

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.

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:

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

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

21 Katrina Karkazis, *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

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. Many³¹ (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:

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.

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

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.

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.

