



Australian  
Human Rights  
Commission

Protecting the Human Rights of  
People Born with Variations in Sex  
Characteristics in the context of Medical  
Interventions

**CONSULTATION PAPER**

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## **1 Introduction**

1. The Australian Human Rights Commission (the Commission) is undertaking a project to consider how best to protect the human rights of people born with variations in sex characteristics in the context of medical interventions.
2. Fundamental to the Commission's approach, and to the Commission's ability to identify how to improve human rights protection in this area, is to consult with people directly affected by this issue and those with relevant expertise. This Consultation Paper aims to support that consultation process.
3. The Consultation Paper provides background information about the project and identifies issues and questions for further analysis and consultation. It does not present finalised research, nor does it articulate the Commission's final position on any of the issues raised.
4. The Consultation Paper includes a number of questions to assist individuals and organisations who would like to provide input for this project. Those wanting to provide input do not need to be limited by the questions.

## **2 About the project**

### **2.1 Background**

5. Terminology in this area is contested. This Consultation Paper primarily uses the term 'people born with variations in sex characteristics' to describe the population whose experience and human rights are the focus of this project. Other terms that are generally understood to refer to the same group of people include 'intersex conditions', 'intersex variations', 'disorders of sex development' and 'differences of sex development' (DSD).<sup>1</sup> The issue of terminology is addressed in detail in part 3 below.
6. People born with variations in sex characteristics in Australia have increasingly raised concerns about human rights violations with the Commission, the Australian Government and the United Nations (UN), especially in relation to medical interventions conducted without the full and informed consent of the person involved.<sup>2</sup> Infants and children are at particular risk of human rights violations. In March 2017, Australian and Aotearoa / New Zealand intersex organisations and independent advocates issued a joint consensus statement (the Darlington Statement) calling for immediate action to address these concerns, including the criminalisation of deferrable medical interventions and the development of human-rights based lifetime standards of care.<sup>3</sup>
7. The Commission has previously highlighted some of the human rights issues experienced by people born with variations in sex characteristics in reports,<sup>4</sup> discussion papers,<sup>5</sup> and submissions to government and the UN.<sup>6</sup> In addition, 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.<sup>7</sup>
8. 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.<sup>8</sup> 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.<sup>9</sup>

9. At the international level, UN treaty bodies, agencies and special rapporteurs have increasingly called on member States to strengthen protections for the human rights of people born with variations in sex characteristics.<sup>10</sup> For example, in 2013 the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment called on all states to:

repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery ... when enforced or administered without the free and informed consent of the person concerned [and] to outlaw forced or coerced sterilization in all circumstances...<sup>11</sup>

10. In June 2017, the Committee on Economic, Social and Cultural Rights recommended that Australia implement the recommendations in the Senate Committee report and report on the involuntary or coerced sterilisation of intersex people in Australia.<sup>12</sup> In November 2017, the UN Human Rights Committee recommended that Australia give due consideration to the recommendations in the Senate Committee report 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’.<sup>13</sup>
11. In summary, there remain concerns about the human rights protection available to people born with variations in sex characteristics and the impacts of medical interventions, surgical and non-surgical, at various stages in their life, including infancy, childhood and adulthood. Other human rights issues that are relevant to people born with variations in sex characteristics, but are beyond the scope of this project, include discrimination in education, workplaces and in sport, lack of support and adjustments in educational institutions and workplaces and issues around legal classifications and documentation. This project focuses on medical interventions and seeks to develop recommendations to improve human rights protection within legal frameworks, clinical practices and education. . While the Commission recognises that there are many ways in which people can be born with variations in sex characteristics,<sup>14</sup> the human rights issues broadly applicable will be considered rather than the intricacies of approaching each particular variation. This is because while the management of different variations may vary, the human rights that must be considered and protected are broadly the same.
12. As noted, the Commission is taking a human rights based approach to considering protections for people born with variations in sex characteristics. Ethical principles in managing the healthcare of this population have been developed and their application discussed in various texts,<sup>15</sup> including ethical principles by medical professionals in Melbourne that have been endorsed internationally.<sup>16</sup> Other approaches have also been considered, for example the Victorian decision-making principles consider the interconnection between principles for supporting patients and parents, medical management, ethical and legal principles, in addition to human rights principles.<sup>17</sup> However, the Commission’s approach will focus on the particular human rights that are engaged when considering people born with variations in sex characteristics in the context of medical interventions, and consider how to best ensure these rights are protected.

13. The Commission will conduct its own research and analysis, but will be primarily guided by community consultation, focusing on those most affected, including people born with variations in sex characteristics, parents and carers, medical practitioners and human rights experts.
14. The project's main aims are to:
  - a) document and analyse existing approaches to medical interventions involving people born with variations in sex characteristics in Australia and overseas; and
  - 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.
15. The Commission's work is guided by Terms of Reference, included in **Appendix A: Terms of Reference**.

## **2.2 Why the Australian Human Rights Commission?**

16. As Australia's national human rights institution (NHRI), the Commission has an important role under international and Australian law to respect, protect and promote the human rights of all people.
17. Under the Principles Relating to the Status of National Institutions (the Paris Principles), NHRIs are responsible for providing opinions, recommendations, proposals and reports to governments and parliaments on any matters concerning the promotion and protection of human rights.<sup>18</sup> This includes the rights of people born with variations in sex characteristics. In recognition of this role, the Office of the High Commissioner on Human Rights (OHCHR) has called on NHRIs to 'research and monitor the human rights situation of intersex people'.<sup>19</sup>
18. The Commission also has a number of functions under Australian law that are relevant to protecting the human rights of people born with variations in sex characteristics. For example, under the *Australian Human Rights Commission Act 1986* (Cth), the Commission may report to the Attorney-General on actions that Australia must take to comply with relevant human rights instruments.<sup>20</sup> In addition, following the 2013 amendments to the *Sex Discrimination Act 1984* (Cth), the Commission may also receive and conciliate complaints of discrimination on the basis of intersex status,<sup>21</sup> and report to the Attorney-General on matters specifically relevant to discrimination on the basis of intersex status.<sup>22</sup>

## **2.3 Ethics approval**

19. The consultation component of this project has been reviewed and approved by an external, independent Human Research Ethics Committee (HREC) at the University of Sydney.
20. Further information about the ethics process is outlined in the Participation Information Statement available on our website.

### 3 Terminology

21. As noted above, the terminology used to describe people born with variations in sex characteristics is contested.<sup>23</sup>
22. Some of the more common terms used to collectively describe these variations include ‘intersex conditions’, ‘intersex variations’, ‘disorders of sex development’ and ‘differences of sex development’ (DSD).<sup>24</sup>
23. ‘Intersex’ is an umbrella term that is used internationally to describe people who are born with atypical genetic, hormonal and/or physical sex characteristics.<sup>25</sup> Many intersex variations exist. Intersex variations may relate to sex chromosomal variations, different physical responses to sex hormones, or different developmental hormone balances and anatomies. Intersex people have many varied kinds of bodies, experiences and identities.<sup>26</sup> Some examples of variations include hypospadias, Androgen Insensitivity Syndrome (AIS), Congenital Adrenal Hyperplasia (CAH), gonadal dysgenesis, vaginal agenesis or Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome, and sex chromosome differences like 47,XXY (commonly diagnosed as Klinefelter syndrome) and 45,X0 (commonly diagnosed as Turner’s syndrome).
24. From a medical perspective, the 2006 Consensus Statement on Management of Intersex Disorders developed by 50 international medical experts (Consensus Statement) proposed ‘disorders of sex development’ (DSD) as an umbrella term for differences in chromosomal, hormonal and/or anatomical sexual development.<sup>27</sup> This term arose in response to concerns at the time about the use of other terms, like ‘pseudo-hermaphrodite’ and ‘intersex’, which were considered controversial and pejorative.<sup>28</sup> Some medical practitioners argue that DSD is ‘more descriptive’ and ‘supportive of people with intersex variations seeking intervention’.<sup>29</sup> A 2016 update to the Consensus Statement notes however that DSD terminology has also been perceived to have negative connotations by some advocacy groups and some people consider other terms like ‘intersex’ or ‘differences of sex development’ to be more appropriate.<sup>30</sup>
25. Some advocates have raised concerns regarding DSD terminology, citing contention over whether intersex is ‘inherently a disorder’ or a ‘healthy variation amongst human bodies’.<sup>31</sup> In its 2013 report, the Senate Committee recommended that ‘governments and other organisations use the term “intersex” and not the phrase “disorders of sex development”’.<sup>32</sup>
26. The Commission also recognises that a number of people born with variations in sex characteristics do not use any collective term to describe themselves or their variation, but instead may only talk specifically about their variation or use their medical diagnosis, or may change the language they use in different contexts.<sup>33</sup>
27. As noted above, in this Consultation Paper, the Commission primarily uses the term ‘people born with variations in sex characteristics’. This term refers to children and adults born with any sex characteristics that do not conform to medical norms for female or male bodies. While there is no universal or perhaps even generally-accepted term across variation groups, human rights discourse and the medical literature to describe this population, the language adopted by the Commission in this Consultation Paper is intended to avoid some of the more commonly-reported concerns expressed regarding terminology in this area — particularly the need to avoid stigma, misconceptions, un-necessary pathologising and unhelpful preconceptions. At the same time, the Commission’s terminology aims to remain precise about the population and human rights concerns that are the subject of this inquiry. The terms ‘intersex’ and ‘disorders of sex development’ are used when referring to specific texts that use those terms.

28. The Commission recognises that the language used to identify a group of people can be vitally important to those people, and that such questions can be difficult to resolve. As a result, the Commission is not proposing to settle the question of terminology in this Consultation Paper and welcomes input about appropriate terminology.
29. Further, the term 'medical intervention' is used in this Consultation Paper to cover surgical and non-surgical interventions. Surgical interventions include procedures like clitoral rescision, vaginoplasty, gonadectomy or mastectomy. Non-surgical interventions include procedures like hormone replacement therapy or dilation. Medical interventions may also cover interventions that do not just affect the sex characteristics of the individual concerned. Particular variations may be associated with other differences too, for example some variations are associated with shorter stature and individuals affected may be put on growth hormones, while other variations are associated with cognitive difficulties and individuals affected may see speech pathologists or occupational therapists.

**Key question:**

1. Is the term 'people born with variations in sex characteristics' appropriate, or is there a better way to describe the people who are the subject of this Consultation Paper?

## 4 Relevance of human rights

### 4.1 Overview

30. People born with variations in sex characteristics have the same human rights as everyone else.
31. UN treaties identify a number of human rights that are relevant to medical interventions (particularly with respect to children). They include:
  - Freedom from torture, cruel, inhuman or degrading treatment, including freedom from medical experimentation<sup>34</sup>
  - Right to security of person<sup>35</sup>
  - Right to the highest attainable standard of health<sup>36</sup>
  - Freedom from violence<sup>37</sup>
  - Equality and non-discrimination<sup>38</sup>
  - Equal recognition before the law, including safeguards relating to the exercise of legal capacity
  - Right to privacy<sup>39</sup>
  - Right to physical and mental integrity<sup>40</sup>
  - Right to found a family<sup>41</sup>
  - Right of child to express views freely in all matters concerning them<sup>42</sup>
  - Right of child to preservation of identity<sup>43</sup>
  - Best interests of the child,<sup>44</sup> and
  - Right of child to ‘maximum extent’ of development.<sup>45</sup>
32. Treaty bodies have recommended States Parties implement measures to guarantee these rights and have increasingly discussed these rights in relation to the medical treatment of people born with variations in sex characteristics.<sup>46</sup>
33. The *Yogyakarta Principles*, a set of influential principles relating to sexual orientation, gender identity, gender expression and sex characteristics further support the human rights of people born with variations in sex characteristics, in particular the right to bodily and mental integrity and the right to truth.<sup>47</sup>
34. How particular treaty bodies and the *Yogyakarta Principles* have referenced relevant human rights in this context are discussed further in **Appendix B: Human rights framework**.



## 5 International developments

### 5.1 Overview

35. Legislative changes, legal cases, reports and statements internationally from governments, organisations and other bodies also support the human rights of people born with variations in sex characteristics. These developments reflect a growing concern regarding the rationales, decision-making processes and outcomes of medical interventions.

### 5.2 Country approaches to medical interventions

36. Most countries have no dedicated oversight or specific regulation over medical interventions performed on people born with variations in sex characteristics. However, some countries have taken some steps towards regulating medical interventions, particularly regarding interventions performed on children. These countries have taken considerably different approaches.

#### (a) Malta

37. In 2015, Malta enacted the *Gender Identity, Gender Expression and Sex Characteristics Act* (2015).
38. This Act makes it unlawful to perform unnecessary sex assignment surgery or treatment on infants, children and adolescents without the child's informed consent.<sup>48</sup> Malta is the first country to make these interventions unlawful.
39. The Act allows interventions to be carried out on a minor in 'exceptional circumstances' as determined by an 'interdisciplinary team'.<sup>49</sup> This team of professionals must reach agreement with the parents or guardians of the child, prioritise the child's best interests, and cannot be driven by 'social factors' in their decision.<sup>50</sup> The Act does not define what constitutes a social factor. Further, the Act requires a 'working group' comprising 'three experts in human rights issues, three psychosocial professionals and three medical experts' to 'review the current medical treatment protocols in line with current medical best practices and human rights standards'.<sup>51</sup>

#### (b) Chile

40. The Chilean Ministry of Health has sought to regulate or guide how medical interventions take place by issuing instructions called a 'Circular'. Circulars 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.<sup>52</sup>
41. 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.<sup>53</sup> The Circular states that decision-making may require the opinion of an ethics committee and 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.<sup>54</sup>

(c) *Colombia*

42. Medical interventions have not been legislatively prohibited in Colombia; however, these practices are regulated through a number of Constitutional Court decisions. These decisions have affirmed the right of the child to bodily autonomy and development of gender identity.<sup>55</sup>
43. The Constitutional Court has held that parents cannot consent on behalf of their child where the child is over the age of five, but can give 'qualified and informed consent' where the child is under five years of age.<sup>56</sup> There has been some concern that this approach expedites medical procedures.<sup>57</sup>

(d) *Germany*

44. German courts have determined a number of civil suits regarding medical interventions on individuals born with variations in sex characteristics. These cases have granted remedies where full and informed consent was not given to the procedures performed.<sup>58</sup>
45. Reform in Germany has focused on the creation of an additional category on birth certificates rather than prohibiting interventions. This approach has largely been criticised by advocates because the legislation requires mandatory allocation into an additional category for infants who do not present as male or female, which may cause parents to feel pressure to consent to medical interventions to avoid their child being assigned to this category. Further, it is the medical community who determines whether the child holds 'clear gender-determining physical characteristics'. The reform has also not been matched with reform in other areas like anti-discrimination protection and marriage/civil partnerships, and therefore individuals assigned to this category face uncertain issues arising in the future.<sup>59</sup>

### **5.3 Significant reports and statements from groups and organisations**

(a) *Human rights bodies*

46. In 2005, the San Francisco Human Rights Commission conducted an investigation into the medical 'normalization' of intersex people.<sup>60</sup> The Commission presented 23 recommendations including that 'normalizing' interventions should not occur in childhood, and care should be patient-centred and emphasise peer support, access to information and focus on full and informed choices.<sup>61</sup> The recommendations also highlighted the lack of funding for organisations that serve the needs of intersex people.<sup>62</sup>
47. In 2012, the German Ethics Council produced a report to consider the situation and challenges of intersex people. Among other things, the Council recommended that as irreversible gender assignment procedures can infringe the right to physical integrity, and sexual and gender identity, the decision is a personal one and therefore should be postponed until it can be made solely by the individual concerned.<sup>63</sup>
48. The Swiss National Advisory Commission on Biomedical Ethics, in Opinion No. 20/2012 ('Swiss Advisory Opinion'), discusses the management of disorders of sex development and ethical issues relating to 'intersexuality'.<sup>64</sup> The Opinion outlines 14 recommendations including that 'all (non-trivial) sex assignment treatment decisions which have irreversible consequences but can be deferred should not be taken until the person to be treated can decide for him/herself'.<sup>65</sup> It also noted the need for decision making within a multidisciplinary team with the involvement of the parent and as far as possible with the child.<sup>66</sup>

49. The Council of Europe has also published reports concerning intersex people. In 2013 in a report entitled 'Children's right to physical integrity', the Rapporteur on Social Affairs, Health and Sustainable Development discussed the need to consider cases where operations in childhood are acceptable and the need to give more voice to children to participate in decisions concerning them.<sup>67</sup> In 2015 the Council of Europe also published an issues paper on human rights and intersex people,<sup>68</sup> and in 2017 the Council of Europe's Committee on Bioethics published a report on the rights of children in biomedicine which included a consideration of the human rights of 'children with differences in sex development and intersex conditions'.<sup>69</sup>
50. The UN High Commissioner for Human Rights has also made statements on this issue. The factsheet *Born Free and Equal* affirmed 'the legal obligations of nations to safeguard the human rights of LGBT and intersex people', including the right to security of the person.<sup>70</sup> A further factsheet in 2015 notes that medical procedures performed without the full, free and informed consent of the person concerned may violate the right to physical integrity.<sup>71</sup> For Intersex Awareness Day (26 October) in 2016, a group of UN and international human rights experts also published a statement urging governments to prohibit medical procedures on intersex infants, children and adolescents without 'the full, free and informed consent of the person concerned'.<sup>72</sup>
51. The New Zealand Human Rights Commission conducted two intersex roundtables in 2008 and 2010 to discuss issues facing people born with variations in sex characteristics. A third roundtable was held in 2016 to bring together intersex people, medical professionals, academics and government stakeholders to share information, review international best practice and plan action.<sup>73</sup> One of the outcomes of the roundtable is a move towards setting up a National Clinical Network, established through the Paediatric Society of New Zealand and funded by the Ministry of Health. The reference group for the network will comprise people born with variations in sex characteristics, medical professionals and members of the New Zealand Human Rights Commission, and will, amongst other things, work to promote nationally coordinated intersex health services and address the recommendations New Zealand received from the UN Committee on the Rights of the Child.<sup>74</sup>
52. Other material highlighting the growing international attention on current practices includes two 2017 reports by Human Rights Watch on medical practices on intersex children in the United States,<sup>75</sup> and a report by Amnesty International on the rights of children with variations in sex characteristics in Denmark and Germany.<sup>76</sup>
53. In response to concerns regarding the human rights implications for current treatment models, some clinicians have worked towards developing various ethical guidelines to approaching the management of people born with variations in sex characteristics.<sup>77</sup> The developments in New Zealand also reflect steps towards medical professionals and people born with variations in sex characteristics working together to improve practices.

(b) *Medical guidelines*

54. People can be born with a range of variations in sex characteristics. An Australian study in 2016 found participants had over 40 different variations.<sup>78</sup> These variations can manifest differently and various medical or other issues can arise depending on the variation or the particular individual concerned. Given how different these variations can be from each other, the different times in someone's life that they may be discovered, and the different issues associated with a particular variation, often medical guidelines exist to manage particular variations rather than all of them. For example, the Endocrine Society Clinical Practices developed guidelines in 2010 for Congenital Adrenal Hyperplasia,<sup>79</sup> and the 2016 Cincinnati International Turner Syndrome Meeting produced clinical practice guidelines for Turner's

syndrome.<sup>80</sup> These guidelines have been developed by multidisciplinary teams in hospitals or by bodies representing particular specialities.

55. While some guidelines focus on particular variations, others are broader and may focus on a number of variations.<sup>81</sup> In 2006 general principles for care were established in a Consensus Statement on the management of intersex disorders. This was published by international medical experts following an international intersex consensus conference in Chicago, USA.<sup>82</sup> The Consensus Statement discusses the management of disorders of sex development and, amongst other things, it highlights the importance of using multidisciplinary teams and the inclusion of psychological support within that structure, recognises the importance and value of peer support, and recognises the need for more long term data.<sup>83</sup>
56. The Consensus Statement has attracted significant criticism by some intersex and human rights advocates, particularly in regard to its support for interventions to ‘minimise family concern and distress’, facilitate parental bonding and mitigate ‘the risks of stigmatization’.<sup>84</sup>
57. A follow-up statement was issued in 2016 to address changes to clinical approaches. It recognises advances in medical and surgical approaches, differences in opinion regarding terminology and the importance of peer support groups. It also acknowledges the ethical, legal and cultural issues that arise in the management of DSDs and the challenges in ‘striking the appropriate balance’ among competing rationales to undertake medical intervention.<sup>85</sup>

(c) *A growing intersex movement*

58. Intersex people have increasingly connected and come together to call for the protection of their human rights.
59. The Third International Intersex Forum produced the Malta Declaration in December 2013.<sup>86</sup> This was a seminal statement outlining demands and a call for action from governments, human rights institutions and organisations, media and funders. The authors were intersex advocates representing 30 intersex organisations from across the world.
60. In 2017, three regional statements were published. In March, intersex advocates from Australia and Aotearoa / New Zealand published the Darlington Statement;<sup>87</sup> in April, intersex people from 16 Council of Europe member states published the Vienna Statement;<sup>88</sup> and in November, intersex people from seven African countries published the Public Statement by the African Intersex Movement.<sup>89</sup> In early 2018, the Asian Intersex Movement also published a Public Statement.<sup>90</sup>

## **6 Consultation**

### **6.1 What does the Commission want to know?**

61. The Commission is broadly interested in two key thematic areas:
  1. The existing approaches to and experiences of medical interventions involving people born with variations in sex characteristics in Australia and overseas.
  2. The identification of changes to existing approaches to medical interventions to better respect and protect the human rights of people born with variations in sex characteristics.

62. Past Australian projects have focused on surgical interventions involving infants or medical interventions resulting in sterilisation. In this project, the Commission is interested in approaches to and experiences of surgical and non-surgical interventions involving children and adults born with variations in sex characteristics. This includes hormone treatment and surgical interventions that do not result in sterilisation.
63. The Commission acknowledges that clinical practices have changed over time in response to research outcomes, feedback from individuals born with variations in sex characteristics and advocacy groups. The Commission is seeking to determine the current state of practice and how this affects individuals' human rights. Given its focus on protecting the human rights of individuals born with variations in sex characteristics, this project will also consider the consequences that flow from past practices and how best to support individuals now and into the future.

## **6.2 Key themes and issues**

64. The key questions identified in paragraph [61] raise a number of interrelated themes and issues. The Commission's consultation will focus on the following issues although it is not intended to be limited to these areas.

### *(a) Understanding lived experiences*

65. Central to protecting the human rights of people born with variations in sex characteristics is an understanding of their lived experiences. The needs and challenges of people born with variations in sex characteristics in the context of medical settings must be considered for any change to be targeted and meaningful.
66. The Senate Committee report identified a lack of education and understanding about the needs and experiences of people born with variations in sex characteristics.<sup>91</sup> This issue has also been raised by intersex and human rights advocates and medical practitioners.<sup>92</sup>
67. At the international level, a number of UN treaty bodies have called on States Parties to facilitate education and awareness raising about the unique needs and experiences of people born with variations in sex characteristics.<sup>93</sup>
68. Different variations have different needs. The Commission is interested in hearing about the different experiences for individuals and the particular concerns that have arisen for them. Some interventions may lead to poor outcomes for some people, but the same interventions may be beneficial for others. We are interested in hearing about both positive and negative experiences and what made it that for you.

#### **Key questions:**

2. Broadly, how would you describe your experiences in the context of medical interventions?
3. What are the current Australian sources of information and education about the experiences of people born with variations in sex characteristics?
4. Are there gaps and/or inconsistencies in sources of information and education that are available about the experiences of people born with variations in sex characteristics? If so, what is the impact of this?

(b) Consent

(i) Overview

69. The capacity to provide full and informed consent to medical interventions is fundamental to the enjoyment of bodily autonomy and integrity and to achieving the highest attainable standard of health, as discussed in sections 0 and 0 of Appendix B. The role of the parent in providing this consent on behalf of their child is considered in section 6.2(b)(ii) below.
70. Various UN instruments, treaty bodies, agencies and special rapporteurs have emphasised the importance of full and informed consent in relation to medical interventions.<sup>94</sup> As the UN Special Rapporteur on Health observed in 2009, ‘informed consent’ extends ‘beyond mere acceptance of a medical intervention’. It also requires:
- A voluntary and sufficiently informed decision, protecting the right of the patient to be involved in medical decision-making, and assigning associated duties and obligations to health-care providers. Its ethical and legal normative justifications stem from its promotion of patient autonomy, self-determination, bodily integrity and wellbeing.<sup>95</sup>
71. Under international law, medical interventions administered without the free and informed consent of the person to whom they are administered may constitute torture or inhumane treatment, as discussed in section 0 of Appendix B.<sup>96</sup>
72. In Australia, the Victorian *Charter of Human Rights and Responsibilities Act 2006* states that a person ‘must not be subjected to medical ... treatment without his or her full, free and informed consent’.<sup>97</sup>
73. Under state and territory law, individuals over the age of 18, or in some states 16 years old, can provide consent to refuse or undergo medical treatment if they have capacity.<sup>98</sup> This means that the individual can understand the doctor’s information about the treatment and, based on this information, can make a reasonable choice.
74. Under Australian law, medical interventions conducted without the consent of the person to whom they are administered, in circumstances where there is no other lawful justification, may constitute trespass. Where the broad terms of the procedure to be performed are explained but not the risks inherent in the procedure, this may constitute negligence.<sup>99</sup>
75. While international and domestic law recognises the necessity of ‘informed consent’ in medical decision-making, what this concept means in practice for different individuals and over time can change. As a consequence, it is important to gauge how informed individuals felt and how satisfied they were with the information they were given over a longer period of time.

**Key questions:**

5. How is the consent of a person born with a variation in sex characteristics currently sought prior to a medical intervention?
6. How do current guidelines or protocols relating to the medical management of people born with variations in sex characteristics deal with the issue of consent, including the ability to withdraw any consent given at any time?
7. What practices/safeguards are in place to ensure any consent obtained remains informed?
8. What could enhance the capacity of people born with variations in sex characteristics or their caregivers to provide full and informed consent?

## (ii) Consent in the absence of legal capacity

76. Intersex advocates, human rights advocates, UN treaty bodies and special rapporteurs have expressed particular concerns about the human rights violations that can occur in relation to medical interventions involving children born with variations in sex characteristics where the child is not capable of providing full and informed consent.<sup>100</sup>
77. In Australia, generally a child under the age of 18 may consent to a medical procedure if medical professionals have formed the view that the child has sufficient maturity and understanding to give valid consent to the procedure (this is known as '*Gillick* competency').<sup>101</sup> If the child is not *Gillick* competent, decision-making responsibility about medical treatment typically vests in the parents or guardians.<sup>102</sup>
78. Parents and carers play an important role in making decisions for their child. A human rights based approach to decision making on behalf of children requires the decision maker to make decisions that are in the 'best interests' of the child. It also requires a consideration of the growing capacity of their child to be increasingly involved in decision-making.<sup>103</sup>
79. In some circumstances, however, regardless of whether the child is *Gillick* competent or whether the parents consent, court authorisation of the decision will be required.<sup>104</sup> These cases are known as 'special medical procedures'. There is no fixed definition of 'special medical procedures'.<sup>105</sup> Following the High Court's decision in *Secretary, Department of Health and Community Services v JWB* (1992) 175 CLR 218 (*Marion's case*), court authorisation is required where the proposed treatment is 'non-therapeutic'; it is invasive, irreversible and considered major treatment; where there is a significant risk of making the wrong decision about the best interests of the child; and where the consequences of a wrong decision are particularly grave.<sup>106</sup>
80. Some hospitals and parents of children born with variations in sex characteristics have applied to the Family Court of Australia to seek court authorisation for a particular intervention or series of interventions. Even in cases where the Court has found that these decisions fall within the scope of parental authority and do not require court authorisation, the Court has held it is able to provide such authorisation under its 'welfare jurisdiction'<sup>107</sup> (see the Case Study below). In providing court authorisation, the Family Court will consider whether the medical procedure is in the 'best interests' of the child.<sup>108</sup>
81. What constitutes the 'best interests' of the child can be difficult to ascertain. The UN Committee on the Rights of the Child noted that the concept should be 'responsive to the situation of individual children' but 'may also leave room for manipulation'.<sup>109</sup> The potential for manipulation

has also been explicitly noted in the *Yogyakarta Principles plus 10* which states that States shall not manipulate the concept of the best interest of the child ‘to justify practices that conflict with the child’s right to bodily integrity’.<sup>110</sup> Similarly, some Family Court judges have observed that the concept of ‘best interests’ could conflict with other rights like a child’s right to privacy, autonomy, self-determination and freedom of expression.<sup>111</sup> However, the Committee on the Rights of the Child has noted that ‘[t]he concept of the best interests of the child is aimed at ensuring both the full and effective enjoyment of all the rights recognized in the Convention’.<sup>112</sup> It has stated that ‘there is no hierarchy of rights in the Convention; all the rights provided for therein are in the “child’s best interests” and no right should be compromised by a negative interpretation of the child’s best interests.’<sup>113</sup> The child’s right to health is therefore central to assessing their best interest and the ‘views of the child must also be given due weight based on his or her age and maturity... and be allowed, when possible, to give their consent in an informed manner’.<sup>114</sup>

82. The Senate Committee considered whether authorisation for these procedures should come under the jurisdiction of the Family Court. It was persuaded that tribunals would be a more accessible and cost-effective option to hear such cases; however, it was reluctant to close off the ‘avenue of expertise’ offered by the Family Court in cases of ‘particular legal complexity’.<sup>115</sup> Accordingly, the Committee recommended that ‘all proposed intersex medical interventions for children and adults without the capacity of consent require authorisation from a civil and administrative tribunal or the Family Court’.<sup>116</sup>
83. Other organisations have suggested different approaches. For example:
- the National LGBTI Health Alliance proposed the creation of a national statutory body in the form of an expert tribunal that includes intersex people and intersex-led community organisations to replace the Family Court in decision-making about medical interventions involving children with congenital variations in sex characteristics;<sup>117</sup>
  - Organisation Intersex International Australia (now Intersex Human Rights Australia) recommended the creation of an expert tribunal;<sup>118</sup>
  - the Australian Paediatric Endocrine Group (APEG) suggested the funding of expert multidisciplinary management teams and the creation of formal processes requiring children with DSD to be reviewed by one of these teams.<sup>119</sup>
  - the Melbourne Royal Children’s Hospital also noted that the care of someone with a DSD requires a multidisciplinary team to provide support and care for them and their family.<sup>120</sup> In 2015, a DSD clinical coordinator was appointed at the Royal Children’s Hospital in Melbourne to manage the provision of care by the multidisciplinary team.<sup>121</sup>
  - the Victorian decision-making principles suggest balancing medical principles, human rights principles, ethical principles and legal principles in a robust, transparent and consistent way.<sup>122</sup>
84. APEG suggests that multidisciplinary management teams may comprise endocrinologists, urologists, gynaecologists, psychologists, geneticists, biochemists, and bioethicists. Intersex advocates have also suggested the inclusion of human rights specialists, child advocates and independent intersex community representatives within these teams.<sup>123</sup> Collaboration with peer support groups was also noted as crucial in the 2016 Consensus Statement update.<sup>124</sup>
85. In the recent Darlington Statement, intersex advocates declared that the Family Court system has ‘failed to adequately consider the human rights and autonomy of children born with variations of sex characteristics, and the repercussions of medical interventions on individuals and their families’.<sup>125</sup> In place of the Court, the authors called for an ‘alternative, independent effective human rights-based oversight mechanism/s to determine individual cases involving persons born with intersex variations who are unable to consent to treatment’, consisting of ‘human rights experts, clinicians and intersex-led community organisations’.<sup>126</sup>



86. Regardless of whether decisions made on behalf of a child are made by parents or carers, the Family Court, or another body, consideration must be given to the growing capacity of the child to consent. A fundamental question is whether change is needed to enable individuals to exercise a greater degree of autonomy in decisions that affect their own bodies.

**Case study: Re: Carla**

In the 2016 Family Court case of *Re: Carla (Medical Procedure)* [2016] FamCA 7,<sup>127</sup> Forrest J found that the surgical treatment proposed by a multidisciplinary team for five-year old Carla, a gonadectomy, was ‘therapeutic’ within the meaning of the term used by the majority in *Marion’s case*. On this basis, the Court concluded that the treatment fell within the bounds of permissible parental authority and did not require Court authorisation.<sup>128</sup> The Court reached a similar conclusion in the 2014 case of *Re: Sarah*<sup>129</sup> and the 2010 case of *Re: Sean and Russell (Special Medical Procedures)*.<sup>130</sup>

In recounting the facts, Forrest J noted that Carla had previously undergone surgery that had ‘enhanced the appearance of her female genitalia’,<sup>131</sup> including a clitoral recession and labioplasty.<sup>132</sup> These procedures were conducted without an application for court authorisation.

Despite finding that court authorisation was not required for the proposed gonadectomy, Forrest J noted that the bringing of an application by a parent or health authority for court authorisation ‘can, in many circumstances, be understandably considered “as a prudent step”’.<sup>133</sup> His Honour declined to set out the conditions that would make the reasons for seeking court authorisation compelling.

Forrest J’s decision in *Re: Carla* departed from Barry J’s decision in *Re: Lesley*, in which his Honour found that the same procedure proposed in *Re: Carla*, a gonadectomy, did require the sanction of the Court.<sup>134</sup>

**Key questions:**

9. To what extent should parents and carers be involved in making decisions on behalf of their child? How can parents and carers be best supported to make these decisions?

10. What, if any, legal oversight mechanism(s) should be in place to guide decision-making about medical interventions involving a person born with a variation in sex characteristics where the person does not have the legal capacity to provide consent?

11. If such a mechanism existed,

- how could this mechanism adequately address different interventions and different variations?
- how can it best respect the future capacity of a child to consent?
- should there be distinct processes for children with parents and for adults who lack legal capacity?

(c) *Medical necessity*

(i) Overview

87. *Marion's case* held that court authorisation was not required for cases where there is a 'therapeutic' need, meaning where the intervention is necessary for the health of the individual.<sup>135</sup> The Court also stated however that there is no clear dividing line between what is 'therapeutic' and 'non-therapeutic'.<sup>136</sup> While interventions may need to be performed for medically necessary reasons, what constitutes medical necessity can be contentious, particularly where psycho-social rationales for interventions are considered. Psycho-social rationales take into account social and cultural factors; for example, understandings of what male and female bodies *should* look like or the functions that men and women *should* be able to have.
88. Justifications for medical interventions are varied. Where multiple interventions are being considered, there may not always be a thorough delineation of which interventions are medically necessary and which are not. A consideration of the rationales behind decision-making helps to inform which human rights are being protected and prioritised, and, where an intervention is being considered in the absence of a child's capacity for consent, how the best interests of the child are being considered.
89. All justifications for intervention also ought to consider the possibility of consequential interventions, either due to complications or because of the very nature of the procedure. For example, the decision to surgically remove gonads (gonadectomy) will require life-long hormone replacement therapy, while the decision not to remove them may require the use of puberty blockers. Similarly, the surgical creation of a vagina (vaginoplasty) may require dilation to maintain length. Interventions are, therefore, not necessarily single, discrete events and may require ongoing management and further interventions in the future.

(ii) Psycho-social rationales for intervention

90. Interventions are often undertaken in an attempt to make bodies look more typically male or female. These rationales often reflect a presumption that an individual's womanhood or manhood is challenged by having genitalia that do not match what is expected of that sex.
91. Psycho-social rationales that have been advanced in favour of medical intervention in this context include:
- Stigma, embarrassment and distress of having a body that does not match the sex of rearing;<sup>137</sup>
  - Mitigating the risk of gender-identity confusion;<sup>138</sup>
  - Risk the child will not be accepted by the parents leading to impaired bonding between parent and child;<sup>139</sup>
  - Minimising family concern and distress;<sup>140</sup>
  - Risk of difficulties in forming intimate relationships;<sup>141</sup>
  - Gendered understandings of functional ability – for example, that a male should be able to stand to urinate;<sup>142</sup>

- Gendered understandings of appropriate appearance of genitalia;<sup>143</sup> for example, a clitoris that is considered too large may be reduced in size, although research has shown significant variations even among people not considered to have atypical genitalia;<sup>144</sup> and
- Gendered understandings of which hormone replacements an individual requires.<sup>145</sup>

92. These rationales are often influenced by the individual's worldview or anecdotal evidence, rather than empirical evidence. For example, there is a lack of evidence to support the idea that having a body that does not typically match the sex of rearing will lead to psychological distress.<sup>146</sup>

93. Further, undertaking interventions based on these rationales may not always consider that the interventions themselves can contribute to the very issues they are trying to prevent.<sup>147</sup> The Consensus Statement noted that interventions can cause shame and confusion.<sup>148</sup>

(iii) Medical rationales

94. Rationales based on physical need include:

- Emergency life-saving treatment; for example, to treat salt-wasting Congenital Adrenal Hyperplasia;<sup>149</sup>
- Ensuring adequate urine flow;<sup>150</sup> and
- Minimising or removing high cancer risks.<sup>151</sup>

95. As much as possible, the 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.<sup>152</sup> However there can still be uncertainty about what constitutes medical need or how to manage these risks. For instance, in respect of mitigating cancer risk, improving methods to effectively monitor gonads rather than removing them could assist in collecting more long term data on risk.<sup>153</sup>

(iv) Rationales based on timing

96. Some interventions are justified on the basis that outcomes are more successful if they are performed earlier.<sup>154</sup>

97. Other interventions are also justified on the basis that they reduce or remove the risk of trauma for children when they are undertaken at an age when the child will not be able to remember that the intervention occurred.<sup>155</sup>

(v) Rationales based on technical considerations

98. Some interventions are justified on the basis of the expected results of the intervention and what is technically possible. For example, the World Health Organization's ICD-11 beta draft classification for 17 $\beta$ -HSD3, the variation that Carla has in the case study above, states that '[i]f 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'.<sup>156</sup> This justification links sex assignment

with technical surgical outcomes and relies on the idea that children need sex characteristics that match their assigned sex.<sup>157</sup>

99. What is technically possible may also depend on other previous interventions that have been undertaken.<sup>158</sup>

(vi) Rationales based on financial considerations

100. Some clinicians have expressed concern that funding models may impact upon whether medical interventions are undertaken. Where there is little funding for psychological support or peer support groups, for both individuals and families, it may seem more cost-effective to pay for discrete surgical interventions than to seek ongoing support to raise a child with a variation in sex characteristics.<sup>159</sup>

**Key questions:**

12. Would a legal definition of medical necessity or therapeutic treatment be helpful and, if so, what should the definition be?

13. 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?

(d) *Regulation*

101. Regulation in this area is difficult and contentious. Some see a blanket legal prohibition on particular interventions as overly blunt, making this option unavailable even where it is clearly of benefit to a particular individual. By contrast, guidelines are more flexible and adaptable, but may not be followed. Challenges also exist in ascertaining whether practices change in line with guidelines and what enforcement options are available when guidelines are not followed.

(i) Legal and policy prohibitions

102. Some intersex organisations and advocates have called for the criminalisation of non-emergency and/or deferrable medical interventions that alter a child's sex characteristics without their personal consent.<sup>160</sup>

103. These advocates and organisations have drawn comparisons with female genital mutilation, which is a criminal offence in all Australian states and territories.<sup>161</sup>

104. Internationally, as discussed in section 5.2, some countries have prohibited surgical interventions involving children who are incapable of providing consent, although the extent to which this is done and which other parties are involved are mixed.

**Key question:**

14. Should all non-emergency and/or deferrable medical interventions that alter a child's sex characteristics, where the child does not have legal capacity to consent, be prohibited by law? If so, should this prohibition be civil or criminal?

(ii) Clinical guidelines

105. Clinical guidelines can establish important principles for medical professionals to approach the care of people born with variations in sex characteristics. These guidelines may be for specific variations or may more broadly cover a number of variations.
106. The Consensus Statement provides guidance for general approaches and considerations in the care of people born with variations in sex characteristics. The Consensus Statement, published in 2006, was updated in 2016 to reflect changes to ‘perceptions and the approach to the diagnosis and care of individuals with DSDs’, as discussed in section 5.3(b). The Consensus Statement update notes, however, that for some important issues regarding the appropriate medical treatment and care of people born with variations in sex characteristics, like indications, timing, procedure and evaluation of outcome of surgery, there is no consensus among medical practitioners.<sup>162</sup>
107. There are currently no national guidelines in Australia; however, APEG contributed to and endorsed the 2016 Consensus Statement update. There also exist a number of international evidence-based guidelines that Australian clinicians may follow.
108. The Senate Committee 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’.<sup>163</sup> In its formal response, the Australian Government has noted that this is a matter for state and territory governments.<sup>164</sup>
109. In 2013, the Victorian Department of Health issued decision-making principles for the care of infants, children and adolescents with intersex conditions. The 2006 Consensus Statement was formative in the development of these principles.<sup>165</sup>
110. The Victorian decision-making principles and Consensus Statements endorsed by APEG provide a framework for medical care and note that medical interventions are not always necessary. As discussed at section 5.3(b), they recommend decision-making by multidisciplinary teams for the long-term management of individuals and encourage open communication with patients and families, as well as participation in decision making.<sup>166</sup> The Australian Commonwealth has encouraged other jurisdictions to adopt these principles or develop specific principles for their jurisdiction.<sup>167</sup> However, some advocates have expressed concern that the principles still allow early interventions to be undertaken and consider psychosocial rationales to be therapeutic (and therefore allow interventions to be framed as medically necessary; see section 6.2(c)).<sup>168</sup> Other clinicians have raised questions about the leadership and predispositions of multidisciplinary teams overseas.<sup>169</sup>
111. The Darlington Statement called for multi-disciplinary teams to ‘operate in line with transparent, human rights-based standards of care’, and should include human rights specialists, child advocates, and independent intersex community representatives.<sup>170</sup> It also called for peer support to be integrated into their approaches, teams and services.<sup>171</sup>

**Key questions:**

15. What are the current approaches to the management of people born with variations in sex characteristics? What are these based on?

16. Do any medical guidelines exist that are considered best practice in Australia or internationally, either for the general management of people born with variations in sex characteristics, or for specific variations?

17. Should there be national guidelines to guide medical interventions involving people born with variations in sex characteristics?

18. If so,

- what factors should the guidelines take into account?
- what should be the legal status of the guidelines?
- what should be the process, including consultation, for drafting the guidelines?
- what should be the oversight mechanism for decisions made under the guidelines?

(e) *Lack of data*

112. A lack of evidence about current practices and procedures and the outcomes of intervention directly impacts the right to the highest attainable standard of health. A lack of evidence can also lead to concerns of medical experimentation.<sup>172</sup>
113. Submissions to the Senate Committee Inquiry repeatedly highlighted the lack of Australian data about the number and types of medical interventions involving people born with variations in sex characteristics.<sup>173</sup>
114. Limited understanding of the long-term physical and psychological outcomes of interventions, the timing of interventions, and the outcomes of not undertaking any interventions, can make it difficult to participate in informed decision-making. Not undertaking medical intervention may also be considered to be a decision in itself and there is little documented evidence on the outcomes of not taking action.
115. In its final report, the Senate Committee expressed serious concern about the lack of evidence to support decision making and recommended that the Australian 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’.<sup>174</sup>

**Key questions:**

19. What are the current Australian sources of data on:

- the number and nature of medical interventions involving people born with variations in sex characteristics
- long-term outcomes of medical interventions involving people born with variations in sex characteristics
- long-term outcomes of people born with variations in sex characteristics not undertaking medical interventions?

20. How adequate are the current Australian sources of data for each of these areas?

21. What barriers exist to nationally consistent data collection?

(f) *Privacy*

116. The right to bodily autonomy and physical integrity is integral to the right to privacy.<sup>175</sup> In the context of medical interventions, privacy includes both the protection of people's physical selves against unwanted invasive procedures, as well as protecting and providing access to an individual's own health information.
117. Principle 37 of the *Yogyakarta Principles plus 10* outlines the right to truth, described as the right for all individuals to 'know the truth about the facts, circumstances and reasons why the violation occurred' and that States shall 'protect individuals' right to know the truth about their medical histories, including through full access to accurate medical records'.<sup>176</sup>
118. In Australia, people born with variations in sex characteristics have faced difficulties in accessing their complete medical records.<sup>177</sup> The *Privacy Act 1988* (Cth) and the Australian Privacy Principles regulate how health organisations collect and handle personal health information and how individuals can access information about them. Access can be refused where it could threaten someone's life, health or safety, or impact on someone else's privacy.<sup>178</sup> This means that access can be refused where a health provider has reasonable grounds to believe that providing access may cause that person significant distress or lead to self-harm or harm to another person.<sup>179</sup> Further, the duration in which medical records must be kept, between 5 to 10 years for adults and until the age of 25 for children depending upon the jurisdiction, can also act as a barrier to individuals finding out about their medical histories later in life.<sup>180</sup>
119. Some people born with variations in sex characteristics have also been subject to unwanted medical photography and unnecessary examinations or examinations in front of more people than necessary.<sup>181</sup> These behaviours can constitute violations of a patient's privacy and, particularly for children, these experiences can normalise these behaviours and create issues around boundaries and consent.<sup>182</sup>

**Key questions:**

- 22. How can medical practices best respect the privacy of people born with variations in sex characteristics?
- 23. Have you faced any difficulties accessing your medical records?
- 24. How can access to medical records and histories be improved?

(g) *Access to services, psychological support and community*

- 120. Access to adequate health services and psychological support is fundamental to the right to the highest attainable standard of physical and mental health.
- 121. People born with variations in sex characteristics may require access to different kinds of health services and supports, including access to medical services related to associated health needs and not just those related to variations in their sex characteristics. For example, different variations are also associated with heart, kidney, spinal, knee, growth, hearing and learning difficulties. Support for these associated health concerns is also important in attaining the highest standard of physical health.
- 122. Access to early psychological support is also crucial but access to trained psychologists can be limited. The *Yogyakarta Principles plus 10* outline that the right to truth requires that in cases of violations of the right to mental and bodily integrity, States should ensure 'effective access to ... where appropriate, psychological support'.<sup>183</sup>
- 123. Peer support is also important for people born with variations in sex characteristics and their families to make informed decisions over their healthcare. It can help alleviate feelings of stigma and isolation and can expose individuals to further information, options and experiences.<sup>184</sup>
- 124. In Australia, the Senate Committee report, the APEG endorsed Consensus Statements, the Victorian decision-making principles and the Darlington Statement all recognise the importance of peer support for people born with variations in sex characteristics and their families and carers.<sup>185</sup>
- 125. While the importance of peer support is clinically recognised,<sup>186</sup> in practice referrals to support groups are inconsistent.<sup>187</sup>
- 126. 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.<sup>188</sup>



**Key questions:**

25. How can people born with variations in sex characteristics and their families and carers be more adequately supported?
26. How can psychological and peer support be more integrated into decision making processes?
27. What barriers exist to connecting individuals to support services?
28. What barriers exist for individuals in accessing support services?
29. How can peer support groups and organisations be adequately resourced and supported?

**6.3 How can I contribute to this work?**

127. You can contribute to the Commission's work in one or more of the following ways:
  - making a written submission
  - participating in a face-to-face consultation
128. The information collected by the Commission may be drawn upon, quoted or referred to in the Commission's future publications. The Commission's submission policy provides further information on the use, publication and access to submissions. The submission policy is located at: <https://www.humanrights.gov.au/submission-policy>.
129. Details on the consultations and submission process, including relevant dates, and further information about the Commission's work can be found at <https://www.humanrights.gov.au/our-work/sexual-orientation-gender-identity-intersex-status/projects/protecting-human-rights-people>.
130. To contact the Commission about this work, you can phone (02) 9284 9650 or send an email to [sogji@humanrights.gov.au](mailto:sogji@humanrights.gov.au).

## **7 Discussion Questions**

### ***Terminology***

1. Is the term 'people born with variations in sex characteristics' appropriate, or is there a better way to describe the people who are the subject of this Consultation Paper?

### ***Understanding lived experiences***

2. Broadly, how would you describe your experiences in the context of medical interventions?
3. What are the current Australian sources of information and education about the experiences of people born with variations in sex characteristics?
4. Are there gaps and/or inconsistencies in sources of information and education that are available about the experiences of people born with variations in sex characteristics? If so, what is the impact of this?

### ***Consent***

5. How is the consent of a person born with a variation in sex characteristics currently sought prior to a medical intervention?
6. How do current guidelines or protocols relating to the medical management of people born with variations in sex characteristics deal with the issue of consent, including the ability to withdraw any consent given at any time?
7. What practices/safeguards are in place to ensure any consent obtained remains informed?
8. What could enhance the capacity of people born with variations in sex characteristics or their caregivers to provide full and informed consent?

### ***Consent in the absence of legal capacity***

9. To what extent should parents and carers be involved in making decisions on behalf of their child? How can parents and carers be best supported to make these decisions?
10. What, if any, legal oversight mechanism(s) should be in place to guide decision-making about medical interventions involving a person born with a variation in sex characteristics where the person does not have the legal capacity to provide consent?
11. If such a mechanism existed,
  - how could this mechanism adequately address different interventions and different variations?
  - how can it best respect the future capacity of a child to consent?
  - should there be distinct processes for children with parents and for adults who lack legal capacity?

### ***Medical necessity***

12. Would a legal definition of medical necessity or therapeutic treatment be helpful and, if so, what should the definition be?

13. 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?

**Regulation – Legal and policy prohibitions**

14. Should all non-emergency and/or deferrable medical interventions that alter a child's sex characteristics, where the child does not have legal capacity to consent, be prohibited by law? If so, should this prohibition be civil or criminal?

**Regulation – Clinical guidelines**

15. What are the current approaches to the management of people born with variations in sex characteristics? What are these based on?
16. Do any medical guidelines exist that are considered best practice in Australia or internationally, either for the general management of people born with variations in sex characteristics, or for specific variations?
17. Should there be national guidelines to guide medical interventions involving people born with variations in sex characteristics?
18. If so:
- what factors should the guidelines take into account?
  - what should be the legal status of the guidelines?
  - what should be the process, including consultation, for drafting the guidelines?
  - what should be the oversight mechanism for decisions made under the guidelines?

**Lack of data**

19. What are the current Australian sources of data on:
- the number and nature of medical interventions involving people born with variations in sex characteristics?
  - long-term outcomes of medical interventions involving people born with variations in sex characteristics?
  - long-term outcomes of people born with variations in sex characteristics not undertaking medical interventions?
20. How adequate are the current Australian sources of data for each of these areas?
21. What barriers exist to nationally consistent data collection?

**Privacy**

22. How can medical practices best respect the privacy of people born with variations in sex characteristics?
23. Have you faced any difficulties accessing your medical records?

24. How can access to medical records and histories be improved?

***Access to support services and peer support***

25. How can people born with variations in sex characteristics and their families and carers be more adequately supported?

26. How can psychological and peer support be more integrated into decision making processes?

27. What barriers exist to connecting individuals to support services?

28. What barriers exist for individuals in accessing support services?

29. How can peer support groups and organisations be adequately resourced and supported?

## **9 Appendix A: 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.

## 9 Appendix B: Human rights framework

### 1. Human rights framework

1.1. In the international human rights context, issues relating to the human rights of people born with variations in sex characteristics have typically, although not exclusively, arisen by reference to one or more of the following themes:

- bodily autonomy and physical integrity
- children's rights
- harmful practices
- torture and cruel, inhuman or degrading treatment
- health, including informed consent
- non-discrimination.

#### (a) *Bodily autonomy and physical integrity*

1.2. The *Convention on the Rights of Persons with Disabilities* (CRPD) includes an express right to physical and mental integrity. Article 17 states that 'every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others'.<sup>189</sup>

1.3. 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 confirmed that the rights to privacy (Art 7) and security of person (Art 9) in the ICCPR include bodily autonomy and physical integrity.<sup>190</sup>

1.4. A number of treaty bodies have recommended that States implement measures to guarantee the bodily autonomy and physical integrity of people with intersex variations.<sup>191</sup>

#### (b) *Children's rights*

1.5. The *Convention on the Rights of the Child* (CRC) contains a number of articles relevant to protecting the human rights of children with congenital 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))
- ensure the survival and development of the child (Art 6(2))
- respect the right of the child to preserve his or her identity (Art 8(1))
- 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 (Art 12(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)

- 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)).<sup>192</sup>

1.6. The Committee on the Rights of the Child has repeatedly called on States Parties to better protect the human rights of children with congenital 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...<sup>193</sup>

1.7. Further, in October 2016, the Committee recommended that New Zealand take the following action:

- Develop and implement a child rights-based health care protocol for intersex children, setting the procedures and steps to be followed by health teams, ensuring that no one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guaranteeing the rights of children to bodily integrity, autonomy and self-determination, and provide families with intersex children with adequate counselling and support;
- Promptly investigate incidents of surgical and other medical treatment of intersex children without informed consent and adopt legal provisions to provide redress to victims of such treatment, including adequate compensation;
- Educate and train medical and psychological professionals on the range of biological and physical sexual diversity and on the consequences of unnecessary surgical and other medical interventions on intersex children;
- Extend free access to surgical interventions and medical treatment related to their intersex condition to intersex children between the age of 16 and 18.<sup>194</sup>

1.8. UN treaty bodies have increasingly considered claimed human rights violations in respect of people born with variations in sex characteristics in relation to medical interventions by reference to ‘harmful practices’.<sup>195</sup> The Committee has previously confirmed that ‘harmful practices’ fall within the scope of ‘all forms of physical and mental violence’ in article 19 of the CRC.<sup>196</sup>

1.9. A number of treaty bodies have also recommended that States Parties implement measures to guarantee rights-based healthcare for children with intersex variations.<sup>197</sup>

(c) *Torture or cruel, inhuman or degrading treatment*

1.10. The right to be free from torture or cruel, inhuman or degrading treatment is guaranteed in a number of key international instruments, including the *Convention Against Torture* (CAT) and the *Universal Declaration of Human Rights* (Art 5).

1.11. The 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).<sup>198</sup>

1.12. 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; and
- 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.<sup>199</sup>

1.13. In 2013, the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment called on all States to repeal all laws that permit intrusive and irreversible medical interventions when enforced without the free and informed consent of the person concerned.<sup>200</sup> 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.<sup>201</sup>

1.14. Further, in a joint statement in May 2015 to mark International Day Against Homophobia, Biphobia and Transphobia, UN and international human rights experts noted that medically unnecessary medical interventions involving intersex children and young people may constitute torture or ill-treatment.<sup>202</sup>

(d) *Health, including informed consent*

1.15. Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) requires States Parties to recognise the right of everyone to the highest attainable standard of physical and mental health.<sup>203</sup> 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.<sup>204</sup>

1.16. 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.<sup>205</sup>

1.17. 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.<sup>206</sup>

1.18. The World Health Organisation addressed the issue of stigma and discrimination experienced by intersex people in the health system in its 2015 report on Sexual Health, Human Rights and the Law. It noted, in particular, the concerns of intersex people, their caregivers, medical professionals and human rights bodies that medical interventions involving intersex children ‘often take place without the informed consent of the children involved and/or without even seeking the informed consent of their parents’.<sup>207</sup>

1.19. In June 2017, the Committee on Economic, Social and Cultural Rights expressed concern that children born with intersex variations in Australia are subject to early surgical and medical interventions before they are able to provide full and informed consent, as part of its discussion of the right to health (Art 12). The Committee recommended that Australia study and implement the recommendations of the Senate Committee Inquiry.<sup>208</sup>

(e) *Non-discrimination and equality before the law*

1.20. The ICCPR recognises the equal rights of men and women (Art 3), the right of protection for every child without discrimination (Art 24) and that all persons are equal before the law and have a right to protection against discrimination (Art 26). In November 2017, the UN Human Rights Committee made recommendations to Australia citing these three articles amongst others in recognising the Committee's concern that infants and children born with intersex variations are sometimes subject to irreversible and invasive medical interventions for the purposes of gender assignment.<sup>209</sup>

1.21. The right of non-discrimination and equality is also guaranteed in the ICESCR (Art 2), the CRC (Art 2(1)), the CPRD (Art (5(2))), the CEDAW (Art 2) and the Universal Declaration of Human Rights (Arts 2 and 7).

## 2. The Yogyakarta Principles

2.1. The *Yogyakarta Principles*, adopted in 2007, are principles on the application of international human rights law in relation to sexual orientation and gender identity. They were developed by a group of academic and UN human rights experts. The experts 'agree that the Yogyakarta Principles reflect the existing state of international human rights law in relation to issues of sexual orientation and gender identity' and 'affirm binding international legal standards with which all States must comply'.<sup>210</sup> 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.<sup>211</sup>

2.2. The original *Yogyakarta Principles* do not explicitly refer to people born with variations in sex characteristics; however, principle 18 does state that States shall, among other things:

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.<sup>212</sup>

2.3. In November 2017, the *Yogyakarta Principles plus 10* were adopted. These additional principles and State recommendations recognise developments in the intervening ten years in understandings of the violence and discrimination affecting individuals on the grounds of sexual orientation and gender identity. They also go further in recognising the distinct yet intersecting grounds of gender expression and sex characteristics.

2.4. In the context of medical interventions, relevant additional principles include the right to bodily and mental integrity,<sup>213</sup> and the right to truth.<sup>214</sup> Additional State recommendations extend the original principles to the grounds of sex characteristics in relation to the right to freedom from torture and cruel, inhuman or degrading treatment or punishment,<sup>215</sup> the right to the highest attainable standard of health,<sup>216</sup> and the right to found a family.<sup>217</sup>

- <sup>1</sup> I. A. Hughes et al, 'Consensus statement on management of intersex disorders' (2006) 2 *Journal of Pediatric Urology* 148, 149; Victorian Government (Department of Health), 'Decision-making principles for the care of infants, children and adolescents with intersex conditions' (February 2013), 2; Tiffany Jones et al, *Intersex: stories and statistics from Australia* (Open Book Publishers, 2016) 95–96.
- <sup>2</sup> See, for example, Organisation Intersex International Australia, 'Shadow Report Submission to the Committee on the Rights of Persons with Disabilities on the Situation of Intersex People in Australia', Submission to the Committee on the Rights of Persons with Disabilities, 8 June 2017. At <https://oii.org.au/wp-content/uploads/2017/06/OIIAU-CRPD-2017.pdf> (accessed 7 July 2017); Organisation Intersex International Australia, Submission No 23 to Senate Standing Committee on Community Affairs, *Involuntary or Coerced Sterilisation of People with Disabilities In Australia*, 15 February 2013. At <http://www.aph.gov.au/DocumentStore.ashx?id=14032f4c-c21b-465c-bf2b-85fee8adb3e3&subId=16126> (accessed 17 January 2018).
- <sup>3</sup> Black et al, *Darlington Statement* (10 March 2017). At <https://oii.org.au/darlington-statement/> (accessed 6 July 2017).
- <sup>4</sup> Australian Human Rights Commission, *Resilient Individuals: Sexual Orientation, Gender Identity & Intersex Rights* (2015). At [https://www.humanrights.gov.au/sites/default/files/document/publication/SOGII%20Rights%20Report%202015\\_Web\\_Version.pdf](https://www.humanrights.gov.au/sites/default/files/document/publication/SOGII%20Rights%20Report%202015_Web_Version.pdf) (accessed 6 July 2017).
- <sup>5</sup> Australian Human Rights Commission, *Surgery on Intersex Infants and Human Rights* (July 2009). At <https://www.humanrights.gov.au/surgery-intersex-infants-and-human-rights-2009> (accessed 22 June 2017).
- <sup>6</sup> 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). At [https://rightstalk.humanrights.gov.au/sites/default/files/AHRC\\_ICESCR\\_LOI\\_2016.pdf](https://rightstalk.humanrights.gov.au/sites/default/files/AHRC_ICESCR_LOI_2016.pdf) (accessed 7 July 2017).
- <sup>7</sup> Senate Community Affairs References Committee, Parliament of Australia, *Involuntary or coerced sterilisation of intersex people in Australia* (2013). At [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Involuntary\\_Sterilisation/Sec\\_Report/~/\\_/media/Committees/Senate/committee/clac\\_cte/involuntary\\_sterilisation/second\\_report/report.ashx](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/~/_/media/Committees/Senate/committee/clac_cte/involuntary_sterilisation/second_report/report.ashx) (accessed 26 June 2017).
- <sup>8</sup> 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> (accessed 17 January 2018) 2.
- <sup>9</sup> 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> (accessed 17 January 2018) 17–22.
- <sup>10</sup> See, for example, Committee on the Elimination of Discrimination against Women, *Concluding Observations on Germany*, UN Doc CEDAW/C/DEU/CO/7-8 (3 March 2017) [23]–[24]; Committee against Torture, *Concluding observations on France*, UN Doc CAT/C/FRA/CO/7 (10 June 2016) [34]–[35]; Committee on the Rights of the Child, *Concluding observations on Ireland*, UN Doc CRC/C/IRL/CO/3-4 (1 March 2016) [39]–[40].
- <sup>11</sup> 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). At <http://daccess-ods.un.org/access.nsf/Get?Open&DS=A/HRC/22/53&Lang=E> (accessed 7 July 2017).
- <sup>12</sup> Committee on Economic, Social and Cultural Rights, *Concluding Observations on Australia*, UN Doc E/C/12/AUS/CO/5 (23 June 2017) [49]–[50].
- <sup>13</sup> Human Rights Committee, *Concluding observations on the sixth periodic report of Australia*, UN Doc CCPR/C/AUS/CO/6 (9 November 2017) [25]–[26].
- <sup>14</sup> Tiffany Jones et al, *Intersex: stories and statistics from Australia* (Open Book Publishers, 2016) 42.
- <sup>15</sup> See, for example, Claudia Wiesemann et al, 'Ethical principles and recommendations for the medical management of differences of sex development (DSD)/intersex in children and adolescents' (2010) 169 *European Journal of Pediatrics* 671; Ellen K. Feder, *Making Sense of Intersex: Changing Ethical Perspectives in Biomedicine* (Indiana University Press, 2014).
- <sup>16</sup> Lynn H. Gillam et al, 'Ethical Principles for the Management of Infants with Disorders of Sex Development' (2010) 74 *Hormone Research in Paediatrics* 412.

- <sup>17</sup> Victorian Government (Department of Health), 'Decision-making principles for the care of infants, children and adolescents with intersex conditions' (February 2013).
- <sup>18</sup> General Assembly, *National Institutions for the Promotion and Protection of Human Rights*, GA Res 48/134, 85<sup>th</sup> plen mtg, UN Doc A/RES/48/134 (20 December 1993) [3(a)]. At <http://www.ohchr.org/EN/ProfessionalInterest/Pages/StatusOfNationalInstitutions.aspx> (accessed 15 June 2017).
- <sup>19</sup> Office of the United Nations High Commissioner on Human Rights, *Intersex Factsheet*, 4 September 2015. At: [http://www.ohchr.org/Documents/Issues/Discrimination/LGBT/FactSheets/UNFE\\_FactSheet\\_Intersex\\_EN.pdf](http://www.ohchr.org/Documents/Issues/Discrimination/LGBT/FactSheets/UNFE_FactSheet_Intersex_EN.pdf) (Accessed 7 July 2017).
- <sup>20</sup> *Australian Human Rights Commission Act 1986* (Cth) s 11(1)(k).
- <sup>21</sup> *Sex Discrimination Act 1984* (Cth) s 5AC.
- <sup>22</sup> *Sex Discrimination Act 1984* (Cth) s 48(g).
- <sup>23</sup> I. A. Hughes et al, 'Consensus statement on management of intersex disorders' (2006) 2 *Journal of Pediatric Urology* 148, 149; Disorder of Sex Development multidisciplinary team Royal Children's Hospital Melbourne, Submission No 92 to Senate Standing Committee on Community Affairs, *Involuntary or coerced sterilisation of intersex people in Australia*, 10 July 2013, 1–8; Organisation Intersex International Australia, Submission No 23.3 to Senate Standing Committee on Community Affairs, *Involuntary or coerced sterilisation of intersex people in Australia*, 30 June 2013, 6; Tiffany Jones et al, *Intersex: stories and statistics from Australia* (Open Book Publishers, 2016) 59–60.
- <sup>24</sup> I. A. Hughes et al, 'Consensus statement on management of intersex disorders' (2006) 2 *Journal of Pediatric Urology* 148, 149; Victorian Government (Department of Health), 'Decision-making principles for the care of infants, children and adolescents with intersex conditions' (February 2013), 2; Tiffany Jones et al, *Intersex: stories and statistics from Australia* (Open Book Publishers, 2016) 95–96.
- <sup>25</sup> Organisation Intersex International Australia, *Public Statement by the Third International Intersex Forum* (1 December 2013). At <http://oii.org.au/24241/public-statement-by-the-third-international-intersex-forum/> (accessed 17 January 2018); Office of the United Nations High Commissioner for Human Rights, *Free & Equal campaign: Intersex Fact Sheet* (5 September 2015). At [https://unfe.org/system/unfe-65-Intersex\\_Factsheet\\_ENGLISH.pdf](https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf) (accessed 18 January 2018).
- <sup>26</sup> Tiffany Jones et al, *Intersex: stories and statistics from Australia* (Open Book Publishers, 2016) 12 and 70; Organisation Intersex International Australia, Submission No 23.4 to Senate Standing Committee on Community Affairs, *Involuntary or coerced sterilisation of intersex people in Australia*, 29 August 2013, 1; Organisation Intersex International Australia, Black et al, *Darlington Statement* (10 March 2017) [3]. At <https://oii.org.au/darlington-statement/> (accessed 6 July 2017).
- <sup>27</sup> I.A. Hughes et al, 'Consensus statement on management of intersex disorders' (2006) 2 *Journal of Pediatric Urology* 148.
- <sup>28</sup> I.A. Hughes et al, 'Consensus statement on management of intersex disorders' (2006) 2 *Journal of Pediatric Urology* 148, 149–150; Georgiann Davis, *Contesting Intersex: The Dubious Diagnosis* (New York University Press, 2015) 46.
- <sup>29</sup> I.A. Hughes et al, 'Consensus statement on management of intersex disorders' (2006) 2 *Journal of Pediatric Urology* 148, 149.
- <sup>30</sup> Peter A. Lee et al, 'Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care' (2016) 85 *Hormone Research in Paediatrics* 158, 159.
- <sup>31</sup> M Carpenter & M Cabral (eds), *Intersex Issues in the International Classification of Diseases: A Revision* (2015). At <https://globaltransaction.files.wordpress.com/2015/10/intersex-issues-in-the-icd.pdf> (accessed 17 January 2018); Tiffany Jones et al, *Intersex: stories and statistics from Australia* (Open Book Publishers, 2016) 21.
- <sup>32</sup> Senate Community Affairs References Committee, Parliament of Australia, *Involuntary or coerced sterilisation of intersex people in Australia* (October 2013) 27 [2.20].
- <sup>33</sup> Tiffany Jones et al, *Intersex: stories and statistics from Australia* (Open Book Publishers, 2016) 95–97.
- <sup>34</sup> *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976) art 7; *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); *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) art 37(a); *Universal Declaration of Human Rights*, GA Res 217A (III), UN GAOR, 3<sup>rd</sup> sess, 183<sup>rd</sup> plen mtg, UN Doc A/810 (10 December 1948) art 5.

- <sup>35</sup> *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976) art 9(1); *Universal Declaration of Human Rights*, GA Res 217A (III), UN GAOR, 3<sup>rd</sup> sess, 183<sup>rd</sup> plen mtg, UN Doc A/810 (10 December 1948) art 3.
- <sup>36</sup> *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(1); *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) art 24; *Universal Declaration of Human Rights*, GA Res 217A (III), UN GAOR, 3<sup>rd</sup> sess, 183<sup>rd</sup> plen mtg, UN Doc A/810 (10 December 1948) art 25(1); *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.
- <sup>37</sup> *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.
- <sup>38</sup> *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, 3<sup>rd</sup> sess, 183<sup>rd</sup> plen mtg, UN Doc A/810 (10 December 1948) arts 2 and 7.
- <sup>39</sup> *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, 3<sup>rd</sup> sess, 183<sup>rd</sup> plen mtg, UN Doc A/810 (10 December 1948) art 12.
- <sup>40</sup> *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976) art 17(2); *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 17.
- <sup>41</sup> *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, 3<sup>rd</sup> sess, 183<sup>rd</sup> plen mtg, UN Doc A/810 (10 December 1948) art 16(1).
- <sup>42</sup> *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) art 12.
- <sup>43</sup> *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) art 8.
- <sup>44</sup> *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) art 3; *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 7.
- <sup>45</sup> *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) art 6(2).
- <sup>46</sup> 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) [48]–[49]; Committee on Rights of Persons with Disabilities, *Concluding observations on Italy*, UN Doc CRPD/C/ITA/CO/1 (31 August 2016) [45]–[46].
- <sup>47</sup> 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) principles 32, 37.
- <sup>48</sup> *Gender Identity, Gender Expression and Sex Characteristics Act* (Malta) Act No XI of 2015, art 14.
- <sup>49</sup> *Gender Identity, Gender Expression and Sex Characteristics Act* (Malta) Act No XI of 2015, art 14(2)–(3).
- <sup>50</sup> *Gender Identity, Gender Expression and Sex Characteristics Act* (Malta) Act No XI of 2015, art 14.
- <sup>51</sup> *Gender Identity, Gender Expression and Sex Characteristics Act* (Malta) Act No XI of 2015, arts 16(4) and (6).
- <sup>52</sup> Circular No. 18 (Chile) 22 December 2015. At <https://oii.org.au/wp-content/uploads/2013/01/Circular-08-22.12.15-Instruye-Sobre-Ciertos-Aspectos-de-la-atencion-de-Salud-a-Ninos-y-Ninas-Intersex.pdf>. Unofficial English translation at: <https://oii.org.au/30250/chilean-ministry-stops-normalising/> (accessed 18 January 2018).
- <sup>53</sup> Circular No. 7 (Chile) 23 August 2016. At <https://oii.org.au/wp-content/uploads/2016/01/Circular7-20160823.pdf> (accessed 18 January 2018).



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- <sup>190</sup> 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)*, 68<sup>th</sup> sess, UN Doc CCPR/C/21/Rev.1/Add.10 [20].
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<sup>201</sup> Juan E. Méndez, *Report of the Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment*, 31<sup>st</sup> sess, UN Doc A/HRC/31/57 (5 January 2016) [48] and [50].

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