The Senate

Community Affairs References Committee

Involuntary or coerced sterilisation of intersex people in Australia

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ABBREVIATIONS

21-OHD	21-hydroxylase deficiency
47, XXY	Klinefelter Syndrome
AIS	Androgen Insensitivity Syndrome
AISSGA	Androgen Insensitivity Syndrome Support Group Australia
APEG	Australasian Paediatric Endocrine Group
CAH	Congenital Adrenal Hyperplasia
CAIS	Complete Androgen Insensitivity Syndrome
CEDAW	Convention on the Elimination of All Forms of Discrimination Against Women
CERG	Clinical Ethics Response Group
DSD	Disorders of Sexual Development *or* Differences of Sexual Development
FGM	Female Genital Mutilation
GCT	Germ Cell Tumour
IGM	Intersex Genital Mutilation
ISNA	Intersex Society of North America
LAT	Less Adversarial Trial
NCAH	Non-classical Congenital Adrenal Hyperplasia
OII	Organisation Intersex International
OII Australia	Organisation Intersex International Australia
OPA	Office of the Public Advocate
PAIS	Partial Androgen Insensitivity Syndrome
RCH	Royal Children's Hospital, Melbourne

SMPAC	Special Medical Procedures Advisory Committee
SW-CAH	Salt-wasting Congenital Adrenal Hyperplasia

GLOSSARY

Chromosome

Chromosomes are found in each cell in the body. Each human cell normally contains 46 total chromosomes – organised in two sets of 23 chromosomes – that come in two types: sex chromosomes and autosomal chromosomes. Each cell in the human body contains these chromosomes which contain genetic material (genes) that make up an individual's DNA (deoxyribonucleic acid). Sex chromosomes determine gender. In the final of the 23 sets of chromosomes, females have two X chromosomes, while males have an X and a Y chromosome; in some intersex people, there are variations in the configuration of the 23rd chromosome set. Phenotypes are produced by multiple chromosomes acting together.

Cryptorchidism

Cryptorchidism refers to the condition in which the testes fail to descend into the scrotum and are retained within the abdomen or inguinal canal.

Clitoroplasty, clitoridectomy

Clitoridectomy is the surgical excision of the clitoris. Until the 1960s clitoridectomy was the principal surgical procedure used to manage enlargement of the clitoris in intersex. Clitoroplasty is a surgical procedure to alter the physiology of the clitoris, and includes procedures in which part of the erectile tissue of the clitoris is removed (clitoral reduction) or relocated (clitoral recession) to reduce the apparent size of the clitoris.

Cloacal Extrophy

Cloacal Extrophy is a condition in which an infant has the bladder and a portion of the intestines exposed outside the abdomen. 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. Frequently the intestine is also short and the anus may not be open.

Dysgenesis

Dysgenesis refers to abnormal organ development during embryonic growth and development of a foetus. Gonadal and adrenal dysgenesis are two of the more common types of dysgenesis. Gonadal dysgenesis may result in a streak gonad.

Endocrinology

Endocrinology is a medical specialisation dealing with the body's production, use and response to hormones.

Genitoplasty

Genitoplasty is the surgical alteration of external genitalia, and is a procedure sometimes performed on individuals with ambiguous genitalia. The two essential elements of feminising genitoplasty are clitoral reduction/recession (clitoroplasty, see above) and vaginoplasty (see below).

Genotype

A person's genotype describes all of the genetic information that is encoded in his or her chromosomes (for example 46,XY or 46XX, among others). It also refers to the genetic information carried by a pair of genes (one from each parent) which controls a particular characteristic.

Germ cell tumour

Germ cells are those embryonic cells that have the potential to develop into gonads. Germ cell tumours are tumorous growths based in those cells, and can be cancerous or non-cancerous.

Gonad

Gonads are reproductive glands; the term can refer to either testicles or ovaries. Gonads in foetuses develop into either testes or ovaries depending on the chromosomal constitution of the foetus. In some intersex people, gonads do not differentiate fully into one type or the other.

Streak gonad

Streak gonads consists of fibrous tissue without any germ cells, and therefore are unable to function.

Gonadectomy

A gonadectomy is the removal of an ovary or testis. In some intersex cases, gonadectomy is undertaken if the testes are inconsistent with the sex of assignment. In some CAIS individuals the testes are intra-abdominal or contained in inguinal herniae (a protrusion of the abdominal cavity).

Histology

Histology is the science dealing with the microscopic identification of specific cells and tissue.

Hypospadias

Hypospadias is a development disorder affecting the urethra. In the male, it is a developmental anomaly in which the urethra opens on the underside of the penis or on the perineum. In females hypospadias is a developmental anomaly in which the urethra opens into the vagina.

Immunohistochemistry

Immunohistochemistry is a medical diagnostic tool. Histochemistry is the study of the chemistry of organic tissue through observing chemical reactions. Immunohistochemistry is a form of histochemistry which relies on the principle of certain antibodies binding specifically to certain receptors (antigens) in biological tissue; these reaction patterns can then be assessed. Immunohistochemistry is widely used to detect specific structures in tissues and in the diagnosis of abnormal cells such as those found in tumours.

Inguinal

Inguinal refers to the region of the groin. In the male foetus the inguinal canals are a pair of openings that connect the abdominal cavity with the scrotum. An inguinal hernia is a protrusion through the lower abdominal wall.

Intra-abdominal

Intra-abdominal refers to the area of the body in which the ovaries and uterus are found. In some intersex conditions, the position of the testes is intra-abdominal rather than scrotal.

Karyotype

A karyotype refers to the number and structure of chromosomes in the nucleus of a cell; that is, the complete set of chromosomes in an individual. The karyotype is usually identical in all the cells of an organism (but not in some rare types of intersex). The standard human karyotype contains 22 pairs of autosomal chromosomes and one pair of sex chromosomes (46 chromosomes in total). The standard karyotype for females is denoted as 46,XX whereas the standard male karyotype is expressed 46,XY.

Labiaplasty

Labiaplasty is a surgical procedure to modify, usually by reducing the size of, the labia, the folds of flesh and skin that surround the female genitals.

Neoplastic

Neoplasty is any abnormal growth of new tissue.

Prophylactic

A prophylactic is an agent or procedure that prevents the development of a condition or a disease.

Phenotype

Phenotype refers to the complete observable characteristics of an individual, including anatomical, physiological, biochemical and behavioural traits, as determined by the interaction of both genetic makeup and environmental factors.

Scarification

Scarification is the creation of scar tissue following surgical procedures.

Scrotal

In relation to the position of the testes, scrotal testes are in the scrotum. Testes can in some intersex variations be intra-abdominal or inguinal.

Vaginoplasty

Vaginoplasty is a surgical procedure to create a vaginal canal. Some intersex conditions such as Complete Androgen Insensitivity Syndrome may cause individuals to develop a blind vaginal pouch that averages 2.5 to 3.0 cm in depth, compared to an average of 10-12 cm depth for non-CAIS individuals. Some individuals in these circumstances will undergo vaginoplasty.

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LIST OF RECOMMENDATIONS

Recommendation 1

2.20 The committee recommends that governments and other organisations use the term 'intersex' and not use the term 'disorders of sexual development'.

Recommendation 2

2.21 The committee recommends that health professionals and health organisations review their use of the term 'disorders of sexual development', seeking to confine it to appropriate clinical contexts, and should use the terms 'intersex' or 'differences of sexual development' where it is intended to encompass genetic or phenotypic variations that do not necessarily require medical intervention in order to prevent harm to physical health.

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.

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.

Recommendation 5

4.43 In light of the complex and contentious nature of the medical treatment of intersex people who are unable to make decisions for their own treatment, the committee recommends that oversight of these decisions is required.

Recommendation 6

5.30 The committee recommends that all proposed intersex medical interventions for children and adults without the capacity to consent require authorisation from a civil and administrative tribunal or the Family Court.

Recommendation 7

5.31 The committee recommends that the Standing Committee on Law and Justice consider the most expedient way to give all civil and administrative tribunals in all States and Territories concurrent jurisdiction with the Family Court to determine authorisation for intersex medical interventions proposed for a child.

Recommendation 8

5.32 The committee recommends that civil and administrative tribunals be adequately funded and resourced to consider every intersex medical intervention proposed for a child.

Recommendation 9

5.38 The committee recommends that the special medical procedures advisory committee draft guidelines for the treatment of common intersex conditions based on medical management, ethical, human rights and legal principles. These guidelines should be reviewed on an annual basis.

Recommendation 10

5.41 The committee recommends that complex intersex medical interventions be referred to the special medical procedures advisory committee for consideration and report to whichever body is considering the case.

Recommendation 11

5.70 The committee recommends that the provision of information about intersex support groups to both parents/families and the patient be a mandatory part of the health care management of intersex cases.

Recommendation 12

5.72 The committee recommends that intersex support groups be core funded to provide support and information to patients, parents, families and health professionals in all intersex cases.

Recommendation 13

6.11 The committee recommends that the Commonwealth Government support the establishment of an intersex patient registry and directly fund research that includes a long-term prospective study of clinical outcomes for intersex patients.

Recommendation 14

6.25 The committee recommends that the Commonwealth government investigate the appropriate regulation of the use of dexamethasone for prenatal treatment of CAH.

Recommendation 15

6.27 The committee recommends that, effective immediately, the administration of dexamethasone for prenatal treatment of CAH only take place as part of research projects that have ethics approval and patient follow-up protocols.

Chapter 1

1.1 On 20 September 2012, the Senate referred the involuntary or coerced sterilisation of people with disabilities in Australia to the Senate Community Affairs References Committee for inquiry and report. On 7 February 2013 the Senate amended the terms of reference of the inquiry to add the following matter:

> 2. Current practices and policies relating to the involuntary or coerced sterilisation of intersex people, including:
>
> (a) sexual health and reproductive issues; and
>
> (b) the impacts on intersex people.

1.2 The addition of this item reflected the growing awareness by both the committee and stakeholders of a significant overlap between issues faced by people with disability and by intersex people. The committee's desire to examine the issues more closely was also fostered by the work of the government and the Senate Legal and Constitutional Affairs committee on the Exposure Draft of Human Rights and Anti-Discrimination Bill 2012, and the subsequent Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013.

1.3 On 17 July 2013 the Community Affairs committee tabled its first report, on involuntary or coerced sterilisation of people with disabilities in Australia. This second, and final, report addresses the term of reference concerning intersex people.

1.4 The committee has benefited from the cooperation of many individuals and organisations, who have responded to questions and helped the committee to understand this extremely complex field of human rights and medicine. The committee is particularly grateful to Organisation Intersex International Australia (OII) for its assistance in locating a range of reference materials, and to a number of specialists in the field, such as Dr Hewitt, Professor Warne, and Dr Cools and her colleagues who provided reference material and answered the committee's questions. The committee recognises the efforts all these people have made to assist the inquiry.

1.5 Because of the technical nature of the inquiry and differences of view between stakeholders regarding the published research, wherever possible the committee considered the original research publications in the field, rather than relying on their interpretation in submissions. For this reason, this report relies to a greater extent than usual on peer-reviewed published research material. The committee is grateful to submitters, the Parliamentary Library, and other libraries around the country for assisting in sourcing this material.

What is intersex?

1.6 'Intersex' describes biological variation in members of a species that means they cannot be comprehensively described by the labels 'male' or 'female'. Intersexuality occurs in many species, including humans, and it represents a range of genetic, chromosomal and hormonal circumstances. Intersex may be evident from *genotype*: a person may have variations in their genes and chromosomes other than the

46,XX and 46,XY that define typical female and male sex respectively. There may be variations in *phenotype*: the observable sex characteristics of the body may differ from those of a typical male or female.

1.7 Intersexuality is sometimes but not always evident at birth:

> [I]ntersex people are diagnosed visually, at birth, or via amniocentesis, by chromosome, and other blood tests… Intersex differences may also be determined during infancy, at puberty, when attempting to conceive, or through random chance.[1]

1.8 Intersex is not the same as transgender or transsexual. As OII explained:

> Trans people include people who are *born unambiguously* one gender but who, later in life, identify and present in the world differently. In contrast, intersex is not based on identity, even though non-standard identities might be regarded as a logical possible consequence of nonstandard anatomies.[2]

1.9 The circumstances that can lead to someone being intersex include unusual combinations of X or Y chromosomes, physiological variations in genitals that are not apparently male or female at birth (and/or subsequently) and variations in hormone production at different stages in development. This was well explained by the World Health Organisation's genomic resource centre:

> Humans are born with 46 chromosomes in 23 pairs. The X and Y chromosomes determine a person's sex. Most women are 46XX and most men are 46XY. Research suggests, however, that in a few births per thousand some individuals will be born with a single sex chromosome (45X or 45Y) (sex monosomies) and some with three or more sex chromosomes (47XXX, 47XYY or 47XXY, etc.) (sex polysomies). In addition, some males are born 46XX due to the translocation of a tiny section of the sex determining region of the Y chromosome. Similarly some females are also born 46XY due to mutations in the Y chromosome. Clearly, there are not only females who are XX and males who are XY, but rather, there is a range of chromosome complements, hormone balances, and phenotypic variations that determine sex.[3]

1.10 The Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne submitted that there is a range of circumstances that meet the criteria of being intersex:

- Some life threatening conditions such as salt wasting congenital adrenal hyperplasia, which requires lifelong medications and medical care;
- Babies born with ambiguous genitalia;

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1 Organisation Intersex International Australia, *Submission 23*, p. 1.

2 Organisation Intersex International Australia, *Submission 23*, p. 1.

3 World Health Organisation, Genomic resource centre, Gender and genetics: Genetic Components of Sex and Gender, http://www.who.int/genomics/gender/en/index1.html (accessed 22 July 2013).

- others which involve significant penis anomalies (hypospadias);
- others involving girls who are born without a vagina and uterus; and
- babies who are born with only one opening for bladder, bowels (and vagina) or where the entire lower abdominal wall and genital area is open and exposed with the inside of the bladder open and the clitoris or penis in 2 un-joined halves.[4]

1.11 There is a bewildering array of terms and medical conditions describing intersex, with many having synonyms. A number of these will be discussed at various stages in this report, and by inquiry participants. These clinical descriptors include:

- Congenital Adrenal Hyperplasia (CAH)
- 47,XXY (or Klinefelter syndrome)
- 45,X (and variants, or Turner's syndrome)
- Partial Androgen Insensitivity Syndrome (PAIS) (or Reifenstein's syndrome)
- Complete Androgen Insensitivity Syndrome (CAIS) (or Morris' syndrome)
- Gonadal Dysgenesis (including, depending on the classificatory approach, Frasier syndrome, Denys-Drash syndrome)
- MRKH (also known as Vaginal Agenesis)
- 5α-Reductase Deficiency
- 3β-Hydroxysteroid Dehydrogenase Deficiency
- 17-Ketosteroid Reductase Deficiency
- 17β-Hydroxysteroid Dehydrogenase Deficiency
- True hermaphroditism.[5]

1.12 Intersex can include circumstances where the person will benefit from – indeed require – medical intervention, and intersex conditions are classified by the World Health Organisation as endocrine disorders.[6] Intersexuality however does not necessarily involve a medical condition:

> Intersex is not a medical condition or a disorder or a disability or a pathology or a condition of any sort. Intersex is differences in the same way

4 Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne, *Submission 92*, pp. 2–3.

5 Organisation Intersex International Australia, *Submission 23*, p. 3; Androgen Insensitivity Syndrome Support Group Australia, *Submission 54*, p. 2; Martine Cools, Stenvert L. S. Drop, Katja P. Wolffenbuttel, J. Wolter Oosterhuis and Leendert H. J. Looijenga, 'Germ cell tumors in the intersex gonad: old paths, new directions, moving frontiers', *Endocrine Reviews*, Vol. 27, No. 5, 2006, p. 470.

6 World Health Organisation, International Statistical Classification of Diseases and Related Health Problems (ICD)-10 Version: 2010, http://apps.who.int/classifications/icd10/browse/2010/en (accessed 22 July 2013).

> height, weight, hair colour and so on are differences. Only a very few ways of being intersex have links to differences that might cause illness. Congenital adrenal hyperplasia (CAH) is the most common. Strangely very few CAH individuals are intersex despite it being classified by medicine as a way of being intersex. We know of no XY CAH individuals who are intersex. We know most XX CAH individuals are females capable of having a child with very few anatomical differences of sex. Some intersex [people] have very striking differences in anatomical presentation but they are usually very healthy and able people.[7]

1.13 Some intersex people are naturally fertile. Others may be infertile, however their gonads—whether ovaries or testes—are capable of producing hormones. There are also some intersex people who, while not capable of unassisted reproduction, may be able to have children with medical support, either with existing reproductive assisting technologies, or as new scientific advances occur.

How common is intersex?

1.14 Figures for the incidence of intersex are difficult to come by. The UK's National Health Service suggests a range of 0.1 to 2 per cent of the population.[8] The Australasian Paediatric Endocrine Group (APEG) indicated that the incidence ranges from:

> 1 in 125 boys for a mild variant, to 1 in 4500 babies where genitalia appear significantly ambiguous at birth such that the sex of the infant is unable to be immediately determined.[9]

1.15 Some mixed sex chromosome conditions – where a person has a configuration of chromosomes other than the usual 46,XX or 46,XY – are considered common, occurring in about 1 in 400 births, with the most frequent being '47,XXX (1:947 girls), 47,XXY (1:576 boys), 45,X (1:1893 girls) and 47,XYY (1:851 boys)'.[10]

1.16 Warne and Hewitt have indicated that one type of CAH – 21-hydroxylase deficiency – is 'the single most common cause of ambiguous genitalia',[11] though ambiguous genitalia is of course not a necessary feature of intersex. In fact two studies found that, for most people, variation from the standard genetic make-up of 46,XX or

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7 OII Intersex Network, What is intersex? 2011, http://oiiinternational.com/intersex-library/intersex-articles/what-is-intersex-oii-australia/ (accessed 2 July 2013).

8 NHS, Disorders of sex development, http://www.nhs.uk/conditions/disorders-sex-development/Pages/Introduction.aspx (accessed 28 June 2013).

9 Australasian Paediatric Endocrine Group, *Submission 88*, p. 1.

10 Jacqueline K. Hewitt and Garry L. Warne, 'Mixed sex chromosome and ovo-testicular DSD', 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. 81.

11 Garry L. Warne and Jacqueline K. Hewitt, '46,XX Disorders of Sex 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. 53.

XY did not result in abnormal genital appearance.[12] While CAH is the commonest cause of ambiguous genitalia, it is rarer than some other intersex conditions, occurring in around 1 in 16 000 births.[13]

1.17 OII reported two studies:

> Fausto-Sterling (2000) reports that 1-2% of the population are intersex. The NSW Ministry of Health reports data from the NSW Mothers and Babies report showing that infants with visible reportable differences of sex anatomy between 2003-2009 comprised 0.59% of all births, while no breakdown of additional (often not visible at this stage) relevant chromosomal "anomalies" is given.[14]

1.18 The definition used by Fausto-Stirling and others was an 'individual who deviates from the Platonic ideal of physical dimorphism at the chromosomal, genital, gonadal, or hormonal levels'.[15] Psychologist Leonard Sax criticised Fausto-Stirling's estimate on the grounds that her definition of intersex was too broad. Sax favoured a definition of intersex as 'those conditions in which (a) the phenotype is not classifiable as either male or female, or (b) chromosomal sex is inconsistent with phenotypic sex'. He then went on to argue that the frequency of intersex according to his narrower definition was approximately 0.018 per cent of the population.[16] Sax's definition however is not accepted elsewhere and his calculations exclude conditions such as Klinefelter syndrome and Turner syndrome: he is the only source to suggest these are not intersex.

1.19 OII commented on the lack of data available, and some steps that would contribute to rectifying this:

> Given a social environment where intersex people are stigmatised, we support registration of intersex infants with a binary sex, however, the birth registration process also means that we have no accurate data on our numbers. Further, no data is available to us on the number or type of surgical procedures on intersex children, or the numbers of intersex children involved.[17]

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12 Jacqueline K. Hewitt and Garry L. Warne, 'Mixed sex chromosome and ovo-testicular DSD', 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. 81.

13 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. 634.

14 Organisation Intersex International Australia, *Submission 23*, p. 1.

15 Melanie Blackless, Anthony Charuvastra, Amanda Derryck, Anne Fausto-Sterling, Karl Lauzanne and Ellen Lee, 'How sexually dimorphic are we? Review and synthesis', *American Journal of Human Biology*, Vol. 12, No. 2, 2000, p. 161.

16 Leonard Sax, 'How common is intersex? A response to Anne Fausto-Sterling', *Journal of Sex Research*, Vol. 39, No. 3, 2002, pp. 174–178.

17 Organisation Intersex International Australia, *Submission 23*, p. 4.

Intersexuality and its assessment

1.20 To assist in understanding subsequent chapters, this section describes a number of different forms of intersexuality, and some of the means by which they are assessed.

Androgen Insensitivity Syndrome

1.21 People with Androgen Insensitivity Syndrome (AIS) have bodies that are either completely insensitive to testosterone and other androgen hormones (CAIS) or partially insensitive to androgens (PAIS).[18]

Complete Androgen Insensitivity Syndrome

1.22 With CAIS, a cell is completely insensitive to testosterone thereby preventing the development of male external genitalia. This results in the development of external female genitalia but without 'ovaries, Fallopian tubes or uterus; and the vagina will be blind-ending and possibly short or absent. Female pubertal development occurs but there will be no menstruation and no possibility of conceiving/bearing children'.[19] Testes are usually present in a 'superficial inguinal position and can be the size found in men'.[20]

1.23 CAIS is caused by an alteration in a gene which 'blocks the body's response to masculinising hormones during foetal development and after birth'.[21] Some common features of CAIS include:

- Female body shape
- Large breasts with juvenile nipples
- Absent/scanty axillary and pubic hair
- No temporal hair recession (balding)
- Female external genitalia with small labia
- Blind-ending vagina
- Absent or rudimentary internal genitalia
- Gonads consistent histologically with cryptorchid testes
- Testes produce androgen and oestrogen.[22]

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18 Organisation Intersex International Australia, *Submission 23*, p. 8.

19 Androgen Insensitivity Syndrome Support Group, *Complete AIS*, http://www.aissg.org/22_CAIS.HTM (accessed 23 September 2013).

20 Garry L. Warne, 'Complete Androgen Insensitivity Syndrome: A Guide for Parents and Patients', 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. 291.

21 Garry L. Warne, 'Complete Androgen Insensitivity Syndrome: A Guide for Parents and Patients', 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. 291.

22 Androgen Insensitivity Syndrome Support Group, *Complete AIS*, http://www.aissg.org/22_CAIS.HTM (accessed 23 September 2013).

1.24 Diagnosis of CAIS has often not taken place until puberty because it is only then that many people discover that they cannot menstruate and that other features of puberty such as the growth of pubic and axillary hair do not occur.

1.25 Past clinical practice refrained from disclosing the nature of the condition to patients and their parents, partly due to a 'paternalistic attitude but it was also due to the perceived difficulty of explaining XY chromosomes and testes to a girl without traumatising her'.[23] This lack of diagnosis often caused much distress to the intersex person:

> The failure of doctors to disclose the true nature of the condition to them and their parents led to major difficulties and this has generated a great deal of anger and resentment.[24]

1.26 A number of medical conditions are associated with CAIS. There is a small increased risk of testicular cancer (3%) and women with CAIS have an increased risk of osteoporosis.[25] Undescended testes can also result in an inguinal hernia in infancy.[26]

Partial Androgen Insensitivity Syndrome

1.27 PAIS is a variant of AIS which can result in children being born with masculinised genitalia. The extent of the variation results in some children with PAIS being raised as boys and some raised as girls.

1.28 A grading system for the phenotypic features in AIS was proposed in 1995 by Dr Charmian Quigley and Dr Frank French. This system categorises the variations of AIS in a range from Partial to Complete. CAIS is shown at Grades 6/7 of the spectrum where the outward appearance of the person is invariably female.[27] A person categorised as Grade 1 PAIS will have outward genitalia that is completely male in appearance. The system is used by the Androgen Insensitivity Syndrome Support Group (AISSG) to illustrate the variation between the two conditions.

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23 Garry L. Warne, 'Complete Androgen Insensitivity Syndrome: A Guide for Parents and Patients', 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.

24 Garry L. Warne, 'Complete Androgen Insensitivity Syndrome: A Guide for Parents and Patients', 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.

25 Garry L. Warne, 'Complete Androgen Insensitivity Syndrome: A Guide for Parents and Patients', 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.

26 Androgen Insensitivity Syndrome Support Group, *Complete AIS*, http://www.aissg.org/22_CAIS.HTM (accessed 23 September 2013).

27 Quigley et al: Androgen Receptor Defects: Historical, Clinical and Molecular Perspectives. Endocrine Reviews, Vol. 16, No. 3, pp 271-321 (1995), reproduced in Androgen Insensitivity Syndrome Support Group, *What is AIS*, http://www.aissg.org/21_OVERVIEW.HTM (accessed 23 September 2013).

Grade 1	PAIS	Male genitals, infertility
Grade 2	PAIS	Male genitals but mildly 'under-masculinized', isolated hypospadias
Grade 3	PAIS	Predominantly male genitals but more severely 'under-masculinized' (perineal hypospadias, small penis, cryptorchidism i.e. undescended testes, and/or bifid scrotum)
Grade 4	PAIS	Ambiguous genitals, severely 'under-masculinized' (phallic structure that is indeterminate between a penis and a clitoris)
Grade 5	PAIS	Essentially female genitals (including separate urethral and vaginal orifices, mild clitoromegaly i.e. enlarged clitoris)
*Grade 6	PAIS	Female genitals with pubic/underarm hair
*Grade 7	**C**AIS	Female genitals with little or no pubic/underam hair

*Before puberty, individuals with Grade 6 or 7 are indistinguishable.

Congenital adrenal hyperplasia

1.29 Congenital Adrenal Hyperplasia (CAH) is a group of intersex conditions affecting the adrenal glands of people (usually women) with XX chromosomes. CAH takes a number of forms, which can be confusing to interpret. The most common type is 21-hydroxylase deficiency (21-OHD), in which the body does not produce enough of some key chemicals (including one called 21-hydroxylase), with potentially serious consequences for hormone production and many bodily functions.

1.30 The more severe form, called Classical CAH, is usually detected in the newborn or in early childhood. However a milder form, called Non-classical CAH (NCAH), may cause symptoms at any time from infancy through adulthood. NCAH is more prevalent than Classical CAH,[28] however it is Classical CAH that is more often discussed in the context of intersex.

1.31 A person with Classical CAH will experience some degree of prenatal virilisation or masculinisation. The degree of virilisation will vary significantly.[29] A person with CAH may be born with genitals that are to various degrees masculinised.

28 Cares Foundation, *Overview – What is Congenital Adrenal Hyperplasia (CAH)?* http://www.caresfoundation.org/productcart/pc/overview_cah.html, (accessed 23 September 2013).

29 Organisation Intersex International Australia, *Submission 23*, p. 11.

For example, the labia may be joined more like a scrotum, the vagina may not be fully formed, or may be joined with the urethra.[30]

1.32 CAH prevents the adrenal glands from producing cortisol, which is necessary for life and also allows the body to 'deal with physical and emotional stress, and maintain adequate energy supply and blood sugar levels'.[31] In addition, 75 per cent of people with Classical CAH also lack the adrenal hormone aldosterone, which is necessary for regulating sodium and potassium levels which help stabilise the heart. Aldosterone also maintains the normal fluid volume of the body. When this deficiency occurs it is called Salt-Wasting CAH (SW-CAH).[32]

Mixed Sex Chromosome DSD

1.33 Humans are typically born with 23 pairs of chromosomes, forming a total of 46. Twenty-two of these pairs are identical whilst the 23rd pair differs between males and females. In this pair females have two copies of the X chromosome while males have one X and one Y chromosome.[33]

1.34 Mixed sex chromosome DSD occurs when there is sex chromosome abnormality in the number of X or Y chromosomes. The most common chromosome abnormalities are 47,XXX; 47,XXY; 45,X; and 47,XYY. Two of these more common mixed sex chromosome conditions are known as Klinefelter Syndrome (47,XXY) and Turner Syndrome (45,X).

1.35 Alternatively an abnormality may form part of a *mosaic* karyotype. Mosaicism is a chromosomal abnormality where not all cells in a person's body have the same number and/or composition of chromosomes. The most common of these are 45,X/46,XX; 45,X/46,XY; 46,XX/47,XXX and 46,XY/47,XXY. In many of the conditions affected by sex chromosome abnormalities and/or mosaicism the development of the gonads is adversely affected.[34]

47, XXY (Klinefelter Syndrome)

1.36 Individuals with 47,XXY are born with an extra sex chromosome. The committee heard that babies with a diagnosis of 47,XXY are typically assigned as

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30 Accord Alliance, *Frequently asked questions*, http://www.accordalliance.org/learn-about-dsd/faq.html, (accessed 2 September 2013).

31 Cares Foundation, *Overview – What is Congenital Adrenal Hyperplasia (CAH)?* http://www.caresfoundation.org/productcart/pc/overview_cah.html, (accessed 23 September 2013).

32 Cares Foundation, *Overview – What is Congenital Adrenal Hyperplasia (CAH)?* http://www.caresfoundation.org/productcart/pc/overview_cah.html, (accessed 23 September 2013).

33 Genetics Home Reference, *How many chromosomes do people have?* http://ghr.nlm.nih.gov/handbook/basics/howmanychromosomes, (accessed 26 September 2013).

34 Jacqueline K. Hewitt and Garry L. Warne, 'Mixed Sex Chromosome and Ovo-Testicular DSD', 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. 81.

male at birth and diagnosed as having Klinefelter Syndrome.[35] Boys and men born with Klinefelter syndrome typically will have smaller-than-average testes and low fertility. The effects of Klinefelter syndrome vary substantially, and some affected persons show very few physical symptoms.[36]

Monosomy X (Turner Syndrome)

1.37 Turner syndrome is a condition in which a person's cells contain the chromosomal component 45,X. In other words, a person has one X chromosome instead of two.[37] The phenotypes of girls with Turner Syndrome may include 'abnormalities in linear growth (average adult height is 144cm), ovarian differentiation, development of the cardiovascular, lymphatic and renal systems, the eyes and ears and other organs.'[38] An extensive number of other medical conditions can also occur through adolescence into adulthood.

Gonadal dysgenesis

1.38 In gonadal dysgenesis, a person's gonads (ovaries or testes) do not develop properly during foetal development, or develop in the wrong place. Gonads that have developed in the inguinal canal that connects the abdominal cavity with the scrotum, or in the abdominal cavity itself, fall into this category. Some dysgenic gonads are described as 'streak gonads', which consist of fibrous tissue that does not function like ovaries or testes. Streak gonads are not capable of contributing to reproduction.[39]

1.39 Depending on their position in the body, dysgenetic gonads may present a high risk of gonadal cancer. According to members of the Disorder of Sex Development multidisciplinary team at the Royal Children's Hospital in Melbourne, the intra-abdominal dysgenetic testes and streak gonads 'must be removed as soon as possible after diagnosis'; other recent advice suggests that inguinal testes can be retained, but 'a risk management strategy is mandatory'.[40] This issue is discussed further in Chapter 4.

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35 Organisation Intersex International Australia, *Submission 23*, p. 13.

36 Accord Alliance, *Frequently asked questions*, http://www.accordalliance.org/learn-about-dsd/faq.html, (accessed 2 September 2013).

37 Accord Alliance, *Frequently asked questions*, http://www.accordalliance.org/learn-about-dsd/faq.html, (accessed 2 September 2013).

38 Jacqueline K. Hewitt and Garry L. Warne, 'Mixed Sex Chromosome and Ovo-Testicular DSD', 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. 85.

39 Accord Alliance, *Frequently asked questions*, http://www.accordalliance.org/learn-about-dsd/faq.html, (accessed 2 September 2013).

40 Jacqueline K. Hewitt and Garry L. Warne, 'Mixed Sex Chromosome and Ovo-Testicular DSD', 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. 82.

Non-hormonal DSD

1.40 There are some DSD conditions that cause genital abnormalities that are not the result of hormone irregularities or chromosomal deviations. Cloacal exstrophy for example is a very serious condition where the abdominal wall fails to close correctly during foetal development. This can result in a number of severe anatomical abnormalities such as the internal organs being exposed and external genitalia not forming in a typical anatomic fashion. [41] According to Hutson (2012), 'the key to recognition of these anomalies is that the external anatomy is outside the range between normal male through to normal female[…]by contrast, in hormonal causes of DSD, the morphological development is otherwise normal'.[42]

1.41 Aphalia and 'micropenis' are conditions where the person is born with either no phallis or penis, or a penis that is 'at least 2.5 standard deviations smaller than the average penis when stretched'.[43]

Prader Scale

1.42 The virilisation or masculinisation of genitalia is a feature of a number of intersex conditions including CAH and AIS. It is frequently measured using the Prader Scale which is a system developed by Dr Andrea Prader in 1954[44] for grading the degree of external genital virilisation.[45] The Scale starts at 0, which is an unvirilised female, and ends at 5 which is a completely virilised female (a female who appears externally male at birth but with the labial/scrotal sac empty since there are no testicles).[46] At the higher end of the scale, the external genitalia appear male while the internal genitalia are those typically associated with females. According to UK paediatricians the Prader Scale provides 'a standard to set surgical procedures against.'[47]

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41 Accord Alliance, *Frequently asked questions*, http://www.accordalliance.org/learn-about-dsd/faq.html, (accessed 2 September 2013).

42 John. M. Hutson, 'Non-hormonal DSD', 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. 89.

43 Accord Alliance, *Frequently asked questions*, http://www.accordalliance.org/learn-about-dsd/faq.html, (accessed 2 September 2013).

44 Perrin C. White and Phyllis W. Speiser, Congenital Adrenal Hyperplasia due to 21-Hydroxylase Deficiency, *Endocrine Reviews***,** vol. 21, no. 3, 2000, pp. 245-291, http://edrv.endojournals.org/content/21/3/245.long (accessed 26 September 2013).

45 Hewitt and Warne, "Management of disorders of sexual development", *Paediatric Health*, Feb 2009, p. 54.

46 Perrin C. White and Phyllis W. Speiser, Congenital Adrenal Hyperplasia due to 21-Hydroxylase Deficiency, *Endocrine Reviews***,** vol. 21, no. 3, 2000, pp. 245-291, http://edrv.endojournals.org/content/21/3/245.long (accessed 26 September 2013).

47 S. Williams; Gender confirming surgery in females with congenital adrenal hyperplasia (CAH), Welsh Paediatrics Society, 2008, http://www.welshpaediatrics.org.uk/gender-confirming-surgery-females-congenital-adrenal-hyperplasia-cah%20 (accessed 25 September 2013).

Intersex and fertility

1.43 The prospective fertility of a person born intersex is important to medical treatment decisions that may be made, and was important to the committee's inquiry. However, assessing fertility can be complex, particularly in infants. In addition, developments in reproductive medicine may change the future capacity of a person to have a child.

1.44 The committee was advised that intersex people may experience reduced fertility compared to the general population, however fertility effects vary greatly between different types of intersex. It also varies according to the severity of the condition.[48]

1.45 The submission from the multidisciplinary team at Royal Children's Hospital, Melbourne indicated that people with XY complete gonadal dysgenesis were infertile, because 'their gonads are neither testes nor ovaries, but rather underdeveloped structures without potential for hormone production or fertility'.[49] There is however a varying degree of fertility according to the severity of the dysgenesis.[50]

1.46 In those with complete androgen insensitivity syndrome or partial androgen insensitivity syndrome, hormone production occurs in the testes but, again, they are not fertile, at least given current medical technology.[51] Medical experts did however draw to the committee's attention an example where that technology may lead to changes in fertility:

> Patients with the severe form CAIS are infertile; however most recently a case report describes fertility in a patient with moderate partial androgen insensitivity following high dose testosterone treatment and intracytoplasmic sperm injection.[52]

1.47 In contrast, fertility exists in a range of other types of intersex. Women with congenital adrenal hyperplasia experience reduced fertility, though the reasons are varied;[53] fertility can be preserved in people with 46,XX ovo-testicular DSD and some

48 Martine Cools, Arianne Dessens, Stenvert Drop, Jacqueline Hewitt and Gary Warne, answers to questions on notice (received 27 September 2013).

49 Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne, *Submission 92*, p. 3.

50 Martine Cools, Arianne Dessens, Stenvert Drop, Jacqueline Hewitt and Gary Warne, answers to questions on notice, (received 27 September 2013).

51 Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne, *Submission 92*, p. 4.

52 Martine Cools, Arianne Dessens, Stenvert Drop, Jacqueline Hewitt and Gary Warne, answers to questions on notice, (received 27 September 2013).

53 Martine Cools, Arianne Dessens, Stenvert Drop, Jacqueline Hewitt and Gary Warne, answers to questions on notice, (received 27 September 2013).

other forms of intersex such as 5α-Reductase Deficiency.[54] There are other types of intersex where the potential for fertility is unknown, such as 17β-hydroxysteroid dehydrogenase deficiency.[55]

1.48 OII indicated that some infertility in intersex people has not been caused by their form of intersex, but by medical intervention that has removed ovaries or testes.[56]

1.49 Submissions to the committee stated that fertility, including potential for future medically-assisted fertility, should be an important consideration when medical interventions are planned for an intersex person.[57]

Ladies and gentlemen, boys and girls?

1.50 This chapter began by explaining that intersex describes people who cannot be comprehensively described by the labels 'male' or 'female'. Often they will have a genetic make-up that varies from the standard chromosomal arrangements in a male or female person.

1.51 Australian culture currently has strong expectations of 'binary' gender, expecting people to appear 'normal' and to be either male or female. This attitude is evident in the introduction to a chapter in the current medical reference text on intersex, written by Australian medical practitioners:

> Genital ambiguity in a baby is almost as devastating in the delivery room as a perinatal death.[58]

1.52 Such medical attitudes to the birth of an intersex baby are analogous to those often displayed at the birth of a baby with a disability. Given that some people with genital ambiguity do not require medical treatment in order to be healthy and thrive, the extraordinary statement in this reference text is cause for reflection on the way we consider intersexuality. If this sentence reflects the clinical and social environment into which intersex people are born, it is not surprising that both parents and doctors

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54 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, pp 281–285; Martine Cools, Arianne Dessens, Stenvert Drop, Jacqueline Hewitt and Gary Warne, answers to questions on notice, (received 27 September 2013).

55 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).

56 Organisation Intersex International Australia, *Submission 23*, p. 3.

57 Organisation Intersex International Australia, *Submission 23*, p. 20; Australasian Paediatric Endocrine Group, *Submission* 88, p. 6; Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne, *Submission 92*, p. 4.

58 John M. Hutson, 'The neonate with ambiguous genitalia', 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. 103.

feel great pressure, and wish as quickly as possible to ensure they have a child that is 'normal', and in particular that gender conforms to sex or vice versa.

1.53 This is not how all cultures approach intersex. As Newman documents, some North American Indians 'do not allocate sex at birth regardless of the appearance of external genitalia, as there is a belief that it may change'. In other societies, a change in gender identity at puberty occurs for some intersex people, in a process that is culturally 'usually unproblematic'.[59] Similar arrangements exist in some societies in relation to transgender people, such as in Samoa, where a kind of 'third gender' exists, *fa'afafine*, for males who adopt a more feminine role.[60]

1.54 In contrast, in Australia, the United States and elsewhere, the prevailing cultural norm is to attempt to ensure 'normalisation' of sex and permanent sex assignment. Still, not all individual parents and doctors approach the issue in Australia and other western developed countries in this way. To a limited degree, the most recent guidelines for medical management of intersex, discussed in a later chapter, are less insistent on immediate sex assignment. Even so, individuals who do not conform to this view may be placed in a difficult position. Researcher Georgiann Davis records an instance when parents who queried proposed surgery to normalise their child were told they should 'see a psychiatrist'.[61]

1.55 OII described how cultural norms have social and medical consequences for intersex people:

> Intersex variations affect perceptions of our realness as men or women, and society still generally requires people to live and identify as male or female. As a result, intersex bodies do not meet societal expectations and intersex people experience homophobia and prejudice. Cultural, familial and medical attitudes towards our differences from sex norms govern which sex we are assigned, and what surgical and other medical interventions will be made to ensure we conform to those norms. Medical interventions seek to erase intersex differences.[62]

1.56 Concillor Tony Briffa talked about some of the problems that come from sex being assigned, despite Tony's desire not to be pigeonholed in that way:

> I feel, and the support group feels, that this is an amazing time for intersex. We see the human rights and antidiscrimination legislation referencing intersex at the moment, which is brilliant, as well as an acknowledgement that we exist and that it is a biological variation, which has been wonderful... My birth certificate, from the state of Victoria, does not

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59 Louise Newman, 'Questions about gender: children with atypical gender 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. 33.

60 Alice Dreger, 'Gender Identity Disorder in Childhood: Inconclusive Advice to Parents', *Hastings Center Report*, Vol. 39, No. 1, 2009, pp 26–29.

61 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.

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

> classify me as male or female. I have certainly had a female birth certificate, I had a male birth certificate at one stage and I have a blank birth certificate now. But we are hoping that one day in the future our birth certificates will actually be able to reflect, for those who want it, the way nature made us. If people feel female that is great, and if they feel male that is great, but there are also people like me: I just accept the way nature made me. I am happy for my birth certificate to say that I am both male and female. One day, hopefully, we will have that as well.[63]

1.57 A number of experts have been critical of the binary, normalising approach to sex that is facilitated by the medical model of treatment of intersex. Regarding the role of sexual desire in intersex treatment, Karkazis writes:

> Typically, heterosexuality is seen as the natural sexuality and the successful sexual outcome for treated children; penile-vaginal intercourse as the exclusive or most important sexual act; and genital appearance as taking priority over sexual pleasure and sensation.[64]

Or as biologist Fausto-Stirling put it, 'penetration in the absence of pleasure takes precedence over pleasure in the absence of penetration'.[65]

1.58 Psychiatrist Professor Louise Newman has observed:

> For the clinician, it is important that adoption of a Western model and formulation of gender identity and development does not preclude an understanding of possible alternative frameworks, and a particular normative model of gender development is not rigidly imposed on children and families seeking to understand gender variation.[66]

1.59 The expectation that children are assigned and will adhere to a binary sex, and for their genitals to appear 'normal', increases pressure for medical decisions to be made during infancy. This is discussed further in chapter three.

Recent developments in Australian law and practice

1.60 The sterilisation of intersex persons is influenced by medical protocol, societal attitude and legal requirements. This report will canvass in detail the medical and social frameworks relevant to the sterilisation of intersex persons. The legal framework for the authorisation of sterilisation procedures will also be examined.

1.61 However, this inquiry is part of recent and growing recognition within Australian society of intersexuality and intersex individuals. The committee notes the

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63 Councillor Tony Briffa, Committee Member, Androgen Insensitivity Syndrome Support Group Australia, *Committee Hansard*, 28 March 2013, pp 4–5.

64 Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority, and Lived Experience*, Duke University Press, Durham, 2008, p. 139.

65 Cited in Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority, and Lived Experience*, Duke University Press, Durham, 2008, p. 138.

66 Louise Newman, 'Questions about gender: children with atypical gender 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. 34.

advances within Commonwealth, State and Territory legislation that give long overdue recognition to intersex persons, including legal protection against discrimination on the basis of a person's intersex status. As this inquiry does not exist in a vacuum but is in part a response to a wider movement to acknowledge intersexuality, the committee has considered key legislative reforms that recognise intersexuality. These legislative developments will inform the committee's consideration of whether the medical, social and legal regulation of the sterilisation and medicalisation of intersex persons is not only best practice but is in keeping with the expectations of Australian governments and Australian society.

1.62 Recent legislative reforms increasingly refer to 'intersex' as a recognised biological trait. Notable developments have occurred in Commonwealth, territory, and state legislation and administrative practice. Overall, the changes point to a growing view within Australian legislatures, and Australian society, that intersex as a biological trait should be recognised, respected and accommodated, and that intersex individuals should not suffer discrimination on the basis of their biology or gender identity.

Commonwealth developments

1.63 Commencing on 1 August 2013,[67] Schedule 1 of the *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013* extends anti–discrimination protections under Commonwealth law to discrimination that occurs as a result of sexual orientation, gender identity, and intersex status.[68] For the purpose of Commonwealth anti–discrimination legislation, intersex is recognised as a biological characteristic; a product of a person's physical, hormonal and genetic features that are neither wholly female nor wholly male, are a combination of female and male, or are neither female nor male.[69] 'Intersex status' is defined separately from gender identity, recognising that intersex relates to an individual's biology.[70] 'Gender identity' is defined as 'the gender–related identity, appearance or mannerisms or other gender–related characteristics of a person (whether by way of medical intervention or not), with or without regard to the person's designated sex at birth.'[71]

1.64 Intersex persons are not required to identify as male or female in order to access anti–discrimination protections under Commonwealth law. However, the Australian Government has made clear that the anti–discrimination amendments do

67 *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Commencement Proclamation 2013*.

68 Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013, Explanatory Memorandum, p. 2.

69 *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013*, Schedule 1, item 7.

70 Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013, Explanatory Memorandum, p. 12.

71 *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013*, Schedule 1, item 6.

not establish a third gender category.[72] The amendments also do not have the effect of broadening the application of the *Marriage Act 1961*.[73]

1.65 The Australian Government has also committed to amending its administrative practice to recognise intersexuality in Commonwealth personal records. Published in July 2013, the *Australian government guidelines on the recognition of sex and gender*:

- define intersex as a "biological condition" linked to a person's biological sex but not necessarily a person's gender;
- outline the Australian Government's preferred approach to collecting information about gender rather than biological sex;
- establish three data recording options for biological sex and/or gender information, namely, M (male), F (female) and X (indeterminate/intersex/unspecified); and
- allow a person to request changes to the biological sex or gender information on their Commonwealth personal records - for proof of gender or biological sex, it will be sufficient to provide a valid Commonwealth travel document, a statement from a registered medical practitioner or an amended state or territory birth certificate.

1.66 The changes to Commonwealth administrative record-keeping practices will be introduced incrementally. All Commonwealth departments and agencies are expected to be fully compliant with the new guidelines by 1 July 2016.[74]

1.67 The *Australian government guidelines on the recognition of sex and gender* have implications for medical practice. The guidelines affirm that the 'necessity of a medical service or associated benefit should be determined by physical need, regardless of a person's recorded sex and/or gender.'[75] Consequently, the Australian Government has announced changes to the Medicare framework. All references to gender will be removed from the descriptions of the approximately 6000 clinical services covered by Medicare. Procedures will be described in detail in using anatomical rather than gender-based language. Patients will not be required to disclose their gender in order to access Medicare benefits, nor will patients be barred from accessing certain benefits on the basis of their gender identity. In announcing the changes, the government recognised that current gender identity requirements may be

72 Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013, Explanatory Memorandum, p. 12.

73 Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013, Explanatory Memorandum, p. 21.

74 Australian Government, *Australian government guidelines on the recognition of sex and gender*, July 2013, p. 8.

75 Australian Government, *Australian government guidelines on the recognition of sex and gender*, July 2013, p. 3.

discriminatory and inappropriate for 'intersex Australians, who may not wish to identify as any gender'.[76]

Australian Capital Territory reforms

1.68 In the Australian Capital Territory, there is growing recognition of the legal rights of transgender and intersex persons. While implementation of the reforms currently underway in the territory differs in certain respects to Commonwealth developments, the territory's reform share a commitment to increasing social and legal recognition of the rights of intersex persons.[77] In 2011, the Australian Capital Territory government commissioned an inquiry into the measures necessary to provide for the legal recognition of transgender intersex people in the ACT. Conducted by the Law Reform Advisory Council, the inquiry reported in June 2012. Recommendations were made, several of which relate to the recognition of intersex individuals. The ACT government responded in 2013 (Figure 1).

76 The Hon. Tanya Plibersek MP, Minister for Health, Minister for Medical Research; Senator the Hon. Jan McLucas, Minister for Human Services, *All Gender Discrimination to be Removed from Medicare*, Media release, 24 July 2013.

77 The Legislative Assembly for the Australian Capital Territory, *Beyond the binary: Legal recognition of sex and gender diversity in the ACT – Government response*, 2013, p. ii.

Figure 1: ACT Government response to ACT Law Reform Advisory Council's intersex recommendations

Recommendation	Government response
3. In ACT legislation, when necessary, specific reference should be made to 'intersex', and 'intersex person' and 'intersex people' to refer to people who, because of their physiological characteristics at birth, do not identify only as female or only as male.	The Government supports this recommendation in principle.
7. In the *Legislation Act 2001* in the definition of intersex, reference to a genetic condition as the reason for a person's intersex status is inappropriate, and it is sufficient to refer to the fact that intersex person's reproductive organs or sex chromosomes are not exclusively male or female.	The Government supports this recommendation.
11. The sex of the child when notified [under the *Births, Deaths and Marriages Registration Act 1997*] should be any of female, male, intersex, to be advised or indeterminate.	The Government supports this recommendation.
13. At the time that the sex of a child is notified as 'intersex' or 'to be advised', the parents and any health practitioners involved in caring for the child should be provided with printed information, advice and resources, developed in consultation with representatives of the intersex community and expert health practitioners, which explain intersex and set out considerations for decisions that can be made about the child's sex and gender identity.	The Government supports this recommendation in principle…The Government will review current policies and practices in this area to ensure that parents and health practitioners are provided with relevant information, advice and resources to provide adequate assistance in caring for the child.
19. When intersex person seek to change the record of sex on the [Births, Deaths and Marriages] register, whether to female, male or intersex, the person need only rely on medical confirmation of intersex status.	The Government supports this recommendation in principle. There is an accepted medical definition of 'intersex' that enables a medical practitioner to clearly identify a person as intersex. This recommendation will be considered further for change of sex.
29 & 30. In the ACT public sector, at least female, male or intersex should be used in all ACT government activity. Person should be asked for their 'sex and gender identity', and should be given the option of female, male, intersex or none of the above.	The Government supports these recommendations in principle.

Chapter 2
Intersex, not disordered

2.1 Does being intersex mean a person has a disorder? There are divisions amongst stakeholders around terminology, and these divisions reflect a range of values, but also the fact that the circumstances labelled 'intersex' encompass a wide range of medical conditions and genetic variations.

2.2 Intersexuality is often referred to, including by some participants in this inquiry, as representing 'disorders of sexual development' or DSD. However, intersex people themselves mostly reject this term,[1] as do some medical scholars in the field.[2] The World Health Organisation uses the term 'intersex' in general, but when describing specific components of intersex refers to them as 'disorders'.[3] The international Women and Gender Equity Knowledge Network uses 'intersex'.[4] The Commonwealth's Department of Health and Ageing concluded that the term disorders of sexual development 'is not generally favoured',[5] and intersex is the term used in Commonwealth law.[6] The Victorian Department of Health noted debate around the terminology and stated:

> Intersex was also endorsed as the preferred terminology by an expert advisory group of Victorian clinicians, with input from intersex community representatives, convened during the initial stages of development of this resource (Victorian Department of Human Services 2009). However, it is important to note that while individuals with intersex conditions may

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1 See, for example, Organisation Intersex International Australia, *Submission 23*; A Gender Agenda, *Submission 85*, p. 8; Androgen Insensitivity Syndrome Support Group Australia, *Submission 54*.

2 For example Milton Diamond, 'Intersexuality', in Erwin J. Haeberle (ed.), *Human Sexuality: An Encyclopedia*, 2006, http://www.hawaii.edu/PCSS/biblio/articles/2010to2014/2010-intersexuality.html#nonhuman (accessed 19 June 2013).

3 See for example World Health Organisation, Genomic resource centre, Gender and genetics: Genetic Components of Sex and Gender, http://www.who.int/genomics/gender/en/index1.html (accessed July 2013).

4 See for example Gita Sen, Piroska Östlin, and Asha George, *Unequal, Unfair, Ineffective and Inefficient Gender Inequity in Health: Why it exists and how we can change it?* Women and Gender Equity Knowledge Network, September 2007, http://www.who.int/social_determinants/resources/csdh_media/wgekn_final_report_07.pdf (accessed July 2013).

5 Commonwealth Department Health and Ageing, *National Lesbian, Gay, Bisexual, Transgender and Intersex Ageing and Aged Care Strategy*, 2012, p. 18.

6 *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013*.

> identify as intersex, not all do, nor might a person consider their condition to be an intersex condition, or indeed a 'condition' at all.[7]

2.3 Intersexuality is often described as a group of 'conditions'. The use of the term 'condition' can be difficult to avoid, but it may also be disliked as it is perceived to pathologise being intersex,[8] which can result in psychological harm.[9] The term 'disorder' is widespread in clinical settings, yet one analyst has concluded that the term 'dangerously pathologises' intersex individuals.[10]

2.4 Not everyone who is intersex has a health problem: whether they experience a 'disorder' is not defined by whether they are biologically 'intersex'. A person might have a form of Androgen Insensitivity Syndrome and present as having an uncommon physiology that appears neither completely female nor completely male, and they may or may not experience health issues. As the Swiss National Advisory Commission on Biomedical Ethics put it:

> not all cases of DSD involve a (pathological) "disorder", i.e. a functional impairment associated with suffering. Not infrequently, a case of DSD may involve a variation from a norm of sex development which does not require medical treatment. From the perspective of those affected, the term "disorder" may thus appear stigmatizing, and accordingly the term "differences of sex development" …has been proposed as an alternative in the literature. The Commission endorses this proposal.[11]

2.5 The history of the terminology is vexed. A 'Consensus Statement' was developed in 2006, based on work that occurred during an International Consensus Conference on Intersex. The meeting was of medical professionals, organised by the Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology.[12] The statement observed:

> Terms such as 'intersex', 'pseudohermaphroditism', 'hermaphroditism', 'sex reversal', and gender-based diagnostic labels are particularly controversial.

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7 Victoria. Department of Health, *Decision-making principles for the care of infants, children and adolescents with intersex conditions*, 2013, p. 2.

8 Commonwealth Department Health and Ageing, *National Lesbian, Gay, Bisexual, Transgender and Intersex Ageing and Aged Care Strategy*, 2012, p. 18.

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

10 Sarah S. Topp, 'Against the quiet revolution: The rhetorical construction of intersex individuals as disordered', *Sexualities*, Vol. 16, No. 1–2, 2013, p. 180.

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

12 Though two intersex advocates were also invited to participate, including Cheryl Chase, founder of Intersex Society of North America. See Katrina Karzakis, *Fixing Sex*, Duke University Press, Durham, 2008, p. 3.

> These terms are perceived as potentially pejorative by patients and can be confusing to practitioners and parents alike. [13]

2.6 The sole piece of published research cited by the authors of that Consensus Statement in support of this claim was a practice note in the BMJ, and comprised a case study of a single patient. The article, when reporting the outcome of a clinical interaction with that one patient, in fact stated:

> [the doctor] arranged for her to see a clinician with expertise in dealing with intersex conditions. She was initially extremely angry when told about her genotype, but knowing about it has led to a positive outcome. She continues to attend for regular follow up.[14]

2.7 This text does not support the contention in the Consensus Statement, as it does not link any particular term to the patient's reaction, nor does it shed light on why she was angry. Even if it did, the publication represents only a single patient interaction. The committee was not provided with, and was unable to locate, any published research to support the contention that the term intersex is regarded as pejorative.

2.8 It was suggested to the committee by the Australasian Paediatric Endocrine Group (APEG) that some 'patient groups in Australia find this term [intersex] pejorative and offensive, and do not want to be termed or referred to as "intersex"'.[15] The committee received no evidence of the term being found pejorative or offensive. There is a group of enzyme production deficiencies collectively known as congenital adrenal hyperplasia, and this is referred to as a 'disorder' on the website of peer support organisation Congenital Adrenal Hyperplasia Support Group Australia.[16] The website does not use the word 'intersex' but also does not indicate there is any issue with the term. Other support organisations in Australia, including Organisation Intersex International and the Androgen Insensitivity Syndrome Support Group, do not refer to intersex as a disorder.

2.9 APEG's policy position appears to reflect the 2006 Consensus Statement referred to above, but as the committee has noted, there is no evidence base to support the nomenclature used in that statement. In support of its position APEG also indicated that there has been a change in practice in North America, and noted the work of:

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13 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 19 June 2013).

14 Jennifer Conn, Lynn Gillam, and Gerard S. Conway, 'Revealing the diagnosis of androgen insensitivity syndrome in adulthood', *BMJ*, Vol. 331, 2005. http://www.bmj.com/content/331/7517/628.full?ijkey=e94755c1047020e887a5ac54fc2fe10c663b6b6f&keytype2=tf_ipsecsha (accessed 19 June 2013).

15 Australasian Paediatric Endocrine Group, *Submission 88*, p. 1.

16 Congenital Adrenal Hyperplasia Support Group Australia, What is CAH? http://www.cah.org.au/v2/index.php?option=com_content&view=article&id=46&Itemid=34 (accessed 20 June 2013).

> Patient support groups such as ISNA (Intersex Society of North America), which has now been renamed Accord Alliance following international disuse of the term 'intersex' to refer to all people with DSD.[17]

2.10 However, the archived website of ISNA does not link the name change to changing practice in terminology at all, but to strategic problems they faced as they sought to have the 2006 Consensus Statement implemented across the medical profession. It states in part:

> Unfortunately, ISNA is considerably hamstrung in being able to fulfill this role. Although it has been very successful in recent years in creating collaborative relationships (our participation in the Intersex Consensus Group and authorship of the influential DSD Guideline handbooks being our most salient examples), there is concern among many healthcare professionals, parents, and mainstream healthcare system funders that ISNA's views are biased or that an association with ISNA will be frowned upon by colleagues and peers. And there is widespread misinformation about ISNA's positions.
>
> For ISNA and many of our collaborators, this has been extraordinarily frustrating and has hindered our ability to champion and move forward in this important work.
>
> We believe the most fruitful way to move beyond the current dynamic is to support a new organization with a mission to promote integrated, comprehensive approaches to care that enhance the overall health and well-being of persons with DSDs and their families.[18]

2.11 The proposed change in organisational name was controversial amongst intersex people, and in responding to those concerns, ISNA explained that the main reason to change was to do with dealing with the medical profession and parents:

> It's not our intention to make intersex an entirely medical issue. But we are addressing people working in a medical context. We have found that the word DSD is much less charged than 'intersex', and that it makes our message of patient-centered care much more accessible to parents and doctors. Our aim is to meet them where they are.[19]

2.12 The new organisation, Accord Alliance, has a clinical focus, strong medical representation amongst its advisory board, and all discussion of terminology on its website is in a clinical or medical context, rather than having a social, consumer or advocacy focus.[20] ISNA's comments, and the nature of the Accord Alliance, are

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17 Australasian Paediatric Endocrine Group, *Submission 88*, p. 1.

18 Intersex Society of North America, Dear ISNA Friends and Supporters, 2008, http://www.isna.org/farewell_message (accessed 28 June 2013).

19 Intersex Society of North America, Why is ISNA using "DSD"? 2006, http://www.isna.org/node/1066 (accessed 28 June 2013).

20 See for example, Accord Alliance, Frequently Asked Questions about: terminology and frequency, http://www.accordalliance.org/learn-about-dsd/faq.html#faqh2 (accessed 28 June 2013).

consistent with the research of Katrina Karkazis, who observed that in North America 'all indications signal that the shift to DSD has deeply angered some individuals, but has pleased a great deal of parents and clinicians'.[21]

2.13 The failure of this proposed new terminology to gain widespread acceptance is reflected in the fact that the Accord Alliance now exists alongside other advocacy and support organisations that reject the DSD terminology, Organisation Intersex International USA,[22] and at least one other support organisation likewise preferring the term intersex.[23] The committee is unaware of any not-for-profits (other than Accord Alliance) in the specific area that prefer DSD to intersex. Other organisations that touch on intersex issues also appear to prefer the term intersex.[24]

2.14 Academic Georgiann Davis interviewed intersex people, parents and doctors as part of a research project on intersexuality in the sociology of medicine. She concluded:

> Medical professionals needed to maintain their authority in the face of intersex activism, and they did so linguistically through a reinvention of the intersex diagnosis. The new DSD terminology constructs "sex" as a scientific phenomenon, and a binary one at that…This places intersexuality neatly into medical turf and safely away from critics of its medicalization.[25]

2.15 Sociologist Alyson Spurgas reached a similar conclusion:

> Many intersex activists feel particularly torn, as they identify as intersex, but recognise the pragmatism in aligning with physicians toward the goal of medical reform, and thus with using the term DSD…
>
> many people who identify as intersex yet understand the strategy in using DSD are interested not only in preserving the well-being of intersex children, but also in preserving the psychic comfort of parents who may be more capable of dealing with their male or female child being born with a disorder than with learning that their child is intersex…
>
> Many actors invested in the debate, including intersex individuals and clinicians, accept the DSD terminology only as temporary or transitional…Many of the problems regarding DSD for activists who reject this terminology are exacerbated by the fact that the new nomenclature [of DSD] does not translate well into other languages and this reflects that the

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21 Katrina Karzakis, *Fixing Sex*, Duke University Press, Durham, 2008, p. 259.

22 Organisation Intersex International USA, http://oii-usa.org/ (accessed July 2013).

23 Bodies Like Ours, http://www.bodieslikeours.org/ (accessed July 2013).

24 See for example, Advocates for Informed Choice, http://aiclegal.org/ (accessed July 2013); Amnesty International Australia, http://www.amnesty.org.au/features/comments/32251/ (accessed July 2013); National LGBTI Health Alliance, http://www.lgbthealth.org.au/ (accessed July 2013).

25 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. 178.

shift itself was an unequivocally North American (specifically U.S. enterprise.[26]

Discussion

2.16 It concerns the committee that there appears to be no evidence to support the position taken on appropriate terminology by the 2006 'Consensus Statement'.

2.17 The committee does sometimes use the term 'disorder' or DSD in this report, particularly when discussing certain medical issues, but notes that for many in the intersex community this is not the preferred or appropriate term in most contexts. The committee has sought to limit its use of the term DSD to those contexts in which therapeutic medical treatment is being discussed by literature that uses the term. In general discussion and in policy documents, the committee endorses the position of the Commonwealth Department of Health and Ageing, the Victorian Department of Health, and Organisation Intersex International, that 'intersex' should be the preferred terminology. This terminology has also now been adopted in Commonwealth Government guidelines to be applied by all Commonwealth agencies.[27]

2.18 The committee acknowledges that difficulty occasionally arises where people, particularly patients, are not comfortable with a term. It certainly does not suggest that patients should be required to use or be subject to terminology they find distressing. Nevertheless, the evidence before this committee is clear that the default term should be 'intersex'.

2.19 The committee notes an alternative term 'differences of sexual development', used by Diamond, Wiesemann and others working in relevant medical fields. This would appear potentially appropriate in clinical and biological research, when discussing the range of biological conditions that are commonly gathered under the umbrella of the DSD acronym.[28] For specific cases, the committee notes the opinion

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26 Alyson Spurgas, '(Un)Queering Identity: The Biosocial Production of Intersex/DSD', in Morgan Holmes (ed.), *Critical Intersex*, Ashgate Publishing, 2009, pp 110–111.

27 Australian Government, *Australian Government Guidelines on the Recognition of Sex and Gender*, July 2013, http://www.ag.gov.au/Publications/Documents/AustralianGovernmentGuidelinesontheRecognitionofSexandGender/AustralianGovernmentGuidelinesontheRecognitionofSexandGender.PDF (accessed July 2013).

28 Milton Diamond, 'Clinical implications of the organizational and activational effects of hormones', *Hormones and Behavior*, Vol. 55, 2009, p. 625; Milton Diamond and Hazel Beh, 'Changes in the management of children with intersex conditions', *Nature Clinical Practice Endocrinology and Metabolism*, Vol. 4, No. 1, 2008, p. 5; Sarah S. Topp, 'Against the quiet revolution: The rhetorical construction of intersex individuals as disordered', *Sexualities*, Vol. 16, No. 1–2, pp 180–194; C. Wiesemann, S. Ude-Koeller, G.H. Sinnecker, U. Thyen, 'Ethical principles and recommendations for the medical management of differences of sex development (DSD)/intersex in children and adolescents'. *European Journal of Pediatrics*, Vol. 169, 2010, pp 671–679.

of the Intersex Society of North America, that 'it is much better for everyone involved when specific condition names are used in medical research and practice'.[29]

Recommendation 1

2.20 The committee recommends that governments and other organisations use the term 'intersex' and not use the term 'disorders of sexual development'.

Recommendation 2

2.21 The committee recommends that health professionals and health organisations review their use of the term 'disorders of sexual development', seeking to confine it to appropriate clinical contexts, and should use the terms 'intersex' or 'differences of sexual development' where it is intended to encompass genetic or phenotypic variations that do not necessarily require medical intervention in order to prevent harm to physical health.

2.22 The committee noted APEG's observation that:

> We acknowledge that all individuals with DSD should be referred to in the manner in which they identify with regard to their gender. This includes those who identify as male or female and who do not identify as intersex… we acknowledge that some prefer not to use medical terminology.[30]

2.23 The committee agrees, noting that biology and identity are separate things. Many[31] (possibly most) intersex people identify as male or female. Medical guidelines actively encourage the assignment of a sex (and by implication identity) to intersex children. This reflects an insistence, both within medicine and in broader society, on defining gender in binary terms. The assignment or development of a person's gender identity does not change their basic biology.

2.24 No matter what an intersex person's gender identity, they should and do have access to anti-discrimination protection on the basis of that biology. The committee supports the approach taken by the Senate Legal and Constitutional Affairs Committee, endorsed by OII, stating that an intersex person should not have to identify as male or female in order to have protection from sex discrimination. The committee endorses the conclusion of the Senate Legal and Constitutional Affairs Committee inquiry, that for the purposes of preventing discrimination, 'intersex' should be defined in biological terms, since identity is not at issue when intersex people encounter discrimination:

> *intersex* means the status of having physical, hormonal or genetic features that are:

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29 Intersex Society of North America, Frequently Asked Questions, http://www.isna.org/faq/printable (accessed 22 July 2013).

30 Australasian Paediatric Endocrine Group, *Submission 88*, p. 1.

31 Gina Wilson, 'Making the Invisible Visible: Intersex Rights are human rights which should be protected under new equality laws', Equality law reform project, Human Rights Law Centre, 2012, http://www.equalitylaw.org.au/elrp-guest-blogs/making-the-invisible-visible-intersex-rights-are-human-rights-which-should-be-protected-under-new-eq (accessed 22 July 2013).

(a) neither wholly female nor wholly male; or

(b) a combination of female and male; or

(c) neither female nor male.[32]

2.25 The committee notes that this approach was accepted and is now enshrined in Commonwealth law.[33]

What are the particular challenges for intersex people?

2.26 Some intersex people can face significant health issues that require treatment, which may include hormone-based therapy or surgery. Others do not require medical intervention. All however experience a range of challenges and problems, and can experience discrimination. Some of these experiences are similar to those of people with disability, described in chapter 2 of the committee's report on involuntary or coerced sterilisation of people with disabilities. Others are specifically the result of a person's intersexuality.

2.27 The challenges begin with the requirement that a newborn child be identified and registered as either a boy or a girl. There are some cases where it is difficult, if not impossible, to immediately determine sex, but administrative systems in hospitals and in government are based on sex being reported. Medical practice also widely recommends that an intersex child always be assigned a gender:

> Optimal clinical management of individuals with DSD should comprise the following:
>
> - gender assignment must be avoided before expert evaluation in newborns;
> - all individuals should receive a gender assignment;…
>
> Initial gender uncertainty is unsettling and stressful for families. Expediting a thorough assessment and decision is required. Factors that influence gender assignment include the diagnosis, genital appearance, surgical options, need for life long replacement therapy, the potential for fertility, views of the family, and sometimes the circumstances relating to cultural practices.[34]

2.28 As noted above, OII (and the Intersex Society of North America) also recommend gender assignment, though at least in part this is because of the stigmatising experience of intersex children.

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32 Senate Legal and Constitutional Affairs Committee, *Report on Exposure Draft of the Human Rights and Anti-Discrimination Bill 2012*, 21 February 2013, para 7.21.

33 *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 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, pp 490–491, http://pediatrics.aappublications.org/content/118/2/e488.full#xref-ref-2-1 (accessed 19 June 2013).

2.29 If a person is not assigned a sex, difficulties can ensue, beginning with family and friends' questions about the new child, through bureaucratic hurdles of school and social security systems, until the person may eventually be advised that they are unable legally to marry because they are not officially male or female,[35] or even have a marriage dissolved because one party's intersex status rendered them ineligible under the law.[36]

2.30 The lack of public understanding of intersex, and the stigmatisation that can easily arise from being different, can drive a person to conceal their intersexuality, with detrimental consequences:

> We have members of our support group who have not even told their partners that they have an intersex condition. Getting information to them is almost impossible. For example, you would not send a newsletter to their address. They would have to catch up with a friend and get information that way because the shame and stigma is so intense that they cannot even tell their partner—'What would my partner think if they knew that I had testes or that I am 46,XY?'[37]

2.31 Given the many social, medical and administrative pressures, a child's intersexuality can cause confusion and anxiety for parents in a binary sex world, encouraging them to insist that their child quickly be assigned a sex consistent with a binary classification of male and female.[38] As one doctor reported during a United States study, 'The stress is "what's the sex of the baby?" The parents will *not* tolerate no sex assignment. I feel like I need to give them a sex assignment within a week'.[39] Parents may face considerable pressures at the time their child is born:

> right now, parents are legally able to represent the best interests of children, but, as you have already heard, parents are confused; they are stressed out; they do not know. When a doctor tells them, 'Look, my medical opinion is that you've got to do this right away,' a lot of times they do not even give parents time to think about it. Those parents will do what they believe is in

35 Councillor Tony Briffa, Committee Member, Androgen Insensitivity Syndrome Support Group Australia, *Committee Hansard*, 28 March 2013, p. 5.

36 Gina Wilson, 'Equal Rights for Intersex People', *The Equal Rights Review*, Vol. 10, 2013, p. 138.

37 Councillor Tony Briffa, Committee Member, Androgen Insensitivity Syndrome Support Group Australia, *Committee Hansard*, 28 March 2013, p. 4.

38 Katrina Karzakis, *Fixing Sex*, Duke University Press, Durham, 2008, p. 98; Swiss National Advisory Commission on Biomedical Ethics, *On the management of differences of sex development: Ethical issues relating to 'intersexuality'*, Opinion No. 20/2012, Berne, November 2012, pp 9–10; Human Rights Commission of the City and County of San Francisco, *A Human Rights Investigation into the Medical 'Normalization' of Intersex People*, San Francisco, April 2005, p. 18; C. Wiesemann, S. Ude-Koeller, G.H. Sinnecker, U. Thyen, 'Ethical principles and recommendations for the medical management of differences of sex development (DSD)/intersex in children and adolescents'. *European Journal of Pediatrics*, Vol. 169, 2010, p. 674.

39 Cited in Katrina Karzakis, *Fixing Sex*, Duke University Press, Durham, 2008, p. 98.

> the best interest of the child based on medical advice. So, in some ways, it is not only about protecting young people, adolescents and adults; it is also about protecting parents from irreversible decisions that they will later regret.[40]

Intersex and medical treatment

2.32 For intersex people, the greatest challenges can arise in the medical field, and much of the remainder of this report is concerned with health care and medical intervention in intersex. There have been significant advances in the treatment of the medical aspects of intersex. There have also been improvements in the protocols guiding such work. Nevertheless there remain significant issues, particularly in relation to 'normalising' genital surgery, the removal of gonadal tissue, and the over-medicalization of intersex.[41]

2.33 Tony Briffa, a member of Androgen Insensitivity Syndrome Support Group Australia, described the role of professionals in guiding proposed surgery when Tony was a child in the late 1970s:

> I had my testes removed when I was seven, so I was raised as a girl. They decided that I could not have testes because I am a girl and they finally convinced my mother to approve me to be castrated. My mother was so convinced not to go through this—my mother is a devout Catholic; I am a fallen Catholic—and she decided that, if God made me like this, God can take it away—'This is the way God meant for her to be.' The doctors were not very happy with that response and booked me in for surgery when I was seven. Mum got to the hospital, changed her mind and took me back home. Would you believe—you would not get this sort of medical treatment anywhere for any other condition—the doctors turned up at my parents' place that night to convince my parents that the surgery should continue, that God had given them the knowledge to treat me and therefore they should continue with the surgery.
>
> I have a few pages here from my medical records…It says: 'Mother now ready for gonadectomy.' I would like to submit those pages. It had taken a number of years to be convinced, but finally my mother was 'ready', they said to the medical profession…
>
> Senator BOYCE: How old were you when your mother was 'ready'?
>
> Councillor Briffa: I was seven. They knew what they were doing. They did a biopsy well beforehand. In fact, they did a biopsy when I was a couple of months old. They worked out there were testes. The histology reports, which I will also tender, show that they were healthy testes. But there was no Family Court approval. If we are talking about coercion, doctors coerce

40 Mr Gavi Ansara, Health Policy Officer, National LGBTI Health Alliance, *Committee Hansard*, 28 March 2013, p. 6.

41 See, for example, Katrina Karzakis, *Fixing Sex*, Duke University Press, Durham, 2008, pp 3–5.

> families, parents, into believing by saying: 'We need to remove these testes because it will make your child normal.'[42]

2.34 While this case was three decades ago, Tony Briffa also provided an account of more recent cases similar in nature:

> I can tell you about another member of our support group who had a daughter with AIS. Like most people, she had never heard of AIS. She had never heard of an intersex condition. The child was born with grade 4 or grade 5 AIS and so was born looking ambiguous. The doctors were not sure if the child was a boy or a girl. But a decision was made pretty quickly that they would raise the child as a girl. The mother was still in hospital having given birth when doctors convinced her to agree to have the child castrated and have the testes removed. We are not talking about a long time ago either. We are talking about a matter of eight years ago in the state [Queensland] you represent, Senator …She was not given any information back then. The only information she was given at the time was, 'We can make this better. Let's do this now. The sooner we do this the better.'…
>
> We have another member of the support group whose child was born coincidentally not only with AIS but with a cleft palate. I can tell you that when the child was born the parents were put in touch with the cleft palate support group but not with us. She was given literature about cleft palates and all the options available to her but nothing about her child's intersex condition.[43]

2.35 While early surgical intervention was standard, the views subsequently expressed by those who were the subjects of those treatments are varied, some positive, and some not; some of the published research in this area is discussed in more detail in the next chapter.

2.36 Mr Ansara explained that concern or trauma resulting from early medical experiences can have broader consequences:

> What you see is that a lot of intersex people do not seek medical care even when emergency treatment is needed, because they are so afraid of further medical abuse. For myself, I had some medical treatments done to me nonconsensually that I, frankly, never talk about because it just is not safe, and there are many people who will avoid medical treatment on that basis.[44]

2.37 Health research confirms that there are broader issues with the protection of intersex people in health care contexts. They frequently report 'being touched and

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

43 Councillor Tony Briffa, Committee Member, Androgen Insensitivity Syndrome Support Group Australia, *Committee Hansard*, 28 March 2013, p. 4.

44 Mr Gavi Ansara, Health Policy Officer, National LGBTI Health Alliance, *Committee Hansard*, 28 March 2013, p. 6.

examined in the genital region for medical purposes against their will'.[45] They may be subject to experimental assessment that creates significant ethical issues.[46]

2.38 The treatment of intersex through surgery that removes gonadal tissue may be sterilising. It also may reduce future options for fertility, even though those options may not currently be available:

> some doctors—perhaps many doctors—will say that sterilisation is not an issue because intersex people are sterile or are mainly sterile. That may be the case at the time, but to remove someone's gonads at one point in time, assuming that there will never be medical advances that will allow that person to reproduce, whether it is through IVF or something similar, is pretty myopic.[47]

Conclusion

2.39 Intersex is a form of biological variation in animals, including humans. Some of the variations in human genes and bodies require medical intervention to ensure health and an ability to grow and function. Others do not. Some genetic variation may produce individuals who appear different, and that difference might also be associated with an increased health risk: the relatively rare recessive gene associated with red hair (and associated elevated risk of skin cancer) is an example.[48] The genes associated with the various forms of intersex are other examples.

2.40 Our society expects a particular anatomy to come with a particular identity, but this is not how nature works. Genes and anatomy are variable, and identity is a social construct. Medical intervention that seeks to try to match anatomy to identity is a risky proposition that can produce a range of problems such as those described by witnesses to this inquiry and others. At the same time failure to intervene, to address physiological or hormonal problems that risk serious illness, can also be a risky – even life-threatening – proposition. Appropriate medical care for intersex people must balance these matters appropriately. The committee has received evidence that health care professionals are working hard to balance priorities, but that there is still some way to go.

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45 Karsten Schützmann, Lisa Brinkmann, Melanie Schacht and Hertha Richter, 'Psychological Distress, Self-Harming Behaviour, and Suicidal Tendencies in Adults with Disorders of Sex Development', *Archives of Sexual Behaviour*, Vol. 38, No. 1, 2009, p. 20.

46 See, for example, Alice Dreger, 'The Dex Diaries, Part 9: The Real Silent Majority', 30 October 2013, *Psychology Today*, http://www.psychologytoday.com/blog/fetishes-i-dont-get/201210/the-dex-diaries-part-9-the-real-silent-majority (accessed July 2013).

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

48 J.L. Rees and N. Flanagan, 'Pigmentation, melanocortins and red hair', *QJM: An International Journal of Medicine*, Vol. 92, No. 3, 1999, pp 125–131; Kerri Smith, ' Redhead pigment boosts skin-cancer risk', *Nature News*, 2012, 11711, http://www.nature.com/news/redhead-pigment-boosts-skin-cancer-risk-1.11711 (accessed July 2013).

2.41 The history of the development of advocacy groups by and for intersex people is, in many ways, analogous to that for people with a disability. Both groups have sought to dislodge the primacy of the prevailing medical perspective which perceives them as 'problems' to be 'solved' by medical professionals using science, rather than as people with the right to control their lives, and choose the services they use.

2.42 The remainder of this report examines the various issues – of identity, medicine and law – associated with medical intervention in the bodies and lives of intersex people, and in particular those interventions that modify genitalia and reproductive tissue.

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'.[1] 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'.[2] 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.[3] However, this was not an approach universally adopted. What was always accepted, though, was that a person had to be assigned a single sex.[4] 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.[5]

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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.

The 'optimal gender policy'

3.7 The committee was advised that surgery as a standard response to intersexuality commenced in the mid–20th century.[6] 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.[7]

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.[8]

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.[9]

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.[10] 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.[11]

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.[12]

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.[13]

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'.[14]

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.[15]

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.[16] 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…[17]

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…[18]

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.[19]

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.[20]

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.[21] 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'.[22]

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',[23] 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[24] 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)[25] 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.[26]

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.[27] 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.[28]

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].[29]

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.[30]

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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'.[31]

Current approaches

The 2006 Consensus Statement

3.27 Medical practitioners emphasised that the medical response to intersex conditions has changed since the 1990s.[32] 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.[33]

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.'[34] 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'.[35]

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'.[36] 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.[37]

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.'[38] 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'.[39] The statement provides further guidance for other kinds of intersex conditions, including 5-α-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).

(5αRD2)-deficiency, 17β-hydroxysteroid dehydrogenase deficiencies and partial androgen insensitivity syndrome.[40]

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.[41]

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'.[42]

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.[43] 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.[44] 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.[45]

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[46]

3.37 The Victorian decision-making guide expressly states that gender assignment 'does not necessitate surgery or other medical treatment.'[47] 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'.[48]

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.[49]

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.[50]

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

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.[51] Victorian hospitals are also encouraged to engage with intersex support groups.[52]

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.[53]

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.[54]

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

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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.

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'.[56] 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.[57]

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.[58]

3.48 Cosmetic surgery continues to be performed on children who are intersex.[59] 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.[60]

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'.[61] 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.[62]

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.[63]

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.[64]

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.[65]

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.[66]

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

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.[68] 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'.[69] Reported physical complications include insensate genitalia, reduced sexual enjoyment, sterilisation, scarification and osteoporosis.[70]

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.[71]

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.[72]

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).[73]

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.[74]

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.

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

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.[76] 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.[77] The committee was advised, however, that other studies produced different results.[78]

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.[79]

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…[80]

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.[81]

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'.[82]

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,[83] 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,[84] 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[85] as adults, and a small number wanted to undergo sex change surgery.[86]

3.69 Claims are sometimes made that outcomes studies may reflect outdated medical practice,[87] and that medical treatment has changed.[88] The committee recognises that there have been significant developments in surgical techniques applied to some forms of intersex.[89] 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.[90] In some cases, these claims have been directly rebutted by other studies.[91] The committee accepts that an experienced specialist working in a team care environment may achieve very good results,[92] but also notes the observation made by OII, that the

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'.[93]

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.[94]

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',[95] 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.[96]

Another researcher in 1999 likewise suggested that concerns were being raised by an unhappy minority.[97]

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

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.[98]

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.[99]

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.[100]

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.[101]

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![102]

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.[103]

'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

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.[104]

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.[105] 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.[106] 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

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.[107]

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.[108] Gender assignment surgeries without the person's consent were characterised as 'well-intentioned but medically unsound violations of basic human rights'.[109]

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'.[110] 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.[111]

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.[112]

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'.[113] 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'.[114] 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.[115]

3.88 Several witnesses considered non-consensual gender assignment surgery to be analogous to FGM, which is legally prohibited.[116]

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.[117]

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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 5th 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 5th 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 5th 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.[118]

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.[119]

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

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.[120]

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.[121]

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,[122] 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.[123]

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

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.[124]

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.[125] 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'.[126] 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 (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.[127]

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.[128]

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.[129] 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.[130] 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 ($P < 0.01$).[131]

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.[132]

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[133] 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

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.[134]

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.[135] 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'.[136] 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. [137]

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.[138]

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.[139] 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.[140] 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.[141] 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,[142] 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

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.[143]

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.[144]

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'.[145] 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.[146]

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.[147]

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143 Intersex Society of North America, Tips for Parents, 2004, 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[148] 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.[149]

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.

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.[150]

3.115 Some other submitters endorsed this approach.[151]

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.[152]

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.[153]

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.[154] 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).[155]

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'.[156]

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'.[157] 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.[158]

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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 Frisén, 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 Frisén, 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'.[159]

3.124 The multidisciplinary team based in Melbourne endorsed the need for specialist team-based care,[160] 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.[161] 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.[162] Policies

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

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.

Chapter 4
Intersex and cancer

Introduction

4.1 Some intersex conditions present an elevated risk of gonadal cancer (cancer in the tissue that forms testes or ovaries). There are different kinds of cancer, and the main risk in intersex people is presented by what are called type-II germ cell tumours (GCT).[1] Removal of gonadal tissue, called gonadectomy, may be an appropriate treatment to manage the risk. The cancer risks however are complex and in some cases poorly understood. The chance that gonads will develop cancer depends on several variables, and the stage in life at which the risk becomes significant varies depending on the type of intersex (though there is limited information available about this).[2] Removal of gonads in infancy is sometimes recommended in order to nullify the risk of cancer, but this potentially conflicts with the principle of avoiding irreversible surgery on a child unless necessary, to allow the person an opportunity to make their own decisions regarding their medical treatment.[3] In some cases retention of gonads is also desirable to preserve natural hormone production.[4]

4.2 It was reported to the committee that there is a trend toward fewer removals of gonads during infancy as a result of changed approaches to intersex.[5] This is a positive development, but it does mean that more attention now needs to be paid to the health risks – particularly the tumour risk – that may arise from those gonads being retained.

4.3 As was noted in chapter 1, some intersex people are fertile, and others are not. It depends on the type of intersex variation a person has, as well as on the specifics of their case. Removal of gonads in many cases would not be sterilising, because they would not be fertile in the first place. In some cases, however, gonads may be fertile, or may contain tissue that could allow fertility as a result of future advances in

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1 J.W. Oosterhuis and L.H. Looijenga, 'Testicular germ-cell tumours in a broader perspective', *Nature Reviews Cancer*, Vol. 5, 2005, pp 210–222.

2 See also Martine Cools, Arianne Dessens, Stenvert Drop, Jacqueline Hewitt and Gary Warne, Answers to questions on notice, received 27 September 2013.

3 Martine Cools, Stenvert L.S. Drop, Katja P. Wolffenbuttel, J. Wolter Oosterhuis and Leendert H.J. Looijenga, 'Germ cell tumors in the intersex gonad: old paths, new directions, moving frontiers', *Endocrine Reviews*, Vol. 27, No. 5, 2006, p. 468.

4 M. Cools, J. Pleskacova, H. Stoop, P. Hoebeke, E. Van Laecke, S.L.S. Drop, J. Lebl, J.W. Oosterhuis, L.H.J. Looijenga, K.P. Wolffenbuttel, and the Mosaicism Collaborative Group, 'Gonadal pathology and tumor risk in relation to clinical characteristics in patients with 45,X/46,XY mosaicism', *Journal of Clinical Endocrinology & Metabolism*, Vol. 96, No. 7, 2011.

5 Australasian Paediatric Endocrine Group, *Submission 88*, p. 2.

medicine. As some decisions to remove gonads are made shortly after birth, this means removal occurs 20 to 40 years before the person might seek to have children – a very long period over which to predict what advances in medicine might occur.

4.4 It is certainly the practice of some specialists to avoid removing potentially fertile tissue wherever possible.[6] This reflects the 2006 Consensus Statement position that 'surgical management of DSD should also consider options that will facilitate the chances of fertility'.[7]

4.5 The main issues raised during the inquiry concerned the estimation of cancer risk, and the way in which medical intervention relies on assessment of those risks. Because there was disagreement amongst participants in the committee's inquiry regarding the levels of cancer risk in intersex people, and appropriate medical responses to those risks, the committee considered in more detail the published research that lies behind this discussion. This chapter explains how cancer risks and diagnostic techniques have been set out in the medical literature. An important part of this discussion involves a table of information that is reproduced in different forms in many publications, and which appeared to be the source of some of the problems that have emerged during debate about gonadectomies in intersex people.

Reviews and clinical recommendations in the medical literature

4.6 Beginning in 2005, a team of researchers largely based in Rotterdam in the Netherlands published a series of articles and reviews regarding the nature, diagnosis and treatment of germ cell tumours in intersex people. Throughout the literature, the discussion is of different 'disorders of sexual development' (DSD), and for consistency of reference to the literature, that terminology will frequently be used in this section of the report. The work of the Dutch team has been pivotal in improving the understanding and management of gonadal cancer in intersex people.

4.7 In 2006, the group published a key review of evidence, titled 'Germ cell tumors in the intersex gonad: old paths, new directions, moving frontiers'. This paper assembled evidence from over a hundred studies in the field, and made a number of contributions, including:

- A proposal that both the classification and terminology associated with DSD be revised;
- A synthesis of data, leading to a summary of 'the estimated germ cell tumor prevalence in patients with DSD', according to the type of DSD;
- A new test and diagnostic approach, to reduce over-diagnosis of cancer or cancer risk in some patients;

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

7 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).

- A new classification model for patient risk, based on morphology and histology; and
- A table ('the 2006 table') that set out a 'summary of the risk of germ cell malignancy in the various forms of DSD, subdivided into high, intermediate, low and possibly no risk' including a column describing 'action needed'.[8]

4.8 It was this table and its subsequent incarnations that featured regularly thereafter in publications, including in submissions to the current inquiry. The 2006 table is reproduced in full, below:

8 Martine Cools, Stenvert L.S. Drop, Katja P. Wolffenbuttel, J. Wolter Oosterhuis and Leendert H.J. Looijenga, 'Germ cell tumors in the intersex gonad: old paths, new directions, moving frontiers', *Endocrine Reviews*, Vol. 27, No. 5, 2006, pp 468–484.

TABLE 7. Summary of the risk of germ cell malignancy in the various forms of DSD, subdivided into high, intermediate, low, and possibly no risk

Risk group	Disorder	Risk (%)	Action needed	No. of studies	No. of patients
High	GD[1](+Y)[2]intra-abd	15–35	Gonadectomy[3]	12	>350
	PAIS nonscrotal	15	Gonadectomy[3]	3	80
	Frasier	60	Gonadectomy[3]	1	15
	Denys-Drash (+Y)	40	Gonadectomy[3]	1	5
Intermediate	Turner (+Y)	12	Gonadectomy[3]	11	43
	17β-HSD	28	Watchful waiting and possible biopsy	2	7
Low	CAIS	0.8	Biopsy[4] and possible irrad/gonadectomy	3	120
	Ovotest. DSD	3	Testicular tissue removal in case of ♀ rearing?	3	426
	Turner (−Y[5])	1	None	11	557
Unknown[6]	5α-Reductase	0	Unresolved	1	3
	Leydig cell hypoplasia	0	Unresolved	1	2
	GD (+Y)[2] scrotal	Unknown	Biopsy[4] and irrad?	0	0
	PAIS scrotal gonad	Unknown	Biopsy[4] and irrad?	0	0

Recommended actions are indicated, as well as the number of studies and patients included in the survey. In case of PAIS, 17β-HSD, and ovotestis, the decision regarding gonadectomy is largely determined by sex of rearing. Relevant data from the recently published study by Hannema *et al*. (107) are not included in this table because it is at present unclear to us to what extent patient series from this study show overlap with patient series from a previously published study by the same group (117). Intra-abd, Intraabdominal located gonad; nonscrotal, nonscrotally located gonad; scrotal, scrotally located gonad; irrad, local irradiation with 18 Gy; ovotest. DSD, formally ovotestis (true hermaphrodite).

1 GD (including not further specified, 46XY, 46X/46XY, mixed, partial, complete).

2 GBY region positive, including the TSPY gene.

3 At time of diagnosis.

4 At puberty, allowing investigation of at least 30 seminiferous tubules, preferential diagnosis based on OCT3/4 immunohistochemistry.

5 PCR detection of Y-chromosomal sequences (in particular the GBY region) is implicated if a marker is identified by karyotyping.

6 Based on current knowledge (single study including limited number of patients, or no studies reported at all).

4.9 A version of this table also appeared in the 2006 'Consensus Statement on management of intersex disorders' (discussed in chapter 2). There are however some significant differences between the versions of the table. Compared to the table above, in the 2006 Consensus Statement version of the table:[9]

9 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, p. 493.

- Two of the disorders – gonadal dysgenesis (GBY region positive, including the TSPY gene) with scrotally located gonad; and partial androgen insensitivity syndrome with scrotally located gonad – have been moved from the 'unknown' or 'possibly no' risk category, and placed in the 'intermediate risk' group;
- The 'unknown' risk category is re-titled 'no(?)' risk;
- In the case of partial androgen insensitivity syndrome (PAIS) with non-scrotally located gonad, it appears one of the three studies used to provide an estimate has been omitted, reducing the number of patients from 80 to 24, and significantly increasing the estimated risk, from 15 per cent to 50 per cent;
- In the case of complete androgen insensitivity syndrome (CAIS), it also appears one of the three studies used to provide an estimate has been omitted, reducing the number of patients from 120 to 55, and increasing the estimated risk, from 0.8 per cent to 2 per cent;
- The main footnote, with its explanation for recommended action in the case of PAIS, 17β-HSD, and ovotestis, is omitted;
- The proposed action for CAIS is changed from 'Biopsy and possible irrad/gonadectomy' to 'Biopsy and ???';
- The proposed action for Ovotesticular DSD is changed from 'Testicular tissue removal in case of ♀ rearing?' to ' Testicular tissue removal?'; and
- The last two footnotes are omitted.

4.10 There were two main effects of these changes. First, they increased the apparent level of cancer risk of some intersex conditions. Second, they removed explanation of the table's content regarding links between the preferred course of action and the chosen sex of rearing, but without removing or modifying the courses of action based on those explanations.

4.11 A 2007 paper by the research team, titled 'Tumor risk in disorders of sex development',[10] contained a table substantively identical to that in the 2006 consensus statement. The table (as reproduced in one of the committee's submissions) is reproduced below:

10 Leendert H.J. Looijenga, Remko Hersmus, J. Walter Oosterhuis, Martine Cools, Stenvert L.S. Drop and Katja P. Wolffenbuttel, 'Tumor risk in disorders of sex development (DSD)', *Best Practice & Research Clinical Endocrinology & Metabolism*, Vol. 21, No. 3, 2007, pp 480–495.

Risk group	Disorder	Malignancy risk (%)	Recommended action	Studies (n)	Patients (n)
High	GD[a] (+Y)[b] intra-abdominal	15–35	Gonadectomy[c]	12	>350
	PAIS non-scrotal	50	Gonadectomy[c]	2	24
	Frasier	60	Gonadectomy[c]	1	15
	Denys–Drash (+Y)	40	Gonadectomy[c]	1	5
Intermediate	Turner (+Y)	12	Gonadectomy[c]	11	43
	17β-HSD	28	Monitor	2	7
	GD (+Y)[c]	Unknown	Biopsy[d] and irradiation?	0	0
	PAIS scrotal gonad	Unknown	Biopsy[d] and irradiation?	0	0
Low	CAIS	2	Biopsy[d] and ???	2	55
	Ovotestis DSD	3	Testis tissue removal?	3	426
	Turner (– Y)	1	None	11	557
No (?)	5α-reductase	0	Unresolved	1	3
	Leydig cell hypoplasia	0	Unresolved	2	

CAIS, complete androgen insensitivity syndrome; 17β-HSD, 17β-hydroxysteroid dehydrogenase deficiency; PAIS, partial androgen insensitivity syndrome.
[a] Gonadal dysgenesis (including not further specified, 46XY, 46X/46XY, mixed, partial, complete).
[b] GBY region positive, including the *TSPY* gene.
[c] At time of diagnosis.
[d] At puberty, allowing investigation of at least 30 seminiferous tubules, with diagnosis preferably based on OCT3/4 immunohistochemistry.

Source: APEG, *Submission 88*, citing Leendert H.J. Looijenga, Remko Hersmus, J. Walter Oosterhuis, Martine Cools, Stenvert L.S. Drop and Katja P. Wolffenbuttel, 'Tumor risk in disorders of sex development (DSD)', *Best Practice & Research Clinical Endocrinology & Metabolism*, Vol. 21, No. 3, 2007, p. 491.

4.12 The 2006 and 2007 papers from the Dutch research team, and the 2006 Consensus Statement, contain no information regarding the omission of one study from the sample, or accounting for the other changes.

4.13 The team of researchers responsible for the 2007 paper were cautious in their presentation of the information. They stated that the application of a combination of diagnostic techniques presented by them 'might *in future* be used to develop a decision tree for optimal management of patients with DSD' (emphasis added).[11] The authors concluded that 'patients with DSD can be classified into high, intermediate, low or unknown risk groups for type-II germ-cell tumors'.[12] They qualified the classification, however, by noting that there are some intersex conditions for which no or insufficient data is available (including 5α-reductase deficiency and Leydig-cell hypoplasia), and by indicating that:

> This first attempt to estimate the risk of the individual patient with DSD developing a type-II germ-cell tumor must be tested using additional cases

11 Leendert H.J. Looijenga, Remko Hersmus, J. Walter Oosterhuis, Martine Cools, Stenvert L.S. Drop and Katja P. Wolffenbuttel, 'Tumor risk in disorders of sex development (DSD)', *Best Practice & Research Clinical Endocrinology & Metabolism*, Vol. 21, No. 3, 2007, p. 480.

12 Leendert H.J. Looijenga, Remko Hersmus, J. Walter Oosterhuis, Martine Cools, Stenvert L.S. Drop and Katja P. Wolffenbuttel, 'Tumor risk in disorders of sex development (DSD)', *Best Practice & Research Clinical Endocrinology & Metabolism*, Vol. 21, No. 3, 2007, p. 491.

> in which proper criteria are used for classifying patients in the different DSD entities…[13]

4.14 In 2009, researchers Professor Gary Warne and Dr Jacqueline Hewitt published a paper in the Medical Journal of Australia, titled 'Disorders of sex development: current understanding and continuing controversy'. Based on the 2007 results in Looijenga et al, Warne and Hewitt stated, regarding risks of cancer:

> In any DSD associated with a Y chromosome, there is an increased risk of germ cell cancer, especially when the testes are intraabdominal (the risk of seminoma in partial androgen insensitivity is 50% for an intra-abdominal testis) or when there is gonadal dysgenesis.[14]

4.15 In relation to clinical management of those children in whom testes are retained, Warne and Hewitt continued:

> The trend for surgeons to recommend male-sex rearing for greater numbers of children with DSD could also mean greater reluctance to remove testes that pose a significant risk of cancer on the grounds that physiologically useful hormone secretion might be retained. It is therefore imperative that a risk management strategy be prepared for each patient. This would mandate:
>
> • educating parents and patients about risk;
>
> • removing all intra-abdominal gonads that cannot be brought down into the scrotum;
>
> • regular clinical and ultrasound surveillance of scrotal gonads with removal of any that contain suspicious lumps;
>
> • biopsy of testes after the onset of puberty, looking for early signs of malignant change; and
>
> • effective communication between paediatric and adult care providers at the time of transition.[15]

4.16 In 2009, the Dutch team published another review paper that incorporated a table similar to that published in 2006, with the larger number of studies for CAIS and

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13 Leendert H.J. Looijenga, Remko Hersmus, J. Walter Oosterhuis, Martine Cools, Stenvert L.S. Drop and Katja P. Wolffenbuttel, 'Tumor risk in disorders of sex development (DSD)', *Best Practice & Research Clinical Endocrinology & Metabolism*, Vol. 21, No. 3, 2007, p. 490.

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

15 Garry L. Warne and Jacqueline K. Hewitt, 'Disorders of sex development: current understanding and continuing controversy', *Medical Journal of Australia*, Vol. 190, No. 11, pp 612–13.

PAIS (3 in each case rather than 2), and repeating the lower risk estimates of their 2006 publication.[16]

4.17 In 2010, the Dutch research team (in a publication with a Czech lead author, J. Pleskacova) published a further paper in the field, somewhat confusingly carrying the same title as the 2007 article. The 2010 publication did not carry a version of the same table, but did contain a similar, smaller table summarising the prevalence of GCT in DSD patients. This table was as follows:

Table 1. Prevalence of type II GCT in various forms of DSD

Risk	Type of DSD	Prevalence %
High	GD in general	12*
	46,XY GD	30
	Frasier syndrome	60
	Denys-Drash syndrome	40
	45,X/46,XY GD	15–40
Intermediate	PAIS	15
	17β-hydroxysteroid dehydrogenase deficiency	17
Low	CAIS	0.8
	Ovotesticular DSD	2.6
Unknown	5α-reductase deficiency	?
	Leydig cell hypoplasia	?

GD = Gonadal dysgenesis; PAIS = partial androgen insensitivity syndrome; CAIS = complete androgen insensitivity syndrome.
* Might reach more than 30%, if gonadectomy has not been performed.

4.18 Notably, the estimates of prevalence for two key disorders, PAIS and CAIS, reflect again the lower estimates in the 2006 publication, which is cited as the principal source for the table.[17] The team of researchers concluded that:

> Presently available tools allow us to assess gonadal tissue of DSD patients and identify gonads at risk for GCT development, i.e. gonads containing dysplastic cells or noninvasive neoplasia. This ability together with precise diagnosis of DSD cases based on molecular-genetic methods may facilitate a more accurate estimation of the tumor risk in various forms of DSD. With that knowledge we might be able to preserve gonads in selected patients.[18]

16 Martine Cools, Leendert H.J. Looijenga, Katja P. Wolffenbuttel, and Sten L.S. Drop, 'Disorders of sex development: update on the genetic background, terminology and risk for the development of germ cell tumors', *World Journal of Pediatrics*, Vol. 5, No. 2, 2009, pp 93–102.

17 J. Pleskacova, R. Hersmus, J.W. Oosterhuis, B.A. Setyawati, S.M. Faradz, M. Cools, K.P. Wolffenbuttel, J. Lebl, S.L. Drop, and L.H. Looijenga, 'Tumor Risk in Disorders of Sex Development', *Sexual Development*, Vol. 4, No. 4–5, 2010, p. 7 (online version).

18 J. Pleskacova, R. Hersmus, J.W. Oosterhuis, B.A. Setyawati, S.M. Faradz, M. Cools, K.P. Wolffenbuttel, J. Lebl, S.L. Drop, and L.H. Looijenga, 'Tumor Risk in Disorders of Sex Development', *Sexual Development*, Vol. 4, No. 4–5, 2010, pp 259–269.

4.19 The Dutch team published two papers in 2011. Neither included a table of data equivalent to that found in earlier publications. One of the 2011 papers related only to one subset of DSD: 45,X / 46,XY mosaicism.[19] The other focussed on 'tumor risk in relation to the gonadal differentiation pattern and the phenotypic presentation of the patient'.[20] The papers do not directly discuss the risks associated with CAIS or PAIS, but do indicate the developing understanding of the relationship between tumour risk and the location and nature of gonadal tissue, concluding 'tumor risk is most pronounced in immature and/or poorly differentiated gonadal tissue and can be – at least in part – predicted from the presence of specific immunohistochemical markers'.[21]

Discussion during the committee inquiry of the medical research

4.20 APEG made a submission to the committee's inquiry that reproduced the table from the 2007 paper, described above. APEG's position in its submission was:

> In high-risk groups the recommendation is to remove the gonads before the individual develops cancer, which can occur in childhood. It would be negligent to expose these children to cancer by leaving the testes/ovaries in when the high risk is known…[and] The recommendation of Warne and Hewitt, and in the current medical literature, is for preventative surgical removal only in the high-risk and intermediate-risk cancer group…[22]

4.21 The Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne (RCH) also discussed the risk of cancer. It reported a number of figures, including the 50 per cent figure that appeared in Warne and Hewitt's 2009 paper, again citing the Dutch team's 2007 publication as the source:

> XY Complete gonadal dysgenesis. Individuals with this condition may have both the external physical appearances of a girl and a uterus, and will most likely identify as female. If [their] gonads are intra-abdominal, there is 15-30% risk of malignancy occurring by the time the young woman reaches her mid 20's…
>
> Partial androgen insensitivity syndrome (PAIS)…There is a considerable spectrum – with some people being born with almost normal male external genitalia, and others having almost normal female genitalia (but all will

19 M. Cools, J. Pleskacova, H. Stoop, P. Hoebeke, E. Van Laecke, S.L.S. Drop, J. Lebl, J.W. Oosterhuis, L.H.J. Looijenga, K.P. Wolffenbuttel, and the Mosaicism Collaborative Group, 'Gonadal pathology and tumorrisk in relation to clinical characteristics in patients with 45,X/46,XY mosaicism', *Journal of Clinical Endocrinology & Metabolism*, Vol. 96, No. 7, 2011, pp E1171–E1180.

20 M. Cools, K.P. Wolffenbuttel, S.L.S. Drop, J.W. Oosterhuis and L.H.J. Looijenga, 'Gonadal development and tumor formation at the crossroads of male and female sex determination', *Sexual Development*, Vol. 5, 2011, p. 177.

21 M. Cools, K.P. Wolffenbuttel, S.L.S. Drop, J.W. Oosterhuis and L.H.J. Looijenga, 'Gonadal development and tumor formation at the crossroads of male and female sex determination', *Sexual Development*, Vol. 5, 2011, p. 178.

22 Australasian Paediatric Endocrine Group, *Submission 88*, pp 3–4.

> have no uterus). If the testes are undescended and inside the abdomen, the cancer risk of the testes is reported to be 50%.[23]

4.22 It should be noted that the 2007 paper cited by the Melbourne team claimed only to summarise major findings from other papers, and referred the reader to the 2006 paper and the Consensus Statement for details.[24] Of these, only the 2006 paper discusses risk for individual types of intersex in detail, and gives a reported cancer risk for PAIS of 15 per cent rather than 50.[25] The 15 per cent figure is likewise reproduced in 2009 and 2010 papers from the same team.[26]

4.23 In its submission, OII commented on the 2009 Warne and Hewitt paper. OII said:

> Warne and Hewitt's assertion regarding the percentage risk of malignancy in internal gonads strongly imply a general, across the board, risk of 50%. This is considerably different from research elsewhere, suggesting either sampling bias, or a hitherto unknown cancer hot spot…
>
> …
>
> The protocol described by Warne and Hewitt means that the testes of all people with CAIS, and very many with PAIS, are removed in infancy. Alternative views are numerous, including international expert Katrina Karkazis or, in the case of AIS specifically, by Quigley *et al* Batch *et al*, Crouch. The AISSG UK summarise some of the research in this field, showing sampling bias in many studies, and far lower risks for most intersex people with internal gonads, albeit risks that increase with age.[27]

4.24 OII's submission went on to cite some of that research, which gives differing rates of cancer risk for different types of intersex condition.[28] The two studies mentioned by OII that were published in medical journals (Quigley *et al* and Batch *et al*) pre-date the work of the Dutch team (and others), who were able to draw on new diagnostic techniques and larger sample sizes.

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23 Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne, *Submission 92*, pp 3–4.

24 Leendert H.J. Looijenga, Remko Hersmus, J. Walter Oosterhuis, Martine Cools, Stenvert L.S. Drop and Katja P. Wolffenbuttel, 'Tumor risk in disorders of sex development (DSD)', *Best Practice & Research Clinical Endocrinology & Metabolism*, Vol. 21, No. 3, 2007, p. 490.

25 Martine Cools, Stenvert L.S. Drop, Katja P. Wolffenbuttel, J. Wolter Oosterhuis and Leendert H.J. Looijenga, 'Germ cell tumors in the intersex gonad: old paths, new directions, moving frontiers', *Endocrine Reviews*, Vol. 27, No. 5, 2006, p. 471.

26 Martine Cools, Leendert H.J. Looijenga, Katja P. Wolffenbuttel, and Sten L.S. Drop, 'Disorders of sex development: update on the genetic background, terminology and risk for the development of germ cell tumors', *World Journal of Pediatrics*, Vol. 5, No. 2, 2009, p. 100; J. Pleskacova, R. Hersmus, J.W. Oosterhuis, B.A. Setyawati, S.M. Faradz, M. Cools, K.P. Wolffenbuttel, J. Lebl, S.L. Drop, and L.H. Looijenga, 'Tumor Risk in Disorders of Sex Development', *Sexual Development*, Vol. 4, No. 4–5, 2010, p. 7 (online version).

27 Organisation Intersex International Australia, *Submission 23*, p. 8.

28 Organisation Intersex International Australia, *Submission 23*, pp 8–9.

4.25 Professor Warne and Dr Hewitt were co-authors (with others) of the APEG submission. That submission responded to evidence from OII, stating:

> The Senate has unfortunately received misleading information in submissions on this issue. We are concerned that some of the information presented appears to have been either misunderstood, or misrepresented in error, leading to inaccurate conclusions. Some authors have misunderstood the difference between high-risk and low-risk cancer groups within DSD, and in particular, one submission incorrectly implied that the cancer risk for a diagnosis in the highest-risk group ('PAIS with non-scrotal/intra-abdominal testes') was quoted by Warne and Hewitt as being the cancer risk for a diagnosis in the low-risk group ('CAIS'), as outlined in Table 2. The implication is that testes or ovaries are being removed from patients with diagnoses at low-risk of cancer, such as CAIS, however this is incorrect.[29]

4.26 Subsequent submissions appear to indicate that there is some common ground,[30] in recognising that cancer risk in some intersex people, especially those with CAIS or ovotesticular DSD, does not warrant prophylactic removal of testes.[31] At the same time, OII, quoting other medical research,[32] maintained that testes are still being removed from low-risk individuals (though presumably not by those specialists who do not support the practice, such as Warne and Hewitt, or the team at RCH Melbourne).[33] The committee received no evidence on the numbers of gonadectomies being performed where surgery was based on cancer risk.

4.27 The committee wrote to authors of the published research, seeking clarification of the variation in the estimated cancer risk or prevalence between different studies. In responding, the group of medical experts noted:

> In any individual with a DSD condition, the decision to perform gonadectomy is reached by weighing benefits and risks of various issues, such as risk for [germ cell tumour], sex of rearing, estimated capacity of the gonad to produce hormones in accordance with or opposite to sex of rearing and/or (developing) gender identity, likelihood of gender dysphoria later in life, etc.
>
> The statement 'In case of PAIS, 17β-HSD, and ovotestis, the decision regarding gonadectomy is largely determined by sex of rearing' should be interpreted in this broader and clinically oriented context, which is different

29 Australasian Paediatric Endocrine Group, *Submission 88*, p. 3.

30 See Organisation Intersex International Australia, *Submission 23.3 (30 June)*, pp 5–6.

31 See, for example, Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne, *Submission 92*, p. 4.

32 Organisation Intersex International Australia, *Submission 23.3 (30 June)*, p. 6, citing soon-to-be published research: Nakhal et al, *Radiology*, Vol. 268, 2013 (in press).

33 For the RCH Melbourne team's position, see *Submission 92*, p. 4.

> from the studies presented later, focusing primarily on tumor risk and in which the clinical emphasis is less elaborated.[34]

Discussion

4.28 The committee identified two related issues in the discussion of intersex and cancer risk:

- The complexity and diversity of cancer risk can become oversimplified, potentially elevating the perceived or communicated risk. Alternative monitoring options may be overlooked.
- The committee is concerned that other matters such as 'sex of rearing' or 'likelihood of gender dysphoria' are interpolated into the discussion of cancer risk. This confusion between treatment options to manage cancer risk and treatment options to manage intersex could undermine confidence in the neutrality of those advocating for surgical interventions.

Simplifying complexity

4.29 One of the difficulties faced by the committee and others when considering this literature is that the application of labels such as 'low risk' or 'high risk' appears to be masking some of the variation between individual intersex conditions. There are also serious questions to be raised about what constitutes 'high risk', and why it is that cases facing an 'intermediate risk' should be subject to prophylactic gonadectomy in infancy.

4.30 As cited above, the APEG submission stated that 'The recommendation of Warne and Hewitt, and in the current medical literature, is for preventative surgical removal only in the high-risk and intermediate-risk cancer group'. However the detail is more complex. In intermediate risk cases, the published literature has recommended gonadectomy only in some cases. For others, there is no definite recommendation.[35]

4.31 The summary classification of intersex conditions by cancer risk may also mask the importance of considering the circumstances of individual cases. There is great genotypic and phenotypic diversity among intersex people, even within a single category of intersex condition, and the literature suggests that these specific circumstances have a bearing on the cancer risk. As Dr Cools pointed out:

> The risk of GCT development varies undoubtedly according to which DSD a person has. However, in view of the very low incidence of most DSD conditions, and given the fact that gonadectomy has been performed prophylactically at an early age in many cases, it is currently impossible to obtain correct estimates of this risk for every DSD condition… any

34 Martine Cools, Arianne Dessens, Stenvert Drop, Jacqueline Hewitt and Gary Warne, answers to questions on notice (received 27 September 2013).

35 See, for example, Leendert H.J. Looijenga, Remko Hersmus, J.Walter Oosterhuis, Martine Cools, Stenvert L.S. Drop and Katja P. Wolffenbuttel, 'Tumor risk in disorders of sex development (DSD)', *Best Practice & Research Clinical Endocrinology & Metabolism*, Vol. 21, No. 3, 2007, p. 491.

> statement about tumor risk on an individual basis is an estimate and is possible only after thorough diagnostic investigations, most often including gonadal biopsy taking and specialized immunohistochemical[36] analysis, which needs expert surgical manipulation and centralization of material, with specialist analysis.[37]

4.32 There are, for example, some types of intersex that are generally classed as at high risk of gonadal cancer, but in which the published research papers indicate that the risk of tumour development depends on the morphology and histology in the individual case.[38] These include people with dysgenetic testes or with 'undervirilising' conditions such as PAIS. For these intersex people, and others, a number of specific factors can be examined in the individual that will influence whether they or not they are at high risk of developing tumours.[39] As the Dutch team concluded in one of its most recent papers:

> Tumor risk is most pronounced in immature and/or poorly differentiated gonadal tissue and can be – at least in part – predicted from the presence of specific immunohistochemical markers. This increase in knowledge has modified our clinical approach to the DSD patient, resulting in an individualized management with regard to tumor risk.[40]

4.33 It is also the case that the authors of the published research continue to repeat their cautions that the estimates and diagnostic models are only preliminary, and are in need of further empirical validation.[41] In these circumstances, the quoting of some of the risk estimates, particularly the higher ones relating to PAIS and 17β-HSD, appears not necessarily to be based on strong evidence. Quoting some of these summary estimates has the potential to hinder the process of objectively assessing individual patient risk, and of ensuring that cancer-related treatment considerations are kept

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36 Histochemistry is the study of the chemistry of organic tissue through observing chemical reactions. Immunohistochemistry studies the reaction patterns associated with the antibodies produced by the immune system. Immunohistochemistry is widely used to detect specific structures in tissues and in the diagnosis of abnormal cells such as those found in tumours.

37 Martine Cools, Arianne Dessens, Stenvert Drop, Jacqueline Hewitt and Gary Warne, answers to questions on notice (received 27 September 2013), emphasis in original.

38 Martine Cools, Stenvert L.S. Drop, Katja P. Wolffenbuttel, J. Wolter Oosterhuis and Leendert H.J. Looijenga, 'Germ cell tumors in the intersex gonad: old paths, new directions, moving frontiers', *Endocrine Reviews*, Vol. 27, No. 5, 2006, p. 479.

39 See also Martine Cools, Arianne Dessens, Stenvert Drop, Jacqueline Hewitt and Gary Warne, answers to questions on notice (received 27 September 2013).

40 M. Cools, K.P. Wolffenbuttel, S.L.S. Drop, J.W. Oosterhuis and L.H.J. Looijenga, 'Gonadal development and tumor formation at the crossroads of male and female sex determination', *Sexual Development*, Vol. 5, 2011, p. 178.

41 See, for example, Martine Cools, Leendert H.J. Looijenga, Katja P. Wolffenbuttel, and Sten L.S. Drop, 'Disorders of sex development: update on the genetic background, terminology and risk for the development of germ cell tumors', *World Journal of Pediatrics*, Vol. 5, No. 2, 2009, p. 100.

visibly separate from other factors (such as urogenital corrective surgery, or normalising treatments).

Action to manage cancer versus action to manage intersex

4.34 The committee concluded that one of the causes of disquiet regarding the management of cancer risk is that some of the published literature does not adequately distinguish between the appropriate clinical course of action regarding an intersex person's risk of cancer, and the appropriate clinical course of action to manage a person's intersex condition itself.

4.35 The footnotes to the 2006 table, missing from other later versions, encapsulate this problem. The 2006 table had notes making it clear that the recommended actions did not arise solely from the cancer risk associated with a variety of intersex, but took account of other factors such as the proposed sex of rearing of the child. This clarity was lost once such notes were omitted. By far the most serious omission was in the case of the 2006 Consensus Statement, because of its broad scope and considerable influence.

4.36 In answering the committee's questions about the communication of cancer risk in the literature, Dr Cools and others argued that the 2006 paper discusses the risks in a 'broader context' that is 'different from the studies presented later, focusing primarily on tumor risk'.[42] The balance of evidence does not support this. The paper that they describe as having a 'broader context' is specifically titled 'germ cell tumours in the intersex gonad', and its abstract refers solely to tumour risk and developments in the field in relation to this. The one apparent exception within that paper – the authors' development of an alternative classification schema for intersex – is itself 'proposed as a tool *to refine our insight in the prevalence of germ cell tumors* in specific diagnostic groups'.[43] Within that paper the table is headed 'summary of the risk of germ cell malignancy in the various forms of DSD, subdivided into high, intermediate, low, and possibly no risk', contradicting the argument that the paper is discussing treatment in a broader context compared to later papers, where the table has a very similar title in all cases. Furthermore, if this explanation was correct, then the 2006 Consensus Statement – which definitely does have a far broader context than any of the individual research papers – should have the additional explanations included, yet it does not. Furthermore, the 2006 Consensus Statement explicitly describes the 'recommended actions' in the table as being 'recommendations for management' of the risk of tumour development, not management of the person's intersex condition generally.[44] This does not appear consistent with the explanations offered in the 2006

42 Martine Cools, Arianne Dessens, Stenvert Drop, Jacqueline Hewitt and Garry Warne, answer to questions on notice, (received 27 September 2013), p. 9.

43 Martine Cools, Stenvert L. S. Drop, Katja P. Wolffenbuttel, J. Wolter Oosterhuis and Leendert H. J. Looijenga, 'Germ cell tumors in the intersex gonad: old paths, new directions, moving frontiers', *Endocrine Reviews*, Vol. 27, No. 5, 2006, p. 468, emphasis added.

paper and elsewhere. Finally, the experts' answer to the committee's question argued that the explanations are included in the 2006 paper because of its 'clinically oriented context', yet the 2007 paper, which lacks the explanations, is even more explicitly clinically oriented, appearing in the journal 'Best Practice and Research Clinical Endocrinology and Metabolism', where each section of the article concludes with 'practice points' for clinicians.[45]

4.37 Dr Cools and her Dutch team have sought to advance the scientific understanding and estimation of cancer risk in intersex individuals, and have done so with considerable success. This was intended to provide better information about one key factor in intersex medical decision-making (assessing the patient's cancer risk). Instead, because of the incorporation of a table column listing 'recommended actions' based in part on consideration of other factors such as sex of rearing but with that explanation frequently omitted (most importantly from the 2006 Consensus Statement), the information risks being interpreted as a guide to clinical action *on the grounds of* cancer risk, which it is not.

4.38 This detail is important. There is considerable debate, some of it outlined in the previous chapter, about the merits of performing surgery at different ages. Intersex organisations, regulators, courts and other decision-makers are closely scrutinising, and sometimes relying on, this medical literature to inform this extremely important discussion taking place in the broader community, beyond just the medical professions. To allow this debate to take place transparently and with the confidence of the intersex community, it is essential that the different reasons for medical treatment, and the attendant risks, are characterised separately. Otherwise, decision-making becomes opaque to families, courts, regulators, support groups, and even to external clinicians. This will undermine confidence, in turn prompting calls for blanket bans on particular medical procedures, removing clinicians from decision-making processes. The committee would see these as undesirable outcomes.

Conclusion

4.39 The committee is aware of a risk, not directly discussed by witnesses to the inquiry, that clinical intervention pathways stated to be based on probabilities of cancer risk may be encapsulating treatment decisions based on other factors, such as the desire to conduct normalising surgery. This kind of encapsulation of factors under a single reason is evident in the published tables discussed in this chapter. This might happen because of the distinction made by Australian courts between 'therapeutic' and 'non-therapeutic' medical intervention. Treating cancer may be regarded as unambiguously therapeutic treatment, while normalising surgery may not. Thus

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44 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).

45 Leendert H.J. Looijenga, Remko Hersmus, J. Walter Oosterhuis, Martine Cools, Stenvert L.S. Drop and Katja P. Wolffenbuttel, 'Tumor risk in disorders of sex development (DSD)', *Best Practice & Research Clinical Endocrinology & Metabolism*, Vol. 21, No. 3, 2007, pp 480–495.

basing a decision on cancer risk might avoid the need for court oversight in a way that a decision based on other factors might not. The committee is disturbed by the possible implications of this.

4.40 If the distinction between therapeutic and non-therapeutic treatment were to be retained, then the committee would draw attention to an example used in Queensland legislation relating to guardianship and the circumstances in which a court should be involved in decisions. The example suggests that decision-makers may need to distinguish between treatment of cancer, and treatment *for the possible risk of* cancer.

> If the child *has cancer* affecting the reproductive system and, without the health care, the cancer is likely to cause serious or irreversible damage to the child's physical health, the health care is not sterilisation.[46]

4.41 An implication of the example is that a treatment for the *risk of* cancer may *not* fall into the category of treatments that do not require authorisation.

4.42 The committee shares others' concerns, however, outlined in the next chapter, regarding the current way in which decision-making occurs for intersex people who are unable to make the decisions for themselves (generally children), including concerns about the distinction between therapeutic and non-therapeutic treatment. The committee does not favour the status quo. Chapter 3 and this chapter have both outlined how complex and contentious is some of the information that supports medical treatment of intersex people.

Recommendation 5

4.43 In light of the complex and contentious nature of the medical treatment of intersex people who are unable to make decisions for their own treatment, the committee recommends that oversight of these decisions is required.

4.44 The next chapter considers what such a system of oversight should look like.

46 *Guardianship and Administration Act 2000 (Qld)*, s. 80B (Example), emphasis added.

Chapter 5
Intersex: protection of rights and best practice in health

The role of the courts and tribunals in the healthcare of intersex people

5.1 For many intersex people, important decisions are made on their behalf regarding sex assignment and medical treatment, during the first years, sometimes the first weeks, of their lives. Submitters asked the committee to consider the most appropriate ways in which these decisions should be made.

5.2 The position adopted by the committee in the first report (the 'Sterilisation Report') of this inquiry into the *Involuntary or coerced sterilisation of people with disabilities in Australia* was that the proper jurisdiction for consideration of sterilisation cases for those unable to consent should remain with the Family Court of Australia but with improved criteria. This chapter explores whether it remains the proper forum for consideration of intersex cases.

5.3 While decision makers in cases involving potential sterilisation have to be cognisant of a range of ethical and medical issues, the sheer range of conditions that fall within intersex medical diagnoses, and the potential outcomes in response to any type of treatment or medical procedures, substantially complicate how decisions are made.

5.4 Sterilisation is only one of the possible consequences of medical treatment of intersex people. Not all intersex medical interventions are sterilising and those that are not would not fall under the decision-making criteria that the committee suggested apply in sterilisation cases.[1] However the treatments are still major with the capacity to impact a person's life in a variety of ways, and therefore carry significant risks. The Victorian Department of Health's recent Guidelines described some of the risks:

- risk of assigning the 'wrong' sex of rearing, meaning a gender that the child will later reject or feel uncomfortable with, potentially leading to depression or other mental health problems
- risk that the child will not be accepted by parents in the chosen sex of rearing, leading to impaired bonding and associated negative consequences
- risk of social or cultural disadvantage to the child, for example, reduced opportunities for marriage or intimate relationships, or reduced opportunity for meaningful employment and capacity to earn an income

1 Senate Community Affairs References Committee, *Involuntary or coerced sterilisation of people with disabilities in Australia*, July 2013.

- risk of social isolation, restrictions or difficulties, for example, caused by embarrassment or social stigma associated with having genitalia that does not match the gender in which the person lives.[2]

5.5 As discussed above, intersex medical interventions are broader and often substantially different from sterilisation cases. The question of which forum is best suited to considering these cases must take these differences into account. Aside from the healthcare differences, the capacity to consent is an example of a legal issue that is likely to be more conspicuous in sterilisation cases. The assessment of 'Gillick competence', or capacity to consent, is less likely to be central to the consideration of many intersex cases because decisions are frequently made during infancy. Instead, consideration of the various options for medical intervention and their consequences are more likely to be the main issue being considered by decision makers.

5.6 While the assessment of capacity to consent may not be the principal issue in intersex cases, OII's representatives submitted that every individual member of their organisation had been subjected to some form of non-consensual medical intervention, including:

- Involuntary gonadectomy (sterilisation) and clitorectomy (clitoris removal or reduction) as an infant, child or adolescent.
- Medical and familial pressure to take hormone treatment.
- Medical and familial pressure to undertake genital 'normalisation' surgery.
- Surgical intervention that went outside the terms of consent, including surgery that was normalising without consent.
- Disclosure of non-relevant medical data to third parties without consent.[3]

5.7 OII commented that most medical treatment decisions for those with an intersex diagnosis 'do not progress to the Family Court, but are managed according to standard therapeutic protocols. It is in this area that we have the most significant concerns.'[4]

The Family Court or Tribunals?

5.8 Both Tribunals and the Family Court have areas of expertise borne from experience. This committee's Sterilisation Report discussed the processes and procedures of Tribunals and the Family Court in relation to sterilisation cases.[5] In a

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

3 Organisation Intersex International Australia, *Submission 23*, pp 2–3.

4 Organisation Intersex International Australia, *Submission 23.1*, p. 15.

5 See for example Chapters 5 and 6 of the Senate Community Affairs References Committee, *Involuntary or coerced sterilisation of people with disabilities in Australia*, July 2013.

complex analysis of the relative merits of the Tribunals and the Family Court to deal with these cases, the committee made a number of recommendations to improve processes in both forums.

5.9 The procedures of the Family Court were criticised by a number of submitters who thought that they were essentially adversarial in approach. The court prefers that parties to proceedings have legal representation, which submitters indicated is costly; there was also discussion of the formality of proceedings and the use of external experts. An application for sterilisation, for example, is heard by a single judge. The judge decides whether to authorise the sterilisation on the basis of arguments put by the applicant and other parties to the application. Appeal of a decision is made to the Full Bench of the Family Court.[6]

5.10 Because some medical decisions affecting intersex children may have sterilising effects, the Family Court may have jurisdiction to consider the decisions, and similar principles would be involved.[7] A Gender Agenda submitted that the court's procedures, particularly the granting of *amicus curiae* status, prevented full participation for the intersex person or their representative:

> It is important to note that the adversarial nature of the court process privileges the voices of the immediate parties to the dispute; specifically, the medical practitioners and parents, to the detriment of intersex people, who may only be heard if the court grants leave to the intersex person or representatives to intervene as amicus curiae or otherwise. The costs and administrative burden of intervening in proceedings, combined with the traditionally strict approach of the courts to granting leave to intervene, make it unlikely that intersex people will have a voice in such matters.[8]

5.11 While the committee accepted that there were improvements required in all of these areas, it also felt that the procedures of the court were not fully understood. The committee also acknowledged that the Family Court has made significant efforts to adopt a less adversarial approach in children's cases with the introduction of the Less Adversarial Trial (LAT), introduced in 2006, provided as an example:

> proceedings are managed in a way that considers the impact of the proceedings themselves (not just the outcome of the proceedings) on the child.[9]

5.12 The Family Court also has extensive experience in considering complex issues in areas that have some similar characteristics to intersex cases. In recent years the Family Court has considered a number of cases that have considered sterilisation as

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6 S. Brady, *The sterilisation of girls and young women with intellectual disabilities in Australia: An audit of Family Court and Guardianship Tribunal cases between 1992-1998.* Australian Human Rights Commission, 2001. http://www.humanrights.gov.au/publications/sterilisation, (accessed 3 September 2013).

7 Ms Diana Bryant, *Submission 36.1*.

8 A Gender Agenda, *Submission 85,* p. 7.

9 Family Law Amendment Bill (Shared Parental Responsibility) Bill 2005, p. 3.

well as gender identity disorders and transgender issues. The capacity to consent has featured heavily in these cases. The most significant of these was *Re: Marion.*

Re: Marion

5.13 Marion's case is a complex legal judgment. The central theme was whether the Family Court should have the authority to override parental authority and decide on medical treatment that is 'an interference with the right to bodily inviolability and the right to decide whether or not to reproduce,' and is also 'irreversible'.[10]

5.14 *Re: Marion* concerned the sterilisation of a 14 year old girl with multiple disabilities. The High Court, on appeal, found by majority that parental authority was insufficient due to the seriousness of the treatment, and that it was the court's role, under section 67ZC of the Family Law Act 1975 to make orders relating to the welfare of children.[11] The High Court judges described the proposed procedure as involving the:

> …'immediate and serious invasion of physical integrity with the resulting grave impairment of human dignity' (Brennan J at 322) and 'the destruction of a natural human attribute and the removal of an integral part of complete human personality' (Deane J at 331).[12]

5.15 The recent case of *Re: Jamie* confirmed the position established in *Re: Marion* that because of the serious and invasive nature of the procedure, and that 'the consequences of a wrong decision are particularly grave',[13] the issue of the capacity to consent 'to treatment which has irreversible effects…must remain a question for the court'.[14]

5.16 Justice Finn in *Re: Jamie* explicitly states that procedures of the type that may apply to intersex cases are beyond the bounds of a parent to consent on behalf of a child. He says they are:

> 'special medical procedures', being procedures which, in her Honour's words, 'fall beyond [the bounds of a parent's responsibility to be able to consent to medical treatment for and on behalf of their child,] and require determination by the court, as part of the court's parens patriae or welfare jurisdiction'. Her Honour cited the High Court decision in Secretary, Department of Health and Community Services v JWB and SMB (1992)

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10 Australian Institute for Family Studies, *Parental Authority and its Constraints The Case of 'Marion'*, http://www.aifs.gov.au/institute/pubs/fm1/fm32mh.html, (accessed 26 August 2013.

11 Australian Institute for Family Studies, *Parental Authority and its Constraints The Case of 'Marion'*, http://www.aifs.gov.au/institute/pubs/fm1/fm32mh.html, (accessed 26 August 2013.

12 Australian Institute for Family Studies, *Parental Authority and its Constraints The Case of 'Marion'*, http://www.aifs.gov.au/institute/pubs/fm1/fm32mh.html, (accessed 26 August 2013.

13 Bryant CJ, Finn & Strickland JJ (2013) FamCAFC 110 (*Re Jamie*), at 140.

14 Bryant CJ, Finn & Strickland JJ (2013) FamCAFC 110 (*Re Jamie*), at 186.

> 175 CLR 218 ('*Marion's case*') in support of this proposition.
> …
>
> I have reservations concerning the usefulness of the expression 'special medical procedure'. I consider that it would be preferable to refer to a 'medical procedure which requires court authorisation'.[15]

Guardianship Tribunals

5.17 The Guardianship Tribunals have a different sphere of expertise than the Family Court. While assessing capacity is a feature of their deliberations, they also approach cases in a markedly different way.

5.18 Tribunals are characterised as having an 'inquiring' or inquisitorial approach. They take a more active role in shaping how a matter develops, what information needs to be collected, and how it is to be collected. They do not require legal representation and charge no fees.

5.19 Two States, New South Wales and South Australia,[16] enacted legislation prohibiting sterilisation of children (emergencies aside) without the approval of their respective Guardianship Tribunals in accordance with specific legislative criteria. Guardianship Tribunals in all Australian States deal primarily with adults with impaired decision making abilities, but in NSW and South Australia, they exercise concurrent jurisdiction alongside the Family Court in relation to the sterilisation of children.[17]

5.20 Appeals of Tribunal decisions are to the Supreme Court in NSW, and to the Administrative Appeals Tribunal in South Australia. Alternatively aggrieved applicants may take the matter to the Family Court for 're-hearing' because the tribunals exercise concurrent jurisdiction. However in the event of a dispute the Family Court's decision takes precedence.[18]

5.21 The Tribunals comprise of people from multi-disciplinary backgrounds. Multi-disciplinary evaluation has been identified as 'one of the most controversial yet one of the most important protections that can be extended' to marginalised groups like

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15 Bryant CJ, Finn & Strickland JJ (2013) FamCAFC 110 (*Re Jamie*), at 151.

16 *Guardianship Act 1987 (NSW)*, Part 5; *Guardianship and Administration Act 1993 (SA)*, Part 5.

17 Australian Human Rights Commission, *The Sterilisation of Girls and Young Women in Australia: issues and progress, Chapter One – The legal framework.* http://www.humanrights.gov.au/publications/sterilisation-chapter-one, (accessed 3 September 2013).

18 S. Brady, *The sterilisation of girls and young women with intellectual disabilities in Australia: An audit of Family Court and Guardianship Tribunal cases between 1992-1998.* Australian Human Rights Commission, 2001. http://www.humanrights.gov.au/publications/sterilisation, (accessed 3 September 2013).

people with disabilities. Tribunal members are mostly part-time and appointed by the State government for fixed terms, usually three years.[19]

5.22 Aspects of the tribunal system were considered in chapter 5 of the Sterilisation Report. The general consensus in the evidence received was that the procedures in tribunals were less formal, and more flexible in terms of how evidence is gathered and how parties can be represented and supported. In addition, the low or no costs for participants compared to those for applications to the Family Court enhance the case for tribunals to be the primary forum for consideration for intersex cases.

5.23 In the Sterilisation Report the committee was concerned about the lack of uniformity across various jurisdictions and the capacity of tribunals to access and appraise the necessary breadth of medical advice available.[20] A number of recommendations were made in the report to address these issues.

5.24 The Victorian Office of the Public Advocate (OPA) in a supplementary submission promoted the idea that all intersex medical interventions should be subject to some form of oversight or authorisation:

> Court authorisation is already (or ought to be) required whenever the performance of an intersex medical intervention upon a child is being proposed.[21]

It argued that state tribunals should be given authority to consider these cases by being given concurrent jurisdiction with the Family Court:

> While the Family Court of Australia does have current jurisdiction on these matters for persons under eighteen-years old, state administrative tribunal systems should be given concurrent jurisdiction with the Family Court to determine authorisation for intersex medical interventions proposed for a child in a more accessible way.[22]

5.25 The OPA argued that tribunals offer advantages over court proceedings 'because of the more accessible nature of the venue, and the increased capacity for an inquisitorial approach that tribunals can provide',[23] but they also flagged that this would require additional resources and changes to state legislation:

> With additional resources, this existing administrative tribunal approach could be used nationally in relation to an intersex medical intervention proposed for a child, sharing the jurisdiction of the Family Court.

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19 Australian Human Rights Commission, *The Sterilisation of Girls and Young Women in Australia: issues and progress, Chapter One – The legal framework.* http://www.humanrights.gov.au/publications/sterilisation-chapter-one, (accessed 3 September 2013).

20 Senate Community Affairs References Committee, *Involuntary or coerced sterilisation of people with disabilities in Australia,* July 2013, p. 112.

21 Office of the Public Advocate, *Submission 14.1,* p. 3.

22 Office of the Public Advocate, *Submission 14.1,* p. 6.

23 Office of the Public Advocate, *Submission 14.1,* p. 9.

> …
>
> We further note that the definition of medical treatment under the GAA [Guardianship and Administration Act 1986 (Vic)] is not consistent with definitions contained in other Victorian legislation. These sorts of issues will need to be addressed as new provisions are considered. An example of particular relevance is that under the guardianship act the administration of pharmaceuticals is not considered 'medical treatment'. [24]

Committee view

5.26 The issue of access to relevant advice, including medical advice, is crucial in contemplating which forum would be the most appropriate for decisions on intersex cases to be considered. Because intersex cases require consideration by an extensive number of medical, psychological and psychosocial professionals, the capacity to access that expertise is a key requirement of any forum. The multi-disciplinary composition of tribunals would assist in drawing in the required expertise.

5.27 The committee is supportive of the proposal from the OPA that *all* intersex medical interventions should require authorisation beyond the managing clinicians. The volume of cases that this may involve has implications for whether the court or a tribunal would be the most appropriate forum. As discussed in the next section, the committee recommends that a two tier approach be considered where more common or routine procedures would have to adhere to agreed national guidelines before being authorised. More complex cases would be considered with the assistance of a national Special Medical Procedures Advisory Committee. In these circumstances the committee view is that the flexibility of tribunals is a significant benefit.

5.28 The committee is persuaded that tribunals are a more accessible and cost-effective option to hear these cases. They will also be able to act quickly, and be more responsive to the needs of intersex people and their families.

5.29 However there may be cases of particular legal complexity that would be properly considered in the Family Court and the committee would not wish to close this avenue of expertise. The committee therefore supports the proposal that tribunals should be given concurrent jurisdiction with the Family Court, and that participants in the case should decide which jurisdiction would best address their needs.

Recommendation 6

5.30 The committee recommends that all proposed intersex medical interventions for children and adults without the capacity to consent require authorisation from a civil and administrative tribunal or the Family Court.

Recommendation 7

5.31 The committee recommends that the Standing Committee on Law and Justice consider the most expedient way to give all civil and administrative tribunals in all States and Territories concurrent jurisdiction with the Family

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24 Office of the Public Advocate, *Submission 14.1*, p. 9.

Court to determine authorisation for intersex medical interventions proposed for a child.

Recommendation 8

5.32 The committee recommends that civil and administrative tribunals be adequately funded and resourced to consider every intersex medical intervention proposed for a child.

Special medical procedures advisory committee

5.33 The Sterilisation Report recommended that a new special medical procedures advisory committee (SMPAC) be established to assist the Family Court in its decision making. The recommendation is as follows:

> Recommendation 4
>
> The committee recommends that the Commonwealth government establish a special medical procedures advisory committee, to provide expert opinion to the Family Court upon request in relation to specific cases, and to other statutory decision-makers and government as appropriate on best practice in relation to sterilisation and related procedures for people with disability; and that the committee must include non-medical disability expertise as well as medical expertise.[25]

5.34 The SMPAC would have the role of an assessor under section 102B of the *Family Court Act 1975*. This section allows the court to 'get an assessor to help it in the hearing and determination of the proceedings, or any part of them or any matter arising under them.'[26] The committee suggested that the SMPAC would be funded and administered by the Department of Health and Ageing and comprise of both medical and non-medical experts.

5.35 While the committee deliberations were concerned with the SMPAC being a resource to the Court in sterilisation cases, it also suggested that it could provide 'similar assistance to other jurisdictions'.[27] The expertise required for membership of the committee could also be utilised in the consideration of intersex cases. It could be argued with some force that due to the range and variation of diagnoses associated with intersex conditions, the need for a multidisciplinary committee to advise decision makers is even stronger in intersex cases than it is in sterilisation cases.

5.36 The committee supports the measures discussed in the following section that have been introduced by the Victorian Department of Health through their *Decision-making principles for the care of infants, children and adolescents with intersex conditions*. The systematic and expansive approach taken by the Royal Children's

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25 Senate Community Affairs References Committee, *Involuntary or coerced sterilisation of people with disabilities in Australia*, July 2013, p. 149.

26 Senate Community Affairs References Committee, *Involuntary or coerced sterilisation of people with disabilities in Australia*, July 2013, p. 147.

27 Senate Community Affairs References Committee, *Involuntary or coerced sterilisation of people with disabilities in Australia*, July 2013, p. 149.

Hospital in Melbourne is also supported. There are elements in both of these approaches that could be adopted in guidance developed by SMPAC. The emphasis on ethical and human rights principles, as well as the desire to ensure a uniform approach in the health care management of intersex people, are positive developments that should be rolled out at a national level.

5.37 The committee suggests that the remit of SMPAC should be expanded to include the provision of advice on intersex cases. However it may not be reasonable for it to provide advice on each intersex that occurs in every hospital in Australia. The committee accepts that there are standard uncontroversial procedures that take place on a fairly routine basis. These include treatments for clear clinical reasons that have an immediate health impact on the patient. To ensure consistency across the country in the treatment of these cases it is suggested that one of the roles SMPAC should be to draft guidelines for the treatment of each condition. These guidelines should be reviewed regularly. In the drafting of these guidelines the SMPAC should be cognisant of all relevant research data and clinical outcomes, and should be guided by principles similar to those utilised by the Victorian guidelines.

Recommendation 9

5.38 The committee recommends that the special medical procedures advisory committee draft guidelines for the treatment of common intersex conditions based on medical management, ethical, human rights and legal principles. These guidelines should be reviewed on an annual basis.

5.39 The committee believes that more complex cases should be referred to the SMPAC for their advice. Not only would this provide oversight, but it would also help to ensure that decisions are taken with recourse to the broadest pool of knowledge, both nationally and internationally. This would benefit the intersex person and their family, as well as the health care professionals engaged in the case.

5.40 The decision on whether a referral is required should be taken by whoever is considering the case. The committee envisages that this would normally be a tribunal, but in some complex cases could be the Family Court. In the committee's view this procedure would assist in objectivity in the decision-making process, as well as providing the opportunity to ensure that international best practice was followed.

Recommendation 10

5.41 The committee recommends that complex intersex medical interventions be referred to the special medical procedures advisory committee for consideration and report to whichever body is considering the case.

Case management

5.42 Before any intersex case gets as far as requiring authorisation for a medical intervention, the complex path from diagnosis to proposed treatment has many different facets that can significantly impact on the intersex person and their family.

5.43 The Androgen Insensitivity Syndrome Support Group Australia (AISSGA) submitted a number of recommendations that would govern aspects of an intersex

diagnosis and ensure that appropriate support and decisions around proposed treatment were made with recourse to all available evidence:

> 1. The AISSGA calls for the human rights of intersex people to be identified and protected at every level of legislation and society.
>
> 2. Intersex people remain 100% consensual with regards to any surgical or pharmacological intervention of their body and that these procedures be indicated by documented long-term medical benefit.
>
> 3. The AISSGA calls for a moratorium on non-urgent medical intervention. This includes gonadectomies on intersex children and clitoral recession.
>
> 4. Reproductive freedoms for intersex people be maintained in terms of access to any future reproductive technologies.
>
> 5. The AISSGA supports the full disclosure of an intersex diagnosis to the parents and the affected individual at the earliest possible appropriate time.
>
> 6. That disclosure of intersex diagnosis be accompanied by a complete explanation of a full range of treatment options available, either for treatment or the likely outcome of non-intervention.
>
> 7. That parents and affected individuals should be advised of the existence of the support group and medical practitioners should recommend and explain the benefits of contact with the group.[28]

5.44 There is consensus around support for multidisciplinary teams of specialists to be preferred in cases requiring medical attention, and for counselling to be available from the outset. The 2006 Consensus Statement argues for this:

> Optimal care for children with DSD requires an experienced multidisciplinary team which is generally found in tertiary care centres. Ideally, the team includes paediatric subspecialists in endocrinology, surgery or urology or both, psychology/psychiatry, gynaecology, genetics, neonatology, and, if available, social work, nursing, and medical ethics.[29]

5.45 Some of those who have been to varying degrees critical of the 2006 Consensus Statement approach are nevertheless supportive of multidisciplinary teams and counselling.[30]

5.46 The emphasis on multidisciplinary teams in the diagnosis and health care management of intersex people is welcomed across the spectrum of stakeholders. However APEG submitted that international practice in the creation and funding of multidisciplinary groups is further advanced than it is in Australia:

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28 Androgen Insensitivity Syndrome Support Group Australia, *Submission 54,* p. 4.

29 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 19 June 2013).

30 For example, Milton Diamond and Hazel Beh, 'Changes in the management of children with intersex conditions', *Nature Clinical Practice Endocrinology and Metabolism*, Vol. 4, No. 1, 2008, p. 5.

> Current consensus recommends expert specialist multidisciplinary management groups to be established to case conference the accurate diagnosis and management of children with DSD. Multidisciplinary groups have now been established and properly funded throughout the world. The composition of the multidisciplinary group may include endocrinologists, urologists, gynaecologists, psychologists, geneticists, biochemists, and bioethicists amongst others.
>
> 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.[31]

5.47 OII also cited comments from a paper by Alice Dreger and others, who critiqued 2010 papers by Gillam, Hewitt and Warne in *Hormone Research in Paediatrics*, and questioned whether the multidisciplinary healthcare management model is actually established in Australia:

> the environment for shared decision making – the highly integrated, interdisciplinary healthcare team that includes behavioral health services called for in the DSD consensus – that makes possible such good decision-making remains elusive…[32]

5.48 The committee also received a submission from the Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne (RCH) that outlined discussed their systematic approach to decision making in intersex cases. The submission emphasised their view that there have been substantial changes to the health care management of intersex people and this is not limited to clinical considerations:

> As with many facets of society and medicine there have been substantial changes in the care of children and people with DSDs over the last few decades. This relates not only to increased medical knowledge and better surgical techniques, but also different societal attitudes and perspectives. In the past, clinical care and practices which were in keeping with medical and societal attitudes were less sensitive to the psychosocial impact of the diagnosis on the young person and their family. These practices have evolved over time as community and medical attitudes has progressed. From a medical perspective, improved knowledge regarding cancer risks of different DSDs, as well as improved capacity to measure the hormonal production and potential fertility of gonads have been particularly seminal

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

32 A. Dreger, D. Sandberg, E. Feder, 'Ethical Principles for the Management of Infants with Disorders of Sex Development', in *Hormone Research in Paediatrics*, Vol. 74, 2010; pp. 412–418, DOI: 10.1159/000316940, http://www.karger.com/Article/Pdf/316940, (accessed 7 July 2013); submitted by Organisation Intersex International Australia, *Submission 23.4*, p. 8.

changes. Health care provision needs to encompass sensitivity to the families and the individual.[33]

5.49 The Melbourne team's approach includes referral to RCH's Clinical Ethics Response Group (CERG).[34] The development of CERG is discussed by Gillam and others in *Disorders of Sex Development: An Integrated Approach to Management*.[35] CERG was introduced in 2011 as a forum that considers the management of intersex treatment after 'diagnosis has been made or confirmed, appropriate investigations and assessments have been completed and a management plan formulated in consultation with the parents, and patient, if old enough to participate'.[36] CERG has now been in place for 2 years and considers every new case in the RCH. It is estimated that the number of referrals is around a dozen per year.

Use of principles of health care management

5.50 CERG decisions are informed by seven ethical principles that have been developed from a philosophical and ethical perspective.[37] The principles are:

- Minimising Physical Risk to Child
- Minimising Psycho-Social Risk to Child
- Preserving Potential for Fertility
- Preserving or Promoting Capacity to Have Satisfying Sexual Relations
- Leaving Options Open for the Future
- Respecting the Parents' Wishes and Beliefs
- Consider the Views of Children and Adolescents.[38]

33 Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne. *Submission 92*, p. 3.

34 Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne. *Submission 92*, pp 4–5.

35 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, p. 153.

36 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, p. 153.

37 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, p. 148.

5.51 According to Gillam and others, the CERG principles are 'general enough to be applicable to any individual case, are not condition-specific and are not specific to the current state of medical knowledge and technical capacity'.[39]

5.52 The ethical principles that underpin CERG considerations have informed the principles adopted by the Victorian Department of Health in their 2013 Guidelines. However as discussed in Chapter 3 the Victorian Guidelines go much further than ethical principles and include: principles for supporting patients and parents; medical management principles; human rights principles; and legal principles.[40]

5.53 The inclusion of ethical and human rights principles that go beyond the medical and legal spheres is particularly welcome. The consideration of the human rights of the intersex person, and the complex and contentious ethical considerations that accompany any decisions regarding their welfare, are the reasons that oversight beyond a clinical perspective is required. The prevailing view of the Family Court since *Re: Marion* supports this proposition.

5.54 The committee was concerned about the application of the legal principles used in the Guidelines to inform whether or not a case requires authorisation through the courts. The Guidelines state that:

> Court authorisation is required for decisions made on behalf of infants, children and adolescents with intersex conditions, who cannot give consent if all of the following four threshold questions apply to a particular treatment, being that:
>
> - the proposed treatment is non-therapeutic; and
> - the proposed treatment is invasive, irreversible and considered 'major' treatment; and
> - there is a significant risk of making the wrong decision about the best interests of the child; and
> - the consequences of a wrong decision are particularly grave.

38 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 149–153.

39 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, p. 155.

40 Victorian Department of Health, *Decision-making principles for the care of infants, children and adolescents with intersex conditions*, February 2013, pp 2–6; tabled by Organisation Intersex International Australia, 28 March 2013.

> Court authorisation may also be required where there is disagreement between decision-making parties about the characterisation of a particular treatment against these principles.[41]

All four of these thresholds need to be met for a case to require authorisation from the court.

5.55 The explanatory notes appended to the Guidelines state that '[t]he tests of Marion's case apply to all intersex conditions and to all contemplated treatments, not only surgical procedures'.[42]

5.56 While the High Court 'hesitated' to make a distinction between therapeutic and non-therapeutic in their judgement, they did make a distinction between surgical intervention that treated 'some malfunction or disease'[43] and surgery that did not. Chief Justice Alistair Nicholson commented in an interview in 2003 on the implications of *Re: Marion:*

> …from then on the law effectively has been that a court's consent is required to perform an invasive and non-therapeutic operation which covers sterilisation. It's been regarded as covering change of sex operations as well so it's a very broad principle.[44]

5.57 The explanatory notes appended to the Guidelines discuss the distinction and state that the judgement in *Re: Marion* defined the term therapeutic:

> In Marion's Case, the court defined a 'therapeutic' treatment as a procedure or treatment that is carried out to treat 'a malfunction of disease', however, this definition is not exhaustive.[45]

5.58 The committee does not share the view that the term or its antonym were defined, even with the caveat that the definition is not exhaustive. The committee's understanding is that the term was employed to assist in describing a distinction in certain cases, but that the emphasis in the judgement was to consider each case on its merits.

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41 Victorian Department of Health, *Decision-making principles for the care of infants, children and adolescents with intersex conditions*, February 2013, p. 6; tabled by Organisation Intersex International Australia, 28 March 2013.

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

43 Mason CJ, Dawson, Toohey and Gaudron JJ, *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (1992) ALJR 300 (*Re Marion*), at 48.

44 ABC Commercial, *Interview with Chief Justice Alistair Nicholson*, 12 May 2003, http://www.abc.net.au/4corners/content/2003/20030616_sterilisation/int_nicholson.htm (accessed 12 April 2013).

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

5.59 The committee heard from a number of witnesses who expressed their view that a definition, and consequent distinction between the terms therapeutic and non-therapeutic were unhelpful and should be avoided.[46] For example APEG's submission raised the question of what the threshold should be for a treatment to be considered 'therapeutic' (and therefore, in most jurisdictions at least, not requiring court order). The submission asked the committee to consider the issue of when the courts should be involved in decisions around gonadectomies in the context of cancer risk, arguing that the current legal situation is unclear:

> In recent years, some doctors have brought cases of DSD to the Family Court for approval of planned gonadectomy. This was under the Special Medical Procedures Act, which outlines the requirement for 'non therapeutic' treatments to be approved by the court.
>
> The ruling of *Re: Sally* FCA 2010 found that gonadectomy could occur in a young person who had a cancer risk of 28%, but that similar cases should be brought before the court. The subsequent ruling of Re: Sean and Russell 2010 found that gonadectomy could occur in two children who had a cancer risk of 40%, but that similar cases should be decided with the parents and doctor, and should not be brought before the court, i.e. they were therapeutic.
>
> At present it appears that the Family Court of Australia consider a cancer risk of >28% as 'therapeutic'. Although gonadectomy in cases with cancer risk of 28% was also deemed therapeutic, further involvement of the Family Court was recommended for all such cases. International guidelines, however, recommend surgery for some diagnoses where the cancer risk is below 28%...[47]

5.60 APEG's argument was that in these cases:

> The stress and considerable financial cost to families in seeking legal approval for medical care of their children is detrimental to the health of the family unit, and is not consistent with holistic or equitable health care. It is also unnecessary if the approval for surgery occurs in conjunction with appropriate discussions with an expert multidisciplinary team.[48]

5.61 The committee notes the concern expressed by APEG, and understands the desire for clarity about the thresholds involved in determining whether a treatment is therapeutic in nature. For this reason the committee is not supportive of adopting as a threshold question a requirement that the proposed treatment be non-therapeutic, as was done in the Victorian Guidelines.

5.62 The committee's principle objection to the terminology being employed is that it dictates whether or not decision-making is escalated beyond the authority of the clinician. If a proposed treatment is classified as therapeutic then no authorisation

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46 Senate Community Affairs References Committee, *Involuntary or coerced sterilisation of people with disabilities in Australia,* July 2013, pp 10–13.

47 Australasian Paediatric Endocrine Group, *Submission 88*, p. 6.

48 Australasian Paediatric Endocrine Group, *Submission 88*, p. 6.

need be sought from the court. If it were an independent assessment then this would not necessarily present as an issue, but the Victorian Guidelines clearly state that the responsibility for deciding whether or not a proposed treatment is therapeutic is a medical decision that lies with the person's clinician, at least in the first instance:

> The characterisation of a treatment as therapeutic or non-therapeutic is a medical decision that is the responsibility of the patient's treating clinician, in collaboration with the multidisciplinary medical, ethical and legal experts assisting with the development of the management plan. Consideration of the management plan against the medical management, human rights and, in particular, the ethical principles in this resource is likely to assist in the characterisation of a proposed treatment as therapeutic or non-therapeutic. [49]

5.63 The concern expressed by the intersex community that sex differences are pathologised sits at the heart of the inquiry. Allowing clinicians to make decisions on whether treatment is for therapeutic reasons or not, noting that the consequences of such a designation could entail decision-making authority is removed from them, does not dispel these concerns.

5.64 The committee understands that a range of factors can influence the decision-making process, including the individual views of the health professional. This issue of objective assessment was raised by Jim Simpson, a lawyer for the NSW Council for Intellectual Disability who gave evidence to the committee:

> To me that issue of the distinction between therapeutic and non-therapeutic is problematic. To a fair degree I think it is in the eye of the beholding gynaecologist. I think the much safer approach is that which you find in most adult guardianship legislation—that all sterilisations require approval, but if there is some obvious medical reason then the comparatively informal, non-adversarial nature of Guardianship Tribunal proceedings compared with the adversarial formality of the Family Court means that there is no unreasonable burden on those involved to go through the Guardianship Tribunal.[50]

5.65 The Guidelines state that in order to achieve objectivity and consistency in diagnoses and treatment, all decisions should be taken with recourse to the Guidelines. If they are followed it would 'maximise the likelihood of achieving the best possible outcomes for patients, [allowing hospitals to] be able explain their decision-making processes and justify any decision taken.'[51]

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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. 22; tabled by Organisation Intersex International Australia, 28 March 2013.

50 Mr Jim Simpson, NSW Council for Intellectual Disability, *Committee Hansard*, 11 December 2012, p. 9.

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

5.66 The Guidelines, and their role in clinical decision-making, have been broadly welcomed by Organisation Intersex International. OII was particularly supportive of the acknowledgement in the guidelines that 'surgical or other medical treatment is not mandatory', however it was critical that the inclusion of intersex support organisations in providing advice to either parents and intersex children or to healthcare professionals was 'largely optional, medicalised, and limited in scope'.[52]

5.67 The inclusion of 'principles for supporting patients and parents' are welcomed by the committee. The Guidelines state that principles outlined are intended to concur with international best practice and are should aim to provide patients and parents with:

- 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. [53]

5.68 The significance of access to peer and other support groups is a principle that is also discussed in the context of the medical management of intersex cases. The Guidelines highlight their value as a resource for patients and parents:

> In addition, support groups have a particularly important role in providing information to patients and parents during the decision-making phase and beyond. The consensus statement encourages dialogue and collaboration between healthcare professionals and support groups, as partners in delivery of care to patients and their families. [54]

52 Organisation Intersex International Australia, *Submission 23.1,* p. 4.

53 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.

54 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.

5.69 The importance of basing decision-making on the wellbeing and needs of the person, rather than that of their parents or carers, was a recurring theme across the current inquiry, and has arisen in previous committee inquiries. Parents need to be given expert and ongoing support in raising a child who is intersex or has a disorder of sexual development. The committee therefore welcomes the recognition in the Guidelines of the importance of access to support groups, reflecting the valuable role they can play. The committee would like to see this commitment become a central part of the health care management of intersex cases.

Recommendation 11

5.70 The committee recommends that the provision of information about intersex support groups to both parents/families and the patient be a mandatory part of the health care management of intersex cases.

5.71 The intersex community has a number of organisations that have assisted the committee through their submissions to this inquiry, and would be well placed to provide the kind of support promoted in the Guidelines. The committee has been impressed with the policy work and professionalism of the organisations that appeared before it. However these organisations are largely volunteer-run and lack the funding and resources to be able to provide the type of services envisaged by the committee.

Recommendation 12

5.72 The committee recommends that intersex support groups be core funded to provide support and information to patients, parents, families and health professionals in all intersex cases.

Chapter 6
Research and future directions

Research on outcomes

6.1 Intersex is a term that embraces a range of biological traits and medical conditions, some requiring medical treatment and some not, with some of the medical treatment being complex and highly specialised. The numbers of people who are intersex are relatively small, and the numbers with any particular variety of intersex smaller still. Knowledge of their needs and experiences is limited, and gaining understanding of intersex has been severely impaired by stigma, ignorance and misunderstanding.

6.2 Despite some excellent studies in the field in relation to long-term outcomes and cancer management, there is a serious shortage of quality information, not only about medical treatment, but about the non-medical dimensions of intersex life. This is most evident in relation to sex assignment, including by surgery, as discussed in chapter three.

6.3 Even where studies are conducted, many suffer from significant methodological problems, some of which were discussed in more detail in chapters three and four. There are very few longitudinal studies following intersex individuals over their life course, and these studies face sampling problems:

> Study bias or methodological problems are frequently encountered. Studies may experience poor patient participation or low numbers because these disorders are so rare. Selection bias is likely to be problematic because of the rare prevalence of the conditions or of the complexities of accruing research subjects.[1]

6.4 All studies face significant risks that the participants as a group may have different features from those who decline to participate, creating a biased sample.

6.5 The 2006 Consensus Statement indicated that there was still much to be learned to address treatment decisions for which it is currently hard to find good guidance. The Statement observed:

> The consensus has clearly identified a major shortfall in information about long term outcome. Future studies should use appropriate instruments that assess outcomes in a standard manner and take cognisance of guidelines relevant to all chronic conditions. These should preferably be prospective in nature and designed to avoid selection bias. Several countries already have registers of DSD cases but there could be added benefit from pooling such

1 William G. Reiner, 'Gender identity and sex-of-rearing in children with disorders of sexual differentiation', *Journal of Pediatric Endocrinology & Metabolism*, Vol. 18, 2005, p. 552.

> resources to enable prospective multicentre studies to be undertaken on a larger number of cases that are clearly defined.[2]

6.6 Research since that time has continued to argue for the importance of larger and better studies. Pleskacova and others, for example, dealing with cancer risk and gonadectomy, stated:

> Of course, large series of patients are required for such an ambitious vision [of identifying which patients would benefit from gonadectomy]. As DSD is relatively rare, multi-centric studies and international cooperation are indispensable.[3]

6.7 The importance of high quality studies was echoed by OII, which argued:

> We still lack sound, clear evidence of both necessity and good outcomes, and we lack longitudinal or control studies. Clinical practice is still based on inconsistent assertions of psychosocial risks and benefits, and cancer risk.[4]

6.8 In this context, OII favoured not only better quality studies, but also the development of capacity to track patients:

> The lack of good data is a common theme in studies on intersex health, including the lack of useful sample sizes, non-standardised measures, lack of control groups, and selection bias in research. We wish for children to continue to receive a male or female assignment with recognition that this is mutable but, independent of this, there is a need for children and adults with an intersex status to be tracked through the health system, and more broadly.[5]

6.9 The concerns of OII were very similar to those of APEG, who called for a patient registry and better studies of long-term outcomes:

> Current international guidelines recommend long-term follow-up of children with DSD who have early surgery. This does not occur in Australia, as there is no co-ordinated registry regarding the management and outcomes for people with DSD.
>
> APEG strongly recommends that governmental funding is made available to create a patient registry to ensure adequate follow-up of patients with DSD who may develop gender dysphoria, sexual dysfunction as a result of surgery, and cancer in any testes/ovaries left in the body, and to support

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2 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).

3 J. Pleskacova, R. Hersmus, J.W. Oosterhuis, B.A. Setyawati, S.M. Faradz, M. Cools, K.P. Wolffenbuttel, J. Lebl, S.L. Drop, and L.H. Looijenga, ' Tumor Risk in Disorders of Sex Development', *Sexual Development*, Vol. 4, No. 4–5, 2010, p. 268.

4 Organisation Intersex International Australia, *Submission 23.3*, p. 3.

5 Organisation Intersex International Australia, *Submission 23.1*, p. 16.

> research to improve care and guide decision making for individuals with DSD.[6]

6.10 APEG recommended that the Commonwealth fund a review of long-term outcomes and management.[7]

Recommendation 13

6.11 The committee recommends that the Commonwealth Government support the establishment of an intersex patient registry and directly fund research that includes a long-term prospective study of clinical outcomes for intersex patients.

Research on hormone intervention

6.12 The committee's attention was drawn to one particular issue regarding research in the field of intersex. This concerned the administering of hormones, specifically dexamethasone, to pregnant women as a treatment for CAH in their foetus.

6.13 CAH is a group of conditions, the most common of which is of women who experience a deficiency of the enzyme 21-hydroxylase. Foetuses with CAH:

> [a]re exposed to unusually high levels of androgens during fetal development, which variably masculinize the genitalia and presumably also the brain and later behaviour.[8]

6.14 Commencing in the mid-1980s, medicine has sought to use hormone treatment to counteract this androgen exposure. The treatment involves treating pregnant women with a steroid, dexamethasone, throughout the pregnancy.[9]

6.15 Research on people with CAH has led to a number of observations around sex and behaviour in CAH women, such as those made by Meyer-Bahlburg in 1999:

> CAH women as a group have a lower interest than controls in getting married and performing the traditional child-care/housewife role. As children, they show an unusually low interest in engaging in maternal play with baby dolls, and their interest in caring for infants, the frequency of daydreams or fantasies of pregnancy and motherhood, or the expressed

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6 Australasia Paediatric Endocrine Group, *Submission 88,* p. 7.

7 Australasia Paediatric Endocrine Group, *Submission 88,* p. 9.

8 Heino F.L. Meyer-Bahlburg, Curtis Dolezal, Susan W. Baker and Maria I. New, 'Sexual orientation in women with classical or non-classical congenital adrenal hyperplasia as a function of degree of prenatal androgen excess', *Archives of Sexual Behavior*, Vol. 37, 2007, p. 87.

9 Alice Dreger, Ellen K. Feder, and Anne Tamar-Mattis, 'Prenatal dexamethasone for congenital adrenal hyperplasia', *Bioethical Inquiry*, Vol. 9, No. 3, 2012, p. 277.

> wish of experiencing pregnancy and having children of their own appear to be relatively low in all age groups.[10]

6.16 Because some of the research (such as that quoted above) has examined non-medical gender stereotypical behaviours, and considered the consequences of treatment for sexual orientation, it has been intensely controversial.

6.17 The controversy is particularly important because some research suggests the administration of prenatal hormones to treat foetal CAH carries with it health risks for the foetus.[11] OII was critical of the idea that:

> The prevention of homosexuality and physical masculinisation is considered to be of greater benefit than the established *cognitive and physical risks* to treated children. These are substantial risks that mean that doctors in Sweden have discontinued treatment. Despite these published, reported risks, dexamethasone treatment is still being sold to parents in the US as 'safe and effective'.[12]

6.18 A 2012 paper from a Swedish team working in the field reported a number of adverse effects of prenatal hormone treatment, to the point where the researchers concluded:

> As a consequence of our findings of possible adverse effects, we have addressed the Regional Ethics Committee in Stockholm in November 2010 and stated that we wish to put further recruitment of patients on hold for the ongoing prospective study of prenatal DEX treatment of CAH in Sweden. Hence, until larger and more conclusive studies are published, we do not consider it ethical to initiate further treatment. The patients who have entered the study during 1999–2010 will continue to be followed according to the study protocol.[13]

6.19 It has been reported that a major review of research in this area has found much of the research to be of relatively poor quality:

> A systematic review and meta-analysis of this intervention, published in 2010 in *Clinical Endocrinology*, indicated that a search of the literature 'identified 1083 candidate studies for review; of which, only four studies were confirmed eligible' for serious scientific consideration (Fernández-Balsells et al. 2010, 438). That is to say, as late as 2010, less than one half

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10 Heino Meyer-Bahlburg, 'What Causes Low Rates of Child-Bearing in Congenital Adrenal Hyperplasia?', *The Journal of Clinical Endocrinology Metabolism*, Vol. 84, No. 6, 1999, pp 1844–1847, cited in Organisation Intersex International Australia, *Submission 23.4*, p. 14.

11 See, for example, Tatja Hirvikoski, Anna Nordenström, Anna Wedell, Martin Ritzén,and Svetlana Lajic, 'Prenatal Dexamethasone Treatment of Children at Risk for Congenital Adrenal Hyperplasia: The Swedish Experience and Standpoint', *Journal of Clinical Endocrinology and Metabolism*, Vol. 97, No. 6, 2012.

12 Organisation Intersex International Australia, *Submission 23*, p. 13.

13 Tatja Hirvikoski, Anna Nordenström, Anna Wedell, Martin Ritzén,and Svetlana Lajic, 'Prenatal Dexamethasone Treatment of Children at Risk for Congenital Adrenal Hyperplasia: The Swedish Experience and Standpoint', *Journal of Clinical Endocrinology and Metabolism*, Vol. 97, No. 6, 2012.

> of one percent of published 'studies' of this intervention were regarded as being of high enough quality to provide meaningful data for a meta-analysis. Even these four studies were of low quality:
>
> > All the eligible studies were observational and were conducted by two groups of investigators (one from the US and one from Europe).…Studies lacked details regarding the use of methodological features that protect against bias. None of the studies reported blinding of the outcome assessors to the exposure (i.e., the researchers estimating each patient's degree of virilization). Loss to follow-up was, in most cases, substantial (Fernández-Balsells et al. 2010, 438).[14]

6.20 A 2010 statement by specialists in the field on treatment of CAH recommended:

> We recommend that prenatal therapy continue to be regarded as experimental. Thus, we do not recommend specific treatment protocols. We suggest that prenatal therapy be pursued through protocols approved by Institutional Review Boards at centres capable of collecting outcomes data on a sufficiently large number of patients so that risks and benefits of this treatment be defined more precisely.[15]

6.21 The committee is aware of a recent peer-reviewed analysis of the research and regulatory approvals process in the United States, which argues that the regulation of the research was poor and that some of the research undertaken 'has been so scientifically weak as to be both clinically uninformative and profoundly unethical'.[16]

6.22 The committee understands from conversations with stakeholders that dexamethasone is being used in Australia. It notes the following information on the CAH support group website:

> If your baby has CAH, your doctor can give you medicine to treat your baby even before he or she is born. Treatment should begin as soon as possible once CAH is diagnosed.[17]

6.23 The committee cannot be certain if this refers to hormone treatment. OII stated:

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14 Alice Dreger, Ellen K. Feder, and Anne Tamar-Mattis, 'Prenatal dexamethasone for congenital adrenal hyperplasia', *Bioethical Inquiry*, Vol. 9, No. 3, 2012, pp 277–294, citing M.M. Fernández-Balsells, K. Muthusamy, and G. Smushkin et al, 'Prenatal dexamethasone use for the prevention of virilization in pregnancies at risk for classical congenital adrenal hyperplasia because of 21-hydroxylase (CYP21A2) deficiency: A systematic review and meta-analyses', *Clinical Endocrinology*, Vol. 73, No. 4, 2010, pp 436–444.

15 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, p. 4138.

16 Alice Dreger, Ellen K. Feder, and Anne Tamar-Mattis, 'Prenatal dexamethasone for congenital adrenal hyperplasia', *Bioethical Inquiry*, Vol. 9, No. 3, 2012, p. 291.

17 Congenital Adrenal Hyperplasia Support Group Australia, What is CAH?, http://www.cah.org.au/education/about-cah/ (accessed 24 September 2013).

> We have attempted for some time to discover whether or not dexamethasone is prescribed 'off-label' in Australia. The Department of Human Services is now assisting, from late 2012, via their LGBTI Working Group, however we do not yet have any data.[18]

6.24 Given the controversial research around pre-natal hormone treatment for CAH, as well as the concerning results regarding possible adverse side-effects, the committee believes that the government should review the use of dexamethasone for prenatal CAH treatment, to determine its safe application. The committee will write to the Minister seeking a briefing on this issue.

Recommendation 14

6.25 The committee recommends that the Commonwealth government investigate the appropriate regulation of the use of dexamethasone for prenatal treatment of CAH.

6.26 In the interim, the committee believes that all hospitals and medical professionals must act to ensure that the use of dexamethasone for prenatal CAH treatment takes place only in a controlled research context.

Recommendation 15

6.27 The committee recommends that, effective immediately, the administration of dexamethasone for prenatal treatment of CAH only take place as part of research projects that have ethics approval and patient follow-up protocols.

Conclusion

6.28 Intersex presents a number of challenges. Best understood is the need, in some cases urgent, for an intersex person to receive medical treatment from birth. Not so well understood, but gaining more attention, is the need for specialised and on-going psychological support and access to counselling for both intersex people and their parents, where appropriate, to assist in addressing issues that arise in the course of growth and development.

6.29 Least well understood is the challenge that intersex variation presents to the rest of society. It is the challenge involved in recognising that genetic diversity is not a problem in itself; that we should not try to 'normalise' people who look different, if there is no medical necessity. It is the challenge of understanding that everyone does not have to fit into fixed binary models of sex and gender, and that nature certainly does not do so.

6.30 A key example of our lack of understanding of how to respond to intersex diversity can be seen in the clinical research on sex and gender of intersex people. The medical understanding of intersex is so strongly focussed on binary sex and gender that, even though its subjects have some sort of sex or gender ambiguity, the committee is unaware of any evidence to show that there are poor clinical or social

18 Organisation Intersex International Australia, *Submission 23*, p. 13.

outcomes from *not* assigning a sex to intersex infants.[19] Why? Because it appears never to have even been considered or researched. Enormous effort has gone into assigning and 'normalising' sex: none has gone into asking whether this is necessary or beneficial. Given the extremely complex and risky medical treatments that are sometimes involved, this appears extremely unfortunate.

6.31 This report has addressed some of the specific issues relating to the medical (and particularly surgical) treatment of intersex people. However there are broader questions around sex and gender identity upon which the committee hopes this report will encourage further reflection.

Senator Rachel Siewert

Chair

19 Martine Cools, Arianne Dessens, Stenvert Drop, Jacqueline Hewitt and Gary Warne, answers to questions on notice (received 27 September 2013).

APPENDIX 1

Submissions and Additional Information received by the Committee (since the tabling of the first report)

Submissions

14.1 Office of the Public Advocate (Victoria)
(Supplementary to submission 14)

23.4 Organisation Intersex International Australia
(Supplementary to submission 23)

36.1 Diana Bryant AO
(Supplementary to submission 36)

92 Disorder of Sex Development multidisciplinary team at Royal Children's Hospital, Melbourne

Additional Information

15 Re: Jamie (2012), judgement of the Full Court of the Family Court of Australia, from Chief Justice Diana Bryant AO, received 2 September 2013

Answers to Questions on Notice

1 Answers to Questions on Notice received from Martine Cools, Arianne Dessens, Stenvert Drop, Jacqueline Hewitt and Garry Warne, 27 September 2013