquiry*.
- 620 Submission 56, *Intersex Inquiry*, 8; Intersex Human Rights Australia, Submission 40, *Intersex Inquiry*, 55; Submission 60, *Intersex Inquiry*.
- 621 Submission 36, *Intersex Inquiry*, 23.
- 622 Submission 60, *Intersex Inquiry*.
- 623 For example, see *Children and Young Persons (Care and Protection) Act 1998* (NSW) s 174(1).
- 624 See, eg, *Guardianship Act 1987* (NSW) pt 5 'Medical and dental treatment'.
- 625 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 6.
- 626 Senate Community Affairs References Committee, Parliament of Australia, *Involuntary or coerced sterilisation of intersex people in Australia* (2013), 101, Rec 10.
- 627 Senate Community Affairs References Committee, Parliament of Australia, *Involuntary or coerced sterilisation of intersex people in Australia* (2013), 101.
- 628 *Australian Human Rights Commission Act 1986* (Cth) s 11(1)(o).
- 629 Family Law Rules 2004 (Cth) r 15.71.
- 630 Family Law Rules 2004 (Cth) pt 15.4.
- 631 The Family Court and the Federal Circuit Court of Australia are to be merged into a unified administrative structure to be called the Federal Circuit and Family Court of Australia, commencing by 1 September 2021: *Federal Circuit and Family Court of Australia Act 2021* (Cth); *Federal Circuit and Family Court of Australia (Consequential Amendments and Transitional Arrangements) Act 2021* (Cth).
- 632 F Garland and M Travis, 'Legislating Intersex Equality: Building the Resilience of Intersex People through Law' (2018) 38(4) *Legal Studies* 587.
- 633 Submission 52, *Intersex Inquiry*, 8.
- 634 Submission 24, *Intersex Inquiry*, 5; Submission 36, *Intersex Inquiry*, 21.
- 635 Submission 56, *Intersex Inquiry*, 6; Submission 61, *Intersex Inquiry*, 6; A Gender Agenda, Submission 52, *Intersex Inquiry*, 6.
- 636 Submission 36, *Intersex Inquiry*, 18.
- 637 Submission 36, *Intersex Inquiry*, 19.
- 638 Submission 36, *Intersex Inquiry*, 18.
- 639 Submission 36, *Intersex Inquiry*, 18; Submission 56, *Intersex Inquiry*, 8 referring to Malta as an example of a legislative approach that adequately upholds all human rights. Submission 41, *Intersex Inquiry*, 8; Submission 60, *Intersex Inquiry*.
- 640 Submission 36, *Intersex Inquiry*, 20.

641 Submission 56, *Intersex Inquiry*, 8; Submission 41, *Intersex Inquiry*, 8; Submission 60, *Intersex Inquiry*.

642 See Yogyakarta Principles, [32], [37].

643 Submission 60, *Intersex Inquiry*; Submission 36, *Intersex Inquiry*, 19; Submission 35, *Intersex Inquiry*, 3; Submission 56, *Intersex Inquiry*, 3; Submission 57, *Intersex Inquiry*; Submission 32, *Intersex Inquiry*, 8; Submission 61, *Intersex Inquiry*, 6.

644 Submission 52, *Intersex Inquiry*, 6.

645 Submission 32, *Intersex Inquiry*, 6, 8.

646 Submission 36, *Intersex Inquiry*, 3.

647 Principle 7 of the Darlington Statement.

648 Submission 32, *Intersex Inquiry*, 8.

649 Submission 70, *Intersex Inquiry*, 2; Submission 60, *Intersex Inquiry*; Submission 56, *Intersex Inquiry*, 6; Submission 59, *Intersex Inquiry*, 3; Submission 32, *Intersex Inquiry*, 8; Submission 36, *Intersex Inquiry*; Submission 52, *Intersex Inquiry*, 6, 8, citing Garland and Travis, 2018; Submission 61, *Intersex Inquiry*, 6, citing the Darlington Statement, Principle 7, and Y+10 (specifically Principle 32(d); Submission 54, *Intersex Inquiry*, 1; Submission 32, *Intersex Inquiry*, 6.

650 Submission 54, *Intersex Inquiry*, 1, 6, 10.

651 Submission 54, *Intersex Inquiry*, 1.

652 Submission 54, *Intersex Inquiry*, 4; Submission 25, *Intersex Inquiry*, 4.

653 Submission 25, *Intersex Inquiry*, 4-5.

654 Submission 32, *Intersex Inquiry*, 8.

655 Submission 60, *Intersex Inquiry*; The Human Rights Law Centre; Submission 71, *Intersex Inquiry*, 23, which noted also that a prohibition would be consistent with CEDAW.

656 Submission 36, *Intersex Inquiry*, 17.

657 Western Australian Multidisciplinary DSD Team, Submission 23, *Intersex Inquiry*, 4.

658 Western Australian Multidisciplinary DSD Team, Submission 23, *Intersex Inquiry*, 4; Submission 67, *Intersex Inquiry*.

659 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 7.

660 Western Australian Multidisciplinary DSD Team, Submission 23, *Intersex Inquiry*, 4; Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 2; Endocrine Society of Australia, Submission 39, *Intersex Inquiry*, 3.

661 The Chilean Ministry of Health sought to guide how medical interventions take place by issuing instructions called a 'Circular', which are not legally binding. In December 2015, the Ministry issued Circular No. 18 instructing health care providers to stop unnecessary 'normalising' medical treatment on intersex children and defer them until the child reaches an age where they can give their own consent: <https://diprece.minsal.cl/wrdprss_minsal/wp-content/uploads/2018/03/Circular-08-22-12-15-Instruye-Sobre-Ciertos-Aspectos-de-la-atenci%C3%B3n-de...pdf>. This Circular was replaced in August 2016 with Circular No. 7, which removed the blanket prohibition on unnecessary treatments. It states that the recommendation not to perform unnecessary surgery does not apply where 'there

is a clearly defined sex' and gives guidance on when interventions should occur for other variations. The Circular states that decision making may require the opinion of an ethics committee and that the possibility of deferring surgery until the child reaches an age where they can demonstrate their own tendencies of sexual identity should be explained to parents.

662 Western Australian Multidisciplinary DSD Team, Submission 23, *Intersex Inquiry*, 5.

663 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 2.

664 Submission 68, *Intersex Inquiry*, 6; Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 2.

665 Submission 55, *Intersex Inquiry*, 9–10; Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 2; Submission 67, *Intersex Inquiry*.

666 Submission 55, *Intersex Inquiry*, 10.

667 NHMRC Funded Research Program, Submission 30, *Intersex Inquiry*, 4; Western Australian Multidisciplinary DSD Team, Submission 23, *Intersex Inquiry*, 4.

668 NHMRC Funded Research Program, Submission 30, *Intersex Inquiry*, 4.

669 Submission 55, *Intersex Inquiry*, 8.

670 Submission 68, *Intersex Inquiry*, 6.

671 Submission 68, *Intersex Inquiry*, 5–6.

672 Submission 68, *Intersex Inquiry*, 5

673 Submission 68, *Intersex Inquiry*, 5.

674 NHMRC Funded Program, Submission 30, *Intersex Inquiry*, 4.

675 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 7.

676 For example, *Guardianship Act 1987* (NSW) s 35.

677 For example, *Crimes Act 1900* (NSW) s 45.

678 See Chapter 6 – Clinical practice and new national guidelines.

679 *Civil Liability Act 2002* (NSW) s 50.

680 *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990).

681 See also Ch 3.

682 *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990).

683 NHMRC Funded Program, Submission 30, *Intersex Inquiry*, 3.

684 Submission 55, *Intersex Inquiry*, 5.

- 685 Submission 36, *Intersex Inquiry*, 10.
- 686 Submission 36, *Intersex Inquiry*, 10.
- 687 Submission 25, *Intersex Inquiry*, 6; Submission 55, *Intersex Inquiry*, 12.
- 688 Submission 36, *Intersex Inquiry*, 29.
- 689 Submission 52, *Intersex Inquiry*, 5.
- 690 Intersex Human Rights Australia, *Review of government, community and related resources in Victoria*, 8 July 2021 <<https://ihra.org.au/38693/review-resources-victoria/>>
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- 695 Submission 36, *Intersex Inquiry*, 29.
- 696 Submission 68, *Intersex Inquiry*, 2.
- 697 Submission 45, *Intersex Inquiry*, 10, citing Jones et al, 2016.
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- 699 The World Health Organization, *Mental Health Action Plan 2013-2020*, p14.
- 700 Peter A. Lee et al, 'Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care' (2016) 85 *Hormone Research in Paediatrics* 160.
- 701 See Chapter 3 – Lived experience.
- 702 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 10; Submission 25, *Intersex Inquiry*, 5; Royal Australian and New Zealand College of Psychiatrists, Submission 26, *Intersex Inquiry*, 2; Submission 36, *Intersex Inquiry*, 33–34; Submission 41, *Intersex Inquiry*, 4; Submission 45, *Intersex Inquiry*, 3; Submission 50, *Intersex Inquiry*, 4; Submission 60, *Intersex Inquiry*; A Gender Agenda, Submission 52, *Intersex Inquiry*, 10-11; Submission 55, *Intersex Inquiry*, 6, 12; Submission 56, *Intersex Inquiry*, 9; Submission 60, *Intersex Inquiry*. This should also allow for opportunities for peer workers and peer organisations to build capability to provide professional services: Submission 70, *Intersex Inquiry*, 2. See also Darlington Statement, paragraphs 27, 43 and 45.
- 703 Submission 36, *Intersex Inquiry*, 35; Submission 25, *Intersex Inquiry*, 5.
- 704 Submission 41, *Intersex Inquiry*, 4.
- 705 Submission 56, *Intersex Inquiry*, 9; Submission 50, *Intersex Inquiry*, 4.

706 Submission 45, *Intersex Inquiry*, 10, citing Jones et al, 2016.

707 A Gender Agenda, Submission 52, 5; Submission 36, *Intersex Inquiry*, 33.

708 Submission 36, *Intersex Inquiry*, 33; Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 10; Submission 21, *Intersex Inquiry*; Submission 54, *Intersex Inquiry*, 6; Submission 56, *Intersex Inquiry*, 9; Submission 59, *Intersex Inquiry*, 3; Submission 60, *Intersex Inquiry*.

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710 NT Anti-discrimination Commission, Submission 41, *Intersex Inquiry*, 4; Submission 52, *Intersex Inquiry*, 11; Submission 36, *Intersex Inquiry*, 34; Submission 55, *Intersex Inquiry*, 3-4, 13; Submission 56, *Intersex Inquiry*, 9.

711 Submission 55, *Intersex Inquiry*, 13.

712 Submission 25, *Intersex Inquiry*, 5.

713 Submission 55, *Intersex Inquiry*, 12; NT Anti-discrimination Commission, Submission 41, *Intersex Inquiry*, 4.

714 Submission 56, *Intersex Inquiry*, 3; Submission 60, *Intersex Inquiry*; Submission 61, *Intersex Inquiry*, 6; Submission 54, *Intersex Inquiry*, 6; Submission 59, *Intersex Inquiry*, 3; A Gender Agenda, Submission 52, *Intersex Inquiry*, 4.

715 Submission 36, *Intersex Inquiry*, 31.

716 Submission 36, *Intersex Inquiry*, 13; Royal Australian New Zealand College of Psychiatrists, Submission 26, *Intersex Inquiry*, 2; Submission 25, *Intersex Inquiry*, 2; Submission 21, *Intersex Inquiry*; Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 9.

717 Submission 45, *Intersex Inquiry*, 10.

718 T Jones, B Hart, M Carpenter, G Ansara, W Leonard and J Lucke, *Intersex: Stories and statistics from Australia* (Open Book Publishers, 2016) 123 <<https://research-management.mq.edu.au/ws/portalfiles/portal/83835078/72593734.pdf>>

719 Submission 40, *Intersex Inquiry*, 66.

720 Submission 36, *Intersex Inquiry*, 28.

721 Submission 25, *Intersex Inquiry*, 6.

722 Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 9; Submission 21, *Intersex Inquiry*; Endocrine Society of Australia, Submission 39, *Intersex Inquiry*, 4; WA Commissioner for Children and Young People, Submission 43, *Intersex Inquiry*, 3; Submission 45, *Intersex Inquiry*, 5.

723 Submission 23, *Intersex Inquiry*, 3 and 5, where it was noted that psychologists needed to have expertise in child and adolescent development, gender issues and variations in sex characteristics.

724 Submission 20, *Intersex Inquiry*, 9.

725 Royal Australian New Zealand College of Psychiatrists, Submission 26, *Intersex Inquiry*, 1; Submission 68, *Intersex Inquiry*, 4; Endocrine Society of Australia, Submission 39, *Intersex Inquiry*, 4; Submission 25, *Intersex Inquiry*, 6; Submission 50, *Intersex Inquiry*, 8.

726 Submission 25, *Intersex Inquiry*, 6.

- 727 Submission 36, *Intersex Inquiry*; Submission 39, *Intersex Inquiry*, 3; Submission 25, *Intersex Inquiry*, 2; Submission 26, *Intersex Inquiry*, 2; Submission 21, *Intersex Inquiry*.
- 728 Submission 21, *Intersex Inquiry*.
- 729 Western Australian Multidisciplinary DSD Team, Submission 23, *Intersex Inquiry*, 5; Submission 39, *Intersex Inquiry*, 4; A Gender Agenda, Submission 52, *Intersex Inquiry*, 5.
- 730 Submission 23, *Intersex Inquiry*, 5.
- 731 Submission 68, *Intersex Inquiry*, 5.
- 732 Submission 23, *Intersex Inquiry*, 5; Submission 20, *Intersex Inquiry*, 9.
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- 734 Submission 21, *Intersex Inquiry*.
- 735 Submission 25, *Intersex Inquiry*, 5.
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- 737 See also Chapter 3 – Lived experience.
- 738 A Gender Agenda, Submission 52, *Intersex Inquiry*, 10; Submission 36, *Intersex Inquiry*, 27.
- 739 Submission 52, *Intersex Inquiry*, 9.
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- 741 Submission 36, *Intersex Inquiry*, 27 – reported in submission from an Intersex peer-support and advocacy organisation that included input from individuals born with variations in sex characteristics.
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- 743 Submission 36, *Intersex Inquiry*, 9 – reported in submission from an Intersex peer-support and advocacy organisation that included input from individuals born with variations in sex characteristics.
- 744 A Gender Agenda, Submission 52, *Intersex Inquiry*, 10; Submission 41, *Intersex Inquiry*, 4, 7; Submission 36, *Intersex Inquiry*, 7.
- 745 Submission 36, *Intersex Inquiry*, 27.
- 746 Submission 25, *Intersex Inquiry*, 5.
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- 748 The Darlington Statement, paragraph 33, cited in Submission 36, *Intersex Inquiry*, 28.
- 749 Submission 52, *Intersex Inquiry*, 9.
- 750 Submission 55, *Intersex Inquiry*, 11.

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- 776 Submission 41, *Intersex Inquiry*, 7; Submission 50, *Intersex Inquiry*, 5.
- 777 The Endocrine Society of Australia, Submission 39, *Intersex Inquiry*, 4; Western Australian Multidisciplinary DSD Team, Submission 23, *Intersex Inquiry*, 4; Intersex Human Rights Australia, Submission 40, *Intersex Inquiry*, 24; A Gender Agenda, Submission 52, *Intersex Inquiry*, 8-9; Submission 68, *Intersex Inquiry*, (observing lack of data to support deferral or early intervention), Australasian Paediatric Endocrine Group, Submission 20, *Intersex Inquiry*, 7; Royal Australian New Zealand College of Psychiatrists, WA Commissioner for Children and Young People, Submission 43, *Intersex Inquiry*, 3; Submission 26, *Intersex Inquiry*, 2.
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- 788 Submission 39, *Intersex Inquiry*, 1; Submission 41, *Intersex Inquiry*, 8; Submission 50, *Intersex Inquiry*, 5.
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- 797 Submission 50, *Intersex Inquiry*, 4.
- 798 Submission 36, *Intersex Inquiry*, 24, 31, citing the Darlington Statement.
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- 802 Submission 54, *Intersex Inquiry*, 9.
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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.

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