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:
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> (a) sexual health and reproductive issues; and
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> (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.