

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 clitorrectomy (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

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)

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

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.

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

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

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:

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

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.

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

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

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.