

# Chapter 3

## Surgery and the assignment of gender

### Introduction

3.1 As the previous chapter explained, intersex is a category that includes a range of biological variations, some of which require medical intervention, and some of which do not. Medical care may include surgery. There are two features of the surgical dimension of intersex that were discussed during the inquiry:

- Surgery to create apparently 'normal' gender appearance, particularly in relation to the genitals; and
- Surgery to manage health risks, particularly of cancer.

3.2 In some circumstances, both can have sterilising effects. Therapeutic surgery in the genital region is sometimes required to address differences of sexual development, such as in the case of cloacal exstrophy where a child 'will have the bladder and a portion of the intestines, exposed outside the abdomen'.<sup>1</sup> However there are other conditions, such as cases of CAH or AIS, where the external manifestation of the condition does not present a health problem. In these cases non-therapeutic surgery may still be considered, to produce the physical appearance of 'normal' male or female genitalia. Such surgery may include labiaplasty (surgery to modify, usually by reducing the size of, the labia), vaginoplasty (the creation, expansion or modification of a vaginal canal), or gonadectomy (the removal of testicles or other external gonadal tissue inconsistent with the sex of assignment).

3.3 The committee understands that surgery is just one element of the medical management of differences in sexual development, but it was the aspect that was of greatest concern to stakeholders. As OII put it, 'surgical cosmetic "normalisation" and involuntary sterilisation are the most serious issues of concern to the intersex community'.<sup>2</sup> This chapter focusses on cosmetic and 'normalising' treatments. The following chapter deals with the issue of medical intervention to manage potentially elevated cancer risk. Both chapters emphasise discussion of treatment in children because of some of the particular human rights issues that this raises, but the committee acknowledges that it is not only children who are affected.

3.4 The chapter begins by describing the development of medical and social thought about intersex and the assignment of gender, in order to help explain the current intense debate about assignment of gender particularly where it includes surgery. The committee considered information provided to it about what is current practice regarding normalising surgery, as well as how the most recent guidelines have signalled some changes of approach. The committee then reviews the various

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1 Urology Care Foundation, Cloacal exstrophy, <http://www.urologyhealth.org/urology/index.cfm?article=92> (accessed 28 June 2013).

2 Organisation Intersex International Australia, *Submission 23*, p. 6.

problems with normalising surgery, before concluding that some further reform to guidelines is needed, as well as more rigorous application of them. Effective application of guidelines is also the subject of the fifth chapter, which includes a proposal to improve the formulation, oversight and application of guidelines.

### **'Normalising' surgery – overview and development**

3.5 As acknowledged in previous chapters, intersex physiology is considered within the medical community as a medical condition with little or no consideration of the individual. This 'condition' has both physical and psychological elements. Medical texts caution against failing to acknowledge and treat the potential psychological consequences of not adhering to standardised societal notions of male and female. As also explored in chapter one, Australian society does not readily acknowledge intersexuality or the intersex variations that traverse the binary of male and female. It is only within the past year that some Australian governments have moved to acknowledge intersexuality in the context of administrative procedures and antidiscrimination legislation.

3.6 An emphasis on removing difference, and thus obscuring intersexuality, is evident in historical medical practice. The rationale for 'normalising' surgery, and the social and medical support for surgical gender assignment, has changed over time. Early thinking was based on the idea of determining a person's 'true sex', which by the early twentieth century meant the sex determined by chromosomal makeup.<sup>3</sup> However, this was not an approach universally adopted. What was always accepted, though, was that a person had to be assigned a single sex.<sup>4</sup> The combination of advances in surgical techniques, scientific understanding of the genetics and biology of sex, and medicalization of intersex, combined to accelerate 'treatment' and the assigning of sex, including through surgery. However, until the 1950s there was no agreed model on how to approach the subject.<sup>5</sup>

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3 Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority, and Lived Experience*, Duke University Press, Durham, 2008, pp 36–38; Heino F.L. Meyer-Bahlburg, 'Gender assignment and reassignment in intersexuality: controversies, data, and guidelines for research', in Zderic *et al* (eds), *Pediatric Gender Assignment: A Critical Reappraisal*, Kluwer Academic / Plenum Publishers, 2002, pp 199–200; Lisa Brinkmann, Karsten Schuetzmann and Hertha Richter-Appelt, 'Gender Assignment and Medical History of Individuals with Different Forms of Intersexuality: Evaluation of Medical Records and the Patients' Perspective', *J Sex Med*, Vol. 4, 2007, p. 965.

4 Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority, and Lived Experience*, Duke University Press, Durham, 2008, pp 38–40.

5 Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority, and Lived Experience*, Duke University Press, Durham, 2008, pp 43–47; Georgiann Davis, "'DSD is a perfectly fine term': reasserting medical authority through a shift in intersex terminology', *Advances in Medical Sociology*, Vol. 12, 2011, p. 160.

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### *The 'optimal gender policy'*

3.7 The committee was advised that surgery as a standard response to intersexuality commenced in the mid–20th century.<sup>6</sup> The advent of 'normalising' surgery coincided with, and was supported by, the development of the 'optimal gender policy', under which intersex children were 'assigned' a gender in infancy. The policy was the result of research published in the 1950s through to the early 1980s by Dr John Money. The Australian Human Rights Commission provided the following summary of Dr Money's theory:

In the 1950s, Dr John Money, a psychologist, believed that children are born without a fixed gender identity. According to this view, it was possible to make the genitalia appear male or female and the child could then be raised as a boy or a girl. Parents and the child were told little about the surgery and treatment to avoid psychological trauma.<sup>7</sup>

3.8 As the Swiss National Advisory Commission on Biomedical Ethics has commented, normalisation surgery was one part of imposing a gendered identity on an infant. A form of social engineering, the surgery assigned to an infant a socially standardised gender category of either male or female:

Until the end of the 20th century, in line with the 'optimal gender policy' advocated by John Money (1955), a child with a DSD was generally assigned a gender at an early age. The child's body was surgically aligned with the assigned gender in the first months and years of its life...The child was then to be consistently reared in the surgically assigned gender role, without it (or the family) being informed about its differences or the reasons for the interventions. Secrecy was maintained even into adulthood. It was believed this approach would enable the child have a 'normal' physical and psychosexual development.<sup>8</sup>

3.9 Reviewing the history of gender assignment theory, Meyer-Bahlberg explained optimal-gender policy in more sophisticated terms:

The question the optimal-gender policy asks at birth is not: "Is this a boy or a girl?", but rather: "Will this child have a better chance for a reasonable life as a male or a female?" Thus, the basis for the gender-assignment decision is what one can predict in infancy, given the child's particular syndrome and its severity, and given all that is known about the natural history of the condition and its treatment options. Under this policy, early surgery of the external genitalia is recommended to avoid discrepancies between the child's assigned gender and genital appearance and thereby, to facilitate consistent sex-typing by the parents and others.

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6 Ms Bonnie Hart, President, Androgen Insensitivity Syndrome Support Group Australia, *Committee Hansard*, 28 March 2013, p. 7.

7 Australian Human Rights Commission, *Surgery on intersex infants and human rights*, 2009, p. 6.

8 Swiss National Advisory Commission on Biomedical Ethics, *On the management of differences of sex development: Ethical issues relating to the intersexuality*, Opinion No. 20/2012, November 2012, p. 8.

...even where there is a local consensus to follow the optimal-gender policy, decision making in the individual case can be difficult, because the prognostic criteria are not necessarily more definitive than the sex-diagnostic ones.<sup>9</sup>

3.10 Meyer-Bahlberg noted that Money's own theories around intersex did evolve over time, leading to rejection of the idea that an infant was a 'blank slate' who could be assigned any gender successfully.<sup>10</sup> Thus, while 'optimal gender' theory began emphasising 'nurture', it evolved to take account of aspects such as the pre- and post-natal influence of hormones. However, the options for surgical normalisation loomed large in decision making. As the Australian Paediatric Endocrine Group (APEG) explained to the committee:

In the past, it was thought that adequate penis size was the main determinant of whether an infant with ambiguous genitalia should be assigned male or female at birth. Following gender assignment, surgery was performed to normalise the appearance of the external genitalia, and to remove testes in children raised female.<sup>11</sup>

3.11 Under the approach taken by Money and others, treatment guidelines were developed. These included:

- Extensive and fast diagnostic of the intersexual state.
- Early sex-assignment (before 18 months) and consequent rearing.
- Early medical correction of the ambivalent genitalia to secure the chosen sex assignment and to avoid the risk of insecurities regarding gender identity and psychological distress.
- In cases of female sex assignment: early removal of the gonads to avoid masculinization during puberty.
- Hormone substitution at time of puberty according to the sex-assignment.
- No disclosure to social environment regarding the intersexual state of the child.<sup>12</sup>

3.12 Professor Sarah Creighton is a gynaecologist who has conducted extensive research in the field. Discussing the reasons behind surgery on infants who are

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9 Heino F.L. Meyer-Bahlburg, 'Gender assignment and reassignment in intersexuality: controversies, data, and guidelines for research', in Zderic *et al* (eds), *Pediatric Gender Assignment: A Critical Reappraisal*, Kluwer Academic / Plenum Publishers, 2002, p. 200.

10 Heino F.L. Meyer-Bahlburg, 'Gender assignment and reassignment in intersexuality: controversies, data, and guidelines for research', in Zderic *et al* (eds), *Pediatric Gender Assignment: A Critical Reappraisal*, Kluwer Academic / Plenum Publishers, 2002, p. 201.

11 Australian Paediatric Endocrine Group, *Submission 88*, p. 2.

12 Lisa Brinkmann, Karsten Schuetzmann and Hertha Richter-Appelt, 'Gender Assignment and Medical History of Individuals with Different Forms of Intersexuality: Evaluation of Medical Records and the Patients' Perspective', *J Sex Med*, Vol. 4, 2007, p. 965.

genetically female but have some male characteristics (referred to as virilisation), Creighton argued:

The traditional management of the virilised female infant has centred on restoring 'normality'. Once the diagnosis has been made and the infant assigned to a female sex of rearing, feminizing genital surgery almost inevitably follows...Proponents of feminizing genitoplasty in infancy cite the following as reasons to operate:

- a more stable development of gender identity;
- a better psychosexual and psychosocial outcome;
- relief of parental anxiety;
- provision of a vaginal introitus for psychological relief;
- menstruation and intercourse in adolescence and adulthood.

There is often an unstated assumption in some of the literature promoting infant vaginoplasty that by performing the surgery in infancy the child can be 'cured' and spared the potential psychological trauma of surgery in later childhood or adolescence.<sup>13</sup>

3.13 As APEG observed, infant surgery was performed on the understanding that this would 'allow the child to develop without the psychosocial stigma or distress which is associated with having genitalia incongruous with the sex of rearing'.<sup>14</sup>

#### ***Criticisms of the 'optimal gender policy'***

3.14 In the 1990s and early 2000s, there was a wide range of criticisms levelled at the prevailing practices of medical treatment of intersex. These criticisms have come from several different points of view.<sup>15</sup>

3.15 Some intersex people were critical of the medical process under which they had been treated without themselves being involved or giving consent. They considered that they had been 'wronged by medical management', with problems such as inappropriate sex assignment, and surgical treatment that impaired sexual function.<sup>16</sup> APEG outlined what happened:

some individuals who were assigned female but later identified as male and who had tissue removed from their clitoris/phallus, as well as those who continued to identify as female but feel they have poor genital outcomes

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13 S.M. Creighton, 'Long-term outcome of feminization surgery: the London experience', *British Journal of Urology International*, Vol. 93, Supplement 3, 2004, p. 44.

14 Australasian Paediatric Endocrine Group, *Submission 88*, p. 5.

15 Heino F.L. Meyer-Bahlburg, 'Gender assignment and reassignment in intersexuality: controversies, data, and guidelines for research', in Zderic *et al* (eds), *Pediatric Gender Assignment: A Critical Reappraisal*, Kluwer Academic / Plenum Publishers, 2002, p. 201.

16 Heino F.L. Meyer-Bahlburg, 'Gender assignment and reassignment in intersexuality: controversies, data, and guidelines for research', in Zderic *et al* (eds), *Pediatric Gender Assignment: A Critical Reappraisal*, Kluwer Academic / Plenum Publishers, 2002, p. 202.

following removal of tissue from the enlarged clitoris, are angry about surgery which was performed in their childhood. These concerns were brought into the public and policy spotlight by patient support groups...<sup>17</sup>

3.16 Researcher Katrina Karkazis recounts a speech given in 2000 by leading American intersex activist Cheryl Chase:

Doctors, she argues, do not understand female sexuality, think homosexuality is a failure of treatment, refuse to refer families to therapists and social workers, and encourage parents never to discuss the diagnosis with others or the child, thus instilling extraordinary shame in parents (and hence the child) about the condition. Focused on normalising infants, she notes, doctors have failed to ask what intersex individuals themselves want. Early genital surgery, she says, is intersex genital mutilation...<sup>18</sup>

3.17 The activist community protested at medical conferences and meetings, opposing unnecessary surgical intervention, and were highly critical of the secrecy that sometimes led people to find out about their intersex nature by accident during adolescence or adulthood.<sup>19</sup>

3.18 The legal and ethical basis for medical intervention was questioned. Feminist author Alice Dreger wrote at the time:

It is not at all clear if all or even most of the intersex surgeries done today involve what would legally and ethically constitute informed consent. It appears that few intersexuals or their parents are educated, before they give consent, about the anatomically strict psychosocial model employed...

At a finer level, many of the latest particular cosmetic surgeries being used on intersexed babies and children today remain basically unproven as well, and need to be described as such in consent agreements.<sup>20</sup>

3.19 Another reason that the 'optimal gender' approach was criticised was that some researchers believed it neglected biological influences on sex and gender, including the role of sex hormones. Prominent among these critics have been Milton Diamond, whose work began in studies of animal and human sexual development; and William Reiner, who has worked with a range of patients both intersex and not.

3.20 Reiner, in a number of studies, found that a large proportion of individuals in cases of cloacal exstrophy, gonadal dysgenesis and partial androgen insensitivity

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17 Australian Paediatric Endocrine Group, *Submission 88*, p. 2.

18 Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority, and Lived Experience*, Duke University Press, Durham, 2008, p. 2.

19 Georgiann Davis, "'DSD is a perfectly fine term": reasserting medical authority through a shift in intersex terminology', *Advances in Medical Sociology*, Vol. 12, 2011, pp 162–172.

20 Alice Domurat Dreger, 'Ambiguous Sex'—or Ambivalent Medicine? Ethical Problems in the Treatment of Intersexuality, *The Hastings Center Report*, Vol. 28, No. 3, 1998, p. 32.

syndrome did not accept their male sex assignment.<sup>21</sup> His research led him to conclude that the effects of hormones during pregnancy 'appeared to dramatically increase the likelihood of recognition of male sexual identity independent of sex-of-rearing'.<sup>22</sup>

3.21 In the mid-2000s, Tom Mazur also examined the relationship between sex assignment and adult gender identification. He examined the extent to which individuals with CAIS, PAIS, or micropenis 'reassigned themselves from their initial gender assignment'. Although he concluded that self-initiated gender reassignment was 'rare',<sup>23</sup> it in fact occurred in ten per cent of cases. More significantly, most people in his sample had not had a gender reassignment by doctors after their birth. Among those few who *had* experienced a reassignment by doctors, those with PAIS appeared to relatively frequently reject<sup>24</sup> that reassignment later in their lives. Nevertheless, samples were small, the follow-up age of subjects was sometimes too young for conclusions to be drawn (as Mazur himself noted)<sup>25</sup> and thus, despite the analysis, outcomes were unclear.

3.22 The views of intersex people about their medical treatment have also challenged medical treatment approaches. Meyer-Bahlburg and others analysed 72 questionnaire responses from intersex persons, concerning satisfaction with their gender, genital status and sexual functioning, and questions about their views about the optimal age for surgical intervention, and whether there should be a third gender category. Most respondents were satisfied with their gender, however most supported some limits on the age at which surgery should occur, a third of the respondents indicated surgery should not occur until the person was an adult and could give their consent, and less than half indicated they were 'mainly satisfied' with their sexual functioning.<sup>26</sup>

3.23 It was recognised that long-term studies in the area were few in number and did not produce consistent results. On the one hand, Creighton surveyed a range of literature and reported on outcome studies of a patient cohort at University College

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- 21 W.G. Reiner, 'Psychosexual development in genetic males assigned female: the cloacal exstrophy experience', in M. Diamond and A. Yates (eds), *Child and adolescent psychiatric clinics of North America: sex and gender*, Vol. 13, 2004, pp 657–674; William G. Reiner, 'Gender identity and sex-of-rearing in children with disorders of sexual differentiation', *Journal of Pediatric Endocrinology and Metabolism*, Vol. 18, 2005, pp 549–553.
- 22 William G. Reiner, 'Gender identity and sex-of-rearing in children with disorders of sexual differentiation', *Journal of Pediatric Endocrinology and Metabolism*, Vol. 18, 2005, p. 549.
- 23 Tom Mazur, 'Gender dysphoria and gender change in androgen insensitivity or micropenis', *Archives of Sexual Behavior*, Vol. 34, No. 4, 2005, p. 411.
- 24 Three out of 11 cases in Mazur's study.
- 25 Tom Mazur, 'Gender dysphoria and gender change in androgen insensitivity or micropenis', *Archives of Sexual Behavior*, Vol. 34, No. 4, 2005, p. 419.
- 26 H.F.L. Meyer-Bahlburg, C.J. Migeon, G.D. Berkovitz, J.P. Gearhart, C.Dolezal and A.B. Wisniewski, 'Attitudes of adult 46,XY intersex persons to clinical management policies', *Journal of Urology*, Vol. 171, 2004, pp 1615, 1617.

London Hospital. Her paper reported widespread complications and negative outcomes, including impairment on several measures in those intersex women who had undergone genital surgery.<sup>27</sup> She concluded:

Surgery has been regarded as the cornerstone of treatment for virilised female infants and parents... However, there is very scanty evidence of a satisfactory postpubertal cosmetic or anatomical outcome... In the absence of firm evidence that infant feminizing genital surgery benefits psychological outcome, then the option of no infant genital surgery must be discussed with the family... The current management of affected patients and their families is difficult and no consensus amongst clinicians has yet been reached.<sup>28</sup>

3.24 On the other hand another team of researchers analysing information on a different group of intersex individuals reached a quite different conclusion:

All participants in this survey who had genital reconstructive surgery had it in infancy or early childhood. In the absence of compelling evidence that deferred surgery would have yielded better outcomes, these results support continuation of the practice of early genital reconstructive surgery for ambiguous genitalia, provided that every attempt has been made to reach a definitive [determination of the cause].<sup>29</sup>

3.25 At an American Academy of Pediatrics conference in the late 1990s, the clinical criticisms made by Diamond and others led to a suggestion for new restrictions on 'the medical management of Differences in Sex Development':

Recommendation 1

There should be a general moratorium on sex assignment cosmetic surgery when it is done without the consent of the patient

Recommendation 2

This moratorium should not be lifted unless and until complete and comprehensive retrospective studies are done and it is found that the outcomes of past interventions have been positive

Recommendation 3

Efforts should be made to undo the effects of past physician deception and secrecy.<sup>30</sup>

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27 S.M. Creighton, 'Long-term outcome of feminization surgery: the London experience', *British Journal of Urology International*, Vol. 93, Supplement 3, 2004; pp 44–46.

28 S.M. Creighton, 'Long-term outcome of feminization surgery: the London experience', *British Journal of Urology International*, Vol. 93, Supplement 3, 2004; pp 45–46.

29 Garry Warne, Sonia Grover, John Hutson and others, 'A long-term outcome study of intersex conditions', *Journal of Pediatric Endocrinology and Metabolism*, Vol. 18, No. 6, 2005, pp 555–567.

30 Milton Diamond, 'Clinical implications of the organizational and activational effects of hormones', *Hormones and Behavior*, Vol. 55, 2009, p. 625.

3.26 Although the first two of these three recommendations have not been adopted, the years leading up to 2006 saw a degree of change in the debate and some reform of treatment standards, culminating in the adoption in 2006 by medical specialists of what is known as the 'Consensus Statement on management of intersex disorders'.<sup>31</sup>

## Current approaches

### *The 2006 Consensus Statement*

3.27 Medical practitioners emphasised that the medical response to intersex conditions has changed since the 1990s.<sup>32</sup> Endorsed by a group of medical specialists in 2006, the *Consensus Statement on Management of Intersex Disorders* is widely presented as current international best practice for the medical treatment of intersex. The statement was developed in response to patient advocacy, and advancements in diagnosis, surgical techniques and the field of psychology.<sup>33</sup>

3.28 The statement begins with the words: '[t]he birth of an intersex child prompts a long-term management strategy that involves myriad professionals'.<sup>34</sup> The statement, therefore, is built on the premise that intersex persons require medical attention and management. It concludes that the optimal treatment of intersex individuals will conform to five principles. These include the directive that 'all individuals should receive gender assignment'. The principles also include the caveat that 'gender assignment must be avoided before expert evaluation in newborns'.<sup>35</sup>

3.29 To avoid 'uncertainty [that] is stressful and unsettling for families', the Consensus Statement approves gender assignment in infancy. However, such assignment may not necessarily be surgical. The statement does not support

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31 Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes et al, 'Consensus Statement on Management of Intersex Disorders', *Paediatrics*, Vol. 118, No. 2, 2006. <http://pediatrics.aappublications.org/content/118/2/e488.full#xref-ref-2-1> (accessed 26 July 2013).

32 See, for example, Australian Paediatric Endocrine Group, *Submission 88*, p. 2; Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne, *Submission 92*, p. 3; Garry L. Warne and Jacqueline K. Hewitt, 'The medical management of disorders of sexual development', in John M. Hutson, Garry L. Warne and Sonia R. Grover (eds), *Disorders of Sex Development: An Integrated Approach to Management*, Springer-Verlag, Berlin, 2012, p. 159.

33 Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes et al, 'Consensus Statement on Management of Intersex Disorders', *Paediatrics*, Vol. 118, No. 2, 2006. <http://pediatrics.aappublications.org/content/118/2/e488.full#xref-ref-2-1> (accessed 26 July 2013).

34 Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes et al, 'Consensus Statement on Management of Intersex Disorders', *Paediatrics*, Vol. 118, No. 2, 2006. <http://pediatrics.aappublications.org/content/118/2/e488.full#xref-ref-2-1> (accessed 26 July 2013).

35 Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes et al, 'Consensus Statement on Management of Intersex Disorders', *Paediatrics*, Vol. 118, No. 2, 2006, <http://pediatrics.aappublications.org/content/118/2/e488.full#xref-ref-2-1> (accessed 26 July 2013).

normalising surgery in every case. It argues that such surgery should only occur for 'severe virilisation (Prader 3–5)', referring to three of the five degrees of virilisation recognised under the Prader scale.

3.30 The Consensus Statement cautions against surgery for purely cosmetic reasons. The emphasis is instead placed on 'functional outcome'.<sup>36</sup> It acknowledges that gender assignment may be determined according to medical and non-medical considerations:

The factors that influence gender assignment include diagnosis, genital appearance, surgical options, [the] need for lifelong replacement therapy, potential for fertility, views of the family, and sometimes, circumstances relating to cultural practice.<sup>37</sup>

3.31 The 2006 Consensus Statement does not prescribe the timeframe in which gender assignment surgery should occur. It does, however, provide general guidance on the factors that should be taken into account when determining when to proceed with surgery. The factors vary according to the particular intersex condition. For example, it is specified that '[v]aginal dilation should not be undertaken before puberty.' In contrast, for 'patients with androgen biosynthetic defects raised female, gonadectomy should be performed before puberty.'<sup>38</sup> Recommendations regarding the timing of surgery can therefore depend not only on the nature of the procedure but also on the assigned gender.

3.32 From a medical perspective, the statement draws conclusions about which gender assignment is more appropriate for some kinds of intersex conditions. It is asserted that 'more than 90% of patients with 46,XX CAH and all patients with 46,XY CAIS assigned female in infancy identify as females.' Accordingly, the statement concludes that there is medical evidence to support assigning a female gender appearance to 'markedly virilised 46,XX infants with CAH'.<sup>39</sup> The statement provides further guidance for other kinds of intersex conditions, including 5- $\alpha$ -reductase

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36 Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes et al, 'Consensus Statement on Management of Intersex Disorders', *Paediatrics*, Vol. 118, No. 2, 2006, <http://pediatrics.aappublications.org/content/118/2/e488.full#xref-ref-2-1> (accessed 26 July 2013).

37 Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes et al, 'Consensus Statement on Management of Intersex Disorders', *Paediatrics*, Vol. 118, No. 2, 2006. <http://pediatrics.aappublications.org/content/118/2/e488.full#xref-ref-2-1> (accessed 26 July 2013).

38 Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes et al, 'Consensus Statement on Management of Intersex Disorders', *Paediatrics*, Vol. 118, No. 2, 2006. <http://pediatrics.aappublications.org/content/118/2/e488.full#xref-ref-2-1> (accessed 26 July 2013).

39 Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes et al, 'Consensus Statement on Management of Intersex Disorders', *Paediatrics*, Vol. 118, No. 2, 2006. <http://pediatrics.aappublications.org/content/118/2/e488.full#xref-ref-2-1> (accessed 26 July 2013).

(5 $\alpha$ RD2)-deficiency, 17 $\beta$ -hydroxysteroid dehydrogenase deficiencies and partial androgen insensitivity syndrome.<sup>40</sup>

3.33 Reflecting the strong belief in 'normalising' sex, the likelihood of achieving a standardised physical appearance is listed as one of the factors for practitioners to consider in sex allocation. For example, in relation to a person with an intersex condition associated with abnormalities of the penis (hypospadias), the statement makes the following observation:

The magnitude and complexity of phalloplasty in adulthood should be taken into account during the initial counselling period if successful gender assignment depends on this procedure. At times, this may affect the balance of gender assignment. Patients should not be given unrealistic expectations.<sup>41</sup>

3.34 Referring to broader 'surgical management' procedures, as opposed to gender assignment procedures, it is noted that practitioners should 'consider options that will facilitate the chances of fertility'.<sup>42</sup>

***Victoria's 'Decision-making principles for the care of infants, children and adolescents with intersex conditions'***

3.35 During the inquiry, the committee's attention was drawn to the recent development of good practice guidelines in Victoria.<sup>43</sup> The committee understands these to be the only detailed public guidelines of their type in Australia. In February 2013, the Victorian Department of Health issued the *Decision-making principles for the care of infants, children and adolescents with intersex conditions*. The resource document, which seeks to guide health professionals to achieve the 'best possible outcomes' for children with intersex conditions, is based on the principles endorsed in the 2006 Consensus Statement. The Victorian Government intends that the decision-making framework will be applied in all intersex cases in Victorian hospitals. However, the framework is not intended to provide directives or clinical protocols about individual cases.<sup>44</sup> While not providing directives in every case, the document

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40 Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes et al, 'Consensus Statement on Management of Intersex Disorders', *Paediatrics*, Vol. 118, No. 2, 2006. <http://pediatrics.aappublications.org/content/118/2/e488.full#xref-ref-2-1> (accessed 26 July 2013).

41 Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes et al, 'Consensus Statement on Management of Intersex Disorders', *Paediatrics*, Vol. 118, No. 2, 2006. <http://pediatrics.aappublications.org/content/118/2/e488.full#xref-ref-2-1> (accessed 26 July 2013).

42 Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes et al, 'Consensus Statement on Management of Intersex Disorders', *Paediatrics*, Vol. 118, No. 2, 2006. <http://pediatrics.aappublications.org/content/118/2/e488.full#xref-ref-2-1> (accessed 26 July 2013).

43 Organisation Intersex International, *Submission 23.1*.

44 Victorian Department of Health, *Decision-making principles for the care of infants, children and adolescents with intersex conditions*, February 2013, p. iii; 3; tabled by Organisation Intersex International Australia, 28 March 2013.

does record the government's intention that in all cases the principles will be applied robustly, transparently and consistently.<sup>45</sup>

3.36 Like the 2006 Consensus Statement, the Victorian Department of Health has endorsed five medical management principles.

- Gender assignment must be avoided before expert evaluation in newborns.
- Evaluation and long-term management must be carried out in a centre with an experienced multidisciplinary team.
- All individuals should receive gender assignment.
- Open communication with patients and families is essential, and participation in decision-making is encouraged.
- Patient and family concerns should be respected and addressed in strict confidence<sup>46</sup>

3.37 The Victorian decision-making guide expressly states that gender assignment 'does not necessitate surgery or other medical treatment.'<sup>47</sup> It also cautions against allowing a sense of urgency to outweigh the need to gather information to make robust, transparent and consistent decisions. It does, however, take the position that gender assignment is 'best practice in most cases'.<sup>48</sup>

3.38 The medical management principles are drawn from the 2006 Consensus Statement. However, unlike the Consensus Statement, the principles are only one part of a broader decision-making framework. The Victorian guide goes beyond the 2006 Consensus Statement by endorsing a set of ethical principles, human rights principles, principles for supporting parents and patients, and legal principles. Along with the medical management principles, these principles apply to decision-making about the health care of intersex infants, children and adolescents in Victoria.

3.39 The endorsed human rights principles reflect the Victorian Charter of Human Rights and relevant international law. The ethical principles are as follows:

To act in the best interests of the patient, decisions should be tested against the ethical principles developed by Gilliam, Hewitt and Warne (2010; 2012), including:

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45 Victorian Department of Health, *Decision-making principles for the care of infants, children and adolescents with intersex conditions*, February 2013, p. 7; tabled by Organisation Intersex International Australia, 28 March 2013.

46 Victorian Department of Health, *Decision-making principles for the care of infants, children and adolescents with intersex conditions*, February 2013, p. 4; tabled by Organisation Intersex International Australia, 28 March 2013.

47 Victorian Department of Health, *Decision-making principles for the care of infants, children and adolescents with intersex conditions*, February 2013, p. 4; tabled by Organisation Intersex International Australia, 28 March 2013.

48 Victorian Department of Health, *Decision-making principles for the care of infants, children and adolescents with intersex conditions*, February 2013, p. 15; tabled by Organisation Intersex International Australia, 28 March 2013.

- minimise physical risk to the child
- minimise psychosocial risk to the child
- preserve potential for fertility
- preserve or increase capacity to have satisfying sexual relations
- leave options open for the future
- consider parents' wishes
- take into account the views of the child.<sup>49</sup>

3.40 Seven principles for supporting patients and parents are outlined, which recommend ongoing medical follow-up and psychological support for patients and their families. The principles are:

- honest and complete disclosure of the diagnosis, risks, options, issues and treatments
- sufficient time and opportunity for discussion of all options for healthcare and a balanced review of risks and benefits
- intensive support, education and counselling during the decision-making phase
- standardised, age-appropriate resources for parents, children and adolescents that provide education about sex and gender diversity
- information about, and referral to, support groups for both parents/families, and the patient
- assistance for parents with informing their child in stages about their condition, and with seeking their child's consent for any medical or surgical intervention
- ongoing follow up and referral to psychological support for patients and their parents throughout the patient's life.<sup>50</sup>

3.41 In addition to outlining a set of decision-making principles, the framework document also recommends hospitals develop multidisciplinary specialised advisory groups underpinned by processes, policies and procedures to guide clinicians on when and how to use the advisory groups. It is also contemplated that such groups will

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49 Victorian Department of Health, *Decision-making principles for the care of infants, children and adolescents with intersex conditions*, February 2013, p. 5; tabled by Organisation Intersex International Australia, 28 March 2013.

50 Victorian Department of Health, *Decision-making principles for the care of infants, children and adolescents with intersex conditions*, February 2013, p. 4.

facilitate consultation and discussion between Victorian practitioners.<sup>51</sup> Victorian hospitals are also encouraged to engage with intersex support groups.<sup>52</sup>

3.42 The Victorian guide acknowledges that normalising surgery is a controversial practice:

Most of the international debate about the healthcare of intersex conditions has been concerned with the ethics of performing genital surgery on infants and children. Generally, the focus of concern is not on medically necessary treatment done to avoid physical harm that is proportionate to the level of physical risk that the condition poses to the patient (for example, ensuring a functioning urinary system). The focus of concern is in cases where treatments for cosmetic effect are carried out for conditions that pose little or no physical risk to the patient (for example, to ‘normalise’ the person’s body to make it look more typically male or female).

Treatments where the medical imperative for intervention is not obvious include those performed to protect against potential psychosocial stress associated with ‘looking different’ and being known by others to look different.<sup>53</sup>

3.43 The document does not explicitly recommend against normalising surgery during childhood. However it makes a number of points that support great caution, including:

- Putting particular emphasis on the fact that assigning gender does not necessitate surgery or other treatment;
- Indicating that keeping open future options is an important factor in considering treatment decisions; and
- Indicating that delaying treatment may be in the patient's best interest.<sup>54</sup>

3.44 OII Australia argued that the Victorian decision-making guide leaves open the possibility of non-therapeutic, purely cosmetic gender assignment surgery.<sup>55</sup>

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51 Victorian Department of Health, *Decision-making principles for the care of infants, children and adolescents with intersex conditions*, February 2013, p. 7; tabled by Organisation Intersex International Australia, 28 March 2013.

52 Victorian Department of Health, *Decision-making principles for the care of infants, children and adolescents with intersex conditions*, February 2013, p. 8; tabled by Organisation Intersex International Australia, 28 March 2013.

53 Victorian Department of Health, *Decision-making principles for the care of infants, children and adolescents with intersex conditions*, February 2013, pp 21–22; tabled by Organisation Intersex International Australia, 28 March 2013.

54 Victorian Department of Health, *Decision-making principles for the care of infants, children and adolescents with intersex conditions*, February 2013, pp 5, 14–15.

55 Morgan Carpenter, Secretary, Organisation Intersex International Australia, Committee Hansard, 28 March 2013, p. 2; Organisation Intersex International Australia, *Submission 23.1*, pp 5–6.

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### *Evidence on current practice*

3.45 Evidence before the committee provided some support for the general statement that 'there is now a slower and more judicious approach to the decision to perform sex-assignment surgery'.<sup>56</sup> However, change is uneven, and surgery of this type is still occurring in infancy and childhood.

3.46 Commenting on international practice, APEG indicated that there are no clear guidelines on the timing of cosmetic surgery:

International medical guidelines exist to define the level of genital ambiguity at which surgery is indicated, however the guidelines state that the optimal timing of surgery remains debatable. This is because there is a lack of strong evidence to either support or refute specific recommendations on timing. According to current consensus guidelines, surgery for the purposes of appearance can ideally be recommended either during infancy, or later at the time of adolescence, when the child can be involved in the decision to operate.<sup>57</sup>

3.47 As the following advice from APEG highlights, there is disagreement among the community about the time to perform gender reassignment surgery:

[T]here can be spontaneous reduction in the size of the clitoris with adequate hormone replacement therapy, and some specialists recommend that surgery be delayed until no further shrinkage is expected, before considering any surgery to further reduce size. In some cases, with adequate hormone treatment, there can be enough natural regression in size during infancy such that surgery is not indicated any more. However, other specialists argue that very early surgery in the first months of life is optimal, and that there is no need to wait for any natural regression in clitoral size.<sup>58</sup>

3.48 Cosmetic surgery continues to be performed on children who are intersex.<sup>59</sup> The National LGBTI Health Alliance cited the results of a survey of practitioners who attended the 2011 IVth World Congress of the International Society on Hypospadias and Disorders of Sex Development, which found that 78 per cent of the practitioners surveyed preferred normalising surgery to be performed before the child is two years old.<sup>60</sup>

3.49 Early surgery appears to be prevalent for two of the main forms of intersex. In a 2012 chapter surveying outcomes of treatment of intersex, Warne notes that

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56 Milton Diamond and Hazel G. Beh, 'Changes in the management of children with intersex conditions', *Nature Clinical Practice Endocrinology and Metabolism*, Vol. 4, No. 1, 2008, pp 4–5.

57 Australasian Paediatric Endocrine Group, *Submission 88*, p. 5.

58 Australasian Paediatric Endocrine Group, *Submission 88*, p. 5.

59 Georgiann Davis, "'DSD is a perfectly fine term": reasserting medical authority through a shift in intersex terminology', *Advances in Medical Sociology*, Vol. 12, 2011, p. 176.

60 National LGBTI Health Alliance, *Submission 60.2*, p. 2.

childhood removal of testes from women with Complete Androgen Insensitivity Syndrome 'is still common practice'.<sup>61</sup> In 2013, presenting information about the treatment of congenital adrenal hyperplasia, Hewitt reported research that indicated almost all Australian and New Zealand respondents to an Australasian Paediatric Endocrine Group recommended genital surgery in cases of virilised genitals, though not all supported this surgery being timed to occur in infancy.<sup>62</sup>

3.50 The Disorder of Sex Development multidisciplinary team at the Royal Children's Hospital, Melbourne advised that decisions about surgical alteration are not made rapidly, but are the subject of careful multidisciplinary consideration. The following illustration regarding gonadectomies was provided:

In the past, a decision regarding gonadectomy may have been made reasonably rapidly...Today, the pathway is far more careful as it is recognised that some individuals with a DSD may want to change their gender identity or wish to identify as indeterminate or intersex...The decision-making process takes time and thus any decision regarding possible gonadectomy would not be made until an informed and considered decision can be made by the person themselves.<sup>63</sup>

3.51 The Melbourne multidisciplinary team did not support general postponement of gender assignment surgeries. It argued that there may be a place for surgery during childhood, as delay may not be appropriate. The team defended early surgery in part on the basis of a lack of evidence of the advantages of delay, though conceding there is no evidence in relation to females:

Although there is no direct evidence regarding the timing of genital surgery in girls, there is evidence from studies on boys. These report better self-esteem and body image, and more positive attitudes towards intimate relationships in adolescents and young men if their genital surgery is completed before the age of 3 years, compared to surgery in mid-childhood. Although some people advocate leaving all genital surgery till later when the person can consent themselves to the procedure, there are no studies to demonstrate a comparison of outcomes with this greater delay.<sup>64</sup>

3.52 The multidisciplinary team described one of the issues with delayed action to undertake gonadectomy:

The potential difficulty with this more conservative approach is that for some young people (e.g. those who definitely identify as female and do not

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61 Garry L. Warne, 'Long-term outcomes of disorders of sexual development (DSD): a world view', in John M. Hutson, Garry L. Warne and Sonia R. Grover (eds), *Disorders of Sex Development: An Integrated Approach to Management*, Springer-Verlag, Berlin, 2012, p. 283.

62 Jacqueline Hewitt, 'Management of virilisation in CAH: where to from here?', Australasian Paediatric Endocrine Group Annual Scientific Meeting, Sydney 2013.

63 Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne, *Submission 92*, p. 5.

64 Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne, *Submission 92*, p. 6.

wish to retain their testes), the perceived delay in surgery and the associated need for gonadal surveillance (with ultrasound or MRI) can be very frustrating.<sup>65</sup>

3.53 There was a view among intersex support groups and representative organisations that medical practice has not materially evolved since Money's theories were first endorsed, and that normalising surgery remains a standard response to intersex conditions. OII Australia submitted that rationales for normalisation surgery remain based on psychosocial theories that give primacy to the perceived need for others to see intersex people as 'normal':

Current protocols in Australia are still based on psychosocial adjustment: minimising family concern, and mitigating the risks of stigmatisation due to physical difference.<sup>66</sup>

3.54 The National LGBTI Health Alliance agreed, submitting that normalising procedures are 'a standard medical practice in Australia and elsewhere today'.<sup>67</sup>

### **What are the problems with current practice?**

#### *There is a weak evidence base for surgery on infants or young children*

3.55 Several witnesses to the inquiry argued that surgery to render genitals 'normal', or consistent with an assigned sex, was problematic and not well-supported by evidence. Indeed, as noted above, this point appeared to be conceded, at least in relation to females, by specialists in the field.<sup>68</sup> Intersex support organisations and representatives reported that sex assignment surgery, particularly if conducted in infancy, causes ongoing medical complications. As the National LGBTI Health Alliance submitted, normalising surgeries are 'creating a sickness when there was no sickness'.<sup>69</sup> Reported physical complications include insensate genitalia, reduced sexual enjoyment, sterilisation, scarification and osteoporosis.<sup>70</sup>

3.56 Potential problems with early normalising surgery are confirmed in the literature. As the 2006 Consensus Statement acknowledges, there is little evidence to support the argument that early intervention provides the best outcome for intersex children:

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65 Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne, *Submission 92*, p. 5.

66 Organisation Intersex International Australia, *Submission 23*, p. 7.

67 National LGBTI Health Alliance, *Submission 60.2*, p. 2.

68 Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne, *Submission 92*, p. 6.

69 Mr Gavi Ansara, Health Policy Officer, National LGBTI Health Alliance, *Committee Hansard*, p. 6.

70 Androgen Insensitivity Syndrome Support Group Australia, *Submission 54*, pp. 3–4; National LGBTI Health Alliance, *Submission 60.2*, p. 2; Organisation Intersex International Australia, *Submission 23*, p. 6.

It is generally felt that surgery that is performed for cosmetics reasons in the first year of life relieves parental distress and improves attachment between the child and the parents; the systematic evidence for this belief is lacking.<sup>71</sup>

3.57 The statement acknowledges that data on long-term outcomes for children subject to gender assignment surgery is inconclusive. The statement also recognises that 'there are no controlled clinical trials of the efficacy of early (<12 months of age) versus late (in adolescence and adulthood) surgery or the efficacy of different techniques'. It is also claimed that analysis of long-term outcomes is difficult, 'complicated by a mixture of surgical techniques and diagnostic categories'. Accordingly, the Consensus Statement recommends that future studies use standardised assessment tools, be prospective in nature, and be designed to avoid selection bias.<sup>72</sup>

3.58 In evidence before the committee, the lack of data was acknowledged by representatives of the medical community. For example, APEG observed:

There is limited evidence reporting long-term outcomes of early surgical management for reasons of appearance. The few outcome studies reported have conflicting results of good and poor outcomes (cosmetic, sexual or psychological).<sup>73</sup>

3.59 The absence of conclusive evidence was also the subject of comment by intersex representative organisations. A Gender Agenda advised that a review of existing studies found:

[T]here are no publications of evidence of the association between genital surgery and improved psychosocial outcome. There is also no evidence that surgery promotes a stable gender identity development or that gender will develop as assigned.<sup>74</sup>

3.60 OII identified an additional reason for the difficulties experienced in obtaining data about outcomes for intersex children, submitting that gender assignment conceals a person's intersex identity:

There is a paucity of data on the impact of surgery on adults, and few long term studies: for example, intersex is erased from official documentation

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71 Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes et al, 'Consensus Statement on Management of Intersex Disorders', *Paediatrics*, Vol. 118, No. 2, 2006. <http://pediatrics.aappublications.org/content/118/2/e488.full#xref-ref-2-1> (accessed 26 July 2013).

72 Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes et al, 'Consensus Statement on Management of Intersex Disorders', *Paediatrics*, Vol. 118, No. 2, 2006, <http://pediatrics.aappublications.org/content/118/2/e488.full#xref-ref-2-1> (accessed 26 July 2013).

73 Australasian Paediatric Endocrine Group, *Submission 88*, p. 4.

74 A Gender Agenda, *Submission 85*, p. 5; the submission does not provide details of the authors, title or publication date of the journal article in which the review findings are published.

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through the assignment of a binary sex of rearing. We have seen no long term studies within Australia.<sup>75</sup>

3.61 The committee considered some of the main studies that were drawn to its attention.

3.62 Since the 2006 Consensus Statement, there have been a few further studies of the outcome of gender normalising and surgical practices. Some studies of adults who have received treatment for intersex 'disorders' reveal a high level of dissatisfaction with one or more aspects of their experience though, as with most aspects of research in the area of intersexuality, sample sizes tend to be small. There are two broad areas of investigation: satisfaction with the assigned gender; and functional outcomes (such as whether intercourse is comfortable or painful, or whether the person is satisfied with their sexual arousal and experience).

3.63 In 2008, Crouch and others reported a study of sexual function and genital sensitivity for intersex women with CAH.<sup>76</sup> The researchers studied 28 intersex women, 24 of whom had undergone genital surgery, and ten controls (that is, women without CAH). The results showed that, both on clitoral sensitivity and sexual function, the women who had surgery reported less sensitivity, and poorer sexual function than either those who had not had surgery, or the controls. The authors concluded that 'genital sensitivity is impaired in areas where feminizing genital surgery had been done', and that more attention should be paid to the concerns of recipients of surgery.<sup>77</sup> The committee was advised, however, that other studies produced different results.<sup>78</sup>

3.64 Brinkmann and others surveyed and assessed 37 intersex people with varying conditions, and found that:

over 60% of the participants show significant psychological distress, despite the fact that all were treated according to the "optimal gender policy" to avoid psychological distress which might result through ambiguous physical appearance.<sup>79</sup>

3.65 A more detailed analysis in 2009 involving the same study led the authors to suggest the possibility:

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75 Organisation Intersex International Australia, *Submission 23*, p. 14.

76 Naomi S. Crouch, Lih Mei Liao, Christopher R.J. Woodhouse, Gerard S. Conway and Sarah M. Creighton, 'Sexual function and genital sensitivity following feminizing genitoplasty for congenital adrenal hyperplasia', *Journal of Urology*, Vol. 179, 2008, pp 634–638.

77 Naomi S. Crouch, Lih Mei Liao, Christopher R.J. Woodhouse, Gerard S. Conway and Sarah M. Creighton, 'Sexual function and genital sensitivity following feminizing genitoplasty for congenital adrenal hyperplasia', *Journal of Urology*, Vol. 179, 2008, pp 634, 638.

78 Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne, *Submission 92*, p. 6.

79 Lisa Brinkmann, Karsten Schuetzmann and Hertha Richter-Appelt, 'Gender Assignment and Medical History of Individuals with Different Forms of Intersexuality: Evaluation of Medical Records and the Patients' Perspective', *J Sex Med*, Vol. 4, 2007, p. 977.

that psychological distress, especially interpersonal insecurities, suicidal tendencies, and self-harming behaviour, are more frequent in [disorders of sexual development] than generally assumed...<sup>80</sup>

3.66 A separate 2012 study of people with a range of forms of intersex, including CAIS, PAIS and gonadal dysgenesis, examined patient satisfaction with genital surgery and sexual life as adults. It found very high levels of dissatisfaction and medical complications. Around half those subjects who received feminising surgery were dissatisfied with the results of surgery and with their experience of clitoral arousal. Issues with sex life, sexual anxieties, and painful intercourse were prevalent among the group.<sup>81</sup>

3.67 Studies involving a group of Melbourne-based researchers who also contributed to the current inquiry showed more positive results in relation to satisfaction with assigned gender. They concluded in one paper that 'cosmetic and anatomic outcomes of surgery for ambiguous genitalia were generally good when undertaken by pediatric surgeons with specific expertise in intersex surgery'.<sup>82</sup>

3.68 Despite these positive results, their survey of the literature identified lower rates of success reported elsewhere:

A long-term outcome study of 50 patients aged 18–32 years who had been treated in Melbourne when they were children showed that mental and physical health outcomes were as good for most of the DSD patients as for those in two control groups; however, there was a small minority of patients whose gender identity as adults was a source of such profound discomfort that they felt compelled to undergo treatment to change it. Clearly, this is unsatisfactory, and management practices have been reviewed internationally by clinicians looking for ways of minimising the risk of making such mistakes about gender assignment.

The main problem relates to feminising genitoplasty,<sup>83</sup> which involves the removal of phallic erectile tissues and skin that cannot be replaced. This type of operation is considered appropriate for 46,XX girls with congenital

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80 Karsten Schuetzmann, Lisa Brinkmann, Melanie Schacht, and Hertha Richter-Appelt, 'Psychological Distress, Self-Harming Behavior, and Suicidal Tendencies in Adults with Disorders of Sex Development', *Arch Sex Behav*, Vol. 38, 2009, p. 32.

81 Birgit Kohler, Eva Kleinemeier, Anke Lux, Olaf Hiort, Annette Gruters, Ute Thyen, and the DSD Working Group, 'Satisfaction with genital surgery and sexual life of adults with XY disorders of sex development: results from the German clinical evaluation study', *Journal of Clinical Endocrinology and Metabolism*, Vol. 97, No. 2, 2012.

82 Wei Ling Lean, Aniruddha Deshpande, John Hutson, and Sonia R. Grover, 'Cosmetic and anatomic outcomes after feminizing surgery for ambiguous genitalia', *Journal of Pediatric Urology*, Vol. 40, No. 12, 2005, p. 1856.

83 'Surgery carried out to give genitalia that were originally ambiguous a more female appearance. Usually involves clitoral reduction (removal of erectile tissue) and surgery to create a vaginal opening separate from the urethra'.

adrenal hyperplasia,<sup>84</sup> who rarely identify as male when they are adults if they are treated with appropriate hormones to maintain androgen suppression from soon after birth and throughout childhood.

However, feminising genitoplasty is much more of a problem in patients with a Y chromosome. For example, in one study of 14 adult patients with genetically confirmed partial androgen insensitivity who were treated at Johns Hopkins University in the United States as children, 25% experienced gender dysphoria<sup>85</sup> as adults, and a small number wanted to undergo sex change surgery.<sup>86</sup>

3.69 Claims are sometimes made that outcomes studies may reflect outdated medical practice,<sup>87</sup> and that medical treatment has changed.<sup>88</sup> The committee recognises that there have been significant developments in surgical techniques applied to some forms of intersex.<sup>89</sup> However, for most forms of intersex, the committee was not presented with evidence to clearly indicate that outcomes are dependent on the era of medical procedure of the specific treatment administered, nor that those procedures responsible for poor outcomes are no longer administered.<sup>90</sup> In some cases, these claims have been directly rebutted by other studies.<sup>91</sup> The committee accepts that an experienced specialist working in a team care environment may achieve very good results,<sup>92</sup> but also notes the observation made by OII, that the

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84 'A genetic disorder caused by a deficiency of the enzyme 21-hydroxylase in the adrenal cortex, and the commonest adrenal disorder of childhood. Cause of virilisation in an affected female fetus'.

85 'Mental distress caused by unhappiness with one's own sex and the desire to be identified as the opposite sex'.

86 Garry L. Warne and Jacqueline K. Hewitt, 'Disorders of sex development: current understanding and continuing controversy', *Medical Journal of Australia*, Vol. 190, No. 11, 2009, p. 612.

87 For example, Christopher P. Houk and Lynne L. Levitsky, 'Management of the infant with ambiguous genitalia', in Denise S. Basow (ed.), *Up To Date*, 2013.

88 For example, Australasian Paediatric Endocrine Group, *Submission 88*, p. 4.

89 See, for example, Phyllis W. Speiser et al, 'Congenital adrenal hyperplasia due to steroid 21-hydroxylase deficiency: an Endocrine Society clinical practice guideline', *Journal of Clinical Endocrinology and Metabolism*, Vol. 95, 2010, pp 4143–4144.

90 There is evidence that some procedures have been abandoned or modified, such as surgical female gender assignment in cases of micropenis, and clitorodectomy in CAH. As Meyer-Bahlburg notes, however, 'to what extent more recent techniques of clitoral resection and recession improve the picture remains to be studied'. Heino F.L. Meyer-Bahlburg, 'Gender assignment and reassignment in intersexuality: controversies, data, and guidelines for research', in Zderic et al (eds), *Pediatric Gender Assignment: A Critical Reappraisal*, Kluwer Academic / Plenum Publishers, 2002, p. 209.

91 See, for example, Naomi S. Crouch, Lih Mei Liao, Christopher R.J. Woodhouse, Gerard S. Conway and Sarah M. Creighton, 'Sexual function and genital sensitivity following feminizing genitoplasty for congenital adrenal hyperplasia', *Journal of Urology*, Vol. 179, 2008, p. 637.

92 See, for example, Wei Ling Lean, Aniruddha Deshpande, John Hutson, and Sonia R. Grover, 'Cosmetic and anatomic outcomes after feminizing surgery for ambiguous genitalia', *Journal of Pediatric Urology*, Vol. 40, No. 12, 2005, pp 1856–1860.

'skill of a particular surgeon in one State provides no basis for a rational, national, human rights-based approach to cosmetic genital surgeries on intersex infants'.<sup>93</sup>

3.70 Many studies of intersexuality suffer from significant methodological problems. There are issues with choosing an appropriate control group against which to assess results. There are very few longitudinal studies following individuals over their life course. Surveys face significant risks of the non-respondents being different in character or outcome from those who choose to respond, creating a biased sample. This is because it is possible that those who have experienced adverse health or social outcomes from treatment are particularly distrustful of medical professionals, potentially including medical researchers, and may be less willing to subject themselves to evaluation.<sup>94</sup>

3.71 The committee is also aware of suggestions that those expressing dissatisfaction with results are not representative of health care outcomes overall. APEG stated that 'some individuals are unhappy with their childhood treatment and have formed advocacy groups or pursued litigation',<sup>95</sup> with Warne putting the claim very bluntly, when he referred to:

the vigorous activities of patient-advocacy organizations who have publicized their unhappiness and disagreement about current practices to the world at large and to politicians in particular.<sup>96</sup>

Another researcher in 1999 likewise suggested that concerns were being raised by an unhappy minority.<sup>97</sup>

3.72 Responding to these claims in an analysis of a debate pertaining to the treatment of CAH, Anne Tamar-Mattis observed:

There's a theory floating around the world of medicine that goes like this: while it is widely known that patients with disorders of sex development (DSD) are unhappy with the treatment they have received – cosmetic genital surgery, unwanted hormone treatment, and humiliating genital exams top the list – they can be safely ignored because there is actually a “silent majority” of patients out there who are doing just fine. This is a

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93 Organisation Intersex International Australia, *Submission 23.4*, p. 7.

94 See, for example, Organisation Intersex International Australia, *Submission 23*, p. 7; Christopher P. Houk and Lynne L. Levitsky, 'Management of the infant with ambiguous genitalia', in Denise S. Basow (ed.), *Up To Date*, 2013; Lisa Brinkmann, Karsten Schuetzmann and Hertha Richter-Appelt, 'Gender Assignment and Medical History of Individuals with Different Forms of Intersexuality: Evaluation of Medical Records and the Patients' Perspective', *J Sex Med*, Vol. 4, 2007, p. 978.

95 Australasian Paediatric Endocrine Group, *Submission 88*, p. 4.

96 Garry L. Warne, 'Long-term outcomes of disorders of sexual development (DSD): a world view', in John M. Hutson, Garry L. Warne and Sonia R. Grover (eds), *Disorders of Sex Development: An Integrated Approach to Management*, Springer-Verlag, Berlin, 2012, p. 279.

97 K.I. Glassberg, 'Gender assignment and the pediatric urologist', *Journal of Urology*, Vol. 161, pp 1308–1310.

comforting idea. It justifies the mistakes of the past, and it allows current practice to continue without all the discomfort of change.

Those of us who work in DSD advocacy hear the theory of the satisfied silent majority all the time. But *no one can find them...*

But there *is* a silent majority out there in the world of DSD treatment. And I have found them. They are the clinicians, the researchers, the junior practitioners, the social workers, the nurses, the psychologists who know or suspect that there is something very wrong with current treatment models, but keep their thoughts to themselves.<sup>98</sup>

3.73 Overall, there are very limited studies of the long-term outcomes of surgery, and some of the results should be of serious concern.

### ***Surgery has risks***

3.74 The Androgen Insensitivity Syndrome Support Group Australia drew attention to the false view that intersex persons are naturally infertile. Given the broad range of intersex conditions, the support group noted that it cannot be assumed that infertility is a consequence of DSD in every case. For intersex persons whose fertility has not been affected, normalising procedures can result in irreversible sterilisation:

Although many intersex people are naturally infertile, this is not the case universally. Many medical interventions to intersex bodies, particularly gonadectomy, can effectively be considered sterilization as they limit any future utilization of healthy reproductive tissue.<sup>99</sup>

3.75 Intersex support organisations and representatives reported that normalising surgery is not a one-off process. Rather, as a statement by Gina Wilson makes clear, the surgery can lead to a lifetime of dependency on further medical intervention:

That 'cure' offered by the medical establishment takes the form of surgery often followed by more surgery and a lifetime of hormonal reinforcement. Intersex genital mutilation (IGM) is conducted on newborn babies when their external genitals do not look 'normal' enough to pass unambiguously as male or female. IGM, like female genital mutilation (FGM), is surgery carried out upon the genitals of newborn babies, infants and children for cultural or religious reasons. Both are forms of infant genital surgery. The surgical procedures conducted can cause irreparable damage to children.<sup>100</sup>

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98 Alice Dreger, 'The Dex Diaries, Part 9: The Real Silent Majority', *Psychology Today*, 2012, <http://www.psychologytoday.com/blog/fetishes-i-dont-get/201210/the-dex-diaries-part-9-the-real-silent-majority> (accessed September 2013).

99 Androgen Insensitivity Syndrome Support Group Australia, *Submission* 54, p. 3.

100 Gina Wilson, 'Equal Rights for Intersex People', *The Equal Rights Review*, Vol. 10, 2013, p. 137.

3.76 Additional reconstructive surgery is sometimes required. As a consequence, rather than experiencing a 'normal' adolescence, intersex teenagers can spend their holidays recovering from additional surgeries.<sup>101</sup>

3.77 Intersex representatives also commented on the irony of normalising surgery – surgery intended to standardise appearance can result in deformity:

One of the things that they say to us is that we need to have our gonads removed because we are different—'We want to make you look normal.' Of course, part of the whole sterilisation thing is that you have a pretty big surgery and scars, so they are making us different!<sup>102</sup>

3.78 Accordingly, it was reported that the physical damage caused by normalising surgery exacerbates difference and, therefore, social isolation:

To remove gonads in AIS results in two significant scars on your pubic area that look like—I call them angry eyebrows; that is what they look like. They are pretty obvious, especially in AIS, where you do not have pubic hair. For a child it means when you go camping, showering or swimming with other people, they cannot help noticing that you have two red scars in your pubic area. They are noticeable and you know what: they are noticeable for years.<sup>103</sup>

### ***'Normalising' surgery on infants and children: human rights implications***

3.79 Any form of involuntary or coerced treatment, particularly where it involves invasive and irreversible procedures, is a serious matter and raises significant human rights concerns. In its first report on the *Involuntary or coerced sterilisation of people with disabilities in Australia*, the committee discussed the human rights implications of involuntary or coerced treatment in the context of persons with disabilities. Similar human rights concerns arise in relation to the issue of 'normalising' surgery on infants and children.

3.80 As a party to the key international human rights treaties, Australia has threefold obligations under international law, namely (i) *to respect* – requiring government not to interfere with or limit human rights; (ii) *to protect* – requiring government to take measures to prevent third parties from interfering with human

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101 Mr Gavi Ansara, Health Policy Officer, National LGBTI Health Alliance, *Committee Hansard*, p. 6; Councillor Tony Briffa, Committee Member, Androgen Insensitivity Syndrome Support Group Australia, *Committee Hansard*, 28 March 2013, p. 6.

102 Councillor Tony Briffa, Committee Member, Androgen Insensitivity Syndrome Support Group Australia, *Committee Hansard*, 28 March 2013, p. 3.

103 Councillor Tony Briffa, Committee Member, Androgen Insensitivity Syndrome Support Group Australia, *Committee Hansard*, 28 March 2013, p. 10.

rights; and (iii) *to fulfill* – requiring government to take positive measures to fully realise human rights.<sup>104</sup>

3.81 'Normalising' surgery on infants and children has the potential to impact on a range of interrelated human rights, including the right to privacy (which extends to the right to personal autonomy/self-determination in relation to medical treatment); the right to equality and non-discrimination; and the prohibition against torture and other cruel, inhuman and degrading treatment (including the prohibition against non-consensual scientific or medical experimentation).

*The right to personal autonomy*

3.82 The right to privacy protects a person's right to autonomy and personal, mental and bodily integrity in the context of medical treatment.<sup>105</sup> It encompasses a person's identity – including their sexuality, physical identifiers including their genetic code, their health, their image, their beliefs and convictions, bodily and psychological integrity and autonomy.<sup>106</sup> Choices about a person's own body in the context of medical interventions therefore fall within its scope.

3.83 In her analysis, *Fixing Sex*, Katrina Karkazis concluded that infant surgery leaves decision-making in the hands of third parties. While Karkazis writes that parents and medical professionals become the 'gatekeepers' of a child's identity and physical appearance, it is clear from her discussion that parents often play a facilitating role to the professionals' decision-making:

Because of the emphasis in the traditional protocol on rapid gender assignment and early surgery, many parents come under pressure to make treatment decisions quickly; and, indeed many are anxious to embark on a course of action that they believe will protect the child from being perceived as freakish or unable to live a 'normal' life. In the absence of rigorous long-term studies regarding treatment outcomes for genital surgery, parents face complex moral decisions about what is best for their child. Inextricably tied to ideas about the child's best interest are parents' views about what bodily parts and capabilities are required to be male or female. Parents are thus put in the position of assessing whether their baby is appropriately and sufficiently gendered, effectively making them

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104 This tripartite typology was originally devised by Henry Shue in his book *Basic Rights: Subsistence, Affluence and U.S. Foreign Policy* (2nd ed, 1996). It has since been adopted by various UN human rights treaty bodies and is accepted by the Australian Government as being an accurate categorisation of its obligations under international human rights law – see, for example, *In Our Hands: A Guide to Human Rights for Australian Public Servants*, p. 9, <http://www.ag.gov.au/RightsAndProtections/HumanRights/PublicSector/Pages/HumanRightsInOurHands.aspx> (accessed 26 September 2013).

105 See, for example, *MG v Germany*, Communication No. 1428/2006, CCPR/C/93/D/1482/2006 (23 July 2008), para 10.2.

106 For a discussion of the scope of the right to privacy, see Manfred Nowak, *UN Covenant on Civil and Political Rights: CCPR commentary*, 2nd rev. edn, NP Engel, Kehl, 2005, pp 385–392.

gatekeepers, along with clinicians, responsible for making irreversible and embodied decisions about the standards of maleness or femaleness.<sup>107</sup>

3.84 It was argued that third-party decision-making about a person's gender is contrary to that person's right to self-determination.<sup>108</sup> Gender assignment surgeries without the person's consent were characterised as 'well-intentioned but medically unsound violations of basic human rights'.<sup>109</sup>

3.85 Concerns about human rights protection echo the views of the Australian Human Rights Commission in its 2009 report *Surgery on intersex infants and human rights*. The Commission concluded that surgery on intersex infants is a human rights issue, affecting the child's 'fundamental rights of non-discrimination and equity before the law'.<sup>110</sup> The Commission advised that Australia's obligations under the Convention on the Rights of the Child have the effect that 'the child who is capable of forming their own views has the right to express those views in all matters affecting them...and for those views to be given due weight'. The Commission further concluded that this right should be exercised in accordance with the child's age and maturity. Accordingly, the Commission held that:

[i]n situations where surgery is not a medical necessity, it might be more appropriate to delay gender-related surgery until the child is at an age where their views concerning their gender identity and surgery can be taken into account.<sup>111</sup>

3.86 The former Tasmanian Commissioner for Children, Paul Mason, has also concluded that gender assignment without the person's consent contravenes internationally recognised human rights. Commenting in 2009, the Commissioner drew particular attention to Article 12 of the Convention on the Rights of the Child:

States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.<sup>112</sup>

3.87 In addition, the former Commissioner also highlighted Australia's obligations under Article 6 of the Convention, which states that 'States Parties shall ensure to the

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107 Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority, and Lived Experience*, Duke University Press, Durham, p. 180.

108 See, for example, Morgan Carpenter, Secretary, Organisation Intersex International Australia, *Committee Hansard*, 28 March 2013, p. 2.

109 Ms Zoe Brain, *Submission 86*, p. 1; National LGBTI Health Alliance, *Submission 60*, p. 2.

110 Australian Human Rights Commission, *Surgery on intersex infants and human rights*, 2009, p. 3.

111 Australian Human Rights Commission, *Surgery on intersex infants and human rights*, 2009, p. 5.

112 Convention on the Rights of the Child, Article 12, available at Office of the High Commissioner for Human Rights, <http://www.ohchr.org/en/professionalinterest/pages/crc.aspx> (accessed 30 July 2013).

maximum extent possible the survival and development of the child'.<sup>113</sup> On the basis of the rights contained in the Convention, the Commissioner concluded that '[a]ll children have the right to grow up and choose how their private parts should look'.<sup>114</sup> Non-consensual surgery, it was argued, interferes with this right:

It is submitted that in respect of all children, unnecessary circumcision and surgery on intersex babies should have the same human rights status as FGM, which has been criminalised in all States and Territories as a discriminatory practice in violation of the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW).

It is submitted that Australia's failure to eradicate non-consensual and medically unnecessary genital alteration of infant boys and of babies with ambiguous genitalia (intersex) for their families' traditional cultural and religious reasons amounts to a breach of children's human rights.<sup>115</sup>

3.88 Several witnesses considered non-consensual gender assignment surgery to be analogous to FGM, which is legally prohibited.<sup>116</sup>

3.89 It was further argued that non-consensual gender assignment surgery is contrary to the right to freedom of religion and expression, and the directive in Article 3 of the Convention that decisions about children are to be in the child's best interests:

Children are accorded the right to freedom of religion and to freedom of expression. Consequently a decision by parents to circumcise a male child to conform to their religious beliefs or select a gender assignment for an intersex child before the child can choose their religion or express their innate sexuality amounts to a violation of the child's right to freedom of religion and expression.

To the extent non-therapeutic circumcision on healthy boys or intersex surgery on infants could be conceptualised as practices based on societal norms and prejudices about what is/is not 'normal', these practices arguably amount to a breach of the 'best interests' principle enshrined in UNCROC Article 3.<sup>117</sup>

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113 Convention on the Rights of the Child, Article 6, available at Office of the High Commissioner for Human Rights, <http://www.ohchr.org/en/professionalinterest/pages/crc.aspx> (accessed 30 July 013).

114 Paul Mason, Commissioner for Children, Tasmania, *Pink or blue - A rights-based framework for medical intervention with intersex infants*, Paper for the 5<sup>th</sup> World Congress on Family Law and Children's Rights, Halifax, Nova Scotia, August 2009, p. 22.

115 Paul Mason, Commissioner for Children, Tasmania, *Pink or blue - A rights-based framework for medical intervention with intersex infants*, Paper for the 5<sup>th</sup> World Congress on Family Law and Children's Rights, Halifax, Nova Scotia, August 2009, p. 22.

116 See, for example, Organisation Intersex International Australia, *Submission 23.3*, pp 2–4; National LGBTI Health Alliance, *Submission 60.2*, p. 1.

117 Paul Mason, Commissioner for Children, Tasmania, *Pink or blue - A rights-based framework for medical intervention with intersex infants*, Paper for the 5<sup>th</sup> World Congress on Family Law and Children's Rights, Halifax, Nova Scotia, August 2009, pp 22–23.

3.90 From the evidence provided, it is clear that similar views have been expressed within the international community. OII referred to evidence provided by Advocates for Informed Choice to the Inter-American Commission on Human Rights for its inquiry into the treatment of intersex persons. As cited by OII, Advocates for Informed Choice argued:

[d]octors are also aware that there is usually no medical necessity for genital-normalising surgery, and offer social justifications, believing that the abuse they commit is necessary to prevent future discrimination against children with bodies that challenge the norm. However, just as it is a violation of the child's human rights to address parental discomfort through surgery on the child, it is a violation to address societal discomfort by the same means...The unavoidable pain of surgery and the high risk of severe, lifelong physical and mental suffering from loss of sexual sensation and function; pain caused by scarring, infertility, castration and violation of body integrity; and irreversible sex assignment to the wrong sex would never be accepted by doctors or parents if the child did not have an intersex body. The belief that such high a risk is acceptable with an intersex condition...drives these human rights violations.<sup>118</sup>

3.91 OII also provided to the committee a copy of the 2005 report of the Human Rights Commission of the City and County of San Francisco into the 'issue of "normalising" medical interventions being performed on intersex infants and children'. That commission concluded:

It is unethical to disregard a child's intrinsic human rights to privacy, dignity, autonomy, and physical integrity by altering genitals through irreversible surgeries for purely psychosocial and aesthetic rationales. It is wrong to deprive a person of the right to determine their sexual experience and identity.<sup>119</sup>

3.92 Similarly, reporting in November 2012, the Swiss National Advisory Commission on Biomedical Ethics held that there was no room for third-party decision-making for intersex children with the capacity to give or withhold consent:

As soon as the child attains capacity, it must consent to medical treatment itself, since such cases involve the exercise of highly personal rights. Parents should not have a right to veto a decision made by a child which has already obtained capacity. People have capacity if they can understand the purpose, appropriateness and effects of a given course of action and are also in a position to act only of their own free will in accordance with

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118 Morgan Carpenter, Secretary, Organisation Intersex International Australia, *Committee Hansard*, 28 March 2013, p. 2.

119 Human Rights Commission of the City and County of San Francisco, *A human rights investigation into the medical 'normalisation' of intersex people*, San Francisco, April 2005, p. 17.

rational judgement and to withstand pressure exerted by third parties within normal limits.<sup>120</sup>

*Prohibition against torture and other cruel, inhuman and degrading treatment*

3.93 There is growing recognition at the international level that medical interventions of an invasive and irreversible nature, absent a therapeutic purpose, may constitute torture or ill-treatment when administered without the free and informed consent of the person concerned.<sup>121</sup>

3.94 Noting that members of sexual minorities may be disproportionately subjected to torture and other forms of ill-treatment because they fail to conform to socially constructed gender expectations,<sup>122</sup> the United Nations Special Rapporteur on Torture has expressed concern at evidence of non-consensual gender assignment surgery:

There is an abundance of accounts and testimonies of...hormone therapy and genital-normalising surgeries under the guise of so-called 'reparative therapies'. These procedures are rarely medically necessary, can cause scarring, loss of sexual sensation, pain, incontinence and lifelong depression and have also been criticised as being unscientific, potentially harmful and contributing to stigma.<sup>123</sup>

3.95 The Special Rapporteur recommended the repeal of all laws and healthcare practices that discriminate against lesbian, gay, bisexual, transgender and intersex persons:

The Special Rapporteur calls upon all States to repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, unethical experimentation, medical display, 'reparative therapies' or 'conversion therapies', when enforced or administered without the free and informed consent of the person concerned. He also calls upon them to outlaw forced or coerced sterilization

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120 Swiss National Advisory Commission on Biomedical Ethics, *On the management of differences of sex development: Ethical issues relating to the intersexuality*, Opinion No. 20/2012, Berne, November 2012, p. 12.

121 See generally, Juan E. Mendez, Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HR/22/53, 1 February 2013. See also UN Committee against Torture, Concluding observations on the fifth periodic report of Germany, CAT/C/DEU/CO/5 (2011), para 20.

122 Juan E. Mendez, Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HR/22/53, 1 February 2013, p. 19.

123 Juan E. Mendez, Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HR/22/53, 1 February 2013, p. 18.

in all circumstances and provide special protection to individuals belonging to marginalized groups.<sup>124</sup>

### *Reasonable limits*

3.96 Most human rights may be subject to reasonable limits. Limitations of rights must pursue a legitimate objective and there must be a reasonable relationship of proportionality between the means employed and the objective sought to be realised. Proportionality requires that the limitation be necessary and rationally connected to the objective; be the least restrictive in order to accomplish the objective; and not have a disproportionately severe effect on the person to whom it applies.<sup>125</sup> In considering whether a limitation on a right is proportionate, relevant factors include:

- whether there were other less restrictive ways to achieve the same aim;
- whether there are effective safeguards or controls over the measures, including provision of due process rights and access to independent review; and
- the extent of the interference with human rights – the greater the interference the less likely it will be considered proportionate.

3.97 The evidence suggests that a human rights consistent framework for 'normalising surgery' where it involves irreversible and invasive procedures must necessarily operate from a presumption in favour of maintaining the status quo for as long as possible except where such a presumption would conflict with the child's best interests. A model that confers rights on third parties, through substitute decision making, before it guarantees the rights of the child, is likely to be a disproportionate limitation of the child's right to autonomy/self-determination.

### *It is not clear what kind of 'normal' is the objective of surgery*

3.98 One of the difficulties that is seldom discussed is how to establish what constitutes 'normal', particularly in relation to what genitals 'should' look like. OII expressed concern about 'the absence of standard objective measures for cosmetic perceptions of "normal" female genitals'.<sup>126</sup> The Androgen Insensitivity Syndrome Support Group Australia held a similar view of current medical practice:

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124 Juan E. Mendez, Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HR/22/53, 1 February 2013, Recommendation 3, p. 23.

125 International and comparative human rights jurisprudence has consistently applied these criteria for assessing whether limitations on rights are permissible. For further information see Attorney-General's Department, *Information Sheet on Permissible Limitations*, at <http://www.ag.gov.au/RightsAndProtections/HumanRights/PublicSectorGuidanceSheets/Pages/PermissibleLimitations.aspx> (accessed 26 September 2013). The Parliamentary Joint Committee on Human Rights has also adopted a similar approach for testing whether legislation is compatible with human rights; see PJCHR, Practice Note No 1 at [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Joint/Human\\_Rights/Practice\\_Notes/practicenote1/index](http://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Human_Rights/Practice_Notes/practicenote1/index) (accessed 26 September 2013).

126 Organisation Intersex International Australia, *Submission 23.4*, p. 15.

It is our experience as a peer led support group that current medical protocol is to overly pathologise intersex bodies and seek to use surgical, hormonal and psycho-social methods to anatomically 'normalise' intersex bodies so that they more closely confirm with accepted standards of either male or female physiological stereotypes. Our anecdotal experiences are backed up by an ever-widening pool of research into contemporary medical practices and their effects on people with intersex conditions.<sup>127</sup>

3.99 APEG advised that the idea of 'adequate' penis size was crucial in medical decisions around intersex:

[i]n the past, it was thought that adequate penis size was the main determinant of whether an infant with ambiguous genitalia should be assigned male or female at birth.<sup>128</sup>

3.100 What little research exists regarding 'adequate' or 'normal' genitals, particularly for women, raises some disturbing questions. A British team of Jillian Lloyd and others measured variations in the dimensions of female genitalia in a small group of 50 women aged between 18 and 50 who did not have any medical condition affecting their genitals. Even in this very small sample, there was enormous variation in the size of genitalia, with the largest clitorises 700 per cent longer, and over 300 per cent wider, than the smallest; the largest labia minora 500 per cent longer, and 700 per cent wider, than the smallest; and with the longest vagina twice the length of the shortest.<sup>129</sup> Despite this range, a recent reference work on surgery on intersex patients in infancy refers simply to creating 'a clitoris that is in the right position and of the right size', without any elaboration, or discussion of what that size might be.<sup>130</sup> The committee received no information indicating whether or not this natural variation in genital size and shape is taken account of in areas such as the application of the Prader scale, or how medical specialists learn about the diversity of appearance of genitals or how they define 'normal' in their clinical practice.

3.101 Studies such as that by Lloyd and others indicate that there is enormous natural variation in the anatomy of sex. However, this is not necessarily reflected in the medical response to that variety. A group of Dutch researchers surveyed 164 physicians regarding their views about the desirable size of a woman's labia minora, by assessing their 'willingness to refer for, or perform, a labia minora reduction'. The doctors were divided into three groups: plastic surgeons, general practitioners, and gynaecologists, and shown pictures of female genitalia with different sized labia. The researchers found that all the doctors regarded smaller labia minora as ideal, and male

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127 Androgen Insensitivity Syndrome Support Group Australia, *Submission 54*, p. 3.

128 Australasian Paediatric Endocrine Group, *Submission 88*, p. 5.

129 Jillian Lloyd, Naomi S. Crouch, Catherine L. Minot, Lih-Mei Liao and Sarah M. Creighton, 'Female genital appearance: 'normality' unfolds', *BJOG: an International Journal of Obstetrics and Gynaecology*, Vol. 112, 2005, pp 643–646.

130 John M. Hutson, 'Surgical treatment in infancy', in John M. Hutson, Garry L. Warne and Sonia R. Grover (eds), *Disorders of Sex Development: An Integrated Approach to Management*, Springer-Verlag, Berlin, 2012, p. 174.

doctors were more likely to recommend surgery than female, regardless of specialisation. The P measures in the following quote indicate that the results were statistically significant:

Ninety percent of all physicians believe, to a certain extent, that a vulva with very small labia minora represents society's ideal (2-5 on the Likert scale). More plastic surgeons regarded the picture with the largest labia minora as distasteful and unnatural, compared with general practitioners and gynecologists ( $P < 0.01$ ), and regarded such a woman as a candidate for a labia minora reduction procedure ( $P < 0.001$ ). Irrespective of the woman's labia minora size and the absence of physical complaints, plastic surgeons were significantly more open to performing a labia minora reduction procedure than gynaecologists ( $P < 0.001$ ). Male physicians were more inclined to opt for a surgical reduction procedure than their female colleagues ( $P < 0.01$ ).<sup>131</sup>

3.102 Both the Dutch and British studies raised the question of whether the increasing availability of pornography, containing 'idealised, highly selective images of the female genital anatomy', is influencing both professional and societal expectations around genital appearance, and encouraging people to seek surgery.<sup>132</sup>

***There is no consensus in key areas of medical practice***

3.103 In the mid-2000s researchers led by David Diamond surveyed paediatric urologists on appropriate clinical management of some intersex cases. The results make for sobering reading, and show both a lack of consensus, and the influence on gender assignment of the medical practitioner's age and experiences:

They overwhelmingly favoured female gender assignment for females even if they were extensively masculinized (Prader V) considering that preservation of female fertility was of foremost importance. For a case involving a male with cloacal exstrophy<sup>133</sup> 70% of respondents recommended male and 30% a female gender assignment. The factor they thought most important in choosing a male identity was the likelihood of brain imprinting by androgens. Those preferring a female gender assignment thought the most important factor to consider was the chance of surgical success. They were less concerned with male fertility. The

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131 W. Reitsma, M.J. Mourits, M. Koning, A. Pascal, and B. van der Lei, 'No (wo)man is an island – the influence of physicians' personal predisposition to labia minora appearance on their clinical decision making: a cross-sectional survey', *The Journal of Sexual Medicine*, Vol. 8, No. 8, 2011, pp 2377–2385.

132 Jillian Lloyd, Naomi S. Crouch, Catherine L. Minot, Lih-Mei Liao and Sarah M. Creighton, 'Female genital appearance: 'normality' unfolds', *BJOG: an International Journal of Obstetrics and Gynaecology*, Vol. 112, 2005, p. 645.

133 'A child with this condition will have the bladder and a portion of the intestines, exposed outside the abdomen, with the bony pelvis open like a book. In males the penis is either flat and short or sometimes split. In females the clitoris is split and there may be two vaginal openings. Also, frequently the intestine is short and the anus is not open'. From Urology Care Foundation, Cloacal Exstrophy, <http://www.urologyhealth.org/urology/index.cfm?article=92> (accessed 25 June 2013).

likelihood of choosing a male or female gender assignment was strongly influenced by respondent characteristics: younger practitioners seemed more willing to attend to brain potential while those older seemed more concerned with surgical outcome.<sup>134</sup>

3.104 The committee recognises that doctors are under enormous pressure and working in very difficult circumstances, and that parents too feel social pressures that they may communicate to physicians. Many specialists are trained to undertake sex assignment surgery, but few are trained to assist in the process of actually assessing what that sex should be.<sup>135</sup> The title of a 2004 journal article expresses the conundrum these health professionals experience: 'Possible determinants of sexual identity: how to make the least bad choice in children with ambiguous genitalia'.<sup>136</sup> Similarly, writing in a more recent article about intersex, Professor Garry Warne observed:

One of my heroes in pediatric endocrinology, Dr. Jud Van Wyk, once told me "It doesn't matter what you decide about DSD, you will be wrong!" His comment reflected the raging controversy about the ethics of decision making that was emerging at the time. Looked at another way, it might be interpreted as meaning that there is no "right" answer, no perfect outcome for the child who has been born with ambiguous genitalia.<sup>137</sup>

3.105 Ms Zoe Brain commented that in her experience 'the medical profession has a very uneven standard of knowledge in a very specialised area of intersex situations'. Writing from her perspective as a member of the intersex community who has worked with medical and psychology students to promote knowledge of intersex issues, Ms Brain questioned the rationales for current medical practice:

Much of what is in standard medical texts can best be described charitably as unevidenced, and uncharitably as folklore and accepted wisdom with no factual basis. Given the immense amount of knowledge medical practitioners have to acquire, this is perhaps understandable, and no fault should be attached to healthcare professionals who follow what they've been taught.<sup>138</sup>

3.106 Dr Jacqueline Hewitt performed a survey for APEG, of specialists' views about treatment of CAH in Australia and New Zealand. APEG provided a preliminary

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134 Milton Diamond, 'Clinical implication of the organizational and activational effects of hormones', *Hormones and Behavior*, Vol. 55, 2009, p. 627.

135 Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority, and Lived Experience*, Duke University Press, Durham, 2008, p. 93.

136 Cited in Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority, and Lived Experience*, Duke University Press, Durham, 2008, p. 93.

137 Jean D. Wilson, Marco A. Rivarola, Berenice B. Mendonca, Garry L. Warne, Nathalie Josso, Stenvert L.S. Drop, and Melvin M. Grumbach, 'Advice on the Management of Ambiguous Genitalia to a Young Endocrinologist From Experienced Clinicians', *Semin Reprod Med.*, Vol. 30, No. 5, 2012, pp 339–350.

138 Ms Zoe Brain, *Submission 86*, p. 1.

overview of the results to the committee.<sup>139</sup> It highlights a great diversity of opinions amongst doctors, and some extreme geographical variation in medical practice. The survey asked a question about when surgery should be conducted on females with CAH who show different degrees of virilisation of their genitals, based on the Prader scale (see chapter 1). For women with low to moderate virilisation (Prader 2), the doctors were evenly divided between those who recommended no surgery at all, and those who suggested it occur in adolescence, with a few suggesting infancy. For moderate virilisation (Prader 3), there was an even split between those favouring infancy and those suggesting waiting until adolescence. Even for the most virilised of females (Prader 5), a significant minority did not support infant surgery.<sup>140</sup> Amongst those who supported early genital surgery, most favoured doing it between 6 and 12 months of age. But when the researchers analysed outliers, they found very strong regional variations. Those favouring surgery at less than 6 months were all from New Zealand, Queensland or outside the region, while those at the other extreme, recommending no infant surgery in any circumstances, were all from New South Wales.<sup>141</sup> This considerable variation in views existed primarily within one medical specialisation (endocrinology), in one geographical region (Oceania), discussing just one type of intersex, and this certainly explains why most of the respondents favoured the development of clinical guidelines to guide treatment decisions.

3.107 The research by Hewitt gives detailed insight to the broader issue, recognised in the 2006 Consensus Statement and elsewhere,<sup>142</sup> that there is no medical consensus around the conduct of normalising surgery.

3.108 Given the lack of consensus, the Intersex Society of North America's advice to parents was to query the necessity of cosmetic surgery, and that providing a supportive environment for the child was the most important thing:

If your surgeon wants to do a surgery to change how your child looks, pause and consider waiting. What we know about people who grew up with "ambiguous genitalia" tells us on average they do well! You may understandably worry that your child will be emotionally hurt by having something other than average-looking genitals, but the evidence suggests your child won't be, especially if you're open, honest, accepting, and supportive. Surgeries may leave your child with diminished health, diminished sexual sensation, scarring, a poor cosmetic outcome, and an unintended message that your child needed to be "fixed" to be accepted by you. So consider waiting and letting your child decide whether to take the

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139 Australasian Paediatric Endocrine Group, Correspondence to the committee, received 27 September 2013.

140 Jacqueline Hewitt, 'Management of virilisation in CAH: where to from here?', Australasian Paediatric Endocrine Group Annual Scientific Meeting, Sydney 2013.

141 Jacqueline Hewitt, 'Management of virilisation in CAH: where to from here?', Australasian Paediatric Endocrine Group Annual Scientific Meeting, Sydney 2013.

142 See, for example, Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne, *Submission 92*, p. 6.

risks. You may discover your child is fine with the way your child is, especially if you let your child know you are.<sup>143</sup>

### **Making intersex invisible?**

3.109 As OII commented, normalisation surgery is more than physical reconstruction. The surgery is intended to deconstruct an intersex physiology and, in turn, construct an identity that conforms with stereotypical male and female gender categories:

[I]ntersex people are regarded by medicine as having an impairment – a disorder of sex development – which affects perceptions of our realness as men or women. Intersex bodies do not meet social expectations. Cultural, familial and medical attitudes govern to which sex we are assigned. Surgical and other interventions are made to erase intersex difference.<sup>144</sup>

3.110 Normalising surgery presupposes that there is an abnormality in need of correction. As the Androgen Insensitivity Syndrome Support Group Australia argued, intersex people 'are treated like damaged goods'.<sup>145</sup> Perhaps unsurprisingly, the committee received evidence of normalising surgery having social and psychological ramifications. These include social stigma, referred to as a 'legacy of shame', difficulties within the child's family unit, adult personal and psychological distress, sexual anxieties, and uncertainty about personal and gender identity.<sup>146</sup>

3.111 Overall, the conclusion that intersex persons require 'normalising' was strongly disputed by the intersex community:

The implication that there are psychosocial risks associated with looking different and that these are greater than the risks associated with social outcomes; appears to be presumed without evidential support. Neither OII Australia, nor are the intersex community or advocacy organisations that we have spoken with (such as the US Advocates for Informed Choice), are aware of any follow-up studies on people who have avoided surgery as a primary or comparison group.<sup>147</sup>

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143 Intersex Society of North America, *Tips for Parents*, 2004, [http://www.isna.org/articles/tips\\_for\\_parents](http://www.isna.org/articles/tips_for_parents) (accessed 2 July 2013).

144 Morgan Carpenter, Secretary, Organisation Intersex International Australia, *Committee Hansard*, 28 March 2013, p. 1.

145 Councillor Tony Briffa, Committee Member, Androgen Insensitivity Syndrome Support Group Australia, *Committee Hansard*, 28 March 2013, p. 7.

146 A Gender Agenda, *Submission 85*, p. 5; Androgen Insensitivity Syndrome Support Group Australia, *Submission 54*, pp 3–4; Organisation Intersex International Australia, *Submission 23*, pp 16–17; Organisation Intersex International Australia, *Submission 23. 2*, p. 7; Organisation Intersex International Australia, *Submission 23. 3*, p. 4.

147 Organisation Intersex International Australia, *Submission 23.1*, p. 7.

3.112 The committee notes that the emphasis in recent guidelines on functional outcomes rather than on cosmetic results<sup>148</sup> provides the potential for clinical practice to move away from rendering intersexuality invisible.

### **Suggestions for reform and for ensuring best practice**

3.113 The argument that normalising surgery is required to protect the child from discrimination was strongly contested. Rather than altering the child, it was submitted that societal attitudes are in need of reform. OII submitted that the appropriate course of action is to expose discrimination rather than to mask physical difference:

Looking different is a human characteristic, and different ethnic appearance is often associated with discrimination and poor health outcomes. We don't require people to modify their appearance as a result; we try to tackle the discrimination.<sup>149</sup>

3.114 OII recommended a focus on family counselling rather than surgical options, and supported changes to the basis on which medical management of intersex is approached:

Our recommended principles for medical interventions are the following:

1. Medical intervention should not assume crisis in our difference, nor normalisation as a goal.
2. Medical, and in particular surgical, interventions must have a clear ethical basis, supported by evidence of long term benefit.
3. Data must be recorded on intersex births, assignments of sex of rearing, and of surgical interventions.
4. Medical interventions should not be based on psychosocial adjustment or genital appearance.
5. Medical intervention should be deferred wherever possible until the patient is able to freely give full and informed consent; this is known as "Gillick competence".
6. Necessary medical intervention on minors should preserve the potential for different life paths and identities until the patient is old enough to consent.
7. The framework for medical intervention should not infantilise intersex, failing to recognise that we become adults, or that we have health needs as adults.
8. The framework for medical intervention must not pathologise intersex through the use of stigmatising language.

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148 See, for example, Christopher P. Houk and Lynne L. Levitsky, 'Management of the infant with ambiguous genitalia', in Denise S. Basow (ed.), *Up To Date*, 2013.

149 Organisation Intersex International Australia, *Submission 23.1*, p. 7.

9. Medical protocols must mandate continual dialogue with intersex organisations.<sup>150</sup>

3.115 Some other submitters endorsed this approach.<sup>151</sup>

3.116 The submission from APEG:

acknowledges the contention in this area, and recommends that until further evidence becomes available, surgery for the purposes of appearance should only occur if consistent with international medical guidelines on degree of ambiguity, and that in terms of timing, parents should be thoroughly counselled about the options of very early surgery, delay until later in infancy or delay until the child can be involved themselves in the decision to operate.<sup>152</sup>

3.117 Regarding how cases should be considered, APEG strongly endorsed the approach set out in the 2006 Consensus Statement in favour of specialist multidisciplinary teams:

Informal multidisciplinary management groups have been established in Australia, however unlike those established overseas, none have received discrete health funding, and they often do not have participation of all the specialists listed above. At present there is no formal process requiring expert multidisciplinary management team review of children with DSD, and thus not all patients receive review by such an expert group.

APEG supports the funding of formal specialist multidisciplinary DSD management groups as a priority, and recommend that all cases of DSD should be discussed with a specialist DSD management group.<sup>153</sup>

3.118 Other recommendations from APEG and the Disorder of Sex Development multidisciplinary team at Royal Children's Hospital Melbourne related to research, rather than to changes in current practice.

### ***Ensuring the best treatment***

3.119 The published literature and submissions indicate that, where surgical intervention takes place, two overlapping features are of great importance. These are the need for assessment and support to be provided by full multidisciplinary teams; and if surgery is undertaken, for it to be done by experienced specialists to the highest standard and informed by the latest research and practice.

3.120 As the committee noted earlier, there is considerable variation in the outcomes of genital surgery reported in the medical literature. The committee is aware that the populations who were included in the studies vary in where they were operated on and what kinds of surgery they received. For example, in a group of eighteen women who had clitoroplasty, Nordenskjöld and others found treatment administered by ten

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150 Organisation Intersex International Australia, *Submission 23*, pp 20–21.

151 A Gender Agenda, *Submission 85*; Alastair Lawrie, *Submission 91*.

152 Australasian Paediatric Endocrine Group, *Submission 88*, p. 5.

153 Australasian Paediatric Endocrine Group, *Submission 88*, p. 5.

surgeons at four hospitals. In contrast, an Australian study by Lean and others dealt with a patient population the majority of which had been seen by one surgeon.<sup>154</sup> When considering the issue of surgical background, they found:

those who had their clitoroplasty done by nonspecialized surgeons showed poorer outcomes, with absence of clitoris, small clitoris, or large clitoris identified at examination... Of the 32 patients examined, 21 (66%) had acceptable overall outcomes (<2 abnormalities on examination) and 11 (34%) had poor outcomes (>2 abnormalities). When these overall outcomes were analyzed based on the institution where the initial surgery was done, patients who had their initial surgery done at [Royal Children's Hospital] (18/22) had better overall outcomes ( $P < .05$ ) than those operated on elsewhere (3/10).<sup>155</sup>

3.121 The paper also reported research by others indicating that 'poor results related to surgeons' lack of experience' and concluded that 'the consistent message for achieving good outcomes is the need for a specialized surgeon and team'.<sup>156</sup>

3.122 Nordenskjöld and others considered the outcomes of treatment of 62 women with CAH. Discussing the experience and consequences of surgery, they observed that women had been subjected to many different kinds of procedures, some of which were no longer used, and that in some cases the researchers 'had difficulties interpreting the operative procedure from the charts because it was not always clearly described'.<sup>157</sup> Given the outcomes the women experienced, the researchers concluded:

our data confirm that feminizing surgery should be restrictive and calls for specialization of the surgeons that are to perform this type of surgery... Indications for surgery should be restrictive given the risk for diminished sensitivity of the clitoris. Given the results from this study and having met these women, we, as others before us, strongly argue that the medical, surgical, and psychological treatment be centralized to specialized teams.<sup>158</sup>

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154 Wei Ling Lean, Aniruddha Deshpande, John Hutson, and Sonia R. Grover, 'Cosmetic and anatomic outcomes after feminizing surgery for ambiguous genitalia', *Journal of Pediatric Urology*, Vol. 40, No. 12, 2005, pp 1856–1860.

155 Wei Ling Lean, Aniruddha Deshpande, John Hutson, and Sonia R. Grover, 'Cosmetic and anatomic outcomes after feminizing surgery for ambiguous genitalia', *Journal of Pediatric Urology*, Vol. 40, No. 12, 2005, p. 1858.

156 Wei Ling Lean, Aniruddha Deshpande, John Hutson, and Sonia R. Grover, 'Cosmetic and anatomic outcomes after feminizing surgery for ambiguous genitalia', *Journal of Pediatric Urology*, Vol. 40, No. 12, 2005, p. 1859.

157 Agneta Nordenskjöld, Gundela Holmdahl, Louise Frisé, Henrik Falhammar, Helena Filipsson, Marja Thorén, Per Olof Janson, and Kerstin Hagenfeldt, 'Type of Mutation and Surgical Procedure Affect Long-Term Quality of Life for Women with Congenital Adrenal Hyperplasia', *Journal of Clinical Endocrinology and Metabolism*, Vol. 93, No. 2, 2008, p. 385.

158 Agneta Nordenskjöld, Gundela Holmdahl, Louise Frisé, Henrik Falhammar, Helena Filipsson, Marja Thorén, Per Olof Janson, and Kerstin Hagenfeldt, 'Type of Mutation and Surgical Procedure Affect Long-Term Quality of Life for Women with Congenital Adrenal Hyperplasia', *Journal of Clinical Endocrinology and Metabolism*, Vol. 93, No. 2, 2008, pp 385–386.

3.123 All of this evidence is consistent with the position taken in the 2006 Consensus Statement, and endorsed in the recent Victorian guidelines, that care should take place in multidisciplinary teams. However, when a group of researchers surveyed the extent to which the Consensus Statement recommendations had been implemented in Europe, the move toward dedicated multidisciplinary teams was found to be incomplete. The survey, responded to by 60 of the 77 medical centres invited to take part, indicated that around one third had what was defined as an 'ideal team' containing all required specialities including psychology, social work and medical ethics. Two thirds were missing one or more of the specialities. It was also the case that over two-fifths of the centres did not hold clinics 'designated solely for DSD patients'.<sup>159</sup>

3.124 The multidisciplinary team based in Melbourne endorsed the need for specialist team-based care,<sup>160</sup> as did the body representing many of the key specialists, APEG. The committee is aware that the team in Melbourne includes at least an endocrinologist, surgeon, endocrine social worker, mental health professional and gynaecologist, as well as involving a clinical ethics committee that has medical ethics expertise.<sup>161</sup> The committee was not advised of the range or depth of skills in other Australian locations undertaking treatment of intersex children. As APEG pointed out, 'at present there is no formal process requiring expert multidisciplinary management team review of children with DSD', and such teams are not directly funded.

### Committee view

3.125 There is nothing easy about decision-making that will irrevocably affect children's future lives. It presents great challenges, some of which the treatment of intersex people historically has failed to meet. Some intersex people have been subject to decision-making similar in nature to that examined in other inquiries conducted by this committee. The similarities include: a goal of resolving issues as soon as possible after birth; concealment of medical procedures from parents or patients; the subsequent loss or inaccessibility of medical records; primacy of medical professional decision-making over other sources of expertise; and the entrenchment in professional practice of theories that may have a limited and contested evidence base.<sup>162</sup> Policies

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159 V. Pasterski, P. Prentice, and I. A. Hughes, 'Consequences of the Chicago consensus on disorders of sex development (DSD): current practices in Europe', *Archives of Disease in Childhood*, Vol. 95, 2010, pp 618–623.

160 Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne, *Submission 92*, p. 7.

161 Lynn Gillam, Jaqueline K. Hewitt, and Garry L. Warne, 'Ethical Principles for the Management of Children with Disorders of Sex Development: A systematic Approach for Individual Cases', in John M. Hutson, Garry L. Warne and Sonia R. Grover (eds), *Disorders of Sex Development: An Integrated Approach to Management*, Springer-Verlag, Berlin, 2012, pp 153–154.

162 See Heino F.L. Meyer-Bahlburg, 'Gender assignment and reassignment in intersexuality: controversies, data, and guidelines for research', in Zderic et al (eds), *Pediatric Gender Assignment: A Critical Reappraisal*, Kluwer Academic / Plenum Publishers, 2002, p. 202; Georgiann Davis, "'DSD is a perfectly fine term": reasserting medical authority through a shift in intersex terminology', *Advances in Medical Sociology*, Vol. 12, 2011, pp 171–178.

based on these features subsequently are recognised as compromising important ethical principles, violating human rights and sometimes causing long-term personal and social damage.

3.126 The evidence received during this inquiry indicates that many of these practices (such as concealing diagnoses, or withholding records) are rejected by all those involved in intersex medical treatment. In some other areas, such as intervention based on limited scientific evidence and the emphasis on resolving issues at birth, improvements are still needed to protect intersex people and their rights.

3.127 The lack of evidence to support intersex medical decision-making is a source of concern, and the committee returns to the issue of research in the final chapter.

3.128 Regarding normalising surgery on intersex people, the committee concludes that:

- Normalising appearance goes hand in hand with the stigmatisation of difference. Care needs to be exercised that medical treatment of intersex is not premised on, and contributing to, the stigma and perceived undesirability of people appearing different from one another.
- There is frequent reference to 'psychosocial' reasons to conduct normalising surgery. To the extent that this refers to facilitating parental acceptance and bonding, the child's avoidance of harassment or teasing, and the child's body self-image, there is great danger of this being a circular argument that avoids the central issues. Those issues include reducing parental anxiety, and ensuring social awareness and acceptance of diversity such as intersex. Surgery is unlikely to be an appropriate response to these kinds of issues.
- Human rights considerations are important in this area, and any decision-making around medical treatment of intersex children must take them into account.
- Irreversible medical treatment, particularly surgery, should only be performed on people who are unable to give consent if there is a health-related need to undertake that surgery, and that need cannot be as effectively met later, when that person can consent to surgery.
- Medical practice has moved, and appears to be continuing to move, in the right direction, by applying increasing caution to normalising treatment of children.
- An evidence base supporting early surgery for some individuals does exist, but it is small, contested, and it is not yet clear what the factors are that determine success (noting also that 'success' is itself a contested subject).
- All major care decisions and case management should take place in a multidisciplinary team setting, and surgery should only be undertaken by highly trained specialists with experience in intersex cases.

3.129 The proposals put forward by Organisation Intersex International have merit, and are consistent with the committee's conclusions. The committee believes that a protocol covering 'normalising' surgery should be developed, and then adhered to in

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all cases of intersex children. Such a guideline should be consistent with Organisational Intersex International's recommendations, particularly 4, 5 and 6.

### **Recommendation 3**

**3.130 The committee recommends that all medical treatment of intersex people take place under guidelines that ensure treatment is managed by multidisciplinary teams within a human rights framework. The guidelines should favour deferral of normalising treatment until the person can give fully informed consent, and seek to minimise surgical intervention on infants undertaken for primarily psychosocial reasons.**

3.131 The next chapter discusses the important issues of how such guidelines should be developed, who should be involved, and how decision-making for intersex children should be supported.

3.132 The committee agrees with APEG that medical care should be undertaken in multidisciplinary teams that include psychological, social work, and ethical expertise, and which work in a human rights framework. The committee supports the provision of some direct funding to team care, to ensure that:

- Intersex people receive multidisciplinary team care across Australia, not only in the one or two locations where it appears to be fully or partly operational;
- The teams are comprehensive in their membership, particularly with respect to psychological and social support, and ethics; and
- The teams have sufficient support and recognition to ensure things like high-quality record-keeping and research capacity (referred to in the final chapter).

### **Recommendation 4**

**3.133 The committee recommends that the Commonwealth government provide funding to ensure that multidisciplinary teams are established for intersex medical care that have dedicated coordination, record-keeping and research support capacity, and comprehensive membership from the various medical and non-medical specialisms. All intersex people should have access to a multidisciplinary team.**

