The Senate

Community Affairs References Committee

Involuntary or coerced sterilisation of people with disabilities in Australia

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43rd Parliament

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ABBREVIATIONS

AADDM	Australian Association of Developmental Disability Medicine Inc.
ACTCAT	ACT Civil and Administrative Tribunal
AGAC	Australian Guardianship and Administration Council
AHRC	Australian Human Rights Commission
ALHR	Australian Lawyers for Human Rights
CEDAW	Convention on the Elimination of All Forms of Discriminations Against Women
CRC	Convention on the Rights of the Child
CRPD	Committee on the Rights of Persons with Disabilities
CWLA	Catholic Women's League Australia Inc.
DNA	Deoxyribonucleic Acid
FGM	Female Genital Mutilation
FPV	Family Planning Victoria
FPNSW	Family Planning New South Wales
GP	General Practitioner
ICCPR	International Covenant on Civil and Political Rights
ICL	Independent Children's Lawyer
IDRS	Intellectual Disability Rights Service Inc.
LARCs	Long Acting Reversible Contraceptives
LIV	Law Institute of Victoria
NDIS	National Disability Insurance Scheme
OPA	Office of the Public Advocate
PWDA	People with Disability Australia
QCAT	Queensland Civil and Administrative Tribunal
RCH	Royal Children's Hospital
SCAG	Standing Committee of Attorneys-General
SCLJ	Standing Council on Law and Justice
SH&FPA	Sexual Health and Family Planning Australia
TGAB	Tasmania's Guardianship and Administration Board
UN	United Nations
UPR	Universal Periodic Review
VCAT	Victorian Civil & Administrative Tribunal
WHO	World Health Organization
WWDA	Women with Disabilities Australia

LIST OF RECOMMENDATIONS

Recommendation 1

2.117 The committee recommends that, in education programs relating to disability and in sex education and family planning information targeted to the disability sector, education about relationships and sexuality for people with disability should be prioritised, with an emphasis on the reasonable and normal aspirations of people with a disability regarding their sexuality and relationships.

Recommendation 2

2.118 The committee recommends that medical workforce training with respect to sexual and reproductive health includes content on supporting sexual relationships and sexual and reproductive health needs for people with a disability.

Recommendation 3

2.119 The committee recommends that medical workforce training include training with respect to the ethical and legal aspects of informed consent, substitute and supported decision making and fertility control.

Recommendation 4

2.121 The committee recommends that, in the development of participant plans (particularly for participants approaching puberty and in their teens), the participant work with any person assisting them with plan development, and with Disability Care Australia, to cover the need for understanding of sexuality and sexual relationships, support for relationships and sex education that meets the participants' needs, and covers appropriate support for menstrual management for girls and women with disabilities.

Recommendation 5

2.127 The committee abhors the suggestion that sterilisation ever be used as a means of managing the pregnancy risks associated with sexual abuse and strongly recommends that this must never be a factor in approval of sterilisation.

Recommendation 6

4.43 The committee recommends that, for a person with a disability who has the capacity to consent, or to consent where provided with appropriate decision-making support, sterilisation should be banned unless undertaken with that consent.

Recommendation 7

4.44 The committee recommends that, for a person with a disability for whom it may reasonably be held that they may develop the future capacity to consent, irreversible sterilisation should be banned until either the capacity to consent exists, or it becomes reasonably held that the capacity to consent will never develop.

Recommendation 8

5.114 The committee recommends that state and territory legislation regulating the sterilisation of adults with disabilities be amended to explicitly state that it is presumed that persons with disabilities have the capacity to make their own decisions unless objectively assessed otherwise. The legislation should be amended to specify that it cannot be presumed that persons are without legal capacity in relation to the proposed special medical procedure, including a sterilisation procedure, even where there is an existing guardianship order in place.

Recommendation 9

5.115 The committee recommends that Commonwealth, state and territory legislation regulating the sterilisation of adults with disabilities be amended to explicitly state that a court or tribunal does not have authority to hear an application for an order approving a proposed special medical procedure, including a sterilisation procedure, where the person with a disability has legal capacity.

Recommendation 10

5.117 The committee recommends that each Australian jurisdiction use the same definition of capacity, to ensure that a person's rights to autonomy and bodily integrity do not vary according to, and are not dependent on, the jurisdiction in which they live.

Recommendation 11

5.126 The committee recommends that all jurisdictions adopt in law a uniform 'best protection of rights' test, replacing current 'best interests' tests, that makes explicit reference to the protection of the individual's rights; and the maintenance of future options and choices.

Recommendation 12

5.127 The committee recommends that, in those cases where the need for supports has a bearing on the assessment of interests, regard should be had to best support services available, rather than the deficit in services provided in the past.

Recommendation 13

5.132 The committee recommends that the states and territories ensure that independent representation is provided for people with disabilities. Representation should be independent; while family or guardians should have a right to be involved, an independent representative should not be a member of the person's family or a caregiver.

Recommendation 14

5.133 The committee recommends that the costs of legal representation for adults should be covered by the relevant legal aid commission. state and territory governments should review legal aid funding arrangements to ensure that there are adequate funds to meet the costs of providing a legal representative for persons with disabilities in special medical procedure cases, including sterilisation cases.

Recommendation 15

5.136 The committee recommends that a legal representative be appointed in each child sterilisation case regardless of the jurisdiction in which the matter is heard. Commonwealth, state and territory legislation should be amended as necessary to ensure that the appointment of a legal representative of the child is mandatory in each sterilisation case.

Recommendation 16

5.137 The committee recommends that legal aid be provided to cover the costs incurred by the child's legal representative. The committee recognises that governments may need to revise current legal aid funding arrangements to ensure that there are sufficient funds to meet the costs of children's representatives in sterilisation cases.

Recommendation 17

5.140 The committee recommends that Commonwealth, state and territory governments work with legal aid commissions and relevant law societies to develop training courses for legal practitioners about children's legal capacity, techniques to communicate, and the varying effects and nature of disability. Successful completion of such courses should be mandatory before being appointed to represent a child.

Recommendation 18

5.144 The committee recommends that Commonwealth, state and territory legislation be amended to provide the right to public advocates, such as the Office of the Public Advocate, to be a party to child or adult sterilisation cases.

Recommendation 19

5.149 The committee recommends courts and tribunals develop information packs and questionnaires to provide guidance for medical experts in sterilisation cases. The information packs should specify the factors that courts and tribunals consider under the relevant legislation, and should also note issues that the courts and tribunals are not authorised to consider such as outdated and paternalistic attitudes to disability, eugenic arguments or assessments of the person's current or hypothetical capacity to care for children. Questionnaires should seek the medical expert's advice about the procedures that could usefully be adopted in the particular case to facilitate both a robust medical assessment and the person's participation in proceedings.

Recommendation 20

6.36 The committee recommends that the Family Court of Australia gives strong consideration to the evidence gathered by this inquiry about the absolute necessity of ensuring that judicial officers participating in special medical procedure cases have appropriate skills and expertise in disability matters. The committee urges the Family Court of Australia to develop training courses about disability matters and to ensure that such courses are completed by any judicial officer who may hear cases concerning special medical procedures.

Recommendation 21

6.45 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.

Recommendation 22

6.47 The committee recommends that legal aid should be provided to cover the costs incurred by the parents or guardians in child sterilisation cases. The legal aid grant should not be subject to capping or to a means or merits test.

Recommendation 23

6.52 The committee recommends that the matter of the scope and operation of the relevant courts and tribunals be placed on the agenda of the Standing Council on Law and Justice for ongoing review.

Recommendation 24

6.55 The committee recommends that the Standing Council on Law and Justice obtain information about the frequency and nature of 'therapeutic' sterilisation cases being conducted, and compare the circumstances of those cases with 'non-therapeutic' cases that have been authorised by courts or tribunals.

Recommendation 25

7.25 The committee recommends that data about adult and child sterilisation cases be recorded, and reported, in the same way in each jurisdiction. Data records should include the number of applications made for a special medical procedure, the kind of special medical procedures specified in the application, the categories of parties to the proceedings (for example, parents, medical experts, public advocates), and the outcome of the case.

Recommendation 26

7.26 The committee recommends that the Department of Human Services investigate the pattern of vasectomy in young males, including the apparently high number occurring in Queensland, and provide information to the Standing Council on Law and Justice if it has reason to believe the figures include sterilisations of men with disability.

Recommendation 27

7.44 The committee recommends that the Council of Australian Governments oversee the development of uniform model legislation to regulate the sterilisation of persons with disabilities. Based on this model, a new division of the *Family Law Act 1975* (Cth) should be created.

Recommendation 28

7.67 The committee recommends that each jurisdiction enact legislation prohibiting the performance or procurement of unauthorised sterilisation procedures. State and Territory legislation should also make it an offence to take, attempt to take, or to knowingly assist a person to take, a child or an adult with a disability oversees for the purpose of obtaining a sterilisation procedure.

Chapter 1

The referral

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 Legislative Committee for inquiry and report by 24 April 2013. The Senate granted an extension of time for reporting to 17 July 2013.

1.2 On 7 February 2013, the Senate added an additional term of reference regarding intersex people:

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

1.3 This second term of reference will be the subject of a second, separate committee report.

Conduct of the inquiry

1.4 Information about the committee's inquiry was advertised in the national press and on the committee's website. The committee commissioned the preparation of an Easy English explanation of the inquiry, which was also released on the committee's website. The committee received 91 submissions from a diverse range of individuals and organisations, which included legal and medical professionals, disability support services, disability advocacy services, family planning services, and private individuals. Several submissions were received from persons with disabilities, and their families. In addition, the committee received correspondence from relevant state and territory courts and tribunals and from academics in the field of international law. This material is available on the committee's website.[1] A list of the individuals and organisations who made submissions is provided at Appendix 1.

1.5 Public hearings were held in Melbourne on 11 December 2012, Sydney on 27 and 28 March 2013, and in Canberra on 31 May 2013. Transcripts of the hearings are available on the committee's website.[2] A list of witnesses who gave evidence at the public hearings is provided at Appendix 2.

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1 Senate Standing Committees on Community Affairs, *Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia: Submissions received by the Committee* http://www.aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=clac_ctte/involuntary_sterilisation/submissions.htm (accessed 12 July 2013).

2 Senate Standing Committees on Community Affairs, *Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia: Public hearings and transcripts* http://www.aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=clac_ctte/involuntary_sterilisation/hearings/index.htm (accessed 12 July 2013).

Acknowledgements

1.6 The committee recognised that it was essential that it talk to and hear from people with disabilities. Their evidence is the most important, because this inquiry is about their bodies and their lives. To this end, it held a number of *in camera* (confidential) discussions with women with disabilities, in Brisbane, Sydney and Adelaide. These discussions were facilitated by trained support workers and interpreters. The committee is grateful not only for their willingness to share their accounts, but also for their willingness to allow the committee to refer to their evidence in the committee's report.

1.7 The committee thanks individuals and organisations who worked hard to facilitate the committee's inquiry. These include Carolyn Frohmader of Women With Disabilities Australia, Karin Swift (Brisbane), Matthew Bowden (Sydney) and Margie Charlesworth (Adelaide). This inquiry could not have been completed without them. The committee also thanks a number of health professionals who provided considerable assistance and answered the committee's many questions. It is grateful to the Australian Guardianship and Administration Council and its member organisations, which helped gather information, and answered questions. The committee is likewise grateful for the assistance of the Chief Justice of the Family Court, Diana Bryant AO.

Previous inquiries

1.8 This inquiry into the coerced or involuntary sterilisation of persons with disabilities is not the first conducted in Australia. The committee acknowledges the seminal work undertaken by both government and non-government organisations in exposing an otherwise hidden practice. In particular, the committee notes the following reports.

1994 report of the Family Law Council

1.9 In October 1992, the then Minister for Justice, Senator Tate, referred to the Family Law Council an inquiry into Commonwealth, state and territory laws regulating the sterilisation of children. Council was asked to consider what principles should govern sterilisation proceedings, whether uniform legislation should be introduced, and what penalties are appropriate in the event a child is sterilised without all necessary authorisations.[3]

1.10 Reporting in November 1994, Council concluded that a uniform and consistent approach is needed for all children regardless of where they live. Accordingly, Council recommended that application for child sterilisation procedures be heard only by the Family Court of Australia. Additionally, Council recommended that only specially trained judges hear sterilisation applications, that the costs of sterilisation cases be met by the government rather than the individual families, and that counselling services be provided. Council further recommended that sterilisation

3 Family Law Council, *Sterilisation and other medical procedures on children*, terms of reference, 1994, paragraph 1.06.

of a child only be authorised if necessary to save a life or to prevent serious damage to the child's physical or psychological health.[4]

1997 and 2001 reports by the Australian Human Rights Commission

1.11 In 1997, the Australian Human Rights Commission released the report *The sterilisation of girls and young women in Australia*. The report highlighted that the number of sterilisations being performed on children and young women with disabilities in Australia exceeded those authorised by a court or tribunal.[5] The Commission concluded that the law had failed to protect persons at risk of involuntary or coerced sterilisation:

> The law has failed to protect significant numbers of children from significant abuse of their fundamental human right to bodily integrity. Worse, the community has aided and abetted that abuse by funding it - all the 1045 sterilisations which are identified can be identified only because they were 'services which qualify for medicare benefit.[6]

1.12 In 2001, this was followed by a second report. The report noted that the 1997 inquiry triggered significant action among the government and non-government sectors. This included amendments to the Medicare scheme in 1998, to require that any claims for Medicare benefits in relation to the sterilisation of children be accompanied by either a court order or clinical details of the need for such a procedure. Additionally, the report noted that the 1997 inquiry prompted a Senate resolution requesting that the Australian Government review the laws relating to the sterilisation of children and adults with disabilities.[7] It was recommended that each state and territory enact legislation concerning the sterilisation of children, and that service providing agencies be provided with concise and accurate information about fertility and menstrual management and the law as it relates to the sterilisation of children.[8]

Government report to the Senate

1.13 In response to a Senate resolution calling for the government to review the legal, ethical and human rights mechanisms required to protect the reproductive health

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4 Family Law Council, *Sterilisation and other medical procedures on children*, terms of reference, 1994, Recommendations 1–4.

5 Australian Human Rights Commission, *The sterilisation of girls and young women in Australia: issues and progress*, http://www.humanrights.gov.au/publications/sterilisation-chapter-two (accessed 12 July 2013).

6 Australian Human Rights Commission, *The sterilisation of girls and young women in Australia: 1997 report*, http://www.humanrights.gov.au/sterilisation-girls-and-young-women-australia-1997-report (accessed 12 July 2013).

7 Australian Human Rights Commission, *The sterilisation of girls and young women in Australia: issues and progress*, http://www.humanrights.gov.au/publications/sterilisation-chapter-five (accessed 12 July 2013).

8 Australian Human Rights Commission, *The sterilisation of girls and young women in Australia: issues and progress*, http://www.humanrights.gov.au/publications/sterilisation-chapter-six (accessed 12 July 2013).

of women with intellectual and other disabilities, on 6 December 2000 the government tabled in the Senate the report *Sterilisation of women and young girls with an intellectual disability*. On the basis of data provided by the Australian Institute of Health and Welfare, the government estimated that there were a few sterilisations of girls with disabilities in the years 1993–1999.

1.14 Reporting to the United Nations' Committee in June 2003, the Australian Government commented that the report provided background information and recent statistics on sterilisation procedures. Following the release of the report, the then Attorney–General wrote to Australian medical colleges and associations to advise of the law and procedure applying to non-therapeutic sterilisation of children with an intellectual disability. In addition, the Attorney–General authorised changes to legal aid guidelines to improve access to legal assistance for Commonwealth child sterilisation cases.[9]

Key concepts and definitions

1.15 Before the committee turns to the substantive issues, there are a number of key concepts that need briefly to be explained, in part because they are quite complex and the subject of more detailed discussion in later chapters. The most significant of these is the final issue in this chapter: the meaning of 'therapeutic' sterilisation.

Definition of disability

1.16 The World Health Organization (WHO) defines 'disability' as:

> …an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.
>
> Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers.[10]

1.17 Persons with a disability who are subject to sterilisation may be of different ages, different genders and have differing levels of capacity. However, it has been observed that sterilisation procedures are usually considered for, or performed on, persons with intellectual disability and/or cognitive impairment. However, the degree to which decision-making capacity is affected depends both on the nature of the

9 Australian Government, *Australia's combined fourth and fifth reports to the United Nations on the Convention on the Elimination of Discrimination against Women*, June 2003, p. 77.

10 World Health Organisation (2013) in Organisation Intersex International Australia Limited, *Submission 23*, p. 2.

disability, the extent of support with which a person is provided, and the subject matter about which the person is being asked to make a decision.[11]

1.18 Coerced or involuntary sterilisation is a gendered practice. According to a number of submissions[12] those subjected to the practice are 'predominantly…women and girls with disability'[13] and most matters that reach the courts and tribunals relate to girls with intellectual disabilities.[14] This is reflected in the evidence before the committee, which was overwhelmingly about the sterilisation of women and girls, and borne out in data received by the committee.

1.19 The committee was informed that the clinical reasons given in support of sterilisation for a person with a disability are usually linked to one of the following outcomes:[15]

- Avoidance of pregnancy;
- Management of menstruation where the cyclic nature of menstruation and the associated hormonal changes adversely impact on other existing health conditions such as epilepsy (increased seizures), asthma (increased breathing difficulties) and identified behavioural disorders (increasingly extreme and dangerous behaviour); or
- Management of menstruation where the cyclic nature of menstruation and the associated hormonal changes impact on the quality of life of the individual, for example meaning they are unable to attend school or to take part in everyday activities.

1.20 As will be discussed in later chapters, however, the arguments made for the use of sterilising procedures can be broader than just clinical in nature, and are controversial.

Definition of sterilisation

1.21 A purpose of this inquiry was to ascertain how sterilisation is understood and defined in the Australian community. The committee received varying definitions of

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11 See, for example, Sexual Health and Family Planning Australia, *Submission 52*, p. 3; Women With Disabilities Australia, *Submission 49*, p. 38.

12 Australian Human Rights Commission, *Submission 5*, pp. 3–4; Women With Disabilities Australia, *Submission 49*, p.19; Brady, J. Briton & S. Grover, *The Sterilisation of Girls and Young Women in Australia: issues and progress*, 2001, p. 28.

13 Women With Disabilities Australia, in Australian Human Rights Commission, *Submission 5*, p. 3.

14 Women With Disabilities Australia, *Submission 49*, p. 19; S. Brady, J. Briton & S. Grover, *The Sterilisation of Girls and Young Women in Australia: issues and progress*, 2001, p. 3.

15 Australian Human Rights Commission, *Submission 5*, p. 8; Women With Disabilities Australia, *Submission 49*, p.30; Professor Gwynnyth Llewellyn, University of Sydney, *Submission 21*, pp. 3–5; S.M. Brady & S. Glover, *The Sterilisation of Girls and Young Women in Australia; A Legal, Medical and Social Context* – report commissioned by the Federal Disability Discrimination Commissioner, 1997, pp. 28–29.

sterilisation. As explored further in chapter 3, it was notable that definitions of sterilisation are not consistent across Commonwealth, State and Territory legislation.[16] Submitters to this inquiry also varied in their understanding of what constitutes a sterilisation procedure.[17]

1.22 Broadly, it was recognised that sterilisation 'is a process or act that renders a person unable to produce children.'[18] However, within this framework various kinds of procedures were noted, including permanent (irreversible) sterilising procedures, medical procedures for which permanent sterilisation is the likely outcome and non-permanent contraceptive measures.

1.23 The permanent sterilising procedures mentioned during this inquiry included:

- Hysterectomy – removal of the uterus and, depending on the need, the removal of the cervix, fallopian tubes, ovaries and part of the vagina.[19]
- Tubal ligation – blocking or closing of the fallopian tubes. It causes infertility but ovulation and menstruation can still occur.[20]
- Endometrial ablation – laser technology or similar is used to destroy the uterine lining, predominantly for the purpose of reducing or stopping menstrual loss. This process alone does not render a woman infertile but it is often performed in association with a tubal ligation.[21]
- Vasectomy – a procedure performed on males, cutting and sealing the vas deferens to prevent sperm passing from the testes to the penis.[22]

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16 See, for example, *Guardianship and Management of Property Act 1991* (ACT) and *Adult Guardianship Act 1988* (NT).

17 See, for example, Australian Human Rights Commission, *Submission 5*, p. 3; Women With Disabilities Australia, *Submission 49*, p. 18.

18 *Mosby's Dictionary of Medicine Nursing and Health Professionals* 2nd Australian and New Zealand Edition Peter Harris; Sue Nagy & Nicholas Vardaxis (Eds) 2009.

19 Department of Paediatric and Adolescent Gynaecology that Royal Children's Hospital, Melbourne, *Submission 69*, p. 3; S.M. Brady & S. Glover, *The Sterilisation of Girls and Young Women in Australia; A Legal, Medical and Social Context* – report commissioned by the Federal Disability Discrimination Commissioner, 1997, pp. 21–22.

20 S.M. Brady & S. Glover, *The Sterilisation of Girls and Young Women in Australia; A Legal, Medical and Social Context* – report commissioned by the Federal Disability Discrimination Commissioner, 1997, p. 23.

21 Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne, *Submission 69*, p. 3; S.M. Brady & S. Glover, *The Sterilisation of Girls and Young Women in Australia; A Legal, Medical and Social Context* – report commissioned by the Federal Disability Discrimination Commissioner, 1997, p.22.

22 Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne, *Submission 69*, p. 3; State of Victoria, Australia, Better Health Channel Fact Sheet Contraception Choices http://www.betterhealth.vic.gov.au/bhcv2/bhcpdf.nsf/ByPDF/Contraception_choices_explained/$File/Contraception_choices_explained.pdf (accessed 10 April 2013)

1.24 Permanent sterilisation procedures are in the majority of cases either completely non-reversible or difficult to reverse. The likelihood of a successful pregnancy after a sterilisation reversal is lower than that prior to sterilisation. However, pregnancy is not impossible if a sterilisation procedure fails. For example tubal ligation has a 3/1000 chance of failure rate.[23] Pregnancy can also be dangerous if a sterilisation procedure fails. For example pregnancy after an endometrial ablation can be life threatening to both the foetus and woman due to uncontrolled bleeding.[24]

1.25 Identified medical procedures for which sterilisation is a secondary, but likely, outcome included:

- Gonadectomies - involve the removal of testes and/or ovaries. These processes are considered sterilisation as they limit any future utilization of healthy reproductive tissue.[25] These procedures are often performed on intersex people.
- Bilateral oophorectomy – removal of both ovaries (because of cancer or other pathological conditions) is not a technique that is used to achieve sterilisation, however sterilisation can occur as the process will result in a cessation of hormone production and bring on menopause.[26]

1.26 The committee was also informed of a range of non–permanent contraceptive and menstrual suppression options. According to Sexual Health and Family Planning Australia 'there is a continuum of non-permanent options and strategies that can be used to help manage menstruation and/or prevent pregnancy.'[27] These range from short acting contraceptives such as the Oral Contraceptive Pill (including the emergency contraceptive pill), male and female condoms, vaginal ring, diaphragms/caps and intrauterine devices, to long acting reversible contraceptives (LARCs). LARCs were discussed regularly by witnesses to the inquiry, and include injections (such as Depo Provera), implants (such as Implanon) and intrauterine systems (such as Mirena).[28]

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23 Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne, *Submission 69*, p. 3.

24 Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne, *Submission 69*, p. 3.

25 Organisation Intersex International Australia Limited, *Submission 23*, p. 3; Androgen Insensitivity Syndrome Support Group Australia Inc., *Submission 54*, p. 3.

26 Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne, *Submission 69*, p. 3; S.M. Brady & S. Glover, *The Sterilisation of Girls and Young Women in Australia; A Legal, Medical and Social Context* – report commissioned by the Federal Disability Discrimination Commissioner, 1997, p. 22.

27 Sexual Health and Family Planning Australia, *Submission 52*, p. 3.

28 The Royal Australian and New Zealand College of Obstetricians and Gynaecologists, *Submission 30*. pp. 1–2.

1.27 Short acting contraceptives are the most common contraceptives used and are easily reversible, usually through simply stopping their use.[29] In comparison to short acting contraceptives, LARCs reduce or eliminate menstrual flow.[30] They are also perceived as being more effective and convenient for carers as they involve minimal maintenance.[31] According to the Department of Paediatric and Adolescent Gynaecology at the Royal Children's Hospital, Melbourne, the aim of menstrual management is to improve the patient's quality of life.[32]

Risks associated with permanent sterilisation procedures

1.28 Evidence before the committee highlighted that there are a number medical risks associated with permanent and non–permanent sterilisation and menstrual suppression procedures. Many permanent sterilisation procedures require surgery under a general anaesthetic and as such require admission to hospital.[33] As a surgical procedure, there are associated risks and potential side effects. These include postsurgical pain, scarring, organ damage or obstruction, surgical injury, and pulmonary issues.[34]

1.29 The committee was also advised of potential risks associated with non–permanent contraceptive and menstrual suppression procedures. These include nausea,

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29 D. Mazza, C. Harrison, A. Taft, B. Brijnath, H. Britt, M. Hobbs, K. Stewart & S. Hussainy, 'Current Contraceptive Management in Australian General Practice: an analysis of BEACH data', *Medical Journal of Australia*, Vol. 197, No. 2, 2012, p. 110. https://www.mja.com.au/journal/2012/197/2/current-contraceptive-management-australian-general-practice-analysis-beach-data?0=ip_login_no_cache%3D81480516041c71bb078031b48a511e93 (accessed 10 April 2013).

30 The Royal Australian and New Zealand College of Obstetricians and Gynaecologists, *Submission 30*. p. 1.

31 D. Mazza, C. Harrison, A. Taft, B. Brijnath, H. Britt, M. Hobbs, K. Stewart & S. Hussainy, 'Current Contraceptive Management in Australian General Practice: an analysis of BEACH data', *Medical Journal of Australia*, Vol. 197, No. 2, 2012, p. 110; https://www.mja.com.au/journal/2012/197/2/current-contraceptive-management-australian-general-practice-analysis-beach-data?0=ip_login_no_cache%3D81480516041c71bb078031b48a511e93; State of Victoria, Australia, Better Health Channel Fact Sheet Contraception Choices http://www.betterhealth.vic.gov.au/bhcv2/bhcpdf.nsf/ByPDF/Contraception_choices_explained/$File/Contraception_choices_explained.pdf (accessed 10 April 2013).

32 Department of Paediatric and Adolescent Gynaecology that Royal Children's Hospital, Melbourne, *Submission 69*, p. 3.

33 Department of Paediatric and Adolescent Gynaecology that Royal Children's Hospital, Melbourne, *Submission 69*, pp. 4–5.

34 Patient.co.uk, *Common Postoperative Complications*, http://www.patient.co.uk/doctor/common-postoperative-complications (accessed 12 April 2013); Australian and New Zealand College of Anaesthetists, *Risks and complications*, http://www.anzca.edu.au/patients/frequently-asked-questions/risks-and-complications.html/?searchterm=risks and complication (accessed 12 April 2013).

breast tenderness, headaches, increased appetite and potential complications such as deep vein thrombosis (blood clots), heart attacks and strokes.[35]

1.30 According to the Royal Australian and New Zealand College of Obstetricians and Gynaecologists, LARCs have the potential to interact with medications commonly used for the control of epilepsy and behavioural disturbance. They state that 'such interactions may decrease their contraceptive efficacy.'[36] Depo-Provera has been reported as causing weight gain and in some cases an increased incidence of depression. Its extended use is also limited by the risk of osteoporosis.[37] Side effects of Implanon can include menstrual irregularity, and variable menstrual flow.[38] The use of Mirena is reported as causing continuous light menstrual bleeding in some women and may be contraindicated by pelvic infection. According to the Royal Australian and New Zealand College of Obstetricians and Gynaecologists, Mirena is not appropriate for disabled women at risk of sexually transmitted diseases.[39]

1.31 On a more practical level there may be difficulties with the use of some of these non-permanent contraceptives, particularly if a person is:

> 'unable to swallow or take anything by mouth, is terrified of needles [or] becomes upset at the sight of even a spot of blood.'[40]

Definition of involuntary or coerced sterilisation

1.32 According to the Australian Human Rights Commission (AHRC), 'involuntary or coerced sterilisation' refers 'to the sterilisation of children (regardless of whether they have a disability), and the sterilisation of adults with disability in the absence of their fully informed and free consent.'[41] The AHRC submitted that there are distinct differences between involuntary sterilisation and coerced sterilisation:

> A sterilisation is 'involuntary' when it is performed against the person's will, or without the person being aware that it has happened (that is, without any form of consent from that person). In this situation, the right to make the decision about the sterilisation is removed from the person…'Coerced' sterilisation refers to situations in which pressure, trickery or inducements are employed to convince the person with disability to 'consent' to the

35 State of Victoria, Australia, Better Health Channel Fact Sheet Contraception – The pill http://www.betterhealth.vic.gov.au/bhcv2/bhcpdf.nsf/ByPDF/Contraception_oral_methods/$File/Contraception_oral_methods.pdf (accessed 10 April 2013).

36 The Royal Australian and New Zealand College of Obstetricians and Gynaecologists, *Submission 30*, p. 2.

37 The Royal Australian and New Zealand College of Obstetricians and Gynaecologists, *Submission 30*, p. 2.

38 The Royal Australian and New Zealand College of Obstetricians and Gynaecologists, *Submission 30*, p. 1.

39 The Royal Australian and New Zealand College of Obstetricians and Gynaecologists, *Submission 30*, p. 1.

40 Australian Association of Developmental Disability Medicine Inc, *Submission 59*, p. 3.

41 Australian Human Rights Commission, *Submission 5*, p. 3.

> procedure or menstrual suppression medication, usually in the absence of information being given to that person about the true nature and implications of the procedure or medication.[42]

1.33 Women With Disabilities Australia also distinguished involuntary sterilisation from coerced sterilisation:

> 'Forced/involuntary sterilisation' refers to the performance of a procedure which results in sterilisation in the absence of the free and informed consent of the individual who undergoes the procedure - including instances in which sterilisation has been authorised by a third party, without that individual's consent. 'Coerced sterilisation' occurs when financial or other incentives, misinformation, misrepresentation, undue influences, pressure, and/or intimidation tactics are used to compel an individual to undergo the procedure. Coercion includes conditions of duress such as fatigue or stress. Undue influences include situations in which the person concerned perceives there may be an unpleasant consequence associated with refusal of consent.[43]

1.34 Some submitters believed that sterilisation could be involuntary or coerced even if authorised by a court or tribunal.[44] This matter is further considered in chapter 4.

Definitions of therapeutic and non-therapeutic sterilisation

1.35 The difference between therapeutic and non-therapeutic sterilisation was a major theme throughout the submissions to this inquiry. Where used, the term 'therapeutic sterilisation' generally referred to procedures undertaken in a medical emergency to prevent serious harm.[45] In contrast, non-therapeutic sterilisations were equated with forced or involuntary sterilisations.[46]

1.36 However, not all submitters agreed with this definition. Ms Lesley Naik argued that the definition of therapeutic needs to be scrutinised to ensure that it genuinely means procedures intended to save lives and prevent serious damage to health. Ms Naik warned that:

> There is a real risk of an illegitimate broadening of the category of sterilisation procedures that may proceed without court or tribunal consent

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42 Australian Human Rights Commission, *Submission 5*, p. 5.

43 Women With Disabilities Australia, *Submission 40*, p. 7.

44 See, for example, Women With Disabilities Australia, *Submission 40*, p. 17.

45 Australian Human Rights Commission, *Submission 5*, p. 3; Women With Disabilities Australia, *Submission 49*, p. 18; Dr Wendy Bonython, *Submission 22*, p. 18; Catholic Women's League Australia Inc., *Submission 32*, p. 2; People With Disability Australia, *Submission 50*, p. 5; Family Planning, Victoria, *Submission 58*, p. 4; Associate Professor Lee Ann Basser, *Submission 61*, pp. 3–5; Queensland Advocacy Incorporated, *Submission 65*, p. 4.

46 See, for example, Australian Human Rights Commission, *Submission 5*, p. 6; Women With Disabilities Australia, *Submission 40*, p. 18.

> if 'therapeutic sterilisation' is not adequately distinguished from procedures that are necessary to 'save life' or prevent 'serious damage' to health.[47]

1.37 This view was shared by Ms Linda Steele, who warned that broad interpretations of 'serious damage to health' reinforce 'gendered and disabled stereotypes'.[48]

Legal definitions

1.38 In Australia, the legally recognised concept of therapeutic and non-therapeutic sterilisation is derived from the High Court of Australia's 1992 decision in *Re Marion*. While noting that there is uncertainty about the dividing line between therapeutic and non–therapeutic sterilisation, the High Court drew a distinction between sterilisation procedures and sterilisation that is a by–product, that is, a secondary outcome, of a medical procedure carried out for some other, necessary, purpose. The High Court held that the latter does not require court authorisation.[49] Specifically, their Honours stated:

> It is necessary to make clear that, in speaking of sterilisation in this context, we are not referring to sterilisation which is a by-product of surgery appropriately carried out to treat some malfunction or disease. We hesitate to use the expressions "therapeutic" and "non-therapeutic", because of their uncertainty. But it is necessary to make the distinction, however unclear the dividing line may be.[50]

1.39 While their Honours did not provide further guidance on the distinction between therapeutic and non-therapeutic sterilisation, the case has been taken as authority for the proposition that there is a distinction between therapeutic and non-therapeutic sterilisation, and, further, that there must be authorisation of 'non-therapeutic sterilisation' that would not be required for 'therapeutic' procedures.[51]

1.40 The Law Institute Victoria advised that the difference between therapeutic and non-therapeutic sterilisation continues to be a subject of debate within the legal community, and has recently been considered by the Family Court of Australia in *Re: Sean and Russell (Special Medical Procedures)* (2010) FamCA 948. In this case, the Family Court held that court approval was not needed for a sterilisation procedure that

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47 Ms Lesley Naik, *Submission 7*, p. 6.

48 Ms Linda Steele, *Submission 44*, p. 30.

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

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

51 See, for example, 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).

was proposed to prevent cancer.[52] Ms Lesley Naik, private capacity, submitted that the courts' interpretation of therapeutic sterilisation is 'restrictive'.[53]

Concerns with the use of the terms 'therapeutic' and 'non-therapeutic' sterilisation

1.41 It has been argued the High Court did not clearly endorse the use of the terms 'therapeutic' and 'non-therapeutic' sterilisation. As the Family Law Council has noted, an endorsement of both terms is clearer in international case law. In the 1986 case *Re Eve*, the Supreme Court of Canada clearly distinguished therapeutic from non-therapeutic sterilisation. As the Family Law Council has explained:

> In its decision in *Re Eve*, the Supreme Court of Canada drew a distinction between therapeutic and non-therapeutic procedures when it decided that sterilisation could not be authorised except for some therapeutic purpose. The court defined a 'therapeutic procedure' as a 'surgical operation that is necessary for the health of the person' and indicated that, by health, the court meant 'mental as well as physical health'.[54]

1.42 The Family Law Council concluded that 'there is no merit in drawing a distinction…between therapeutic and non-therapeutic sterilisation'. Rather, the Council recommended that legislation provide precise criteria for decision-makers to take into account before making a decision in a particular case.[55]

1.43 Submitters to this inquiry also debated the merits of using the terms 'therapeutic' and 'non-therapeutic' sterilisation. According to Dr Wendy Bonython, Assistant Professor, School of Law, Faculty of Business and government and Law, University of Canberra, the meaning of the terms is unclear:

> The term ‘therapeutic’ itself is difficult to define. Pertaining to ‘therapy’, it is not clear whether legally it is limited to clinical treatment of a physical disorder, or whether it can encompass broader aspects of health and welfare, such as minimising emotional or behavioural disturbances.[56]

1.44 Some submitters were concerned that the terms therapeutic and non-therapeutic sterilisation were also inappropriate for members of the medical community. Ms Lesley Naik submitted that the term is unhelpful for medical professionals, providing little guidance about legal requirements. Ms Naik advised that 'the legal meaning of the term therapeutic sterilisation differs from the meaning of the term as understood by medical practitioners.' For example, Ms Naik submitted that the legal notion of therapeutic sterilisation 'often results in a sterilisation procedure that may be described as therapeutic according to principles of medical ethics being

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52 Law Institute Victoria, *Submission 79*, p. 15.

53 Ms Lesley Naik, *Submission 7*, p. 4.

54 Family Law Council, *Sterilisation and other medical procedures of children*, November 1994, paragraph 4.15, citing *Re Eve* (1986) 31 DLR (4th) 1.

55 Family Law Council, *Sterilisation and other medical procedures of children*, November 1994, paragraph 4.18.

56 Dr Wendy Bonython, *Submission 22*, p. 17.

described as non-therapeutic'.[57] The Office of the Public Advocate also noted that the legal terminology may be unhelpful for the medical community, advising that since *Re Marion* 'the distinction between "non-therapeutic" and "therapeutic" sterilisations has become blurred'.[58]

1.45 It was submitted that legislation should avoid these terms, and instead simply and clearly articulate the circumstances in which court approval is required. The Law Institute of Victoria preferred an approach whereby legislation clearly specifies the nature of the sterilisation procedures that require approval.[59] Such an approach, it was submitted, would provide greater clarity for members of the medical and legal community, and reduce the potential for court approval being sought merely to reduce a medical practitioner's potential liability.[60] Similarly, Dr Wendy Bonython recommended that rather than using terms such as 'therapeutic' or 'non-therapeutic', legislation should clearly articulate the circumstances under which court authorisation should be sought.[61]

1.46 Later in this report, and in its forthcoming report on intersex issues, the committee will discuss the issue of circumstances that should require authorisation, and how these should be defined.

57 Ms Lesley Naik, *Submission 7*, p. 3.

58 Office of the Public Advocate, *Submission 14*, p. 6.

59 Law Institute of Victoria, *Submission 79*, p. 22.

60 Law Institute of Victoria, *Submission 79*, p. 22.

61 Dr Wendy Bonython, *Submission 22*, p. 4.

Chapter 2

Sexual and reproductive health and people with disabilities

2.1 People with disabilities are no different to other people: they have a range of goals and aspirations, they want to live independent lives. They want to be able to control their relationships and their sexual and reproductive health in the same ways as others, they want the same choices as others, and they may want to be parents like others. However each person may require specific supports in order to enjoy rights equally with other people, and to have the choices and opportunities that other people have.

2.2 The committee heard however that people with disability encountered discrimination, stereotyping and disadvantage in trying to achieve goals and aspirations similar to those of the rest of the population. And, in areas where people with disability were different and needed specific supports, those supports were often lacking. They encountered 'the worst of both worlds': treated differently when they expected to be treated the same, and treated indifferently when they needed appropriate supports or care. Carers and families often fared little better as they worked to raise a child with disability or to care for and support an adult.

The experience of disability: womanhood, sexuality and parenthood

2.3 For women with disabilities and for their families, issues around fertility and sterilisation often first arise when anticipating puberty and the onset of menstruation.

People with disabilities and menstruation

2.4 Issues with managing menstruation are a common reason for applications to sterilise women with a disability. This is due in part to the fears of parents, carers, and medical professionals that 'menstruation will be distressing and unmanageable'[1] for the young woman with the disability:

> …there are many moderate-severe intellectually disabled women who are extremely distressed due to their inability to cope with menstruation leading to loss of dignity... A number of such disabled women have an aversion to menstruation and the sight of blood and are unable to independently cope with menstrual pads, etc. Some of these women are unable to attend supported employment (Sheltered Workshops) or attend respite weekends or camps or stay overnight at an intellectually disabled friend's house, during menstruation. We are aware of a number of instances where an intellectually disabled woman has remained in the bathroom at the supported employment with blood over her clothes, due to the onset of

1 Family Planning Victoria, *Submission 58*, p. 6.

> menstruation. Consequently, there can be a significant reduction in quality of life and thus damage to the person's emotional or psychological health.[2]

2.5 Not only is there a fear of managing menstruation, there is a perception held by a number of submitters that sexual and reproductive health is not something that is easily discussed in society in general:

> In our modern Western culture, it is the norm that children are uncomfortable in discussing matters relating to their sexuality, such as contraception…[3]

2.6 When people with a disability reach an age where sexual and reproductive health needs to be addressed many submitters believe this issue is magnified.

> We believe that there is an underlying fear and resistance to discussing sex and managing the sexual and reproductive health needs of girls and women with a disability. We believe that this lack of confidence in, and fear of consequences of, sex education is a universal issue for parents and carers whether the young person has a disability or not and we acknowledge the difficulty that parents and carers, as well as health, community, and education professionals experience in talking about sexual and reproductive health matters.[4]

2.7 Women with disabilities said that the issue of reticence and discomfort sometimes lay with doctors, with parents and sometimes with support services:

> Donna: But there are also going to be people with intellectual disabilities who have no verbal capacity, and a lot of parents are making decisions to get their daughters done because then they do not have the issue of the pads and things like that. They would say that their daughter is not capable of looking after her own body so it is better to take her to the doctor to be fixed.
>
> Senator Boyce: But you do have to go to the family court or tribunal to get their approval.
>
> Donna: But I am talking about the earlier days, when you did not have to go to family courts; you just went to your GP and they referred you to a gynaecologist, and the gynaecologist said 'Yes, we'll do it, but you can't do it in the public hospitals, so we'll send you to a private hospital'—where it is all hush-hush, under the counter.[5]

2.8 Research undertaken in the 1990s indicated that there can be a wide range of expectations and views amongst parents, carers and professionals regarding menstrual management, even for the same individual girl. That research demonstrated that parents can find the approach of menarche very difficult, but also that appropriate information and support could modify concerns and lead to greater success in

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2 Dr and Mrs John and Merren Carter, *Submission 20*, p. 1.

3 Office of the Public Advocate, *Submission 14*, p. 26.

4 Family Planning Victoria, *Submission 58*, p. 6.

5 Donna, *Proof Committee Hansard*, 30 January 2013, p. 5.

menstrual management.[6] The committee was advised of a study that indicated that most mothers of women and girls with intellectual disability considered menstrual care as a reason for sterilisation.[7]

2.9 One woman explained that while at home with her family's assistance she had been using pads and tampons, but once living independently, the situation changed:

> So that I could self-toilet, or go to the toilet by myself, I stopped wearing underwear. This meant that pads were no longer an option. When I approached the service—a large service—that was supporting me, about tampons, I was told in no uncertain manner that tampons were not an option, that support workers could not insert or change tampons. So I really had no choice in the matter, I tried taking the pill for 90 days at a time and then having a short break to bleed…
>
> I also tried Depo-Provera, but that made me gain weight. It was just not nice; it made me angry and grumpy, and there was still breakthrough bleeding…
>
> Eventually I made the choice, given those circumstances, of having no other choice and not being able to use tampons like every other woman, to have endometrial ablation and have my tubes tied.[8]

2.10 A number of women agreed that, as Fran put it, 'workplace health and safety should not be an excuse to sterilise someone because we cannot manage their menstruation'.[9]

2.11 Ms Kathryn Knight, the mother of a daughter with intellectual disability, agreed with Family Planning Victoria regarding the existence of fear and resistance. She felt that these fears were perpetuated by society's attitude towards menstruation:

> The second issue is about the taboos around menstruation, and there was mention that this was persistent. These issues go very deeply into our cultural psyche. There has been theoretical work around what is called abjection. The processes of a woman's body are very closely linked with this sense of abjection. Of course, menstruation is one of those. If we put that together with disability, particularly intellectual disability, which is also abjected in our society, we have an intersection at a critical point about women's bodily functions together with intellectual disability. That creates a very strong sense of abhorrence in our society. It is right to say that menstruation, for some reason, is considered to be worse than wee and poo because it is part of a woman's very hidden bodily function…The sense of

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6 Jeni Griffin, Glenys Carlson, Miriam Taylor and Jill Wilson, 'An introduction to menstrual management for women who have an intellectual disability and high support needs', *International Journal of Disability, Development and Education*, Vol. 41, No. 2, 1994, pp. 103–116.

7 Cited in, Jan Dyke, *Sterilisation of people with disability*, Background paper for Queensland Advocacy, November 2004, p. 29.

8 Fran, *Proof Committee Hansard*, 30 January 2013, p. 3.

9 See, eg, Fran, Donna, *Proof Committee Hansard*, 30 January 2013, p. 16.

> abjection that we find when we put those two issues together is at the heart of what we are talking about.[10]

2.12 In this regard, it was noted by women with disabilities and committee members that a distinction seems to be made in disability care such that the insertion some items into their bodies, such as enemas, is permitted, yet other items such as tampons are not.[11] This would be consistent with Ms Knight's observation about taboos. Miriam Taylor made similar observations:

> The issues are really heavily focussed once again on difference. We fear those people in our societies who are different, and we fear even more primal things, including menstrual blood and semen. I think it is that basic. It is a primal fear. The primal fear in our society is that we do not want different people to replicate.[12]

2.13 Ms Knight explained that the arrival of womanhood should be celebrated in any woman's life irrespective of their level of disability:

> …I have come across many women with daughters who have similar disabilities to my own daughter's. When they found out that Amelia had started her period, their initial response to me was, 'What are you going to do about it?' To me, that was not an issue. It was just something we took in our stride. But there is this automatic response of, 'We've got to solve this problem.' This is another sense of abjection that we as a family are being exposed to… But my message today goes a little bit beyond human rights, I believe, to talk about celebration of the coming into womanhood of our daughters with disability. I think this is seriously lacking in the debate—a sense that, when our daughters with disability begin menstruating, it is a cause for celebration, as it is with their sisters. There may be difficulties that are incurred, but these are to be got over, along with their siblings. Most mothers of girls with intellectual disabilities, I believe, share my position.[13]

People with disabilities and sexuality

2.14 Some of the continuing community attitudes towards people with a disability highlighted by submitters were attitudes towards their sexuality, 'hyper-sexuality', or perceived 'lack of' sexuality.[14] It was noted that there was a 'broader societal misconception that people with disabilities are not or should not be sexual.'[15]

> … there are still a number of very powerful myths that exist more generally in society about the sexuality of people with a disability. Some of those

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10 Ms Knight, *Committee Hansard*, 27 March 2013, p. 50.

11 *Proof Committee Hansard*, 30 January 2013, p. 4.

12 *Proof Committee Hansard*, 30 January 2013, p. 6.

13 Ms Knight, *Committee Hansard*, 27 March 2013, p. 46.

14 For example Stella Young, *Submission 68*; Advocacy for Inclusion, *Submission 35*; Ms Frohmader, *Committee Hansard*, 11 December 2012, p. 15; WWDA, *Submission 49*.

15 Advocacy for Inclusion, *Submission 35*, p. 8.

> include things like the belief that people with disability are, firstly, asexual or do not have a sexuality—that, because they have a disability, therefore their sexuality is disabled as well. There are other strong myths like: if we provide people with disability information about sexuality then they will act on that information or become deviant, problematic or predatory in their behaviour; or providing education will in some way open a whole can of worms. So, while these myths and beliefs still pervade society, they become big barriers in terms of providing practical support in the area of relationships.[16]

2.15 Ms Stella Young wrote to the committee of her experience with such approaches to her sexuality:

> Often I am confronted with presumptions about my sexuality or lack thereof, even from the medical profession. At the age of 23 I saw my endocrinologist about migraines. It was her suspicion that they might have been caused by taking the contraceptive pill. The solution, she said was simple; I was to stop taking it. When I said I was willing to do that, but I'd like to talk to her about other forms of contraception, she was incredulous. She asked me, mouth agape, if I was sexually active. When I confirmed that I was, she laughed. Yes. She actually laughed.
>
> She was unsure about contraceptive options for me, so she wrote me a referral to a gynaecologist. It said: "Stella Young has severe Osteogenesis Imperfecta. Surprisingly, however, she is sexually active and requires contraception." I felt deeply humiliated, as though I had no right to experience sex and to express myself sexually.[17]

2.16 Assumptions are made that people with disabilities should not have sexual relationships, and in the process, this also means they do not learn how to protect themselves from unwanted attention:

> I have done quite a lot of interviews with both women with intellectual disability and support workers and family members. The overwhelming thing coming out of that is the lack of knowledge that women with intellectual disability have. I interviewed one woman who actually did not have a clue what sexual intercourse was. Lack of education, lack of permission for relationships, people living in supported accommodation who simply could not have someone of the opposite gender – or even the same gender probably – in their room. They did not have permission for the sexual relationship, they were taught no protective skills…There is a whole culture around not allowing that to happen and actually obstructing it from happening.[18]

2.17 The researcher's experience from the interviews was also that support workers were willing to engage in education around sexuality and protective skills, but that 'parents admitted to quite a deal of embarrassment about the issue. The subject was

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16 Mr Hardy, *Committee Hansard*, 27 March 2013, p. 16.

17 Stella Young, *Submission 68*, p. 2.

18 Woman A, *Proof Committee Hansard*, 30 January 2013, p. 10.

very, very uncomfortable for them'.[19] This was evident in the evidence from Katherine, a woman with a disability:

> there are peers of mine whose parents did not tell them anything, because they were so wrapped up in the fact that they had a child with disability that they forgot, or put to one side, or could not cope with the idea of it. So then you get the shock of getting your period, and you don't know what it is and you think you are bleeding to death or whatever. So people miss out on that kind of education.[20]

2.18 On the other hand, both Katherine and another witness at the same hearing, Kristen,[21] reported receiving good education through their own parents. Later in this chapter, evidence will also be provided that family planning professionals are indicating that parents often want access to information and educational resources.

People with disabilities as parents

2.19 The committee heard from women who wanted to have children but were unable to, because of their sterilisation:

> [Woman A] I wanted to have children and mix with other mothers who have children. I wanted to have children who would be friends with other people's children. The good thing is when you are a mother you get to mix with the other mothers and their children…
>
> [support worker]…you were told that you should not have children. Is that right?
>
> [Woman A] Yes I was told. My father said to me that my disability would pass on to my child and it would be more handicapped than me…
>
> [support worker] You had conversations with your father where he said you should not have children. Then he said 'I want to get you sterilised'. Is that right?
>
> [Woman A] Yes
>
> …
>
> [support worker] You had your relationship with [a boyfriend to whom she was engaged]. Did you want to have children with [your boyfriend?]
>
> [Woman A] Yes…[22]

2.20 As would be expected, parents were often central to the decision:

> Acting Chair: We would like to know what you want to say to us about [sterilisation] and about how it has impacted on you.
>
> [Woman C]: My father did that

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19 Woman A, *Proof Committee Hansard*, 30 January 2013, p. 10.

20 Katherine, *Proof Committee Hansard*, 19 February 2013, p. 2.

21 Katherine, *Proof Committee Hansard*, 19 February 2013, p. 2.

22 *Proof Committee Hansard*, 1 February 2013, p. 3.

Acting Chair: What happened? Did your dad say that you should not have children?

[Woman C] He said that people with a disability should not have kids.

Acting Chair: How did you feel about that?

[Woman C] Upset.

Acting Chair: What happened?

[Woman C] He told me I was going into hospital to have my tonsils out.

Acting Chair: That was not what happened?

[Woman C] I did not have a sore throat afterwards.

…

Acting Chair: When did you find out what happened?

[Woman C] After, when I was trying to have kids.

…

Acting Chair: Did you have a long-term partner?

[Woman C] Yes

Acting Chair: How did he feel?

[Woman C] He left me because he wanted to have kids and I could not have kids.

…

Acting Chair: In terms of how you feel now, what do you think should have happened?

[Woman C] I should have been told the truth. They should have told me.[23]

2.21 And again:

Acting Chair: Did you try to have babies?

[Woman D]: I wanted to have babies.

Acting Chair: Did you think you were going to have babies?

[Woman D]: No. I had two operations.

…

Acting Chair: Do you know what the operations were for?

[Woman D]: To stop me having children.

Acting Chair: What did people tell you? Who did you talk with about having those operations?

[Woman D]: My parents.

Acting Chair: What did they say?

23 *Proof Committee Hansard*, 1 February 2013, pp. 6–7.

[Woman D]: You have to have the operation and that is it.

Mr Bowden [advocate]: Did you have a say?

[Woman D]: They forced me.

Senator Boyce: Did you say 'No, I don't want to?'

Woman D]: Yes.[24]

2.22 Some of these women described the different ways in which the loss of this opportunity manifested itself for them. One woman spoke of how she feels jealous of her friends and relatives who have children and how she sometimes found it difficult to relate to them, knowing they had something that she herself could not. But she often found a way around these difficulties:

> Woman A: I got a photo of the baby and I keep it beside my bed. I keep a lot of other baby photos beside my bed because a number of people from my school have a baby. I have sent them baby clothes and they sent me thank you cards with photos. I keep it all beside my bed. I have kept X's baby girl photo beside my bed to show that I love them all and pretend that they are my children, pretend I can take them to bed with me and read them stories.[25]

2.23 Another woman who spoke to the committee collected the things she would have used as a mother. Disability advocate Matthew Bowden assisted her when she had to move house:

> Mr Bowden: I gave you a hand with moving. There was a lot of stuff, wasn't there, to move and sort out. What was there lots of?
>
> Woman D: Prams
>
> Senator Boyce: Lots of prams?
>
> Woman D: And lots of nappies.
>
> Mr Bowden: There were nappies.
>
> Woman D: There were baby clothes and toys.
>
> Senator Boyce: Had you bought all of those things?
>
> Woman D: Yes, and found some of them.
>
> Acting Chair: And you had kept them.
>
> Mr Bowden: How many prams do you think that we–
>
> Woman D: About 100.
>
> Senator Boyce: How many?
>
> Woman D: One hundred.
>
> Senator Boyce: A hundred prams! Goodness!

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24 *Proof Committee Hansard*, 1 February 2013, p. 12.

25 *Proof Committee Hansard*, 1 February 2013, p. 3.

> Mr Bowden: And they were the things that you liked to collect the most, weren't they, the prams and the baby things?
>
> Senator Boyce: How many prams do you have now?
>
> Woman D: None.[26]

2.24 Women with physical or intellectual disabilities, spoke of needing help to parent. One witness referred in positive terms to a friend who had a child that was in long-term foster care, but with whom the parents had an ongoing relationship.[27]

2.25 The experience of having parenting desires and options ignored applied to women with physical disability as well as women with intellectual disability:

> Debra: When I acquired my disability at 37, I did have a gynaecologist who said 'hysterectomy'. He said, 'You'll never have a baby now.' …
>
> Senator Boyce: So, you had to have a hysterectomy for medical reasons? Or because someone thought it was a good idea?
>
> Debra: He thought it would be a quick fix for my problem. After all, 'you'll never have a baby now.' But if I was not in a wheelchair or did not have impaired speech, he would not have said that.
>
> Fran: So Debra, you did not [have the hysterectomy]?
>
> Debra: No, I did not.[28]

2.26 There was a significant amount of evidence provided to the committee with respect to current attitudes towards people with disabilities being parents and the assumption that they are not capable of being a parent because they have a disability:[29]

> In Australia, people with disabilities, especially women, are discouraged or denied the right to reproduce and participate in sexual relationships. Instead, people with disabilities are being perceived as incapable of taking care of their children and as being dependent on the assistance of carers and relatives. One perception is that people with intellectual disability are viewed as 'childlike'.
>
> Women with intellectual disability in Australia are discriminated against in regards to their capabilities of handling motherhood. It is not uncommon for them to feel pressured to demonstrate a socially acceptable performance as a parent due to society's idea of what good parenting is.[30]

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26 *Proof Committee Hansard*, 1 February 2013, pp. 15–16.

27 Confidential evidence, 1 February 2013.

28 *Proof Committee Hansard*, 30 January 2013, p. 4.

29 For example Centre for Disability Research and Policy, *Submission 21*; Australian Institute on Intellectual and Developmental Disabilities, *Submission 84*; Advocacy for Inclusion, *Submission 35;* Mr Simpson, *Committee Hansard*, 11 December 2012, p. 15.

30 Australian Institute on Intellectual and Developmental Disabilities, *Submission 84*, p. 10.

> …because of the picture that we have of intellectual disability and parenting, we always think of people who have cognitive disabilities as being cared for and childlike, not people who could care for a child.[31]

2.27 As several families pointed out to the committee, however, there are cases where the severity of a disability may affect the child's capacity to understand and consent to parenting, or to understand and consent to sexual relations. In these cases, the situation may be different:

> Should my daughter be able to have a boyfriend? Yes. Should my daughter be able to have consensual sex? Yes. But should my daughter be able to have children? No. She can barely look after herself. If your ten year old daughter came home and was pregnant, wouldn't you be upset? She would not understand what was happening to her body. She would not understand why she was in so much pain, during labour.[32]

2.28 And again:

> If she fell pregnant, regardless of her age, it would be considered sexual abuse because she is not capable of understanding the implications of sexual intercourse due to her significant intellectual impairment. Given her level of understanding, processing and comprehension I believe that should she fall pregnant and give birth to a child she would be traumatized beyond repair.[33]

2.29 Many submitters provided evidence that perceptions of incapacity were contributing towards high levels of child removal by child protection agencies and an over-representation in child protection proceedings.[34] Evidence from the Centre for Disability Research and Policy at the University of Sydney indicated there was:

> …considerable evidence from Australia and other higher income countries that persons with disability especially although not exclusively intellectual disability, face discriminatory attitudes and practices in relation to parenting. Most telling are the consistently high figures of child removal from parents with intellectual disability across high income countries, typically reported as between 40%-60%, proportionally higher than for other parent groups including those with mental illness and those from indigenous populations.[35]

2.30 Advocacy for Inclusion referred to a study that showed

> A study by Llewellyn, McConnell and Ferronato at two Children's Courts in NSW revealed that parents with cognitive disabilities were involved in

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31 Dr Spencer, *Committee Hansard*, 27 March 2013, p. 23.

32 *Submission 11*, p. 2.

33 *Submission 29*, p. 1.

34 Centre for Disability Research and Policy, *Submission 21;* Advocacy for Inclusion, *Submission 35;* Australian Institute on Intellectual and Developmental Disabilities, *Submission 84;* Dr Spencer, *Committee Hansard*, 27 March 2013, p. 18.

35 Centre for Disability Research and Policy, *Submission 21*, p. 4.

> almost one third of child protection cases. The study found a disproportionate amount of children of parents with intellectual disabilities were placed on wardship orders and outside of the family network.[36]

2.31 Some submitters said these statistics showed that 'the decision to remove a child is based on a presumption of incompetence'[37] and a belief that parents 'with intellectual disabilities cannot learn parenting skills.'[38] Some[39] expressed concern that:

> … there is a presumption on the part of core processes that removal is the better option based on the parent's disability and for no other factor.[40]

2.32 The committee heard of an instance in which a child was removed and the parents had to go through a convoluted process to get it returned:

> Fran: I knew of a couple in Townsville who knew that the person she was supporting was pregnant and organised to be at the hospital for the whole birthing experience. She tried to physically stop Child Protection from seizing that child. This was a person who at the time worked for an independent advocacy group and was doing strong advocacy. Even though she was doing that strong advocacy during the pregnancy, when the baby was born Child Protection whisked it away. Rather than being given a chance to parent…, the woman had to fight for the opportunity to parent.
>
> Senator Boyce: Did she win?
>
> Fran: I think she did, but [it was] after the child went into foster care and she had to win through visits, through trial, through such turmoil that she would not do it.[41]

2.33 Kristen, a woman who fostered many children but did not have one herself, queried a double-standard that exists between parents with disabilities and parents without disabilities:

> Recently my brother and his partner had a child—he is older than me—at the very last minute. I am 42, so Pete is 44. It turns out actually that everybody needs support to parent… It turns out that maybe the problem is not with women with disabilities wanting to have children. Maybe the problem is entirely, wholly and solely with the society that we live in. People seem to think that it is okay for everybody else to need support to parent, but it is not okay for us to need that support…
>
> Katherine: It takes a village to raise a child. People do not do this in isolation.

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36 Advocacy for Inclusion, *Submission 35*, p. 11.

37 Dr Spencer, *Committee Hansard*, 27 March 2013, p. 22.

38 Advocacy for Inclusion, *Submission 35*, p. 11.

39 Ms Ryan, *Committee Hansard*, 27 March 2013, p. 22; Ms Pearce, *Committee Hansard*, 11 December 2012, p, 16.

40 Ms Ryan, *Committee Hansard*, 27 March 2013, p. 22.

41 *Proof Committee Hansard*, 30 January 2013, p. 13.

> Kristen: Except us; we are meant to.[42]

2.34 Some submitters felt that 'outmoded' thinking with respect to children of a person with a disability inheriting their parents disability is a contributing factor towards the thinking that a person with a disability cannot care for a child.[43]

> Inaccurate and /or stereotypical knowledge about disability in the community for example leaves many community members still believing that disability is inherited. Thus if the parent or parents have a disability so too will their children.[44]

2.35 However there was evidence presented to the committee that in some instances there is a strong chance that the particular disability can be passed on and that this would introduce additional complications to what is already for some a traumatic experience:

> My brother can't have a "normal" child. His DNA is affected and he will pass on faulty DNA. In my experience special needs children have different care requirements that can be more taxing on the parents. My brother struggled to cope with my perfectly healthy niece for more than twenty minutes when she was a baby, the chances of him coping with full time fatherhood are slim to be polite.[45]

2.36 Arguments that a population can be improved by selecting in favour of some, and against other, genetic content, including disability, are referred to as 'eugenics'. Such theories were influential in the early 20th century in the areas of family planning and public health and resulted in an acceptance of sterilisation practices:

> In the early 20th century in Australia and elsewhere the belief that people with disability would produce offspring that were burdensome to society resulted in many women – and men – with disability being sterilised.[46]

> One of the aims of eugenic thinking was to eradicate 'a wide range of social problems by preventing those with 'physical, mental or social problems' from reproducing.'[47]

2.37 Although the formal application of eugenic theory is no longer legal in Australia, it was claimed that 'vestiges still remain within some areas of the legal and medical establishments and within the attitudes of some sectors of the community,'[48] particularly in relation to people with disabilities:

> …there are so many inaccurate beliefs floating around about people with disabilities, particularly those held by people in the society with more

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42 *Proof Committee Hansard*, 19 February 2013, pp. 13–14.

43 Centre for Disability Research and Policy, *Submission 21*, p. 3.

44 Centre for Disability Research and Policy, *Submission 21*, p. 3.

45 *Submission 12*, p. 2.

46 Centre for Disability Research and Policy, *Submission 21*, p. 3.

47 WWDA, *Submission 49*, p. 20.

48 WWDA, *Submission 49*, p. 20.

> valued positions—so more powerful or more influential. That is particularly the case for men and women with intellectual disability. That leads to, as it were, permitting in our society some actions which would never happen to other citizens. That in itself is cause for concern. It also leaves families and carers in a difficult place because, no matter what their personal views, there are often pressures on them in society to see their sons and daughters in particular devalued ways…it leads to is discrimination against those people with disabilities, which tends to violate their human rights. It is not only in the area of sterilisation; it is in many other areas as well…in our society we have this lack of attention to people with disability as if they were not humans like us. In other words, they are often seen as something less than human which allows some of these activities to occur.[49]

2.38 Despite many submitters claiming that such thinking has 'moved on' significantly since the peak of the eugenic movement there was a pervading message from advocacy groups[50] that some medical professionals and others in the community find:

> …it is very easy to have a kind of either judicial or eugenic imperialism when it comes to making a decision about either the parents and carers or about the disabled young people or older people in question.[51]

2.39 One submitter advocated eugenic arguments alongside family welfare considerations in considering the issue:

> The factors bearing on society's decision to intervene in the reproductive faculties of an individual should be:
>
> - The burden on society created by an incompetent person bringing a life into the world to whom they have no, or severely limited, capacity to support. This includes practically, financially, and emotionally.
>
> - The burden placed directly on the immediate families and carers of people with profound disabilities, both in terms of the burden of caring for a disabled person's child, but also the management of menstruation, inappropriate promiscuous behaviour, etc.
>
> - The likelihood that the progeny of a person suffering from certain types of genetic defect will also share that defect. It is acknowledged that not all genetic disabilities are transmissible, but authorizing bodies should not shy from this issue and should not be put off by an accusation of Eugenic intent.[52]

2.40 The committee's attention was also drawn to evidence given by a doctor during a 2004 court case, where an opinion was expressed regarding proposed

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49 Professor Llewellyn, *Committee Hansard*, 27 March 2013, p. 40.

50 For example: Qld Centre for Intellectual and Developmental Disability, Queenslanders with Disabilities Network, and Qld Advocacy Inc. *Submission 37*.

51 Mrs Krohn, *Committee Hansard*, 27 March 2013, p. 41.

52 Name withheld, *Submission 13*.

sterilisation of a girl, that 'given the genetic nature of her disorder and the 50% inheritance risk thereof, this would in my view be of great benefit to H'.[53] The committee will later in this report consider and reject the suggestion that the Family Court accepted eugenic arguments. The committee understands, however, the risks associated with such arguments, which make presumptions about the decisions a person might make regarding the genetic make-up or health of their children. The committee finds this especially problematic when presumptions are made in the case of someone such as H, where the choice is between the possibility of having a child with a disability, and having no child at all.

Conclusion

2.41 Many of the attitudes reported to the committee and experienced by people with disabilities regarding sexual and reproductive health have contributed towards a perception by some that irreversible sterilisation is the best solution to a range of needs and issues, particularly for women with disabilities.

> ….we are still unable to properly confront issues of sexuality of the disabled in our community and still as a community have an enormously long way to go in that area.
>
> The institutions that exist….still have a lot of learning to do. Institutions such as the child welfare agencies across Australia et cetera have to change their attitudes and approaches, and governments have to be prepared to make vastly more resources available.
>
> …there is certainly an overwhelming need for additional resources in this area if we are going to treat the disabled with the equality that they deserve.[54]

2.42 The lack of resources, both for people with disabilities and their carers, was a recurring theme in submissions to the committee.

Insufficient support and the need for sterilisation

2.43 Amongst the families and carers of people with disability there was a range of views about the processes that should guide decisions about sterilisation, and the circumstances under which it might be appropriate. What was most evident, however, was how much of that evidence related to the circumstances of the care of the person with a disability. Time and again, parents and carers gave evidence that related to a lack of appropriate education, care or support in their lives. The issue of sexual abuse is a case in point.

2.44 Witnesses to the inquiry did not suggest that sterilisation was a relevant or appropriate means for preventing abuse, but the consequences of abuse did prey on their minds:

> So don't judge parents who make the decision to go overseas to have their precious children sterilized, because you don't know the half of it. You

53 Professor T, *Re H* [2004] FamCA 496, at para. 49.

54 Mr Martin, *Committee Hansard*, 27 March 2013, pp. 30–31.

> don't lie awake at night worrying about them being abused and getting pregnant, or how you are going to manage for the next day, week, month and year caring for them.[55]
>
> There are enormous concerns regarding the possibility of M being abused at some future date. At 18 when she finishes at Special School, the parents have little idea what lies ahead for them or M, nor how to manage any unknown risks that may be "out there" for their daughter.[56]

2.45 Evidence from Professor Carter, who had extensive contact with other parents of children with intellectual disabilities, was clear that preventing pregnancy as a consequence of abuse was a factor in parental decisions:

> A lot of mothers that we know are concerned about the possibility of sexual abuse of their daughters and therefore the possibility of pregnancy. We gave an example in our submission about a young lady who went to New Zealand for a hysterectomy. She is a very attractive young lady and her mother certainly was—quite apart from the fact that she was tearing her hair out because the daughter could not cope with menstruation, after many years of trying—desperately worried that her daughter would be assaulted or abused and become pregnant. In our experience, that is a significant factor for a number of mothers.[57]

2.46 Parents spoke of how the care for any child of their own child would fall either to welfare services or to themselves as grandparents:

> My disabled daughter should never have a child.
>
> What has led me to this conclusion? Her own life is not stable enough to support another life. Advocates who say she has the "right" to have a child need to factor in her ability to be RESPONSIBLE for that child.
>
> Bearing a child, and giving birth to a child, would be traumatic experiences for my daughter…So traumatic would be this event that I firmly believe no services or supports put in place after the event would help restore her spirit or loss of self.
>
> A child born to my daughter would have limited life and prospects.
>
> Care for this child would have to be picked up by others. I have a well-developed sense of responsibility – I guess I always have and always will. So if my daughter did have a child, I would be the person most likely to make sure mother, baby and all are as well as can be.[58]

2.47 Though arguing against her daughter having a child, the above submitter explained that her daughter was in supported accommodation, now had a boyfriend, and was using long-term contraception (which had been implanted in order to assist with menstrual management). Thus some submitters believed that there were

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55 Name withheld, *Submission 4*.

56 Name withheld, *Submission 10*, p. 3.

57 Professor John Carter, *Committee Hansard*, 27 March 2013, p. 55.

58 Name withheld, *Submission 2*.

circumstances where a person with a disability might be able to consent to sexual relationships, but not be able to share responsibility for having a raising a child.

> She would be incapable of looking after a baby adequately. In the end she would have more pain as DOCS stepped in and took her baby away, and she would not understand this either. Or else we as her parents would have to look after this child, as well as the mother and probably the father as well.[59]

> Left in my daughter's sole care an infant would be lucky to survive for longer than an hour. Furthermore, in the event that my daughter should fall pregnant and have a child, the raising of the child would become my responsibility which is unfair to both my daughter and me.[60]

2.48 Witnesses expressed concern about respite or residential care services that led them to decline to use these, putting more pressure on them as individual carers:

> Our family has decided that respite care is not an option for Eliza: we do not trust it and we will not put Eliza at risk of sexual abuse. I am aware of many personal experiences where disabled children have been victims of assault in residential respite care. There have been many research studies, reports and articles that have concluded that residential care is unsafe for disabled persons. Eliza's school is associated with Yooralla. We receive regular articles regarding incidents involving sexual assault within Yooralla's facilities. One is too many. Our only respite is through the support of trusted and loving members of our family and friends.[61]

2.49 And again:

> An abiding concern for me is my daughter's vulnerability to physical and sexual assault, particularly in the day program and respite services she attends without my participation.[62]

2.50 Another submission from a parent, which the committee quotes at length below, starkly indicates how the issues to which sterilisation procedures respond are inextricably linked to the lack of support for families, and a lack of opportunities for the person with a disability (emphases added):

> Of course the onset of menstruation when she was 14 years old was a major difficulty for her and for us. She refuses point blank to wear a bra, and there was no way in the world she would tolerate wearing a pad in her underwear. It was not even possible to put one on her and have her try it out. She would just pull it straight out. *When you think about the day to day management we already deal with, having a monthly period on top of it drove me nearly to breaking point*. She would just bleed all over her clothes and it was impossible for school to be able to manage her.

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59 *Submission 11*, p. 2.

60 *Submission 29*, p. 1.

61 Mrs Louise Robbins, *Committee Hansard*, 27 March 2013, p. 47.

62 Name withheld, *Submission 55*, p. 2.

> Many people may say that my daughter's fertility is her issue and not mine but you would be wrong. You see, *the way that mother's like myself are expected to care for our children until we die, it does become my issue because I am totally responsible for my girl in all ways, and I will continue to be because society has washed their hand of the responsibility of children like mine*…
>
> What I don't understand about our society is that when the issue of fertility and "rights" comes up they jump up and down about my daughter's "right" to have a child if she wishes to. But no-one jumps up and down about her "right" to be able to live independently (which she has no chance of doing in Australia at this present time because places just don't exist). They don't jump up and down about her "right" to have a job or a meaningful adult life (because the money is not there to enable this for her). They don't jump up and down about her being able to access affordable dental care (which she can't as an adult with a disability). They don't jump up and down about my life. Yes, you say it isn't about me, but you are wrong. *Our society makes it about me.* Why don't you protest about something that could improve my daughter's life?
>
> …
>
> *If people are going to stand up about the "right" of my daughter to be able to have children if she chooses, then why don't you stand up about all her other "rights" that she is refused in this society on a daily basis?* Put your energies into fighting a fight that WILL make a difference to her life, not towards an impossible dream.[63]

2.51 The limitations described above are contributing to the consideration of sterilisation procedures in order to manage things other than choices around fertility itself. Research and submissions from professional organisations all confirmed the impact on sterilisation and sexual health decisions that is being caused by a lack of appropriate and adequate support for both people with disabilities and their carers.[64]

2.52 The ability of both people with disabilities and their carers to prepare for adulthood and its associated needs such as menstrual management, is further compromised by inadequate support in education and training.

Services, Support, Training and Education

Current Situation

2.53 It was evident from the majority of submissions that the general approach to sexual and reproductive health for people with disabilities in terms of services, support, training and education was inadequate. Evidence from various studies in

63 Name withheld, *Submission 4*.

64 See, for example, Women's Health West, *Submission 38*, p. 6; Miriam Taylor Gomez, Glenys M. Carlson and Kate van Dooren, 'Practical approaches to supporting young women with intellectual disabilities and high support needs with their menstruation', *Health Care for Women International*, Vol. 33, 2012, pp. 678–694.

addition to experiences and other anecdotal evidence suggested that when compared to their peers, girls and women with disabilities:

> experience less opportunity for appropriate information and learning about their sexual and reproductive health
>
> experience a lack of services supporting their sexual and reproductive health needs (including in primary health care)
>
> experience many negative, unhelpful and inaccurate prejudices about their capacity for safe and healthy sexual relationships and decision-making
>
> are vulnerable to abuse of their human rights, including the right to be free from violence (e.g. sexual assault) and the right to make decisions about their own bodies.[65]

2.54 It was acknowledged that access to appropriate education surrounding sexual and reproductive health was an issue for the general population however the consensus was that people with disabilities 'do not have the same opportunities to learn as the general population':[66]

> …I think people with disabilities have an increased vulnerability for several reasons: for one, they do not have as many opportunities to seek out the information themselves from other avenues, whether it is from health professionals or even family or friends. They may not even know to seek it out, but even if they do there are lots of barriers to them achieving that... We know that the health literacy in Australia is very poor in general—not just about sexual and reproductive health—but this is a group of the community that is vulnerable for so many reasons and lacks the opportunity and the access to improving that in any way.[67]

2.55 It was acknowledged that supports and services such as counselling, heath resources and education are provided by family planning centres and state government departments.[68] There were, however, concerns about the availability, appropriateness and accessibility for people with a disability, as well as the current lack of consistency across the states and territories:[69]

> The Commission notes that there are supports and services to assist women and girls with disability (and their carers) with menstrual management, and services which provide education to people with disability in relation to sexual and reproductive health, including how to have positive and safe relationships, how to say 'no', and how to recognise violence. However,

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65 Family Planning Victoria, *Submission 58*, p. 7.

66 Johnson et al., 2001 as cited in Sexual Health and Family Planning Australia, *Submission 52*, p. 2.

67 Ms Hamilton, *Committee Hansard*, 27 March 2013, p. 12.

68 Ms Chivers, *Committee Hansard*, 27 March 2013, p. 12; Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne, *Submission 69*, p 7; Family Planning NSW, *Submission 25*, p. 5.

69 Adult Guardian of Queensland and The Public Advocate of Queensland, *Submission 19*, p. 9.

> these services are few in number and limited in scope, and there is a general lack of knowledge concerning their existence and how they may be accessed.[70]

2.56 Many submitters felt that there were limited supports and services for people with disabilities and their families in terms of sexual and reproductive health or even on the consequences of sterilisation. It was of concern to many that what did exist was often reactive or focused on 'problem solving':

> There are very few services, supports, counselling, training, education and skills building options for children and adults with disability and their families in relation to sex education, sexuality and relationships, sexual and reproductive health, menstrual management, pregnancy, contraception or family planning.[71]

> [Family Planning Victoria] considers there is a great lack of service across all areas of sexual and reproductive health care for people with disabilities and the approach to services has focused on the prevention or management of problems (i.e., unwanted pregnancy, sexual assault, sexual offending, pregnancy and abuse) rather than positive sexuality or supporting the full rights for reproductive health (including the right to reproduction). FPV advocates for increased support for people with disabilities and parents, carers and professionals who support them.[72]

2.57 The committee was informed that the main reason for lack of services was due to a lack of or limited funding:

> PWDA is aware that many sexual health and family planning organisations across Australia lack the necessary funding to provide comprehensive, targeted, gender and age specific services to people with disability.[73]

> While there is some good information in states around Australia it is typically located in metropolitan based services that have funding restrictions which inhibit their capacity to provide this information to regional and remote communities.[74]

2.58 Both Family Planning New South Wales and Family Planning Victoria noted that this meant that supports and services were often sacrificed as a result:

> …when we provide training we are building the capacity of disability workers, parents and carers to then provide education to people with a disability. At Family Planning New South Wales we currently do not have funding or the services to provide that direct education to people with disability.[75]

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70 Australian Human Rights Commission, *Submission 5*, p. 11.

71 People With Disability Australia, *Submission 50*, p. 7.

72 Family Planning Victoria, *Submission 58*, p. 7.

73 People With Disability Australia, *Submission 50*, p. 32.

74 National Council on Intellectual Disability, *Submission 77*, p. 12.

75 Mr Hardy, *Committee Hansard*, 27 March 2013, p. 11.

> Disability organisations are very stretched as it is with their funding, so it is difficult for them to be able to prioritise sexual education…there are a lot of people who will miss out on services and basic information education because there is no funding.[76]

2.59 The committee was informed that the lack of consistency in the type of education provided to people with a disability was not only evident in family planning and health services but also in schools:

> We have found huge variation in how that is delivered within schools. It is very much dependent on the school itself and on the individual teachers, their comfort levels with delivering sexuality education, their own skills and knowledge or opportunities to receive training in how to deliver that. Students with intellectual disability can slip between the cracks in the school education system because either they are not receiving sexuality education or it is not being tailored in a way that they can understand.[77]

2.60 It was particularly noted by both the Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne and Office of the Public Advocate that sexual and reproductive health are often not taught on a consistent basis to both students with or without a disability and that often subjects relating to conducting appropriate relationships are not taught at all:

> As clinicians we are aware of seeing young women attending schools (including some special schools) where the issue of menses, menstrual care, and reproductive health issues are not taught. But this also applies to the education for young women without disabilities. There would not appear to be minimal standards of what should be taught across all school.[78]

> Special schools and mainstream schools may not provide adequate sex education and human relationships counselling on relationships and social and legal expectations of relationships to the pupils and their parents. [79]

2.61 Sexuality education for adults with a disability is reported by some submitters as being even more limited and usually often only offered when there is a 'behaviour of concern' not as a proactive measure:[80]

> Often the sexuality of a person with a disability does not come to the surface at all until there is a problem that is affecting the people around that person. When the problem is impacting the staff or the family, that is often when the discussion is started rather than being part of the overall care of that person's life.[81]

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76 Ms Hamilton, *Committee Hansard*, 27 March 2013, p. 12.

77 Mr Hardy, *Committee Hansard*, 27 March 2013, p. 11.

78 Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne, *Submission 69*, p. 4.

79 Office of the Public Advocate, *Submission 14*, p. 27.

80 Ms Hamilton, *Committee Hansard*, 27 March 2013, p. 11.

81 Ms Hamilton, *Committee Hansard*, 27 March 2013, p. 11.

2.62 Sex education is often not appropriately targeted. However, it is also undermined by the persistent message that young people with disability get, that they are different and that sex education does not apply to them:

> I have worked with girls who go to their school sex-ed class or whatever but think it does not apply to them because they get the messages all the time that they are different to the other girls. So they go to their sex-ed class and they come to groups that I have run in the past and say, 'That doesn't apply to us'—or it is pitched at the wrong level, so they just switch off and do not get access to it because it is not pitched at their level of understanding. So they just think, 'I can't understand this' or 'This doesn't apply to me'. That is quite problematic.
>
> I have heard girls have a frank discussion about how they were just turned off by the way it was delivered. So they did not get anything out of it; they just thought it was yucky and they did not listen to the stuff. That was a group of girls who had autism and Asperger's syndrome, and they were not keyed into the education about it. But, at the same time, they were very vulnerable—in fact, in that group one of the girls disclosed that she had been assaulted by a peer at school. So, on the one hand they are getting this sex education and stuff that is not sinking in and on the other hand they are very vulnerable.[82]

2.63 The issue may be particularly acute for men:

> Woman A: We have found it almost impossible to get any kind of sexuality support and education for, particularly, adult men. Young boys are under Family Planning's agenda. They will educate and provide information for boys up to the age of 18. Their mandate cuts out for adult men and I do not know of any organisations that will advocate or provide information for adult men…It is a huge gap.[83]

2.64 Other issues that were seen as barriers by some submitters included that:

> …people with disabilities may only be able to access health services through a carer or family member. For many reasons, carers and family members may not facilitate the person seeking out appropriate services; for example, they may not think that the person's sexuality is a relevant consideration, or cultural/language, religious factors may come into play.[84]
>
> This is particularly a problem for individuals who live in supported accommodation arrangements such as group homes. Their lives are heavily influenced by organisational practices and rules that can ignore, control or directly block their sexual and reproductive rights.[85]

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82 Katherine, *Proof Committee Hansard*, 19 February 2013, p. 2.

83 *Proof Committee Hansard*, 30 January 2013, p. 17.

84 Susan Hayes, *Submission 47*, p. 6.

85 Advocacy for Inclusion, *Submission 35*, p. 8.

2.65 It was observed that the availability and effectiveness of services, support, training and education was not only an issue for people with a disability but for their carers and families too:

> It is extremely difficult for guardians, carers and the individuals with disabilities to locate educational programs or practitioners who can provide such programs either for groups or individuals. The issue is not specifically related to sterilisation or other sexual and reproductive health issues, but to the general issue of access to and provision of health services for people with disabilities, in accord with UN Conventions.[86]

> …there are few resources available to assist with developing individual programs to assist the individual and their family/carers with managing these issues on a daily basis in practical terms in the home and community.[87]

2.66 Support workers and care facilities also faced challenges with respect to a lack of educational resources:

> …[there] is an enormous problem of providing the people who undertake the task of providing care and support for people with disability with the educational resources to enable them to carry out their work.[88]

2.67 It was suggested that support workers in particular also struggle with providing a duty of care in the context of legal and organisational rules and regulations which they do not fully understand. In this context the committee heard that many support workers and care facilities think that they have to protect people in their care 'from all sorts of risk and harm' and unintentionally limit the freedom of the individual, including in regards to their sexual activity or their ability to make decisions:[89]

> Information about people's rights around their bodies and menstruation management principles and guidelines would be a really important resource to develop to support people in their work. There is quite a gap.[90]

2.68 Health and family planning services and medical professionals identified gaps in their ability to provide easily accessible, adequate and appropriate services for people with a disability with some submitters raising the possibility that this is largely as a result of a fragmented and under-resourced health system.[91]

2.69 In terms of family planning centres it was observed that:

> From a clinical perspective across all the family planning organisations there are clinical services for people with disability…Following on from

86 Susan Hayes, *Submission 47*, p. 7.

87 Susan Hayes, *Submission 47*, pp. 6–7.

88 Mr Martin, *Committee Hansard*, 27 March 2013, p. 33.

89 Ms Chivers, *Committee Hansard*, 27 March 2013, p. 16.

90 Ms Chivers, *Committee Hansard*, 27 March 2013, p. 15.

91 Office of the Public Advocate, *Submission 14*, p. 27.

> seeing that person in the clinical context, it can sometimes be challenging then to have additional supports around their non-clinical needs.[92]

2.70 The environment in public hospitals, and a lack of continuity of care were also identified as issues in providing appropriate health supports and services:

> Adult gynaecology services in public hospitals do not have dedicated services for women with disabilities. They usually provide services without continuity of care, meaning that women often see a different doctor each visit… Waiting times in the public outpatient clinics can be lengthy and for young women with disabilities this can be very challenging to be in a strange, potentially busy and impersonal environment.[93]

2.71 Issues with the services of health professionals were not confined to tertiary settings. Evidence was provided by carers and parents of children with disabilities that some medical professionals are unable to provide adequate support for sexual and reproductive health issues:

> I am sure that you and other women I know who have daughters with severe disabilities know that very little comes up in terms of information, education and medical advice when your daughter reaches the menarche. It is completely hidden. It is not addressed. GPs are absolutely hopeless with it.[94]

2.72 Advocacy groups echoed these observations claiming that the reluctance of many GPs to address such issues satisfactorily is because they:

> …may not have ready access to comprehensive information about reversible menstrual management options [and] do not feel comfortable relating to a female with ID who has difficulty communicating or is prone to aggressive outbursts.[95]

2.73 Medical professionals themselves provided evidence that both GPs and specialists are 'not necessarily well informed of options, or are unaware of options or resources':[96]

> Families expect their local doctor and their paediatrician to be able to advise them, but a recent study (unpublished undertaken at RCH) revealed that many general practitioners and paediatricians had very limited knowledge and were uncomfortable giving advice. A number of paediatricians felt that a hysterectomy was the first line option for menstrual management when given a case scenario - this is despite RCH

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92 Dr Bateson, *Committee Hansard*, 27 March 2013, p. 12.

93 Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne, *Submission 69*, p. 4.

94 Ms Knight, *Committee Hansard*, 27 March 2013, p. 50.

95 Australian Association of Developmental Disability Medicine Inc., *Submission 59*, p. 3.

96 Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne, *Submission 69*, p 4.

> gynaecologists efforts to educate paediatricians regarding menstrual management issues for over 10 years.
>
> Most adult gynaecologists have not had a lot of practical clinical exposure to young women with disabilities. The issues regarding level of skills, other medical problems, communication with the young woman or with the carers who themselves may not be fully aware of all the relevant health issues, are all challenges for the clinician.[97]

2.74 It was suggested that, in addition to a lack of specific knowledge of relevant health matters, doctors may be not aware of all the legal and ethical issues involved in treating people with a disability. Negative or paternalistic attitudes in some medical professionals may be due to fears about the legal and professional ramifications of any decisions they may make:[98]

> I think there are still quite a lot of paternalistic attitudes towards people with disabilities, and many health professionals often feel that we want to help to protect our clients and our patients. A lot of doctors I speak to feel very nervous about it because, in their minds, upholding the rights of the person with a disability makes them vulnerable to things like pregnancy, and the outcomes of that are seen as overly negative. So certainly it is a very strong anxiety that comes through in every single one of our training sessions with GPs. It is consistent. Every time I talk to GPs as a group, this issue comes up, and it is very clear that they really struggle to understand their professional boundaries within the situation and find it difficult to place the rights of the person with a disability first. Often I hear: 'What if they fall pregnant? What about the child?' They are not thinking about the person with a disability first.[99]

2.75 If follows that it has been observed by some submitters that medical professionals may:

> …also be reluctant to challenge parent's views, believing that the parents have authority to make such decisions when these have been reserved for the courts.[100]

2.76 Dr Grover, an experienced gynaecologist and researcher in the field, observed:

> We do still get straight-out requests regarding hysterectomies…I get horrified when it happens. We still get doctors writing us occasional letters. I was thinking as I came in here that we have recently done a survey of GPs and paediatricians. The work has not actually been published yet. We were

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97 Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne, *Submission 69*, p. 4.

98 Family Planning Victoria, *Submission 58*, p. 7; Qld Centre for Intellectual and Developmental Disability, Queenslanders with Disabilities Network, and Qld Advocacy Inc. *Submission 37*, p. 6.

99 Ms Hamilton, *Committee Hansard*, 27 March 2013, p. 16.

100 Office of the Public Advocate, *Submission 14*, p. 27.

> asking them a few questions about how comfortable GPs and paediatricians felt about fixing young women's health related problems. Of the 300 GPs and paediatricians, 12 of them mentioned hysterectomy early in the menstrual management issue for intellectually disabled young women.[101]

2.77 It was claimed that the reasons for such approaches by medical practitioners stem from the fact that they are not provided with adequate education, training and professional development[102] in relation to people with disabilities (particularly in relation to intellectual disabilities),[103] sexual and reproductive health,[104] informed consent,[105] how to assess capacity[106] and how to effectively communicate with people with disabilities and their carer or advocates. Often when training or professional development is undertaken it is self-funded and after-hours and resources are often limited or out of date.[107]

Impact of a lack of services, support, education and training

2.78 The flow-on effects of a lack of services, support, education and training were seen by many submitters to have a detrimental impact on people with a disability. Advocacy for Inclusion stated:

> As a result, some people with disabilities do not understand their reproductive health needs, their rights and boundaries in relationships and in the community, and the basics of safe and healthy relationships.[108]

2.79 Family Planning Victoria asserted that this could have effects on their quality of life:

> …a lot of people with disabilities, even as adults, lack basic understanding and knowledge of their sexual and reproductive health and relationships and that that has significant impacts on their quality of life more broadly.[109]

This sentiment was echoed quite strongly by some carers and parents of people with a disability:

> To give a right, then set a person to fail because of inadequate and appropriate education, is worse than not giving the right.[110]

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101 Dr Grover, *Committee Hansard*, 11 December 2012, p. 4.

102 Office of the Public Advocate, *Submission 14*, p. 14.

103 Susan Hayes, *Submission 47*, p. 7; Qld Centre for Intellectual and Developmental Disability, Queenslanders with Disabilities Network, and Qld Advocacy Inc. *Submission 37*, p. 6.

104 Susan Hayes, *Submission 47*, p. 7; Qld Centre for Intellectual and Developmental Disability, Queenslanders with Disabilities Network, and Qld Advocacy Inc. *Submission 37*, p. 6.

105 Family Planning Victoria, *Submission 58*, p. 7.

106 Family Planning Victoria, *Submission 58*, p. 7.

107 Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne, *Submission 69*, p. 4.

108 Advocacy for Inclusion, *Submission 35*, p. 7.

109 Ms Hamilton, *Committee Hansard*, 27 March 2013, p. 11.

2.80 Unplanned pregnancies were identified as a tangible consequence of a lack of services, support, education and training. A two-year audit of women with cognitive impairments contacting a Melbourne hospital based Pregnancy Advice Service reported in 2010 found:

> …that support, education and contraceptive needs are not being adequately met with 45% of women in the study seeking assistance with an unplanned pregnancy at 12 weeks gestation or later, compared with 20% of the general population of women using the Pregnancy Advice Service. One quarter of the women recognised their pregnancy too late to obtain an abortion compared with only 2% of the general population of women using the service. Only half of the women had support from formal services, but in half of these cases the service involved was Child Protection. None of the twenty women in the study were living in disability supported accommodation services.[111]

2.81 Advocacy for Inclusion informed the committee that a lack of support for parents with disabilities was also contributing to instances of child removal:

> The information existing in Australia and internationally overwhelmingly indicates that many parents with disabilities lack support to parent. In the Australian court study, the lack of support services available often directly resulted in child removal because the parents were not considered competent without supports…[112]

2.82 Evidence was provided that the lack of adequate support and education services for both people with a disability and the families and carers had a significant impact on the decision making process with respect to sterilisation:

> SH&FPA is concerned that [the steps to determine free and informed consent and "best interest'] are predicated on there being adequate active support and education services to allow individuals to fully understand the connections between fertility, menstruation management, sexual activity, pregnancy, parenting with a disability and the full range of available options.
>
> It is our view that at present, there are insufficient support structures to help individuals, their carers, the courts and the state to make these decisions in a fully informed way.[113]

2.83 Women's Health West concurred:

> Extensive research has been carried out into the stresses and strains that parents of women and men with a disability face in their role as carer (Cuskelly, 2006). It is possible that many of these strains, including fears around sexual harm, the perceived threat of pregnancy and its consequences

110 Name withheld, *Submission 26*, p. 2.

111 Office of the Public Advocate, *Submission 14*, p. 11.

112 Advocacy for Inclusion, *Submission 35*, p. 12.

113 Sexual Health and Family Planning Australia, *Submission 52*, p. 4.

> could be prompting the extreme nature of measures sought by families of girls and women with a disability. This is indicative of the lack of support for women and their families.[114]

2.84 Some submitters[115] felt that this was a key reason why sterilisation was occurring:

> …sterilisation continues not only because the women who are sterilised are believed to be incapable of motherhood but also because of the continuing lack of resources and services to support parents, carers and the women themselves.[116]

> …there are all of these informal processes impacting—if you like, reinforcing and extending—the occurrence of what, in the definition as the commission views it, would include forced or coerced sterilisation.[117]

2.85 Although others noted there was no research supporting this:

> The dearth of accessible and appropriate services and programs does not necessarily directly relate to increased numbers of unnecessary sterilisation procedures…[118]

Better services and supports

2.86 Improved services and supports will have a wide range of benefits. In the specific context of this inquiry, the committee begins by noting the consensus that it could reduce the need for surgical interventions and sterilisation. Despite their sometimes contrasting views, most submitters informed the committee that they felt it was clear that the provision of adequate supports and services have a role to play in lowering the perceived need for sterilisations:

> There is good reason to believe, however, that many applications will be diverted if appropriate services are offered early in the piece, before partisan legal involvement. The experience in Queensland has been relatively positive. It has shown that where services are accessed by families, before lawyers are engaged or an application is made to the court, they will more often than not choose less invasive options.[119]

> They do respond to the information that is given to them when they are given that information. So people who have arrived at our doorstep saying, 'We think our daughter will need a hysterectomy,' leave without a

114 Women's Health West, *Submission 38*, p. 7.

115 Office of the Public Advocate, *Submission 14*; Catholic Social Services Victoria, *Submission 39*.

116 Associate Professor Meekosha, *Committee Hansard*, 27 March 2013, p. 2.

117 Mr Innes, Hearing, 27 March 2013, p. 38.

118 Susan Hayes, *Submission 47*, p. 7.

119 See Brady, Briton and Grover (2001) p. 41, as referred to in *Submission 18*, p. 5.

> hysterectomy, so education does work with the parents but they have got to access people who will provide them with support…[120]

2.87 Women's Health West stated:

> Evidence shows that girls and women with a disability are able to manage their menstruation successfully in similar ways to girls and women without a disability if well supported…[121]

2.88 Other research cited earlier in this chapter reaches similar conclusions. The Australian Human Rights Commission was adamant that a structured framework of education and support would ultimately decrease the number of requests for involuntary or coerced sterilisation:

> A broad educational and support framework will help eliminate the consideration of involuntary or coerced sterilisation as a way to, for example, deal with menstrual management, control fertility, or avoid pregnancy as a result of rape.[122]

2.89 The committee received considerable evidence on what services were needed to achieve better outcomes, and these were required for people with disabilities, their carers, and medical professionals.

People with a disability - Managing sexual and reproductive health

2.90 From evidence provided to the committee it was identified that there needs to be more 'accessible education and information on sexual and reproductive health' for people with disabilities as well as a need for:

> …primary health care needs to better respond to the informational and related support needs of people with intellectual disabilities, and other cognitive disabilities.[123]

2.91 There was broad support for:

> …development of a broad education and support framework for women and girls with disability, their families and carers, and health service providers.[124]

2.92 It was proposed that primary services and supports would include:

- Menstruation management
- Education about the range of options to protect against the possibility and consequences of unwanted pregnancy
- Support for sexual behaviours of concern

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120 Professor Grover, *Committee Hansard*, 11 December 2013, p. 17.

121 Women's Health West, *Submission 38*, p. 6.

122 Australian Human Rights Commission, *Submission 5*, p. 11.

123 Office of the Public Advocate, *Submission 14*, p. 25.

124 Australian Human Rights Commission, *Submission 5*, p. 11.

- Strategies to prevent and protect against sexual abuse or exploitation
- Support for those women with disabilities that do wish to have children or already have children
- Relationships and sexuality education for people with disabilities (both physical and intellectual)[125]

2.93 The provision of such services, it was argued, is essential to meeting human rights obligations, including compliance with:

> …article 25 of the CRPD to provide women and girls with disability 'the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health'.[126]

2.94 It was noted that there is also a specific need for support such as counselling, mentoring and respite for families where parents have disabilities[127] and for people with disabilities considering having children.[128]

> Families facing difficulties in parenting for many different reasons are able to access (albeit limited) supports to ensure equality of life and opportunity for children. If such support was available more widely to families where a parent or parents have a disability which compromises their capacity to parent, it would benefit those families and possible alleviate the fears of carers and extended families. Respite care and innovate programs such as family mentoring are an essential part of the service mix.[129]

2.95 Supported decision making is important in facilitating the rights of many people with disability in general, and in the context of major medical and personal decisions in particular. Supported decision making is particularly critical to determining capacity, which will be discussed later in this report. There was broad consensus that 'better education is going to lead to better and more supported decision making'.[130]

2.96 Although supported decision making may not be practicable for all people with a disability it was acknowledged that:

> The ability of a person with disability to make decisions and exercise free and informed choice can be developed over time, with the provision of comprehensive and accessible information, counselling and support.[131]

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125 Sexual Health and Family Planning Australia, *Submission 52*, p. 4.

126 Australian Human Rights Commission, *Submission 5*, p. 11.

127 Catholic Social Services Victoria, *Submission 39*, p. 2.

128 Family Planning NSW, *Submission 25*, p. 5.

129 Catholic Social Services Victoria, *Submission 39*, p. 2.

130 See, for example, Mr Innes, *Committee Hansard*, 27 March 2013, p. 37.

131 Family Planning NSW, *Submission 25*, p. 5; Centre for Disability Research and Policy, *Submission 21*, p. 9.

2.97 There was a broad consensus from submitters that support and education for people with a disability should be based on the 'individual needs and learning style of each person'[132] and 'in formats that meet their specific learning needs':[133]

> The importance of specialised resources is of increasing importance given the policy shift to individualised service approaches for people with cognitive impairment which depends on comprehensive, accessible and responsive specialised and mainstream services.[134]

2.98 The Office of the Public Advocate identified that, in the case of people with intellectual disability, specialised resources could include educational resources 'presented simply in plain English and simple English'.[135] Other submitters suggested resources such as parent forums, social media, online resources, family-to-family mentoring, outreach education and one-on-one support could be expanded or explored:[136]

> We recommend…current specialised family planning services are expanded throughout the country and made accessible to women and men with disabilities of child bearing age utilising social media and e-health or mhealth applications, and with outreach education to family members and service providers…[137]

2.99 There was also broad acceptance that people with disabilities require life-long education that not only includes education at school but education that progresses into adulthood:[138]

> Students with disabilities:…Require explicit and systematic education/training, often over a longer period of time, with high levels of reinforcement and cognitive prosthesis and a simplified social model, to navigate the complex social world around them to be successfully 'included' in social environment during adolescence and post-school.[139]

2.100 Although a number of existing sexual and reproductive health education and support service providers, resources and programs have been identified 'there is no real understanding of what can potentially be offered'[140] to people with a disability,

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132 National Council on Intellectual Disability, *Submission 77*, p. 9.

133 Advocacy for Inclusion, *Submission 35*, p. 7.

134 Office of the Public Advocate, *Submission 14*, p. 25.

135 Office of the Public Advocate, *Submission 14*, p. 25.

136 Family Planning NSW, *Submission 25;* Centre for Disability Research and Policy, *Submission 21*; Ms Knight, *Committee Hansard*, 27 March 2013, p. 46.

137 Centre for Disability Research and Policy, *Submission 21*, p. 9.

138 Sexual Health and Family Planning Australia, *Submission 52*; Office of the Public Advocate, *Submission 14;* Ms Chivers, *Committee Hansard*, 27 March 2013, p. 11; Advocacy for Inclusion, *Submission 35*.

139 Sexual Health and Family Planning Australia, *Submission 52*, p. 6.

140 Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne, *Submission 69*, p. 7.

their carers, health professionals and support workers. It was conveyed to the committee that there 'is an urgent need for resources and better coordination and linkage between sectors.'[141] Sexual Health and Family Planning Australia provided an example:

> SH&FPA is trying to address some of the issues in relation to sharing of knowledge and resources through the Disability Special Interest Group, however, members of the group are often overstretched in their roles within their Member Organisations and there is no dedicated funding to support the work of the group in an ongoing manner. What is needed is a fully funded and supported network of specific disability sexual and reproductive health service trainers and providers and qualified teachers that also includes comprehensive pre and post education assessment to evaluate learning, decision making processes and capacity to consent.[142]

2.101 Sexual Health and Family Planning Australia went on to propose that progress could be made in this area under the umbrella of the NDIS:

> SH&FPA believes that if the development and implementation of the National Disability Insurance Scheme includes consideration of sexual and reproductive health services, this could potentially provide a key opportunity to help better integrate sexual and reproductive health services with other disability services.[143]

2.102 Other submitters[144] also expressed a desire for reproductive and sexual health services for people with a disability to be covered by the NDIS, including support for people with disabilities as parents and their children:

> We want to suggest that the NDIS does need to recognise that parenting is one of the roles that people with disabilities play and that supports need to recognise that they might need to be provided in that space.[145]

2.103 It was clear from evidence received from individual carers, as well as from stakeholders generally, that support for carers is currently insufficient. Whilst the impost on carers should be improved to a significant degree through the roll-out of Disability Care Australia to adequately meet the needs of individuals with a disability, this roll-out will take some time, and there may in any case be some needs best met by supporting carers directly.

Carers, parents, guardians

2.104 There was broad consensus from submitters that:

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141 Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne, *Submission 69*, p. 7.

142 Sexual Health and Family Planning Australia, *Submission 52*, p. 4.

143 Sexual Health and Family Planning Australia, *Submission 52*, p. 4.

144 See for example Office of the Public Advocate (Victoria), *Submission 14*, p. 28; National Council on Intellectual Disability, *Submission 77*, p. 9.

145 Ms Ryan, *Committee Hansard*, 27 March 2013, p. 24.

> Carers play an important role in the Australian community and deserve appropriate government and community support to assist them.[146]

2.105 It was acknowledged that a lack of adequate support and services was adding to the distress that many carers were suffering and there was:

> …no point to demanding the rights of people with disability, if we cannot also support families and carers in their challenging role to help achieve that.[147]

> The contribution of families and carers of women and girls with a disability must be valued and given adequate support to ensure their capacity to uphold the human rights of women with a disability.[148]

2.106 In order to provide the most appropriate support, Family Planning NSW argued that:

> The concerns of parents for the current and future health and safety of their son or daughter need to be acknowledged and respected. Their anxiety about the consequences of the decisions their family member makes, particularly about having a child, is of course understandable. This is an area of potential conflict because one person's decisions may significantly and negatively impact on another person. There needs to be support offered that helps to resolve this situation but it needs to be managed without taking away a person's right to make their own decisions.[149]

2.107 It was identified that respite for both carers and for individuals with a disability was also an essential component of such support:

> In addition to the practical need for assistance, support to carers is essential so that they do not become isolated and feel that they are 'solely responsible' for their family member. Increased respite and support through formalised and informal support groups for families living with disability is vital.[150]

> Ongoing and regular family support needs to be provided to families to assist in the day-to-day care and the needs of the person with disability within the family. At all times, the family unit needs to be supported and encouraged by providing regular, meaningful and effective respite from caring, which are suitable to their needs and take into account their circumstances, for example, families that are without extended family or

146 Australian Medical Association, *Submission 53*, p. 1. See also, Women's Health West, *Submission 38;* Australian Catholic Bishops Conference, *Submission 56;* Australian Human Rights Commission, *Submission 5.*

147 Australian Catholic Bishops Conference, *Submission 56*, p. 4.

148 Women's Health West, *Submission 38*, p. 7.

149 Family Planning NSW, *Submission 25*, p. 5.

150 Australian Catholic Bishops Conference, *Submission 56*, p. 5.

> community assistance. This is especially true for families in remote and rural areas.[151]

2.108 It was also recommended that the focus on support should not only be on the parents but also on the other children in the family:

> Sibling support programmes should be increased and supported financially to ensure siblings of children with disability, or children with parents with intellectually disability or mental health issues, are properly supported and encouraged to continue to seek and achieve their own goals and dreams.[152]

2.109 There was also broad consensus that carers need to be able to access current and appropriate knowledge and resources which focus on issues such as sexuality and disability, puberty, and protective behaviours, so they can make informed decisions and educate, inform and provide proactive and positive support to their children on these issues:

> Family Planning New South Wales has identified a really strong need of parents and carers for information and education…Overwhelmingly, what we found was that parents have a great desire and need for the information about how they can support their child to live a full life, to experience a safe positive sexuality and ultimately intimate relationships also. Very rarely do we find parents actually raise the issue of sterilisation...[as] they are there because they want to learn about the broad gamut of sexuality issues they need to teach their children.[153]

> Education and support may reduce fear, and is one of the most important components of care. However, accessing reliable information regarding menstrual management issues and contraception for young women with disabilities and their families and carers is challenging.[154]

2.110 Parents and carers need to have the confidence to seek assistance, and this comes partly from increasing their awareness that they are not alone, and that there can be a range of options available to assist them:

> …to provide information to parents and carers to assure them that they are not alone in the issues they face. Some parents feel uncomfortable about raising issues and seeking expert assistance around their child's physical and sexual growth and development.[155]

2.111 The committee recognises that for support for carers to be effective, they need to be confident of the professionalism and expertise of services: earlier in the chapter the committee has quoted evidence from parents indicating that some have serious reservations about the safety of respite and residential care. One of the most important

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151 Australian Catholic Bishops Conference, *Submission 56*, p. 5.

152 Australian Catholic Bishops Conference, *Submission 56*, p. 5.

153 Mr Hardy, *Committee Hansard*, 27 March 2013, p. 13.

154 Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne, *Submission 69*, p. 4.

155 Family Planning NSW, *Submission 25*, p. 5.

issues that has to be addressed (not just in the context of this current inquiry) is the protection of people with disability from sexual abuse and assault.

Medical Practitioners

2.112 There was an identified need for medical practitioners to receive additional training in dealing with the sexual and reproductive needs people with a disability, not only from a clinical perspective but from an ethical and legal perspective.[156] Family Planning NSW stated that medical practitioners:

> '…must have the skills and expertise to talk about reproductive and sexual health issues including understanding how informed consent relates to a person with disability making a decision about their reproductive and sexual health.'[157]

2.113 This includes being able to 'recognise and adequately communicate with and treat people with disabilities, as well as understanding the process of substitute and supported decision making.[158] Although it was recommended that a large portion of this training should be a part of pre-service programs,[159] ongoing professional development[160] was considered essential, particularly as it 'would be useful to increase the number of clinicians with the appropriate expertise.'[161]

2.114 The issue of medical expertise in the context of court and tribunal decision-making is discussed further in later chapters.

Conclusion

2.115 The committee concluded that there is a shocking lack of resources available for people with a disability to assist them with:

- choices about relationships and sexuality, sexual and reproductive health, including contraception and sterilisation; and
- menstrual management.

2.116 The Committee believes that improved education about relationships and sexuality for people with a disability and their families and service providers should have priority. We hope this would ultimately lead to better understanding within the disability sector, health professions and the general community of the reasonable and

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156 Family Planning NSW, *Submission 25;* Office of the Public Advocate, *Submission 14*; Family Planning Victoria, *Submission 58;* Dr Chesterman, *Committee Hansard*, 11 December 2012, p. 14.

157 Family Planning NSW, *Submission 25*, p. 4.

158 Susan Hayes, *Submission 47*, p. 7; Ms Pearce, *Committee Hansard*, 11 December 2012, p. 13; IDRS, *Submission 67*, p. 27; FPNSW, *Submission 25*, p. 6.

159 Family Planning Victoria, *Submission 58*, p. 7

160 Family Planning Victoria, *Submission 58*, p. 7; Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne, *Submission 69*, p 7.

161 Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne, *Submission 69*, p. 7.

normal aspirations of people with a disability regarding sexuality and relationships. This should then lead to more appropriate support for people with disability regarding menstrual, contraceptive and behavioural management

2.117 There is a lack of resources and training available for carers, families and the medical profession to support the sexual and reproductive health needs of a person with a disability. These deficiencies are having extremely serious consequences, not only in reduced welfare for people with disabilities and their families, but in contributing to decisions to undertake sterilising procedures that would not otherwise be made.

Recommendation 1

2.118 The committee recommends that, in education programs relating to disability and in sex education and family planning information targeted to the disability sector, education about relationships and sexuality for people with disability should be prioritised, with an emphasis on the reasonable and normal aspirations of people with a disability regarding their sexuality and relationships.

Recommendation 2

2.119 The committee recommends that medical workforce training with respect to sexual and reproductive health includes content on supporting sexual relationships and sexual and reproductive health needs for people with a disability.

Recommendation 3

2.120 The committee recommends that medical workforce training include training with respect to the ethical and legal aspects of informed consent, substitute and supported decision making and fertility control.

2.121 The new Disability Care Australia scheme can and should be addressing some of these issues. The preparation of Participant Plans under chapter 3 part 2 of the National Disability Insurance Scheme Act is where this process would begin. It would then proceed through the provision of appropriate supports, including, where required:

- resources that ensure access to relationships and sex education that meets the needs of the person;
- assistance and training for family members involved in assisting the participant in all aspects of sexuality, including menstrual management; and/or
- support worker engagement in menstrual management, and other matters, that is consistent with participant goals and aspirations.

Recommendation 4

2.122 The committee recommends that, in the development of participant plans (particularly for participants approaching puberty and in their teens), the participant work with any person assisting them with plan development, and with Disability Care Australia, to cover the need for understanding of sexuality and sexual relationships, support for relationships and sex education that meets

the participants' needs, and covers appropriate support for menstrual management for girls and women with disabilities.

2.123 It is clear to the committee that there are very serious deficiencies in disability care and support around sexual relationships and sexual abuse. Supported accommodation and similar services in particular need to undergo significant change to improve in these areas, if the anecdotal information provided to the committee is anything to go by.

2.124 It was acknowledged by a number of submitters that 'in Australia, women and girls with disabilities are at higher risk of sexual exploitation and abuse than the greater female society.'[162] It was also acknowledged that:

> People with a disability 'are often discouraged' to report instance of sexual abuse because 'they are less likely to be believed, less likely to be able to give consistent evidence and less likely to have their case go to court. And, if they go to court, they are less likely to secure a conviction.'[163]

2.125 There was concern that there is a prevailing focus on what may result from a sexual assault of a person with a disability—pregnancy—rather than the fact the assault occurred. Many found this kind of attitude abhorrent:

> When claims are made that sterilisation is a means for preventing unwanted outcomes of sexual activity (i.e. pregnancy), my heart stops. [name removed]'s impairment means that she does not have the capacity to consent to sexual activity; 'activity' in her case is synonymous with assault. The emphasis should and must be on eliminating the possibility of the sexual assault of our daughters with high support needs, not on keeping them from getting pregnant in case this happens to them.[164]

2.126 Two things need to be achieved. The first is providing support that ensures that people with disability can enter into relationships, including sexual relationships, should they wish. At the same time, the second thing that is required is protection from sexual assault where the person does not want the relationship. At present it appears that some care settings seek to achieve one of these objectives by preventing the other, but often neither is possible.

2.127 Though this was not a subject central to the committee's terms of reference, the committee concluded that it is one of the most serious and urgent matters requiring reform.

Recommendation 5

2.128 The committee abhors the suggestion that sterilisation ever be used as a means of managing the pregnancy risks associated with sexual abuse and strongly recommends that this must never be a factor in approval of sterilisation.

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162 Australian Institute on Intellectual and Developmental Disabilities, *Submission 84*, p. 8.

163 Ms Pearce, *Committee Hansard*, 11 December 2012, p 15.

164 Name withheld, *Submission 55*, p. 2.

Chapter 3

Legal frameworks relevant to the sterilisation of people with disabilities in Australia

The international human rights framework

3.1 Australia's regulation of the involuntary or coerced sterilisation of persons with disabilities is influenced by a network of international treaties that seek to protect the rights of, and promote the highest attainable standards of health for, persons with disabilities.[1] As identified by submitters to the inquiry, the international human rights framework includes numerous treaties that expressly specify the rights of individuals. Relevant treaties include the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities.[2] While not as commonly cited, the International Convention on the Elimination of All Forms of Racial Discrimination and the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment were also noted as relevant.[3]

3.2 As a signatory to these treaties, Australia has chosen to be bound by the treaty requirements. Accordingly, Australia is obligated to give good faith effect to their terms.[4] As Australian Lawyers for Human Rights submitted:

> Australia has ratified each of the above international legal Conventions and is, therefore, obliged to ensure that the rights contained in each of the above Conventions are respected and protected, including the rights of people with disabilities.[5]

3.3 What follows is an overview of key provisions of treaties identified as relevant to Australia's regulation of the sterilisation of persons with disabilities, highlighting key aspects of international law as identified by submitters to the inquiry.

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1 Office of the United Nations High Commissioner for Special Procedures of the Human Rights Committee, AL Health (2002–7) G/SO 214 (89–15), 18 July 2011, p. 2, as cited in Women With Disabilities Australia, *Submission 49*, Attachment 1, p. 86.

2 See, for example, Advocacy for Social Inclusion, *Submission 35*, p. 5; Australian Association of Developmental Disability Medicine Inc., *Submission 59*, p. 1; Australian Lawyers for Human Rights, *Submission 41*, p. 5; Adult Guardian of Queensland and the Public Advocate of Queensland, *Submission 19*, p. 2.

3 Law Institute of Victoria, *Submission 79*, p. 6; Women With Disabilities Australia, *Submission 49*, pp. 58–59, 68.

4 *Commonwealth v Tasmania (the Tasmanian Dam Case)* (1983) 158 CLR 1, 219 – 220 (per Brennan J).

5 Australian Lawyers for Human Rights, *Submission 41*, p. 5.

The Convention on the Rights of Persons with Disabilities

3.4 The Convention on the Rights of Persons with Disabilities seeks to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities'.[6] Notably, the preamble declares that 'discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person', and emphasises 'the need to incorporate a gendered perspective in all efforts to promote the full enjoyment of human rights and fundamental freedoms by persons with disabilities'.[7]

3.5 Article 12 provides that persons with disabilities have the right to legal recognition, and to enjoy legal capacity, on an equal basis with others. This right includes access to necessary support to exercise their legal capacity. Article 17 declares that '[e]very person with disabilities has the right to respect for his or her physical and mental integrity on an equal basis with others'. This principle underscores the direction in Article 23 for States Parties to take 'effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others'. Article 25 notes the relevance of obtaining free and informed consent. Specifically, clause (d) of Article 25 states:

> [In particular, States Parties shall] Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care.[8]

3.6 Submitters also drew attention to Articles 4 to 7, which collectively reiterate the State's obligation to protect the equality of all persons before the law. Article 4 makes clear that the State's obligation to give effect to the rights expressed in the treaty may require legislative and administrative action, and the evaluation of policies and programs. Articles 5, 6 and 7 direct States to give particular consideration to ensuring equal access for women and children. Article 16 was also noted. This Article directs States to take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home,

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6 Convention on the Rights of Persons with Disabilities, Article 1, United Nations, *Convention on the Rights of Persons with Disabilities*, http://www.un.org/disabilities/convention/conventionfull.shtml (accessed 3 May 2013).

7 Convention on the Rights of Persons with Disabilities, clause h, clause s, United Nations, *Convention on the Rights of Persons with Disabilities*, http://www.un.org/disabilities/convention/conventionfull.shtml (accessed 3 May 2013).

8 Convention on the Rights of Persons with Disabilities, Article 25(d), United Nations, *Convention on the Rights of Persons with Disabilities*, http://www.un.org/disabilities/convention/conventionfull.shtml (accessed 3 May 2013).

from all forms of exploitation, violence and abuse. Article 16 specifically notes the potential for gender-based exploitation, violence and abuse.[9]

3.7 It was put to the committee that the Convention has the effect that 'an individual's right to decision-making cannot be substituted by decision-making of a third party'.[10] However, Australia's obligations are shaped by reservations made at the time Australia entered into the Convention. Australia's consent to the provisions of the Convention on the Rights of Persons with Disabilities was not without caveats. In entering to the treaty, Australia declared its view that the Convention allows for substituted decision-making and compulsory medical treatment:

> Australia declares its understanding that the Convention allows for fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards…Australia further declares its understanding that the Convention allows for compulsory assistance or treatment of persons, including measures taken for the treatment of mental disability, where such treatment is necessary, as a last resort and subject to safeguards.[11]

3.8 Australia's reservation seems to reflect the objects of the largely superseded Article 7 of General Assembly Resolution 2856 (XXVI) (1971). The resolution, using the dated language of that time, considered the possibility of a need for third-party involvement in decisions affecting persons with intellectual disabilities:

> Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.[12]

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9 Convention on the Rights of Persons with Disabilities, Articles 4, 5, 6, 7, 16, United Nations, *Convention on the Rights of Persons with Disabilities*, http://www.un.org/disabilities/convention/conventionfull.shtml (accessed 3 May 2013). See, for example, Associate Professor Lee Ann Basser, *Submission 61*, pp. 2–3; Australian Human Rights Commission, *Submission 5*, p. 7.

10 Women With Disabilities Australia, *Submission 49*, p. 56.

11 United Nations, *United Nations Treaty Collection*, http://treaties.un.org/pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en#EndDec (accessed 3 May 2013).

12 Declaration on the Rights of Mentally Retarded Persons, University of Minnesota, Human Rights Library, *Declaration on the Rights of Mentally Retarded Persons*, http://www1.umn.edu/humanrts/instree/t1drmrp.htm (accessed 7 May 2013); United Nations enable, *Developmental and psychiatric disabilities*, http://www.un.org/esa/socdev/enable/disdevelopmental.htm (accessed 7 May 2013).

The Convention on the Rights of the Child

3.9 The Convention on the Rights of the Child (the CRC) commits Australia to respect and ensure the rights of every Australian child. The CRC makes clear that rights equally apply to every child regardless of the child's, or his or her parents', race, colour, sex, language, religion, political opinion, national, ethnic or social origin, property, disability, birth or other status. The CRC further directs that actions concerning children undertaken by courts of law shall have as their primary consideration the child's best interests.[13] Article 37 requires States Parties to ensure that no child is subject to torture or other cruel, inhuman or degrading treatment or punishment.[14] Article 19 enjoins States to take all appropriate legislative, administrative, social and educational measures to protect children from all forms of physical or mental violence.[15]

3.10 Article 5 makes specific provision for the recognition of the responsibilities of a child's parents or guardians in relation to the exercise and implementation of a child's rights:

> States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention.[16]

3.11 Article 3(2) also directs States Parties to consider the rights and duties of a child's parents or guardians:

> States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally

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13 Convention on the Rights of the Child, Articles 2 and 3, available at Office of the High Commissioner for Human Rights, http://www.ohchr.org/en/professionalinterest/pages/crc.aspx (accessed 3 May 2013).

14 Convention on the Rights of the Child, Article 37, available at Office of the High Commissioner for Human Rights, http://www.ohchr.org/en/professionalinterest/pages/crc.aspx (accessed 3 May 2013).

15 Convention on the Rights of the Child, Article 19, available at Office of the High Commissioner for Human Rights, http://www.ohchr.org/en/professionalinterest/pages/crc.aspx (accessed 3 May 2013).

16 Convention on the Rights of the Child, Article 5, available at Office of the High Commissioner for Human Rights, http://www.ohchr.org/en/professionalinterest/pages/crc.aspx (accessed 3 May 2013).

responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.[17]

3.12 Australia has made one reservation under the CRC, however, the reservation does not relate to the Articles relevant to the sterilisation of children.[18]

The Convention on the Elimination of All Forms of Discrimination against Women

3.13 The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) 'affirms women's rights to reproductive choice'. CEDAW also requires State Parties to take all appropriate measures to eliminate discrimination against women in the area of health care. This requirement extends to ensuring access to healthcare services such as services relating to family planning.[19]

3.14 In accordance with Article 24, through becoming a signatory to CEDAW Australia undertook to 'adopt all necessary measures at the national level aimed at achieving the full realisation of the rights recognised in the…Convention'.[20] In entering into CEDAW, the Government specified two reservations. However, neither affect the Articles relevant to the sterilisation of persons with disabilities.[21]

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17 Convention on the Rights of the Child, Article 3(2), available at Office of the High Commissioner for Human Rights, http://www.ohchr.org/en/professionalinterest/pages/crc.aspx (accessed 3 May 2013).

18 Article 37 requires any child in prison to be separated from adults unless it is considered to be in the child's best interest to do otherwise. In signing the treaty, Australia advised that it only accepted the obligation to detain children in facilities separate from adults to the extent that responsible authorities consider this to be feasible and consistent with the child's right to maintain contact with their families, having regard to the geography and demography of Australia.

19 Convention on the Elimination of All Forms of Discrimination against Women, Articles 12 and 16, United Nations, Division for the Advancement of Women, Department of Economic and Social Affairs, http://www.un.org/womenwatch/daw/cedaw/text/econvention.htm (accessed 8 April 2013).

20 Convention on the Elimination of All Forms of Discrimination against Women, Article 24, United Nations, Division for the Advancement of Women, Department of Economic and Social Affairs, http://www.un.org/womenwatch/daw/cedaw/text/econvention.htm (accessed 8 April 2013).

21 At the time of signing CEDAW, Australia made two reservations. First: 'The Government of Australia states that maternity leave with pay is provided in respect of most women employed by the Commonwealth Government and the Governments of New South Wales and Victoria. Unpaid maternity leave is provided in respect of all other women employed in the State of New South Wales and elsewhere to women employed under Federal and some State industrial awards. Social Security benefits subject to income tests are available to women who are sole parents.' Second: 'The Government of Australia advises that it is not at present in a position to take the measures required by article 11 (2) to introduce maternity leave with pay or with comparable social benefits throughout Australia.'

The Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment

3.15 Women With Disabilities Australia (WWDA) highlighted Australia's obligations under the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.[22] Article 2 directs State Parties to take effective legislative, administrative, judicial and other measures to prevent acts of torture in any territory under its jurisdiction.[23]

3.16 The Convention adopts a narrow definition of torture that focuses on the circumstances in which severe pain or suffering is intentionally afflicted:

> For the purposes of this Convention, the term 'torture' means any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as:
>
> - obtaining from him or a third person information or a confession;
> - punishing him for an act he or a third person has committed or is suspected of having committed;
> - intimidating or coercing him or a third person; or
> - for any reason based on discrimination of any kind
>
> when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.
>
> It does not include pain or suffering arising only from, inherent in or incidental to lawful sanctions.[24]

The International Covenant on Civil and Political Rights

3.17 The International Covenant on Civil and Political Rights prohibits torture, and cruel, inhuman or degrading treatment. This includes an express prohibition on subjecting a person to medical and scientific experimentation without his or her free

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22 Women With Disabilities Australia, *Submission 49*, p. 58.

23 Australian Government, *Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment - Human rights at your fingertips - Human rights at your fingertips*, http://www.humanrights.gov.au/convention-against-torture-and-other-cruel-inhuman-or-degrading-treatment-or-punishment-human-rights (accessed 7 May 2013).

24 Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Article 1; Australian Government, *Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment - Human rights at your fingertips - Human rights at your fingertips*, http://www.humanrights.gov.au/convention-against-torture-and-other-cruel-inhuman-or-degrading-treatment-or-punishment-human-rights (accessed 7 May 2013).

consent. The Covenant also recognises the right to privacy and the right to marry and found a family, and mandates special protections for children.[25]

The International Covenant on Economic, Social and Cultural Rights

3.18 Article 10 of the International Covenant on Economic, Social and Cultural Rights directs that 'special protection should be accorded to mothers during a reasonable period before and after childbirth'. Article 12 recognises the 'right of everyone to the enjoyment of the highest attainable standard of physical and mental health'.[26]

Treaty interpretation – United Nations' committees and officials

3.19 According to the Human Rights Committee, it is the role of United Nations' committees and officials to provide guidance about treaty provisions to avoid doubt about their scope and meaning. Such guidance is provided in *General Comments*, which 'are normally directed at States parties and usually elaborate the Committee's view of the content of the obligations assumed by States'.[27] United Nations' committees have commented on several Articles identified as relevant to the sterilisation of persons with disabilities. The following provides an overview of the broad approach adopted by United Nations committees. Comments specifically relating to Australian law and practice are provided in chapter 4.

The Convention on the Rights of Persons with Disabilities

3.20 Commenting on the implementation of the Convention by States Parties, the Committee on the Rights of Persons with Disabilities has exhorted States Parties to 'abolish the administration of medical treatment, in particular sterilization, without the full and informed consent of the patient'.[28]

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25 International Covenant on Civil and Political Rights, Articles 7, 17, 23, and 24; available at Office of the High Commissioner for Human Rights, http://www.ohchr.org/EN/ProfessionalInterest/Pages/CCPR.aspx (accessed 3 May 2013).

26 International Covenant on Economic, Social and Cultural Rights, available at Office of the High Commissioner for Human Rights, http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx (accessed 3 May 2013).

27 United Nations, Human Rights Committee, *Human Rights Committee – Working Methods*, http://www2.ohchr.org/english/bodies/hrc/workingmethods.htm#a9 (accessed 8 April 2013).

28 See, for example, Committee on the Rights of Persons with Disabilities, *Consideration of reports submitted by States parties under article 35 of the Convention, Concluding observations of the Committee on the Rights of Persons with Disabilities–Spain*, 19 October 2011, p. 6.

The Convention on the Rights of the Child

3.21 The Committee on the Rights of the Child has defined physical violence, for the purposes of Article 19, to include forced sterilisation.[29] The committee has also commented on the application of the child's best interest test, concluding that any interpretation of 'child's best interests' must be consistent with all rights and principles established by the CRC:

> The Committee emphasizes that the interpretation of a child's best interests must be consistent with the whole Convention, including the obligation to protect children from all forms of violence. It cannot be used to justify practices, including corporal punishment and other forms of cruel or degrading punishment, which conflict with the child's human dignity and right to physical integrity. An adult's judgment of a child's best interests cannot override the obligation to respect all the child's rights under the Convention.[30]

3.22 In relation to the sterilisation of children with disabilities, the Committee on the Rights of the Child has urged States Parties to prohibit the forced sterilisation of children with disabilities:

> The Committee is deeply concerned about the prevailing practice of forced sterilisation of children with disabilities, particularly girls with disabilities. This practice, which still exists, seriously violates the rights of the child to her or his physical integrity and results in adverse life-long physical and mental health effects. Therefore, the Committee urges States Parties to prohibit by law the forced sterilisation of children on the grounds of disability.[31]

The Convention on the Elimination of All Forms of Discrimination against Women

3.23 The committee was advised that the Committee on the Elimination of All Forms of Discrimination against Women has 'clearly articulated the link between forced sterilisation and violation of the right to reproductive self-determination'.[32] Further, it was submitted that the United Nations committee 'characterises forced sterilisation as a form of violence against women, and directs States to ensure that forced sterilisations do not occur.'[33]

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29 Committee on the Rights of the Child, *General comment No. 13 (2011)*, p. 10, http://www2.ohchr.org/english/bodies/crc/docs/CRC.C.GC.13_en.pdf (accessed 7 May 2013).

30 Committee on the Rights of the Child, *General comment No. 13 (2011)*, p. 23, http://www2.ohchr.org/english/bodies/crc/docs/CRC.C.GC.13_en.pdf (accessed 7 May 2013).

31 United Nations, Committee on the Rights of the Child, *General Comment No. 9 (2006): The rights of children with disabilities*, CRC/C/GC/9, 27 February 2007, Article 60.

32 Women With Disabilities Australia, *Submission 49*, p. 60.

33 Women With Disabilities Australia, *Submission 49*, p. 60.

3.24 Commenting on Article 16 of the Convention, (regarding the elimination of discrimination against women in matters relating to marriage and family relations) the Committee expressed its view of the effects of compulsory sterilisation and abortion:

> Compulsory sterilization or abortion adversely affects women's physical and mental health, and infringes the right of women to decide on the number and spacing of their children.[34]

3.25 The United Nations Committee has formed the view that Article 16 also provides a right to access education and family planning services, arguing that such services can reduce the incidence of forced sterilisations:

> Some reports disclose coercive practices which have serious consequences for women, such as forced pregnancies, abortions or sterilization. Decisions to have children or not, while preferably made in consultation with spouse or partner, must not nevertheless be limited by spouse, parent, partner or Government. In order to make an informed decision about safe and reliable contraceptive measures, women must have information about contraceptive measures and their use, and guaranteed access to sex education and family planning services, as provided in article 10 (h) of the Convention.[35]

The Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment

3.26 As noted by WWDA, the Committee Against Torture has criticised the involuntary sterilisation of women.[36] However, in keeping with the ambit of the Convention, the Committee's comments are focused on incidences where sterilisation appears to be part of a broader racial discrimination agenda. For example, calls for the Czech Republic and Slovakia to impartially investigate allegations of the involuntary sterilisation of Roma women were made in the context of condemning attacks on the Roma population.[37] Similarly, the committee's 2013 reprimand of Peru for sterilisations that occurred between 1996 and 2000 was made in the context of

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34 Committee on the Elimination of All Forms of Discrimination against Women, *General recommendation No. 19*, paragraph 22, http://www.un.org/womenwatch/daw/cedaw/recommendations/index.html (accessed 7 May 2013).

35 Committee on the Elimination of All Forms of Discrimination against Women, *General recommendation No. 21*, paragraph 22, http://www.un.org/womenwatch/daw/cedaw/recommendations/index.html (accessed 7 May 2013).

36 Women With Disabilities Australia, *Submission 49*, pp. 59–60.

37 Committee Against Torture, *Consideration of reports submitted by States parties under article 19 of the Convention, Concluding observations of the Committee against Torture–Slovakia*, 17 December 2009, p. 4, http://www2.ohchr.org/english/bodies/cat/sessions.htm (accessed 7 May 2013); Committee Against Torture, *Consideration of reports submitted by States parties under article 19 of the Convention, Concluding observations of the Committee against Torture–Czech Republic*, 13 July 2012, pp. 4–5, http://www2.ohchr.org/english/bodies/cat/sessions.htm (accessed 7 May 2013).

allegations that the sterilisations were part of a broader policy of targeting ethnic minorities.[38] In 2005, the Committee reviewed Australia's implementation of the Convention. In contrast to comments contained in other States' reviews, the Committee did not comment on any sterilisation procedures occurring in Australian jurisdictions.[39]

3.27 As WWDA,[40] Australian Lawyers for Human Rights,[41] and others submitters citing WWDA's analysis,[42] noted, relevant United Nation's comments are also found in reports of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment. Most recently, the 2013 *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment* focuses on 'abusive practices that occur under the auspices of health care policies', and 'abuse in healthcare settings that may cross the threshold of mistreatment that is tantamount to torture or cruel, inhuman or degrading treatment or punishment'.[43] In considering the issue, the Special Rapporteur sought to identify 'abuses that exceed the scope of violations of the right to health and could amount to torture and ill-treatment'.[44] The report recognises a growing consensus among the international community that torture may occur in contexts other than interrogation, punishment or intimidation of a detainee.[45]

3.28 The Special Rapporteur noted that discrimination on the grounds of disability:

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38 Committee Against Torture, *Consideration of reports submitted by States Parties under article 19 of the Convention, Concluding observations of the Committee against Torture–Peru*, 21 January 2013, pp. 5–6, http://www2.ohchr.org/english/bodies/cat/sessions.htm (accessed 7 May 2013).

39 Committee Against Torture, *Consideration Of Reports Submitted By States Parties Under Article 19 of the Convention: Concluding observations of the Committee against Torture–Australia*, 22 May 2008 http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G08/421/66/PDF/G0842166.pdf?OpenElement (accessed 7 May 2013).

40 Women With Disabilities Australia, *Submission 49*, p. 8.

41 Australian Lawyers for Human Rights, *Submission 41*, p. 5.

42 See, for example, Mr Graeme Innes, Disability Discrimination Commissioner, Australian Human Rights Commission, *Committee Hansard*, 27 March 2013, p. 34.

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

44 Juan E. Mendez, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/22/53, 1 February 2013, p. 2.

45 Juan E. Mendez, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/22/53, 1 February 2013, p. 4.

> is particularly relevant in the context of medical treatment, were serious violations and discrimination...may be defended as 'well intended' on the part of health-care professionals.[46]

3.29 Focusing on situations of powerlessness and denial of legal capacity, the Special Rapporteur concluded:

> medical treatments of an intrusive and irreversible nature, where lacking a therapeutic purpose, may constitute torture or ill-treatment when enforced or administered without the free or informed consent of the person concerned.[47]

3.30 The report specifically warned against giving 'dubious grounds of medical necessity' priority over a person's legal capacity and right to provide, or withhold, free and informed consent.[48] Sterilisations performed for reasons of racial discrimination, 'coercive' family planning policies, and notions that certain persons, such as persons with disabilities, are 'unfit to bear children' were criticised.[49]

3.31 The report concluded that the grounds on which a medical procedure can be performed without a person's free and informed consent should be the same for persons with or without a disability.[50] However, recommendations contained in the report do not include explicit calls for the prohibition of sterilisation without informed consent.

The International Covenant on Civil and Political Rights

3.32 The Australian Human Rights Commission advised that '[t]he Human Rights Committee has also recognised that involuntary or coerced sterilisation of women may breach the prohibition against torture in article 7 of the International Covenant on Civil and Political Rights.'[51] Similarly, WWDA stated that the Human Rights Committee 'has clarified to State parties that forced sterilisation is in contravention of Articles 7, 14, 17 and 24 of the [International Covenant on Civil and Political Rights]'.[52]

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46 Juan E. Mendez, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/22/53, 1 February 2013, p. 5.

47 Juan E. Mendez, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/22/53, 1 February 2013, p. 7.

48 Juan E. Mendez, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/22/53, 1 February 2013, p. 8.

49 Juan E. Mendez, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/22/53, 1 February 2013, p. 11.

50 Juan E. Mendez, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/22/53, 1 February 2013, p. 15.

51 Australian Human Rights Commission, *Submission 5*, p. 6.

52 Women With Disabilities Australia, *Submission 49*, p. 63.

3.33 In support of these statements, the committee was provided with the Human Rights Committee's *General Comment No. 28*, paragraphs 11 and 20. However, the General Comment does not contain an express condemnation of the practice of involuntary or coerced sterilisation. Rather, the text directs States to report on the incidence of sterilisation and other matters:

> 11. To assess compliance with article 7 of the Covenant, as well as with article 24, which mandates special protection for children, the Committee needs to be provided information on national laws and practice with regard to domestic and other types of violence against women, including rape. It also needs to know whether the State party gives access to safe abortion to women who have become pregnant as a result of rape. The States parties should also provide the Committee with information on measures to prevent forced abortion or forced sterilization. In States parties where the practice of genital mutilation exists information on its extent and on measures to eliminate it should be provided. The information provided by States parties on all these issues should include measures of protection, including legal remedies, for women whose rights under article 7 have been violated.[53]

3.34 A similar direction is provided at paragraph 20:

> 20. States parties must provide information to enable the Committee to assess the effect of any laws and practices that may interfere with women's right to enjoy privacy and other rights protected by article 17 on the basis of equality with men. An example of such interference arises where the sexual life of a woman is taken into consideration in deciding the extent of her legal rights and protections, including protection against rape. Another area where States may fail to respect women's privacy relates to their reproductive functions, for example, where there is a requirement for the husband's authorization to make a decision in regard to sterilization; where general requirements are imposed for the sterilization of women, such as having a certain number of children or being of a certain age, or where States impose a legal duty upon doctors and other health personnel to report cases of women who have undergone abortion. In these instances, other rights in the Covenant, such as those of articles 6 and 7, might also be at stake. Women's privacy may also be interfered with by private actors, such as employers who request a pregnancy test before hiring a woman. States parties should report on any laws and public or private actions that interfere with the equal enjoyment by women of the rights under article 17, and on the measures taken to eliminate such interference and to afford women protection from any such interference.[54]

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53 Human Rights Committee, General *Comment No. 28*, paragraph 11, http://www.unhchr.ch/tbs/doc.nsf/0/13b02776122d4838802568b900360e80 (accessed 7 May 2013).

54 Human Rights Committee, General *Comment No. 28*, paragraph 20, http://www.unhchr.ch/tbs/doc.nsf/0/13b02776122d4838802568b900360e80 (accessed 7 May 2013).

3.35 However, the Human Rights Committee has made clear its view on the need for 'free and effective legal representation' in cases concerning a person's legal capacity. The Committee has also noted its concern with the potentially negative consequences of the courts' authority to authorize procedures such as abortion and sterilization for women with disabilities who are considered to be without legal capacity. The committee's recommendation provides clear direction about court procedure in these cases. States are directed to provide free and effective legal representation for cases concerning a person's legal capacity, and to 'take appropriate measures to facilitate legal support to persons with disabilities in all matters impacting on their physical and mental health'.[55]

International Covenant on Economic, Social and Cultural Rights

3.36 The Committee on Economic, Social and Cultural Rights has held that Article 14 of the International Covenant on Economic, Social and Cultural Rights defends a person's right to control one's health and body. This includes the right to sexual and reproductive freedom and the right to be free from interference, which has been defined to include non-consensual medical treatment.[56] Further, the committee has concluded that sterilisation of a woman with disabilities without her prior informed consent is a 'serious violation' of Article 10 of the Convention:

> Women with disabilities also have the right to protection and support in relation to motherhood and pregnancy. As the Standard Rules state, 'persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood'. The needs and desires in question should be recognized and addressed in both the recreational and the procreational contexts. These rights are commonly denied to both men and women with disabilities worldwide. Both the sterilization of, and the performance of an abortion on, a woman with disabilities without her prior informed consent are serious violations of article 10 (2).[57]

Thematic study on the issue of violence against women and girls and disability

3.37 The United Nations' interpretation of international obligations is also found in thematic studies. In its 2012 *Thematic study on the issue of violence against women and girls and disability*, the Human Rights Committee emphasised the importance of obtaining the person's consent prior to performing a sterilisation procedure. As the

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55 Human Rights Committee, *Consideration of reports submitted by States Parties under article 40 of the Covenant, Concluding observations adopted by the Human Rights Committee at its 150 session, 9–27 July 2012–Lithuania*, p. 4, http://www2.ohchr.org/english/bodies/hrc/hrcs105.htm (accessed 7 May 2013).

56 United Nations, Committee on Economic Social and Cultural Rights, *General Comment No. 14 (2000)*, http://www.unhchr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En (accessed 8 April 2013).

57 United Nations, Committee on Economic Social and Cultural Rights, *General Comment No. 5*, http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/4b0c449a9ab4ff72c12563ed0054f17d?Opendocument (accessed 8 April 2013).

Committee noted, 'consent to treatment is one of the most important human rights issues relating to mental disability'. Accordingly, States are obligated to ensure that 'procedural safeguards protecting the right to informed consent are both watertight and strictly applied'.[58] These safeguards extend to children. The Human Rights Committee has directed States Parties to facilitate the genuine participation of children in processes affecting their development.[59] Further, the Committee has cast doubt on the use of 'best interests' tests, advising that 'international human rights standards…prohibit the coerced treatment of people suffering from intellectual disabilities, regardless of arguments of their "best interests"'.[60]

The federal framework

3.38 Australia gives effect to its international treaty obligations through, federal, state and territory legislation. As noted in Article 28 of the International Covenant on Civil and Political Rights, human rights obligations in the Covenant are binding on Australia as a whole. Accordingly, the obligations must be given effect to at the Commonwealth and State and Territory levels.

3.39 In keeping with Australia's federal system of government, the Commonwealth government has recognised that the implementation of treaty provisions will be affected by constitutional powers and governing arrangements throughout all Australian jurisdictions. Express declarations to this effect are attached to Australia's ratification of the International Covenant on Civil and Political Rights, and the Convention on the Elimination of All Forms of Discrimination against Women:

> Australia has a federal constitutional system in which legislative, executive and judicial powers are shared or distributed between the Commonwealth and the constituent states. Implementation of the treaty throughout Australia will be affected by the Commonwealth, State and Territory authorities having regard to their respective constitutional powers and arrangements concerning their exercise.[61]

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58 Office of the United Nations High Commissioner for Human Rights, *Thematic study on the issue of violence against women and girls and disability: Report of the Office of the United National High Commissioner for Human Rights*, A/HRC/20/5, 30 March 2012, pp.10–11.

59 Office of the United Nations High Commissioner for Human Rights, *Thematic study on the issue of violence against women and girls and disability: Report of the Office of the United National High Commissioner for Human Rights*, A/HRC/20/5, 30 March 2012, p. 11.

60 Office of the United Nations High Commissioner for Human Rights, *Thematic study on the issue of violence against women and girls and disability: Report of the Office of the United National High Commissioner for Human Rights*, A/HRC/20/5, 30 March 2012, p. 10.

61 UN Treaty Collection, International Covenant on Civil and Political Rights, http://treaties.un.org/pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-4&chapter=4&lang=en#EndDec (accessed for July 2013).

Commonwealth

3.40 The Commonwealth's jurisdiction in child sterilisation cases was confirmed by the High Court of Australia in the 1992 case *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (1992) 66 ALJR 300 (*Re Marion*). The High Court held that decisions about the non–therapeutic sterilisation of children fall outside of the scope of parental authority.[62] Court authorisation is required.

3.41 The High Court identified two reasons for the finding that parents are unable to validly consent to the non-therapeutic sterilisation of their child:

> Court authorisation is required, first, because of the significant risk of making the wrong decision, either as to a child's present or future capacity to consent or about what are the best interests of a child who cannot consent, and secondly, because the consequences of a wrong decision are particularly grave.[63]

3.42 In commenting upon the consequences of a 'wrong decision', the High Court noted that:

> [t]he gravity of the consequences of wrongly authorising a sterilisation flows both from the resulting inability to reproduce and from the fact of being acted upon contrary to one's wishes or best interests. The fact of violation is likely to have social and psychological implications concerning the person's sense of identity, social place and self-esteem.[64]

3.43 The High Court confirmed that the Family Court of Australia's (Family Court) child welfare jurisdiction under section 67ZC of the *Family Law Act 1975* (Family Law Act) empowers the court to make orders for the sterilisation of a child. Before making an order, the Family Court must be satisfied that two conditions are met. First, the sterilisation is, in the circumstances of the particular case, in the child's best interests.[65] Second, alternative and less invasive procedures have failed or it is certain that no other procedure or treatment will work.[66]

3.44 The High Court concluded that '[i]n the circumstances with which we are concerned, the best interests of the child will ordinarily coincide with the wishes of

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62 The meaning of therapeutic and non-therapeutic sterilisation is considered in the previous chapter.

63 Mason C.J., Dawson, Toohey and Gaudron JJ, *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (1992) 66 ALJR 300 (*Re Marion*), at 49.

64 Mason C.J., Dawson, Toohey and Gaudron JJ, *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (1992) 66 ALJR 300 (*Re Marion*), at 51.

65 Mason C.J., Dawson, Toohey and Gaudron JJ, *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (1992) 66 ALJR 300 (*Re Marion*), at 73; *Family Law Act 1975*, ss. 67ZC(2).

66 Mason C.J., Dawson, Toohey and Gaudron JJ, *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (1992) 66 ALJR 300 (*Re Marion*), at 74.

the parents'.[67] However, it was also noted that whether sterilisation is in the child's best interests is a matter to be determined according to the circumstances of each case.[68]

The best interests test

3.45 As noted in section 67ZC, sections 60CB to 60CG of the Family Law Act detail how the court is to determine the child's best interests. In addition, the Family Court has developed rules to assist the adjudication of applications for special medical procedures. These rules can be found in case law and the *Family Law Rules 2004* (Family Law Rules).

3.46 In the 1994 case *Re Marion (No. 2)* (1994) FLC 92-448, the Family Court endorsed consideration of the following factors to determine whether the procedure would be in the child's best interests:

- the particular condition of the child which requires the procedure or treatment;
- the nature of the procedure or treatment proposed;
- the reasons for which it is proposed that the procedure or treatment be carried out;
- the alternative courses of treatment available in relation to the condition;
- the desirability and effect of authorising the procedure or treatment proposed rather than available alternatives;
- the physical effects on the child and the psychological and social implications for the child of authorising or not authorising the proposed procedure or treatment;
- the nature and degree of any risk to the child of authorising or not authorising the proposed procedure or treatment; and
- the views expressed by the guardians of the child, a person who is entitled to the custody of the child, the person who is responsible for the daily care and control of the child, and the child.

3.47 Division 4.2.3 of the Family Law Rules imposes additional requirements for the conduct of proceedings for applications for 'special medical procedures', defined to include sterilisation procedures. The rules require applications for special medical procedures to include evidence from a medical, psychological or other relevant expert witness about the nature and purpose of the proposed medical procedure, the particular condition of the child, and the likely long-term physical, social and

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67 Mason C.J., Dawson, Toohey and Gaudron JJ, *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (1992) 66 ALJR 300 (*Re Marion*), at 76.

68 Mason C.J., Dawson, Toohey and Gaudron JJ, *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (1992) 66 ALJR 300 (*Re Marion*), at 73.

psychological effects on the child if the procedure is, or is not, carried out. In addition, expert evidence must establish:

- the nature and degree of any risk to the child from the procedure;
- the reason the procedure is recommended instead of any available alternative and less invasive treatments;
- that the procedure is necessary for the welfare of the child;
- whether the child agrees to the procedure– if the child is capable of making an informed decision about the procedure;
- if the child is incapable of making an informed decision about the procedure– that the child is currently incapable of making an informed decision and is unlikely to develop sufficiently to be able to make an informed decision within the time in which the procedure should be carried out, or within the foreseeable future; and
- whether the child's parents or carer agree to the procedure.[69]

3.48 The Family Court may appoint an independent children's lawyer (an ICL).[70] An ICL does not act on the child's instructions and is not the child's legal representative. Rather, an ICL is required to form an independent view of what is in the best interests of the child. An ICL must ensure that any views expressed by the child are fully put before the court.[71] An ICL's costs are paid by the Commonwealth rather than the child's family. This issue is considered further in chapter 5.

Concurrent jurisdiction

3.49 The Family Court's jurisdiction exists concurrent with State and Territory legislation. That is, where State and Territory legislation regulates the involuntary or coerced sterilisation of children, the Family Court's jurisdiction continues to operate. Parents or guardians may seek orders in either jurisdiction.

3.50 Commenting in 1994, the Family Law Council summarised the effect of this concurrent jurisdiction. The Council noted that State and Territory tribunals or courts are unable to hear cases where the Family Court has already adjudicated the matter.[72] Further concerns around the operation and expertise of the Family Court in child sterilisation cases are discussed in chapter 6. The committee has seriously considered the question of whether it is appropriate for the Family Court to continue hearing child sterilisation cases. At present, the committee concludes that it would not be appropriate for the jurisdiction to be removed. As the Commonwealth court, the

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69 *Family Law Rules 2004*, r. 4.09.

70 *Family Law Act 1975*, s. 68L.

71 *Family Law Act 1975*, s. 68LA.

72 Family Law Council, *Sterilisation and other medical procedures of children*, November 1994, paragraph 3.30; *P v P* (1994) 120 ALR 545.

Family Court provides consistency for all Australian children regardless of where they live. It is the one court where the child residing in, for example, the Australian Capital Territory will be treated in the same way as a child living in, for example, Victoria. Accordingly, Family Court decisions can act as a benchmark for consistency and uniformity for all Australian children.

3.51 As the committee will discuss, it is concerned that this uniformity and consistency is lacking in State and Territory jurisdictions. Given the current inconsistency throughout the State and Territory legislation, the committee is concerned that were the Family Court's jurisdiction to be removed, protections of the child will depend on where the child lives. The committee is particularly concerned about the rights of children in jurisdictions which have not legislated to regulate child sterilisation cases.

State and Territory

3.52 Additional regulatory requirements in relation to sterilisation exist at the State and Territory level. Each State and Territory has the autonomy to determine its own rules and legislative frameworks. Accordingly, the requirements can differ across jurisdictions. Furthermore, State and Territory requirements for the sterilisation of adults with disabilities can differ from the requirements that apply to the sterilisation of children.

3.53 In addition to the legislative provisions, which are outlined below, the states and territories have adopted the *Protocol for Special Medical Procedures (Sterilisation)*. Developed in May 2009 by the Australian Guardianship and Administration Council (AGAC), the protocol has been endorsed by AGAC members, which include State and Territory guardianship Tribunals, Public Guardians, Adult Guardians and Public Advocates.[73] The protocol, which applies to both cases involving adult disabilities and cases involving children, is intended to promote consistency in like sterilisation cases regardless of the jurisdiction in which the case is heard.[74] Its objectives also include:

- promoting, enhancing, and protecting the best interests of the person;
- ensuring clarification of, and delineation between, what is in the best interests of the person and what is in the interests of person's caregivers;
- promoting positive outcomes for the person;
- providing the people involved an opportunity to raise and discuss all relevant issues; and

73 Australian Guardianship and Administration Council, *Submission 28*, p. 1.

74 Australian Guardianship and Administration Council, *Submission 28*, Attachment 1, *Protocol for Special Medical Procedures (Sterilisation)*, cl. 3.2.

- ensuring that sterilisation is a last resort, having tried or considered alternative and less invasive procedures.[75]

3.54 AGAC advised that it considers the protocol to be consistent with Article 23 of the *Convention on the Rights of Persons with Disabilities*.[76]

3.55 The following outlines of State and Territory regulatory frameworks are based on the legislation operative in each jurisdiction. Further details about the protocol are provided in chapter 5.

Australian Capital Territory

Child

3.56 The Australian Capital Territory (ACT) has not expressly conferred jurisdiction to hear child sterilisation cases on any ACT court or tribunal. In the ACT, families may only apply to the Family Court.

Adult

3.57 Part 5 of the *Guardianship and Management of Property Act 1991* authorises the ACT Civil and Administrative Tribunal to make orders to authorise prescribed medical procedures in certain circumstances. The Tribunal's authority applies in circumstances where a guardian has been appointed,[77] following the decision by the Tribunal that the person has impaired decision making ability for matters affecting the person's health or welfare.[78] A parent may be appointed the person's guardian. A person is taken to have impaired decision-making ability if their decision-making ability is impaired due to physical, mental, psychological or intellectual condition or state. A person may be found to have impaired decision-making ability even if the condition or state is not a diagnosable illness.[79]

3.58 'Prescribed medical procedure' is defined to include reproductive sterilisation, hysterectomies, and medical procedures concerned with contraception.[80] The Tribunal may make an order consenting to the prescribed medical procedure if satisfied that the treatment would be in the person's best interests. To determine this, the Tribunal must take into account the person's wishes, insofar as they can be ascertained, the likely consequences were the procedure not carried out, the availability of alternative treatments and whether the treatment can be postponed because better treatments may

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75 Australian Guardianship and Administration Council, *Submission 28*, Attachment 1, *Protocol for Special Medical Procedures (Sterilisation)*, cl. 3.2.

76 Australian Guardianship and Administration Council, *Submission 28*, p. 5.

77 *Guardianship and Management of Property Act 1991*, s. 69.

78 *Guardianship and Management of Property Act 1991*, s. 7.

79 *Guardianship and Management of Property Act 1991*, s. 5.

80 *Guardianship and Management of Property Act 1991*, Dictionary.

become available.[81] The Tribunal must appoint the person's guardian, the public advocate or some other independent person as the person's representative.[82]

3.59 If a person purports to provide consent to medical treatment but is not authorised to do so, the medical practitioner does not commit an offence if he or she acted in good faith and did not know, or could not reasonably be expected to know, that the person did not have authority to provide consent.[83]

New South Wales

Child

3.60 In New South Wales, the sterilisation of children aged no more than 16 years is governed by section 175 of the *Children and Young Persons (Care and Protection) Act 1998*. The Act authorises the Guardianship Tribunal to consent to 'special medical treatment' for children in certain circumstances. 'Special medical treatment' is defined to include any medical treatment that:

- is intended to, or is reasonably likely to have the effect of, rendering the person permanently infertile;
- is conducted for the purpose of contraception or menstrual regulation, if such treatments have been declared by the regulations to be a special medical treatment; or
- is in the nature of a vasectomy or tubal occlusion.[84]

3.61 The Guardianship Tribunal must not consent to treatment unless satisfied that it is necessary to save the child's life or to prevent serious damage to the child's psychological or physical health.[85] For these proceedings, a child has a right to legal representation.[86] However, the legislation does not direct the Guardianship Tribunal to consider whether the child is capable of consenting to the treatment.[87]

3.62 It is an offence subject to a maximum penalty of imprisonment for seven years for a person to carry out special medical treatment without Tribunal authorisation. That is, a medical practitioner does not commit an offence if, in his or her opinion, the special medical procedure is necessary, as a matter of urgency, to save the child's life or to prevent serious damage to the child's health.[88] In addition, it

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81 *Guardianship and Management of Property Act 1991*, ss. 70(3).

82 *Guardianship and Management of Property Act 1991*, ss. 70(2).

83 *Guardianship and Management of Property Act 1991*, s. 69.

84 *Children and Young Persons (Care and Protection) Act 1998*, ss. 175(5).

85 *Children and Young Persons (Care and Protection) Act 1998*, ss. 175(3).

86 *Children and Young Persons (Care and Protection) Act 1998*, ss. 175(4).

87 New South Wales Government, *Submission 66*, p. 3.

88 *Children and Young Persons (Care and Protection) Act 1998*, ss. 175(1).

is not an offence to conduct life-saving medical treatment even where infertility is an 'unwanted consequence'.[89]

Adult

3.63 Part 5 of the *Guardianship Act 1987* authorises the Guardianship Tribunal to provide consent to 'special (medical) treatment' for persons who are 16 years of age or older and who are incapable of consenting to medical treatment.[90] A person is considered to be incapable of giving consent to the medical procedure if he or she is incapable of understanding the general nature and effect of the proposed treatment, or is incapable of indicating whether or not he or she consents or does not consent to the treatment.[91]

3.64 'Special treatment' is defined to include any treatment that is intended, or is reasonably likely, to have the effect of rendering permanently infertile the person on whom it is carried out.[92] The Tribunal must not give consent unless satisfied that the treatment is necessary to save the patient's life or to prevent serious damage to the patient's health.[93]

3.65 A person who carries out special medical treatment without Tribunal authorisation commits an offence subject to a maximum penalty of imprisonment for seven years.[94]

Northern Territory

Child

3.66 In the absence of express legislation, the Family Court's child welfare jurisdiction under the Family Law Act applies to non-therapeutic sterilisation.[95] However, a child capable of providing consent may consent to therapeutic sterilisation. Where a child is incapable of giving valid consent, for example due to intellectual disability or immaturity, the child's parents or guardians may consent to the child's therapeutic sterilisation.[96]

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89 *Children and Young Persons (Care and Protection) Act 1998*, ss. 175(5); New South Wales Government, *Submission 66*, p. 3.

90 *Guardianship Act 1987*, s. 34.

91 *Guardianship Act 1987*, s. 33.

92 *Guardianship Act 1987*, s. 33.

93 *Guardianship Act 1987*, s. 45.

94 *Guardianship Act 1987*, s. 35.

95 Northern Territory Government, *Submission 34*, p. 3.

96 Northern Territory Government, *Submission 34*, p. 2.

3.67 It is an offence subject to a maximum of 85 penalty units to perform sterilisation as a treatment for mental illness, mental disturbance or complex cognitive impairment such as behavioural disturbance.[97]

Adult

3.68 The *Adult Guardianship Act* authorises the local courts to make orders consenting to major medical procedures for adults for whom a guardianship order is in effect and adults who, due to an intellectual disability, lack decision making capacity.[98] Intellectual disability is defined as 'a disability in an adult resulting from an illness, injury, congenital disorder or organic deterioration by reason of which the person appears to be unable to make reasonable judgments or informed decisions relevant to daily living'.[99] Decisions of local courts may be appealed to the Supreme Court of the Northern Territory.[100]

3.69 'Major medical procedure' is defined to include procedures that relate to contraception. However, procedures that remove an immediate threat to a person's health are not considered to be major medical procedures for which court authorisation is required.[101] A court may make an order authorising the proposed major medical procedure if satisfied that the procedure would be in the best interests of the person.[102] In exercising its authority, the court is to have regard to the requirement in section 4 of the Act for decisions to:

- be the least restrictive of a represented person's freedom of decision and action as is possible in the circumstances;
- promote the best interests of the represented person; and
- give effect to the person's wishes where possible.

3.70 A court must ascertain the wishes of the person as far as reasonably possible, and give effect to the person's wishes if satisfied that the person understands the nature of the proposed procedure and is capable of giving or refusing consent.[103]

3.71 Proceedings for professional misconduct may be taken against a medical practitioner who performs a major medical procedure without court authorisation.[104]

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97 *Mental Health and Related Services Act*, s. 60.

98 *Adult Guardianship Act*, s. 21.

99 *Adult Guardianship Act*, s. 3.

100 Northern Territory Government, *Submission 34*, p. 1.

101 *Adult Guardianship Act*, s. 21.

102 *Adult Guardianship Act*, s. 21.

103 *Adult Guardianship Act*, s. 21.

104 *Adult Guardianship Act*, ss. 21(2) Note.

Queensland

Child

3.72 In Queensland, the sterilisation of certain children is governed by Chapter 5A of the *Guardianship and Administration Act 2000*. The Act applies only to individuals under 18 years with a cognitive, intellectual, neurological or psychiatric impairment (the legislation uses the term 'child with an impairment'). As the Adult Guardian of Queensland and the Public Advocate of Queensland advised, the Queensland Civil and Administrative Tribunal does not have authority to hear applications for the sterilisation of children without 'an impairment'.[105]

3.73 The legislation authorises the tribunal to order the sterilisation of a child with an impairment in certain circumstances. Sterilisation is defined as a procedure that would make permanently infertile a child who is, or who is likely to be, fertile. Examples specified in the Act include hysterectomy and vasectomy. However, sterilisation is expressly defined to not include sterilisation that occurs as a consequence of a medical procedure that is necessary to prevent serious or irreversible damage to a child's physical health. The legislation provides the following example:

> If the child has cancer affecting the reproductive system and, without the health care, the cancer is likely to cause serious or irreversible damage to the child's physical health, the health care is not sterilisation.[106]

3.74 The Tribunal may only make a child sterilisation order if the order is in the child's best interests.[107] The Act contains criteria that must be satisfied for the sterilisation to be considered in the child's best interests. The criteria focus on the medical and social needs of the child, and whether the child's impaired capacity to consent is likely to continue into adulthood.[108] They also require that, unless the sterilisation is 'medically necessary', it can only be conducted if postponement would be unreasonable and if either:

> the child is, or is likely to be, sexually active and there is no method of contraception that could reasonably be expected to be successfully applied; [or]
>
> if the child is female—the child has problems with menstruation and cessation of menstruation by sterilisation is the only practicable way of overcoming the problems.[109]

105 Adults Guardian of Queensland and the Public Advocate of Queensland, *Submission 19*, p. 3.

106 *Guardianship and Administration Act 2000*, s. 80B (Example).

107 *Guardianship and Administration Act 2000*, s. 80C.

108 *Guardianship and Administration Act 2000*, ss. 80D(1).

109 *Guardianship and Administration Act 2000*, ss. 80D(1).

3.75 Sterilisation will automatically be taken to not be in the best interests of the child if it is proposed for eugenic reasons or to remove the risk of pregnancy resulting from sexual abuse.[110]

3.76 The Tribunal is required to take into account the child's views in a manner appropriate for the child, for example orally, in writing, or by conduct.[111] The Tribunal must appoint a child representative to act in the child's best interests and, to the greatest extent practicable, represent the child's views and wishes.

Adult

3.77 Chapter 5, Part 3 of the *Guardianship and Administration Act 2000* authorises the Queensland Civil and Administrative Tribunal to consent to the sterilisation of an adult with 'impaired capacity'.[112] A person is taken to have impaired capacity if he or she does not have 'capacity for the matter'. In determining whether a person has capacity, the Tribunal considers whether the person:

- is capable of understanding the nature and effect of decisions about the matter;
- can freely and voluntarily make decisions about the matter; and
- can communicate their decisions in some way.[113]

3.78 'Sterilisation' is defined as 'health care of an adult who is, or is reasonably likely to be, fertile that is intended, or reasonably likely, to make the adult, or ensure the adult is, permanently infertile'. The Act lists endometrial oblation, hysterectomy, tubal ligation and vasectomy as examples of sterilisation. Sterilisation is expressly defined not to include medical procedures that are primarily to treat organic malfunction or disease.[114]

3.79 The Tribunal may only make a sterilisation order if satisfied that:

- the sterilisation is medically necessary;
- the person is, or is likely to be, sexually active;
- there is no method of contraception that could reasonably be expected to be successfully applied; and

110 *Guardianship and Administration Act 2000*, ss. 80D(2).

111 *Guardianship and Administration Act 2000*, ss. 80D(4).

112 *Guardianship and Administration Act 2000*, s. 70.

113 *Guardianship and Administration Act 2000*, Schedule 4.

114 *Guardianship and Administration Act 2000*, s. 9.

- for women, there are problems with menstruation for which cessation of menstruation by sterilisation is the only practicable way of overcoming these problems.[115]

3.80 The Act specifies that sterilisation is taken to not be medically necessary if it is for eugenic reasons or to remove the risk of pregnancy resulting from sexual abuse.[116] The Tribunal must also consider whether other forms of health care are available or are likely to become available in the future, and the nature and extent of the short term and long term significant risks associated with the proposed procedure and alternative forms of health care.[117]

3.81 All active parties to proceedings have a right to appear before the Tribunal in person.[118] 'Active party' is defined to include the person who would be the subject of the proposed sterilisation order.[119]

South Australia

Child

3.82 South Australia's *Guardianship and Administration Act 1993* applies without regard to age, and therefore the arrangements for adults, described below, may also apply to children. In practice, it is understood child applications are very rare. Families may also apply to the Family Court.[120]

Adult

3.83 The *Guardianship and Administration Act 1993* authorises the Guardianship Board of South Australia to make sterilisation orders for persons who are the subject of a guardianship order under the Act.[121] A guardianship order may be made if the Board is satisfied that the person subject to the application has a mental incapacity.[122] 'Mental incapacity' is defined as an inability to look after personal health, safety or welfare or to manage personal affairs, because of damage to, or any illness, disorder, imperfect or delayed development, impairment or deterioration of, the brain or mind;

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115 *Guardianship and Administration Act 2000*, ss. 70(1).

116 *Guardianship and Administration Act 2000*, ss. 70(2).

117 *Guardianship and Administration Act 2000*, ss. 70(3).

118 *Guardianship and Administration Act 2000*, s. 103.

119 *Guardianship and Administration Act 2000*, s. 123.

120 Office of the Public Advocate, *Prescribed medical treatment*, http://www.opa.sa.gov.au/documents/10_Fact_Sheets/10-Prescribed_Medical_Treatment_GAA.pdf (accessed 15 July 2013).

121 *Guardianship and Administration Act 1993*, s. 61.

122 *Guardianship and Administration Act 1993*, s. 29.

or any physical illness or condition that renders the person unable to communicate his or her intentions or wishes in any manner whatsoever.[123]

3.84 Sterilisation is defined as 'any treatment given to a person that results in, or is likely to result in, the person being infertile'.[124] The Board may make a sterilisation order if satisfied that sterilisation is therapeutically necessary. Alternatively, the Board may make a sterilisation order if satisfied that:

- the Board has no knowledge of any refusal on the part of the person to consent to the carrying out of the sterilisation, being a refusal that was made by the person while capable of giving effective consent and that was communicated by the person to a medical practitioner;
- there is no likelihood of the person acquiring at any time the capacity to give an effective consent;
- the person is physically capable of procreation; and
- the person is, or is likely to be, sexually active, and there is no method of contraception that could, in all the circumstances, reasonably be expected to be successfully applied; or in the case of a woman, cessation of her menstrual cycle would be in her best interests and would be the only reasonably practicable way of dealing with the social, sanitary or other problems associated with her menstruation.[125]

3.85 If reasonably practical, in the person's best interests and in the Board's view appropriate, the Board must hear from the person's parents prior to making an order.[126]

3.86 Except in circumstances of emergency medical treatment, as defined by the *Consent to Medical Treatment and Palliative Care Act 1995*, a medical practitioner commits an offence subject to $10 000 fine or imprisonment for up to two years if performing a sterilisation without the Board's consent.[127]

Tasmania

Child

3.87 In Tasmania, the *Guardianship and Administration Act 1995* authorises the Guardianship and Administration Board to make orders for the 'special (medical) treatment' of persons with a disability who are incapable of giving consent to medical treatment. A person is taken to be unable to provide consent if he or she is incapable

123 *Guardianship and Administration Act 1993*, s. 3.

124 *Guardianship and Administration Act 1993*, s. 3.

125 *Guardianship and Administration Act 1993*, s. 61.

126 *Guardianship and Administration Act 1993*, s. 61.

127 *Guardianship and Administration Act 1993*, s. 61.

of understanding the general nature and effect of the proposed treatment or is incapable of indicating whether or not he or she consents or does not consent to the carrying out of the treatment.[128] The Board's jurisdiction extends to children with disabilities.[129]

3.88 'Special treatment' is defined to include any treatment that is intended, or is reasonably likely, to have the effect of rendering permanently infertile the person on whom it is carried out.[130] The Board may consent to special treatment if the treatment is otherwise lawful and in the best interests of the person.[131] To determine the best interests of the person, the Board is to consider the person's wishes, so far as they can be ascertained, the consequences to the person if the treatment is not carried out, any alternative treatments available, whether the proposed treatment can be postponed on the ground that better treatment may become available and whether that person is likely to become capable of consenting to the treatment.[132] Applicants for special treatment orders must supply a written Health Care Professional Report provided by a medical practitioner or psychologist detailing the person's decision making capacity.[133]

3.89 A person who carries out unauthorised special treatment commits an offence liable to imprisonment for a period not exceeding one year or to a fine not exceeding 10 penalty units or both.[134] However, it is not an offence to carry out special medical treatment if the medical practitioner considers that, as a matter of urgency, the treatment is necessary to save the person's life or to prevent serious damage to person's health.[135] It is also an offence to purport to give consent to special medical treatment. A person who gives unlawful consent to treatment is guilty of an offence subject to a fine not exceeding 20 penalty units.[136]

3.90 More broadly, the Family Court's child welfare jurisdiction under the Family Law Act applies to applications for the sterilisation of children without disabilities,[137] and exists concurrent with Tasmania's jurisdiction over children with disabilities.[138]

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128 *Guardianship and Administration Act 1995*, s. 36.

129 Tasmanian Government, *Submission 57*, p. 2.

130 *Guardianship and Administration Act 1995*, s. 3.

131 *Guardianship and Administration Act 1995*, s. 45.

132 *Guardianship and Administration Act 1995*, ss. 45(2).

133 Tasmanian Government, *Submission 57*, p. 3.

134 *Guardianship and Administration Act 1995*, s. 38.

135 *Guardianship and Administration Act 1995*, s. 40.

136 *Guardianship and Administration Act 1995*, s. 42.

137 Tasmanian Government, *Submission 57*, p. 2.

138 *P v P* (1994) 120 ALR 545.

Adult

3.91 The legislative requirements applying to orders of the sterilisation of children with disabilities also applies to orders for the sterilisation of adults with disabilities.

Victoria

Child

3.92 Victoria has not expressly conferred jurisdiction to hear child sterilisation cases on any Victorian court or tribunal. Families may only apply to the Family Court.

Adult

3.93 The *Guardianship and Administration Act 1986* authorises the Victorian Civil and Administrative Tribunal to make an order giving consent to special (medical) treatment for persons 18 years of age or older who are incapable of consenting to the proposed treatment.[139] A person is considered to be incapable of providing consent if he or she is incapable of understanding the general nature and effect of the proposed procedure or treatment, or is incapable of indicating whether or not he or she consents or does not consent to the carrying out of the proposed procedure or treatment.[140]

3.94 'Special procedure' is defined to include any procedure that is intended, or is reasonably likely, to have the effect of rendering a person permanently infertile.[141] The Tribunal may consent to the carrying out of a special procedure only if satisfied that the person is incapable of giving consent and is not likely to be capable, within a reasonable time, of giving consent; and the special procedure would be in the person's best interests.[142] To determine whether the special procedure would be in a person's best interests, the Tribunal is to consider the following:

- the person's wishes, so far as they can be ascertained;
- the wishes of any nearest relative or any other family members of the patient;
- the consequences to the person if treatment is not carried out;
- any alternative treatment available;
- the nature and degree of any significant risks associated with the treatment or any alternative treatment; and
- whether the treatment to be carried out is only to promote and maintain the person's health and well-being.

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139 *Guardianship and Administration Act 1986*, s. 36, s. 39.

140 *Guardianship and Administration Act 1986*, s. 36.

141 *Guardianship and Administration Act 1986*, s. 3.

142 *Guardianship and Administration Act 1986*, s. 42E.

3.95 It is an offence subject to imprisonment for two years or a fine of 240 penalty units or both for a registered practitioner to conduct a special procedure without Tribunal consent.[143] However, it is not an offence, or professional misconduct, for the registered practitioner to act in response to a medical emergency or in good faith reasonably believing that consent had been obtained.[144] It is also an offence to purport to give consent to special medical treatment. A person who gives consent to treatment knowing that he or she is not authorised to do so is guilty of an offence subject to a fine not exceeding 20 penalty units.[145]

Western Australia

Child

3.96 The Family Court of Western Australia exercises both Commonwealth and Western Australian jurisdiction. If the parties to the court proceedings are, or were, married and the child resides in Western Australia, the Family Court of Western Australia applies the provisions in the Family Law Act. Accordingly, the Family Court of Western Australia has the authority to adjudicate sterilisation cases under section 67ZC of the Family Law Act.

3.97 For the children of de facto couples, the Family Court of Western Australia has authority to make sterilisation orders under section 162 of the *Family Court Act 1997*. Section 162 mirrors section 67ZC of the Family Law Act.

Adult

3.98 The *Guardianship and Administration Act 1990* authorises the Full Tribunal of the State Administrative Tribunal to consent, or to withhold consent, to the sterilisation of a person subject to a guardianship order under the Act.[146] A guardianship order may be made for persons 18 years of age or older who are incapable of looking after their own health and safety, unable to make reasonable judgements, is in need of oversight, care or control in the interests of their health and safety or the protections of others, and who are considered to be in need of a guardian.[147]

3.99 For sterilisation procedures to be lawfully conducted, both the Tribunal and the guardian must consent.[148] The Act expressly states that a guardian cannot validly

143 *Guardianship and Administration Act 1986*, s. 42G.

144 *Guardianship and Administration Act 1986*, s. 42A.

145 *Guardianship and Administration Act 1986*, s. 42.

146 *Guardianship and Administration Act 1990*, s. 13, s. 56A.

147 *Guardianship and Administration Act 1990*, s. 43.

148 *Guardianship and Administration Act 1990*, s. 57.

consent to the proposed sterilisation unless the Tribunal's consent has first been obtained.[149]

3.100 Sterilisation does not include lawful procedures that incidentally result, or may result, in sterilisation.[150] The definition of sterilisation adopted under the Act also does not include treatment such as oral contraception. [151]As correspondence from the Western Australian State Administrative Tribunal noted, this narrow definition of sterilisation has the effect that 'some sterilisation procedures do not require specific application'.[152] Accordingly, in Western Australia the circumstances in which sterilisation may occur without court authorisation are broader than what may exist in other states and territories. As the Tribunal advised:

> Unlike legislation, such as in New South Wales, which focuses on the effect of the proposed treatment, section 56 of the *Guardianship and Administration Act 1990* focuses on the purpose of the procedures. A procedure that incidentally results or may result in sterilisation is specifically excluded. Treatment which is not for the purpose of sterilisation, even if it results in sterilisation, it is not required the consent of the Tribunal.[153]

3.101 The Tribunal may only make a sterilisation order if satisfied that sterilisation is in the person's best interests.[154]

3.102 Prior to conducting a hearing to determine whether to make a sterilisation order, the Tribunal must provide at least seven days' notice to the Public Advocate and any other person who, in the Tribunal's opinion, has sufficient interest in the proceedings.[155]

Conclusion

3.103 As a signatory to numerous relevant international treaties, Australia's regulation of the sterilisation of persons with disabilities cannot be viewed in isolation. Australian law and practice must be viewed through the lens of international policy and legal requirements. The committee received extensive information about the international legal framework, and it extends its thanks to submitters for the

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149 *Guardianship and Administration Act 1990*, s. 45, s. 58.

150 *Guardianship and Administration Act 1990*, s. 56.

151 Correspondence received from the State Administrative Tribunal Western Australia, 2 May 2013, p. 1.

152 Correspondence received from the State Administrative Tribunal Western Australia, 2 May 2013, p. 1.

153 Correspondence received from the State Administrative Tribunal Western Australia, 2 May 2013, p. 1.

154 *Guardianship and Administration Act 1990*, s. 63.

155 *Guardianship and Administration Act 1990*, s. 60.

comprehensive material provided. Further analysis revealed that not all the information cited, in particular United Nations committee comments, was directly relevant, and some, while expressing opinion, is not legally binding. However, all information is of value in identifying the tenor of international community views and determining international best practice. The implications of international law for Australian policy and practice are the subject of chapter 4.

3.104 Domestically, it is evident that Australia has a multilayered and multifaceted approach to the regulation of the sterilisation of persons with disabilities. Differences abound and affect fundamental matters such as the kinds of procedures that require court or tribunal authorisation, the factors used to determine whether a sterilisation procedure may be authorised, and ease of access to legal representation and participation in the proceedings. There are even differences in defining for whom a court or tribunal order is required before that person may access a sterilisation procedure. Subsequent chapters will examine some of these differences, and consider whether any of the laws and practices that regulate the sterilisation of persons with disabilities in Australia provide an adequate safety net for the protection of fundamental individual human rights.

Chapter 4

Should sterilisation of people with disability be banned?

4.1 There was a strong, clear and consistent theme across the evidence to the inquiry that the regulation of the sterilisation of persons with disabilities is a human rights issue. This view was held by individuals, academics and members of the medical professions, as well as by disability advocates. However, views differed as to the scope and effect of relevant human rights principles. Some argued forcefully that international law is clear – it requires Australia to prohibit the sterilisation of children and of adults without their free and informed consent. Conversely, it was just as emphatically argued that the right to dignity and to quality of life necessitates a case-by-case approach that would be violated by any blanket prohibition on sterilisation without consent.

Arguments for the prohibition of the sterilisation of children, and the sterilisation of adults without their free and informed consent

4.2 The coerced or involuntary sterilisation of persons with disabilities, it was argued, contravenes immutable human rights as protected by, and enshrined in, international law.

Prohibited under international law

4.3 The committee was advised that international law prohibits the sterilisation of children and the sterilisation of adults without their free and informed consent.[1] The involuntary or coerced sterilisation of persons with disabilities, it was argued, is an 'egregious form of human rights abuse'.[2] Citing the views of United Nations committees, Women's Legal Service NSW concluded that 'involuntary or coercive sterilisation of people with disabilities falls within the definition of physical violence under international law'.[3] Similarly, Women With Disabilities Australia (WWDA) submitted that sterilisation in the absence of the person's free and informed consent is a clear violation of Australia's obligations under international law:

> Forced sterilisation breaches every international human rights treaty to which Australia is a party. Legal authorisation of forced sterilisation procedures directly implicate the Australian Government in the perpetration of torture against disabled women and girls. Any law which authorises forced sterilisation is a law which authorises violence against women, the consequence of which is severe pain and suffering, including 'drastic and emotionally painful consequences that are un-ending'.[4]

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1 See, for example, STAR, *Submission 42*, p. 1.

2 People with Disability Australia, *Submission 50*, p. 5.

3 Women's Legal Service NSW, *Submission 70*, p. 4.

4 Women With Disabilities Australia, *Submission 49*, p. 8.

4.4 As WWDA's submission indicates, some submitters held that Australian governments have been, and continue to be, complicit in apparent violations of the rights of persons with disabilities. In support of this view, submitters noted comments by United Nations' committees about relevant laws, policies and practices in Australia. As Women's Legal Service NSW stated:

> [I]t is important that the Inquiry recognise that Australia has come under considerable scrutiny from both the UN Special Procedures and Committees in relation to its current position on sterilisation of women and girls with disabilities.[5]

4.5 Three United Nations' committee reports were frequently quoted. First, Australian Lawyers for Human Rights, Women's Legal Service NSW, and People with Disabilities Australia (PWDA) noted recommendations by the Committee on the Elimination of All Forms of Discrimination against Women (the CEDAW Committee), for Australia to prohibit the sterilisation of girls, except where there is a serious threat to life or health, and the sterilisation of adult women with disabilities in the absence of their fully informed and free consent.[6] Specifically, the CEDAW Committee stated:

> The Committee also notes with concern that non-therapeutic sterilizations of women and girls with disabilities continue to be practiced in some states in Australia and notes that the Commonwealth Government considers this to be a matter for state governments to regulate…The Committee recommends that the State party enact national legislation prohibiting, except where there is a serious threat to life or health, the use of sterilisation of girls, regardless of whether they have a disability, and of adult women with disabilities in the absence of their fully informed and free consent.[7]

4.6 PWDA characterised this statement as 'a clear affirmation that involuntary or coerced sterilisation of girls and women with disability is a form of gender-based violence'. Accordingly, PWDA submitted that Australia is obligated to adhere to the CEDAW Committee's recommendation to prohibit the involuntary or coerced sterilisation of persons with disabilities.[8]

4.7 Second, multiple submitters advised that Australia's laws regulating the sterilisation of persons with disabilities were noted with concern as part of the 2011 United Nations' Human Rights Council's Universal Periodic Review – Australia.[9] Of

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5 Australian Lawyers for Human Rights, *Submission 41*, p. 7; Women's Legal Service NSW, *Submission 70*, p. 5; People with Disabilities Australia, *Submission 50*, p. 26.

6 Women's Legal Service NSW, *Submission 70*, p. 5.

7 Committee on the Elimination of All Forms of Discrimination against Women, *Concluding observations of the Committee on the Elimination of Discrimination against Women – Australia*, 30 July 2012, CEDAW/C/AUS/CO/7, p. 7.

8 People with Disability Australia, *Submission 50*, p. 26.

9 Australian Lawyers for Human Rights, *Submission 41*, p. 7; People with Disabilities Australia, *Submission 50*, p. 13; Women's Legal Service NSW, *Submission 70*, p. 5.

the approximately 47 Working Group member countries which reviewed Australia,[10] four made the following recommendations about the sterilisation of women and girls with disabilities:

> Comply with the recommendations of the Committee on the Rights of the Child and the Committee on the Elimination of All Forms of Discrimination against Women concerning the sterilization of women and girls with disabilities (Denmark); enact national legislation prohibiting the use of non-therapeutic sterilization of children, regardless of whether they have a disability, and of adults with disability without their informed and free consent (United Kingdom); repeal all legal provisions allowing sterilization of persons with disabilities without their consent and for non-therapeutic reasons (Belgium); abolish non-therapeutic sterilization of women and girls with disabilities (Germany)[11]

4.8 Emeritus Professor Ivan Shearer advised that reviewed States are permitted under United Nations General Assembly resolution to accept or reject recommendations made through the Universal Periodic Review process.[12] On 31 May 2011, the Australian Government provided the following response to the recommendation:

> **Accepted–in–part:** The Australian Government considers that the 'best interests' test as articulated and applied in Australia is consistent with Australia's international obligations. In response to concerns expressed internationally and domestically, the Attorney-General intends to initiate further discussions with state and territory counterparts.[13]

4.9 In contrast to the government's response, Australian Lawyers for Human Rights concluded that the Universal Periodic Review compels Australia to ban involuntary or coerced sterilisation:

> ALHR urges the Commonwealth, and all State and Territory Governments to comply with their obligations under the above international laws. These laws are unambiguous in their articulation that involuntary or coerced

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10 The Universal Periodic Review is conducted by the UPR Working Group which consists of the 47 members of the Council. In addition, any UN Member State can take part in the discussion/dialogue with the reviewed States. See, *Basic facts about the UPR*, http://www.ohchr.org/EN/HRBodies/UPR/Pages/BasicFacts.aspx (accessed 8 July 2013).

11 Human Rights Council, *Report of the Working Group on the Universal Periodic Review – Australia*, 24 March 2011, paragraph 86.39, http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G11/122/90/PDF/G1112290.pdf?OpenElement (accessed 8 July 2013).

12 Advice by Emeritus Professor Ivan Shearer, 24 May 2013, p. 4.

13 Australian Government, *Report of the Working Group on the Universal Periodic Review – Australia*, *Addendum*, p. 4; http://lib.ohchr.org/HRBodies/UPR/Documents/Session10/AU/A_HRC_17_10_Add.1_Australia_E.pdf (accessed 8 July 2013).

> sterilisation is repugnant to human rights, including the rights of women and girls with a disability.[14]

4.10 Third, Australian Lawyers for Human Rights also noted comments by the Committee on the Rights of the Child about the incidence of sterilisation procedures performed on persons with disabilities in Australia.[15] Commenting in June 2012, the United Nations' committee noted its concern that the sterilisation of women and girls with disabilities continues. The comment was made as part of the committee's discussion of the incidence of violence against women and children in Australia.[16] The United Nations' committee recommended that Australia 'adopt a specific plan of action to make operational… such measures as developing and enforcing strict guidelines to prevent the sterilisation of women and girls who are affected by disabilities and are unable to consent'.[17] In addition, the committee recommended that Australia:

> Enact non-discriminatory legislation that prohibits non-therapeutic sterilization of all children, regardless of disability; and to ensure that when sterilization which is strictly carried out on therapeutic grounds does occur, that this be subject to the free and informed consent of children, including those with disabilities.[18]

4.11 These comments by the Committee on the Rights of the Child formed the basis of WWDA's recommendation that Australia enact national legislation to prohibit the forced or involuntary sterilisation of adults with disabilities and children.[19] In support of this, WWDA also submitted that the Committee on the Rights of the Child 'clearly identified non-therapeutic sterilisation as a form of violence against girls and women'.[20] The Australian Human Rights Commission also cited this report as evidence that '[t]he UN Committee on the Rights of the Child (CRC Committee) views involuntary or coerced sterilisation of children as breaching Australia's

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14 Australian Lawyers for Human Rights, *Submission 41*, p. 7.

15 Australian Lawyers for Human Rights, *Submission 41*, p. 7.

16 Committee on the Rights of the Child, *Consideration of reports submitted by States parties under article 44 of the Convention – Concluding observations: Australia*, 15 June 2012, p. 10; http://www2.ohchr.org/english/bodies/crc/docs/co/CRC_C_AUS_CO_4.pdf (accessed 8 July 2013).

17 Committee on the Rights of the Child, *Consideration of reports submitted by States parties under article 44 of the Convention – Concluding observations: Australia*, 15 June 2012, p. 10; http://www2.ohchr.org/english/bodies/crc/docs/co/CRC_C_AUS_CO_4.pdf (accessed 8 July 2013).

18 Committee on the Rights of the Child, *Consideration of reports submitted by States parties under article 44 of the Convention – Concluding observations: Australia*, 15 June 2012, p. 14; http://www2.ohchr.org/english/bodies/crc/docs/co/CRC_C_AUS_CO_4.pdf (accessed 8 July 2013).

19 Women with Disabilities Australia, *Submission 49*, p. 12.

20 Women with Disabilities Australia, *Submission 49*, p. 25.

obligation under article 19 of the CRC to protect children from all forms of physical and mental violence.[21]

The force and effect of United Nations committee statements

4.12 While views and recommendations of United Nations committees were noted, submitters also provided advice about the nature of such comments. Overall, the committee was advised that such comments are not binding on a state party. Mr Graeme Innes, Disability Discrimination Commissioner, Australian Human Rights Commission, acknowledged that statements by United Nations committees are 'soft law'. The views and recommendations of United Nations' committees are not enforceable.[22] This advice was reiterated by Emeritus Professor Ivan Shearer AM, who advised that statements by United Nations committees and officials are not legally binding.[23]

4.13 The Commonwealth Attorney-General's Department likewise did not agree with the view that Australia is obligated to adhere to the views and recommendations of United Nations committees and officials. The department held that Australia's obligations are found in the text of international treaties to which Australia is a party (subject to any reservations made at a time of entering the treaty).[24] The department further advised that Commonwealth, State and Territory laws are reviewed prior to Australia entering into a treaty to ensure compliance with proposed international obligations:

> It is the Government's policy that Australia will not become a party to a treaty until any necessary implementation action has been taken, either by the Commonwealth or by State or Territory Governments. For example, prior to ratifying the CRPD [Convention on the Rights of Persons with Disabilities], the Government undertook a national interest analysis in which it determined that Australia's Commonwealth, State and Territory legislation, policies and programs were in compliance with the immediately applicable obligations and substantially achieve implementation of the progressively realisable obligations under the CRPD.[25]

4.14 However, advice provided by the Australian Human Rights Commission and Emeritus Professor Shearer revealed that there are further considerations than just the strict letter of the law. Mr Innes advised that the situation is 'nuanced' – while the comments are not binding, they should not be disregarded:

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21 Australian Human Rights Commission, *Submission 5*, p. 6.

22 Mr Graeme Innes, Disability Discrimination Commissioner, Australian Human Rights Commission, *Committee Hansard*, 27 March 2013, p. 36.

23 Advice by Emeritus Professor Ivan Shearer, 24 May 2013, p. 2.

24 Commonwealth Attorney-General's Department, *Answer to question on notice*, 14 April 2013 (received 14 May 2013).

25 Commonwealth Attorney-General's Department, *Answer to question on notice*, 14 April 2013 (received 14 May 2013).

> [T]here is a line of cases which suggest that courts ought to take those international instruments into account when making their decision. Whilst they are not strictly part of Australian law, there is a line of case law which says that those decisions ought to be taken into account. So it is not quite correct to suggest that international instruments are not binding on Australian law. The situation is a little bit more nuanced than that.[26]

4.15 Similarly, Emeritus Professor Shearer advised the views and recommendations of United Nations' committees and officials, while not legally binding, 'must be considered seriously by Australian governments, at the legislative, executive and judicial levels'.[27] Emeritus Professor Shearer's advice also made clear that treaty obligations may evolve with time and international practice and, as such, are subject to an evolving interpretation:

> The Vienna Convention on the Law of Treaties, article 31(3)(b), allows for taking into account, together with the context, 'any subsequent practice in the application of the treaty which establishes the agreement of the parties regarding its interpretation'.[28]

4.16 State practice, it was noted, does not include statements by UN bodies and officials but the actions of State parties.

4.17 Emeritus Professor Shearer's advice to the committee provides an analysis of various kinds of statements that may be made by United Nations committees and officials, and the legally binding status of each category. The advice is clear that Australia is not obligated to adhere to the various views and recommendations. Nevertheless, Emeritus Professor Shearer provided a similar view to the Australian Human Rights Commission, that Australia's domestic laws should not depart from the views and recommendations of United Nations committees and officials without sound and compelling policy reasons.[29]

Equality under the law

4.18 In support of a ban on involuntary or coerced sterilisation, it was further submitted that the principles of equality protected by international law require sterilisation without consent to be prohibited. Involuntary or coerced sterilisation, it was argued, denies persons with disabilities their right to freedom of choice and bodily integrity.[30] As the Australian Association of Development of Disability Medicine Inc. maintained:

> [p]eople with disabilities have the same rights as other people to exercise choices regarding sexual expression and relationships and have freedom

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26 Mr Graeme Innes, Australian Human Rights Commission, *Committee Hansard*, 27 March 2013, p. 36.

27 Advice by Emeritus Professor Ivan Shearer, 24 May 2013, p. 2.

28 Advice by Emeritus Professor Ivan Shearer, 24 May 2013, p. 3.

29 Advice by Emeritus Professor Ivan Shearer, 24 May 2013, p. 2.

30 See, for example, Australian Lawyers for Human Rights, *Submission 41*, p. 7; Australian Women Against Violence Alliance, *Submission 80*, p. 1.

> over their body to make such choices. It is critical that the rights of people with disabilities are affirmed, defended and respected.[31]

4.19 Similarly, WWDA submitted that involuntary coerced sterilisation interferes with the right to equality before the law. This argument was one of the several put forward to give weight to the view that the Australian Government is obligated to prohibit involuntary or coerced sterilisations.[32] As WWDA stated:

> The Australian Government is in violation of international human rights law by allowing women and girls with disabilities to be sterilised in the absence of their free and informed consent. Among the fundamental rights governments are required to respect, protect, and fulfil are: the right to be free from torture, and cruel, inhuman, or degrading treatment or punishment; the right to the highest attainable standard of physical and mental health; the right to life, liberty, and security of person; the right to equality; the right to non-discrimination; the right to be free from arbitrary interference with one's privacy and family; and the right to marry and to found a family.[33]

4.20 PWDA shared this view, advocating that the principle of equality upheld by the Convention on the Rights of Persons with Disabilities 'effectively calls for the prohibition of involuntary or coerced sterilisation of children and adults with disability'.[34] The Australian Human Rights Commission reiterated that involuntary or coercive medical treatment is contrary to the principle of equality before the law:

> People with disability are entitled to enjoy all their human rights, including sexual and reproductive rights, on an equal basis with the rest of the Australian population. In the commission's view, national legislation should be enacted to criminalise, except where there is a serious threat to life or health, firstly, sterilisation of children regardless of whether they have a disability and, secondly, the sterilisation of adults with disability in the absence of their fully informed and free consent.[35]

Arguments against a broad-based prohibition

4.21 Not all submitters shared the view that upholding the rights of persons with disabilities requires sterilisation without the person's consent to be prohibited. Indeed, it was submitted that sterilisation without the person's consent is not only consistent with, but can safeguard, the rights of a person with disabilities. Three grounds were submitted in support of this argument.

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31 Australian Association of Developmental Disability Medicine Inc., *Submission 59*, p. 1.

32 Women with Disabilities Australia, *Submission 49*, p. 11.

33 Women with Disabilities Australia, *Submission 49*, p. 55.

34 People with Disability Australia, *Submission 50*, p. 23.

35 Mr Graeme Innes, Australian Human Rights Commission, *Committee Hansard*, 27 March 2013, p. 35.

The right to dignity and quality of life

4.22 Dr Wendy Bonython commented that international human rights law affirms and protects multiple human rights, which should be equally respected and held in balance. The right to dignity and quality of life should not be discounted:

> The right to produce and have a family are not the only human rights we recognise, although they are the ones that seem to attract the most attention from activists in the human rights discourse on this topic. There are other rights as well, including dignity and quality of life, that are just as important to the individual.[36]

4.23 The importance of quality of life, and the capacity of sterilisation to support and protect the right to dignity, is evident in the exchange between Ms Carolyn Frohmader from WWDA, and Associate Professor Sonia Grover, a gynaecologist with Royal Children's Hospital:

> **Prof. Grover:** I would put a little bit in there. I look after many, many young women. It is a substantial part of my work. Say if a young woman has horrible and painful periods. Well, half the Olympic athletes would be suppressing their periods using the continuous pill because they just find life easier without a period. With them they are all aiming for improved quality of life. I am certainly not saying everyone with a disability needs to be on the continuous pill, but I think, given my starting premise is periods are not allowed to mess up your life, that if stopping periods and skipping them is helpful to quality of life then I do not care if you have got a disability or not as I am there to help.
>
> **Ms Frohmader:** But how much of that is around their choice? Who makes that choice?
>
> **Prof. Grover:** It should be the young woman's choice. But where somebody has a very severe disability with the incapacity to communicate, or is getting seizures with her periods—and the information I am getting is that she is bashing her head against the wall when she has her period—I am going to try and suppress her periods. I do not have formal consent but I am doing it with the best information for her improved quality of life.[37]

4.24 As evident from this discussion, considerations of the right to quality of life can require a focus on the individual needs of the person with a disability. As evident in the following statement by Ms Louise Robbins, a number of carers who contributed to the inquiry were opposed to broad-based calls for involuntary or coerced sterilisation to be prohibited on human rights grounds. It was questioned whether advocates of a prohibition understood that persons with disabilities are not an homogenous group but are individuals with unique and diverse needs:

> I must say: the people who should have been here were Yooralla and Scope—the people who actually work with people with a disability—not the associations, who are two tiers up. And I am sorry, but they are two tiers

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36 Dr Wendy Bonython, private capacity, *Committee Hansard*, 27 March 2013, p. 62.

37 *Committee Hansard*, 11 December 2012, p. 18.

> up. It is the mothers, the helpers in the classroom, the physiotherapists, the OTs and the speech therapists: they work hands-on with these children…I found the submissions today not relevant to the everyday life of a carer and the implication of violence I found insulting.[38]

4.25 Catholic Women's League Australia Inc. also questioned whether broad rights-based arguments can lose the focus on the person with a disability as an individual:

> Opposition to involuntary or coerced sterilisation of people with disabilities is often expressed in terms of human rights…CWLA recognises the potential of this type of rights to talk to polarise this sensitive and complex issue…Sadly, this phenomenon is sometimes seen in relation to the issue now before the committee, where a mere assertion of rights (rather than reason giving) can shut down discussion.[39]

The need to support persons without the capacity to consent

4.26 Family Planning Victoria highlighted, the nature and severity of disability can vary. Accordingly, the capacity of a person with a disability to consent to medical procedure cannot be assumed. Family Planning Victoria submitted that there are two broad categories of persons with disabilities – those with the capacity to consent, with or without assistance, and those who lack decision-making capacity and therefore require a substituted decision-maker.[40] It is this latter category of individuals that was the focus of several submissions to the inquiry, which highlighted that proposals to prohibit sterilisation without consent fail to address the needs of persons who are without legal capacity. As Mrs Robbins noted, the calls for sterilisation to be prohibited in the absence of the consent of the person with a disability do not recognise decision-making incapacity:

> The Human Rights Commission were talking about how they wanted to delegalise sterilisation, making it illegal, and you could not take them overseas without consent—but they never actually gave an option for the people that cannot make consent, cannot make assisted consent. There are people, like my daughter, who cannot consent to getting dressed, when to eat and when to shower. How could she possibly give consent to a medical procedure? She cannot give consent, so she is totally excluded. They never really gave an option for the people that cannot give consent.[41]

4.27 Similar points were made by the Adult Guardian of Queensland and the Public Advocate of Queensland, the National Council on Intellectual Disability, Queensland Advocacy Inc, and Dr Bonython. The Adult Guardian of Queensland and the Public Advocate of Queensland recognised that substituted decision-making may be necessary to defend and protect human rights:

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38 Ms Louise Robbins, private capacity, *Committee Hansard*, 27 March 2013, p. 52.

39 Catholic Women's League Australia, *Submission 32*, p. 3.

40 Family Planning Victoria, *Submission 58*, p. 4.

41 Ms Louise Robbins, private capacity, *Committee Hansard*, 27 March 2013, p. 55.

> [B]ecause people with the decision-making impairment are prima facie not able to exercise their rights in the same manner as persons without impairment a mechanism should be put in place to objectively ensure that, as far as possible, the true wishes of the person with impairment are ascertained and complied with and the decision that is made is one made in their best interests.[42]

4.28 Queensland Advocacy Inc also concluded that sterilisation without the person's consent may be 'a legitimate option':

> As an option of last resort, it should not be offered on a discriminatory basis. Therefore, it is crucial to consider whether sterilisation would be offered to a person without disability in the same circumstances or given the same medical indications. For this reason, we are reluctant to say that sterilisation should never be authorised for someone with decision making incapacity (given that such an option would be available to someone with capacity who was able to give informed consent). We concede that it may be possible that in rare circumstances, the complex health needs of a person with a disability and lack of other appropriate alternatives may make sterilisation a legitimate option.[43]

4.29 Reiterating the need to protect quality of life, Dr Bonython also argued that sterilisation without consent is appropriate in some circumstances:

> I do think that sterilisation of anyone without their consent should be an extremely rare occurrence; however, there are some circumstances where sterilisation of a person who is incapable of providing consent may be justified if the results of authorising the procedure yield improved quality of life.[44]

4.30 Family Planning NSW supported the occurrence of sterilisation without consent, on the basis that if consent is the litmus test persons without capacity to consent are left without medical options:

> Sterilisation is classified by law, in all states and territories, as a special medical treatment. If a person lacks the capacity to consent to the procedure then, legally, the decision to proceed with the procedure can only be made under the direction of the appropriate state authority. It is important that legal processes offer protection but that they also uphold people's right to receive quality reproductive and sexual health services that are offered to other people in the community.[45]

Discrimination against persons with disabilities

4.31 It was clear from the opinions, and evidence presented to the inquiry that views regarding the involuntary or coerced sterilisation of persons with disabilities are

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42 Adult Guardian of Queensland and the Public Advocate of Queensland, *Submission 19*, p. 2.

43 Queensland Advocacy Inc, *Submission 65*, p. 6.

44 Dr Wendy Bonython, private capacity, *Committee Hansard*, 27 March 2013, p. 62.

45 Family Planning NSW, *Submission 25*, p. 4.

polarised. This is perhaps most evident in the argument that a prohibition on the involuntary or coerced sterilisation of persons with disabilities is a form of disability discrimination. As the Adult Guardian of Queensland and the Public Advocate of Queensland advocated:

> It is suggested by some that the whole process of sterilisation should be illegal for children and adults with disability. To do so however would constitute discrimination against children and against people with disability (both children and adults) and constitute a denial to them of a right to access a procedure available to persons without disability.[46]

4.32 The Adult Guardian of Queensland and the Public Advocate of Queensland further submitted that:

> Preventing discrimination is as much about allowing people with disabilities the right to decide between the same range of options that are available to people who do not have a disability as it is about ensuring that people with disability are not forced to undergo procedures that would not be applied to a person without disability where all other circumstances are equal. Applying an equal rights perspective to the Convention, this would provide people who have a disability that affects their capacity to decide the right to choose to undergo a sterilisation procedure as much as it provides for the right to choose not to be sterilised. In accordance with this approach, if society and the law allow a Queensland adult without disability to undergo a medical sterilisation procedure by a medical practitioner, then adults with disability, including those with impaired decision-making capacity, should be afforded the same entitlement.[47]

4.33 The National Council on Intellectual Disability also argued that equality before the law requires equal access to medical options - options that would be available to persons with a capacity to consent should be equally available to those without legal capacity:

> [W]e are advocating that what is best practice for a person without a disability, should be available to a person with a disability. This means that there are times when hysterectomy is required to manage fibroids, endometriosis and long periods of heavy menstruation that lead to poor health for a girl or woman, as with girls or women without a disability, the evidence based practice response should be available.[48]

4.34 Certainly, amongst those women with disability who gave evidence to the committee, there were those who themselves sought sterilising procedures for varying reasons, and those who did not want them. The latter group included some whose accounts were outlined in a previous chapter, and who had undergone such procedures

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46 Adult Guardian of Queensland and the Public Advocate of Queensland, *Submission 19*, p. 2.

47 Adult Guardian of Queensland and the Public Advocate of Queensland, *Submission 19*, pp. 2–3.

48 National Council on Intellectual Disability, *Submission 67*, p. 8.

against their will. Among people with disability, there is a strong desire to have the same choices as others.

Committee view

4.35 The involuntary or coerced sterilisation of persons with disabilities is an emotive, complex, and deeply personal issue. The committee appreciates the range of views provided throughout this inquiry. Despite the diversity of opinion, each view has at its core a commitment to defending, supporting and protecting the rights of persons with disabilities. While views were in some ways contradictory, the committee concluded that all submitters to this inquiry believed they were, and are, working towards a similar goal. It is a goal that the committee shares – the rigorous defence of the rights of persons with disabilities as equal, valued and productive members of Australian society.

4.36 The views of United Nations committees and officials, as conveyed by submitters to the inquiry, clearly articulate the need to eliminate discrimination. Some members of the international community indicated that there is no place for sterilisation to occur without the consent of persons concerned. However, as many submitters to this inquiry recognised, direction from the international community about how best to support persons without capacity to consent is not clear. As the committee has considered in chapter 3, and will go on to consider further in chapter 5, supported decision-making is not only appropriate but is necessary to support the dignity and rights of persons with disabilities. The committee expects that, with appropriate supported decision-making, there will be very few Australians who altogether lack decision-making capacity. However, the rights of persons without decision-making capacity are no less valuable and no less valid. The rights of this minority require support and defence.

4.37 An outright ban of non-therapeutic sterilisation procedures without consent potentially denies the rights of persons with disabilities to access all available medical support on an equal basis with persons without a disability. It is a 'one size fits all' solution to a complex problem. An outright ban removes the focus from the needs and interests of the individual, placing it instead on generic notions of what is best for persons with disabilities as an homogenous group. On balance, the committee does not agree that Australia's laws, including relevant court and tribunal procedures, should be unable to consider the circumstances of individuals. Flexibility in strictly limited circumstances may help to ensure that all appropriate support is provided to people with a disability.

4.38 In all cases, the starting point must be the determination of whether the person has legal capacity. There are three elements to determining this threshold question:

- Does a person have capacity?
- Would the person have capacity if provided with sufficient supports (such as a disability support worker and/or technologies to assist communication)? As the committee's review of the National Disability Insurance Scheme Bill 2013 brought to light, and as reiterated by this inquiry, all appropriate support should be provided to assist persons with disability to actively participate in

decisions affecting their lives. This was not the experience of a number of women who gave evidence to the committee.

- Could the person develop capacity in the future, though they may not have it at present? Clearly there can be never be a completely certain answer to this question, but expert assessments are able to be made, and must be considered in assessing this threshold issue.

4.39 Failure to determine capacity strips persons with disabilities of their equality before the law. It perpetuates myths and stereotypes. It appears to be contrary to Australia's undertakings upon signing the Convention on the Rights of Persons with Disabilities. There is no place for substituted decision-making in Australia without first determining that the person is without the capacity to decide for themselves.

4.40 As the committee held in its review of the National Disability Insurance Scheme Bill 2013, it should be presumed that people have the capacity to make their own decisions unless objectively assessed otherwise.[49] The committee urges the Commonwealth and State and Territory governments to review legislation affecting persons with disabilities, not only in relation to sterilisation but in all matters, to ensure that capacity is a threshold consideration. The committee considers that there is no role for third parties, whether that means parents or courts and tribunals, to make a decision on another person's behalf in relation to sterilisation procedures if the person has the capacity, or may develop the capacity, to decide for themselves. 'Best interests' tests (discussed at a number of points in this report) should not be considered, if there is current or potential future capacity of the person in question.

4.41 In those cases where there is currently no capacity to consent, but where that capacity may exist in future, decision-making should take account of what actions might protect or advance the person's rights while that capacity has the opportunity to develop. The committee wishes to avoid unintended consequences that might hamper the use of measures to advance a person's welfare consistent with their rights, as is demonstrated by this scenario:

- A family asks a court to approve the use of a long-acting contraceptive for their 12 year-old daughter with intellectual disability, to be reviewed every year. They seek this intervention to help manage menstruation that currently causes the daughter great distress, and which the family have been unable to manage using pads or other means, despite assistance from a disability support worker. The court notes that the girl has an intellectual age of four, but expert evidence indicates that by the time she reaches her twenties, she may develop the capacity, with support, to express views about managing her periods.

4.42 In such a case, it may be consistent with the protection of the girl's rights to support the use of a long acting reversible contraceptive, subject to periodic reviews. But it would not be appropriate to support the use of irreversible measures, when it is

49 Community Affairs Legislation Committee, *National Disability Insurance Scheme Bill 2012 [Provisions]*, March 2013, pp. 24–25.

believed that supported decision-making by the girl may be possible when she is older.

Recommendation 6

4.43 The committee recommends that, for a person with a disability who has the capacity to consent, or to consent where provided with appropriate decision-making support, sterilisation should be banned unless undertaken with that consent.

Recommendation 7

4.44 The committee recommends that, for a person with a disability for whom it may reasonably be held that they may develop the future capacity to consent, irreversible sterilisation should be banned until either the capacity to consent exists, or it becomes reasonably held that the capacity to consent will never develop.

4.45 In those cases where there is not capacity for consent, and no reasonable prospect that it may develop, laws and procedures may permit the sterilisation of persons with disabilities, but the circumstances in which this may occur must be narrowly circumscribed, and based on the protection and advancement of the rights of the person. In the following chapter, the committee will closely review the laws and practices that apply to relevant courts and tribunals in Australia to determine whether the laws and practices currently provide a robust defence of the rights of persons with disabilities who lack the legal capacity to determine whether or not to undergo a sterilisation procedure. In undertaking is review, the committee has as its objective the defence of the rights of persons with disabilities. This will also be considered in the context of Australia's reservation to the Convention on the Rights of Persons with Disabilities, under which Australia has undertaken to ensure that substituted decision-making occurs only as a last resort and only with all necessary safeguards.

Chapter 5

Australia's court and tribunal procedures

5.1 In considering the laws and practices of relevant Australian courts and tribunals, the committee took as its starting point Australia's commitment under its reservation to the UN Convention on the Rights of Persons with Disabilities. This commitment requires Australian governments to ensure that substituted decision-making occurs only as a last resort and only with all necessary safeguards. As noted in chapter 4, the committee considers that courts and tribunals must have robust laws and procedures in place for the defence of the rights of persons with disabilities. Submitters identified several areas where safeguards are reportedly lacking or are in need of improvement. Some areas are common across jurisdictions, whereas others are specific to children's cases conducted under Commonwealth law. Issues specific to the exercise of Commonwealth law by the Family Court of Australia will be considered in the next chapter.

Representation and participation in proceedings before courts and tribunals

5.2 A number of concerns raised were relevant to both Commonwealth and State and Territory procedures. Notably, submitters questioned whether the processes used across jurisdictions ensured that the opinions of the disabled person were sought and given full weight. Access to legal representation and medical opinion were key aspects of this discussion.

Participation in proceedings – adults with disabilities

5.3 For adults with disabilities, arrangements for their participation in sterilisation proceedings differ across the States and Territories. Legislative requirements can also differ from procedures under the Australian Guardianship and Administration Council (AGAC) *Protocol for Special Medical Procedures (Sterilisation).*

Capacity to consent

5.4 In three jurisdictions, relevant legislation permits the court or tribunal to hear an application for an order authorising a sterilisation procedure if there is an existing guardianship order in place. In these jurisdictions, namely, the Australian Capital Territory (ACT), South Australia and Western Australia, analysis of whether the person has the capacity to consent to the contemplated medical procedure is not a prerequisite for determining whether the court has standing to hear the matter.[1]

5.5 In contrast, in New South Wales, Queensland, Tasmania and Victoria, the fact that a guardianship order is in place does not necessarily give a court or tribunal authority to hear a sterilisation case. Under the relevant State and Territory legislation,

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1 *Guardianship and Management of Property Act 1991* (ACT), s. 69; *Guardianship and Administration Act 1993* (SA), s. 61; *Guardianship and Administration Act 1990* (WA), s. 13; s. 56A.

a court or tribunal may hear a sterilisation case only if the person is considered incapable of giving, or refusing, consent to the proposed procedure. The person's capacity to understand the nature and effect of the proposed procedure is considered on a case-by-case basis.[2] In these jurisdictions it appears that there is a two-stage process to determine whether to make a sterilisation order. First, it must be ascertained whether the person has the capacity to consent to the procedure. Second, if the person is found to be without capacity, the court or tribunal is to determine whether to authorise the proposed sterilisation procedure.

5.6 In the Northern Territory, relevant legislation adopts a hybrid approach. The *Adult Guardianship Act* authorises the local courts to hear a sterilisation case where there is an existing guardianship order in place. However, the court must ascertain whether the person has capacity to consent to, or to refuse, the proposed procedure. If the person has capacity, the court must give effect to the person's wishes.[3]

5.7 The AGAC's *Protocol for Special Medical Procedures (Sterilisation)* requires tribunals to adopt a two-stage inquiry process. As a starting point, the tribunal must consider whether a person has the capacity to consent to the proposed treatment.[4] The protocol defines 'capacity' to mean capable of:

- understanding the nature and effect of their decisions about the proposed sterilisation;
- freely and voluntarily making decisions about the proposed sterilisation; and
- communicating their decisions in some way.[5]

5.8 Specific direction is given to tribunal officers regarding the steps needed to determine whether a person has capacity. In particular, the protocol advises that neither an adult nor child will be able to give valid consent if he or she is unable to understand the nature and significance of the treatment and associated risks.[6] The protocol also draws attention to the need to consider if the person is, or may be, affected or influenced by the differing views of his or her carers.[7] However, while requiring tribunals to consider capacity to consent as a threshold question, the protocol

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2 *Guardianship Act 1987* (NSW), ss. 33–34; *Adult Guardianship Act* (NT), s.21; *Guardianship and Administration Act 2000* (QLD), s. 70; *Guardianship and Administration Act 1995* (Tas); *Guardianship and Administration Act 1986* (VIC), s. 36, s. 39.

3 *Adult Guardianship Act*, s.21.

4 Australian Guardianship and Administration Council, *Submission 28*, Attachment 1, *Protocol for Special Medical Procedures (Sterilisation)*, cl. 3.2.

5 Australian Guardianship and Administration Council, *Submission 28*, Attachment 1, *Protocol for Special Medical Procedures (Sterilisation)*, cl. 5.11.

6 Australian Guardianship and Administration Council, *Submission 28*, Attachment 1, *Protocol for Special Medical Procedures (Sterilisation)*, cl. 5.13.

7 Australian Guardianship and Administration Council, *Submission 28*, Attachment 1, *Protocol for Special Medical Procedures (Sterilisation)*, cl. 5.14.

does not expressly prohibit tribunals from hearing a case where it is determined that a person has capacity.

Legal representation and participation in hearing

5.9 Arrangements for the person's participation in proceedings differ across the states and territories. An outline of the procedures under the *Protocol for Special Medical Procedures (Sterilisation)*, the protocol as applied by the Queensland Civil and Administrative Tribunal, and ACT legislation and practice, illustrate the various procedures that may be adopted.

5.10 Under the protocol, tribunals are directed to first determine the question of capacity. To address this issue, the protocol encourages tribunals to hold a preliminary hearing.[8] However, the protocol does not expressly require the tribunal to consider whether it is practicable to speak directly with the person. Rather, the protocol states that the tribunal may obtain an independent, that is, a third party, assessment of the person's capacity. Once the tribunal has considered the question of capacity, the protocol contemplates that the tribunal may make orders, known as directions, about how the hearing will be conducted.[9] Directions can include orders for a third party, such as a 'next friend', 'separate representative' or the person's 'legal guardian', to represent the person.[10] The protocol does not expressly encourage or require tribunals to consider the potential for the person to directly engage with the hearing process.

5.11 The Queensland Civil and Administrative Tribunal provided an explanation of the tribunal's application of the protocol. The tribunal noted that a third party may be appointed to represent the adult. The committee was advised that representatives are appointed to ensure that the tribunal can 'obtain a more robust analysis of the adult's capacity to give consent than would be obtained via an applicant whose interests may not always fully align with the interests of the adult.' The committee was further advised that tribunal members may directly engage with the adult, as 'a member of the tribunal can speak to the adult (if possible).'[11]

5.12 In the ACT, the *Guardianship and Management of Property Act 1991* provides two relevant procedural directions for the tribunal to follow in sterilisation cases. The tribunal must obtain the person's wishes, and give effect to the person's wishes to the extent that to do so would be consistent with the person's interests.[12] The tribunal must appoint a third party to represent the person. Section 70 of the Act

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8 Australian Guardianship and Administration Council, *Submission 28*, Attachment 1, *Protocol for Special Medical Procedures (Sterilisation)*, cl. 5.8; 5.15.

9 Clause 5.21 of the Protocol states 'When the tribunal is satisfied on the two crucial questions, the Tribunal may give any or all of the following directions'. The two threshold questions are 'Does the person has capacity' (cl. 5.8–5.15) and 'Is sterilisation required' (cl. 5.16–5.20).

10 Australian Guardianship and Administration Council, *Submission 28*, Attachment 1, *Protocol for Special Medical Procedures (Sterilisation)*, cl. 5.21.

11 Correspondence received from the Queensland Civil and Administrative Tribunal, 3 May 2013, p. 3.

12 *Guardianship and Management of Property Act 1991* (ACT), s.4.

directs the tribunal to appoint the person's guardian, the Public Advocate, or some other independent person. The committee was advised that, generally, orders are made to appoint the Public Advocate of the ACT.[13] The committee was advised that the tribunal typically requests the Public Advocate to report on the views of the person, to the extent that the person's views can be ascertained.[14] Additionally, the tribunal must consult the person's carers, unless this would adversely affect the person's interests.[15]

5.13 Advice provided by the General President of the Australian Capital Territory Civil and Administrative Tribunal indicated that the tribunal may adopt procedures in addition to those contemplated by the Act. In particular, the committee was advised that the tribunal will seek the person's views in each case. To do so, the tribunal may speak directly to the person during the hearing. Additionally, if requested or appropriate in the circumstances, tribunal members may separately meet with the person. [16]

5.14 Accordingly, a person's access and entitlements to legal representation can vary according to the jurisdiction in which they reside.

Stakeholder views – capacity to consent

5.15 Similar to the views of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, as explored in chapter 3, submitters warned against practices that could deny the legal capacity of persons with disabilities. The central importance of capacity was noted by private individuals, Public Advocates, and disability and human rights advocates.[17] As the Adult Guardian of Queensland and the Public Advocate of Queensland advised, it cannot be presumed that persons with disabilities are unable to exercise their legal autonomy:

> Many people have various forms of disability that in no way impact upon their capacity to exercise their legal rights or make decisions about themselves or their bodies.[18]

5.16 Family Planning New South Wales also noted that disability should not be equated with an inability to make decisions about personal health matters:

> Too often people with disability are presumed not to have the ability to make their own decisions because they have a disability. Many people who

13 Correspondence received from the Australian Capital Territory Civil and Administrative Tribunal, 12 May 2013, p. 2.

14 Correspondence received from the Australian Capital Territory Civil and Administrative Tribunal, 12 May 2013, p. 3.

15 *Guardianship and Management of Property Act 1991*, s. 4.

16 Correspondence received from the Australian Capital Territory Civil and Administrative Tribunal, 12 May 2013, pp. 4–5.

17 See, for example, Adults Guardian of Queensland and the Public Advocate of Queensland, *Submission 19*, p. 1; Professor John Carter, private capacity, *Committee Hansard*, 27 March 2013, p. 48; Janine Truter, *Submission 18*, p. 1.

18 Adults Guardian of Queensland and the Public Advocate of Queensland, *Submission 19*, p. 1.

> have an intellectual disability can make decisions about their reproductive and sexual health.[19]

5.17 There was a general theme throughout submissions to the inquiry that persons with disabilities should receive appropriate support to exercise their legal capacity.[20] As the New South Wales Council for Intellectual Disability submitted, the starting point should be consideration of whether there are appropriate support mechanisms in place:

> [T]he really big important bit in the middle there is whether the people themselves are able to make the decision. While there need to be really good practical safeguards to ensure that that really is an informed and free choice, our aim should be that as much as possible, at the end of the day, it is people with disability themselves who are making their own choices about whether or not they have any form of contraception or menstrual management.[21]

5.18 Accordingly, there was strong consensus that consent and support for legal capacity are paramount. Determining capacity to consent was, therefore, considered to be a threshold issue to be settled before any third-party involvement in the decision-making process.[22] However, views were divided on whether the legal or medical community has a legitimate role to play in the absence of capacity to consent.

5.19 Two arguments were put forward in support of the view that third parties, such as courts and tribunals, have no role to play in the decision-making process for the non-therapeutic sterilisation of persons with disabilities. As noted in chapter 3, disability and human rights advocates argued that there are no legitimate grounds on which a sterilisation may be performed without the person's consent. As further noted in chapter 3, this view was challenged on the basis that this approach does not cater for persons without decision-making capacity.

5.20 Additionally, it was intimated that substituted decision-making is prohibited under international law. Notwithstanding Australia's caveat to this Article, which asserts that substituted decision-making may be appropriate in certain circumstances,[23] it was submitted that Australia's obligations under Article 12 of the Convention on the Rights of Persons with Disabilities require the provision of support

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19 Dr Deborah Bateson, Medical Director, Family Planning New South Wales, *Committee Hansard*, 27 March 2013, p. 10.

20 See, for example, Name Withheld, *Submission 63*, p. 1. This issue is further explored below.

21 Mr Simpson, New South Wales Council for Intellectual Disability, *Committee Hansard*, 11 December 2012, p. 10.

22 See, for example, Family Planning Victoria, *Submission 58*, p. 4.

23 United Nations, *United Nations Treaty Collection*, http://treaties.un.org/pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en#EndDec (accessed 3 May 2013).

for persons with disabilities to exercise their legal capacity.[24] As People with Disability Australia (PWDA) submitted:

> Implementation of article 12 requires establishing supported decision-making alternatives to substitute decision-making regimes. It will also require effective safeguards to be introduced in relation to supportted decision-making arrangements to prevent abuse in accordance with international human rights law.[25]

5.21 PWDA further commented that the successful implementation of Article 12 will require 'fundamental reforms':

> Implementation of article 12 is critical for people with disability to achieve many of the rights contained in the CRPD, and it will require 'fundamental reform in the current legal, administrative and service arrangements that regulate legal capacity of people with disability so that supported decision-making can be recognised, developed and promoted'. In this context, the legal prohibition of voluntary or coerced sterilisation must be complemented by the fundamental reforms required for the development of a comprehensive supported decision-making system that contains appropriate and effective safeguards.[26]

5.22 Such statements reflect comments by United Nations' committees and officials, for example the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, that Article 12 requires 'the replacement of substituted decision-making regimes with supported decision-making'.[27] As the statement of Dr Deborah Bateson, Medical Director, Family Planning New South Wales, indicates, supported decision-making was equated with protection against coercion:

> It is important to say from the outset that we support the rights of people with disability to make decisions about their reproductive and sexual health and we strongly oppose involuntary or coerced sterilisation of people with disability.[28]

5.23 Therefore, it was questioned whether courts and tribunals have a recognised role for sterilisation matters within the international law framework. This is reflected in assertions that a sterilisation procedure may be involuntary or coerced despite being

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24 See, for example, People with Disability Australia, *Submission 50*, p. 18.

25 People with Disability Australia, *Submission 50*, p. 18.

26 People with Disability Australia, *Submission 50*, p. 18; citing Disability Representative, Advocacy, Legal and Human Rights Organisations, *Disability Rights Now – Civil Society Report to the United Nations Committee on the Rights of persons with Disabilities*, August 2012, p. 187.

27 Mendez, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/22/53, p. 7.

28 Dr Bateson, Family Planning New South Wales, *Committee Hansard*, 27 March 2013, p. 10.

authorised by a court or tribunal.[29] This view was encapsulated in the submission by Ms Linda Steele, Lecturer, Faculty of Law, University of Wollongong:

> It also follows from the current legal framework for sterilisation that involuntary sterilisation pursuant to a court or tribunal order is not only a form of violence but is specifically a form of *legal violence*. Legal violence is violence that is specifically made possible by and authorised by the law. Sterilisation is legal violence because without the court or tribunal order (under legislation giving jurisdiction to a court and tribunal to make such an order), the involuntary sterilisation of people with disability is not lawfully possible and if committed could be unlawful and attract a criminal penalty.[30]

5.24 Accordingly, Ms Steele concluded that 'the current legal framework requires broad scale reform to shift from the legal framework of *regulation* to a framework of complete prohibition'.[31] Similarly, People with Disability Australia argued:

> [A]uthorisation of sterilisation by a court or tribunal on behalf of an adult with disability in the absence of serious risk to life or health constitutes involuntary or coerced sterilisation.[32]

5.25 Conversely, other submitters argued that in the absence of capacity it is appropriate for courts and tribunals to make decisions affecting a person with a disability. As the statement by Family Planning Victoria makes clear, there was a view that third parties may properly make decisions for persons without the capacity to decide for themselves:

> FPV considers that there are two broad groups of people with a disability who are affected by the practice of involuntary or coerced sterilisation and that these two groups, and those who support them, require different elements of support, education, and protection. These two groups [include] people with a disability who lack capacity to consent and require a substitute decision–maker.[33]

5.26 This was reiterated by the disability advocacy service Intellectual Disability Rights Service Inc., which held that 'if a person cannot understand sufficiently to make their own decisions then it is important that the decision go before a court or a tribunal.'[34] Catholic Social Services Victoria also contended that determinations by 'decision-making bodies' may be appropriate where a person is without capacity to

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29 See, for example, Mr Graeme Innes, Disability Discrimination Commissioner, Australian Human Rights Commission, *Committee Hansard*, 27 March 2013, p. 10; People with Disability Australia, *Submission 50*, p. 6.

30 Ms Linda Steele, *Submission 44*, p. 8.

31 Ms Linda Steele, *Submission 44*, p. 6.

32 People with Disabilities Australia, *Submission 50*, p. 14.

33 Family Planning Victoria, *Submission 58*, p. 4.

34 Ms Janene Cootes, Executive Officer, Intellectual Disability Rights Service Inc, *Committee Hansard*, 27 March 2013, p. 18.

consent, particularly in situations where caregivers are unable to provide 'all reasonable care'.[35] Further, the committee was offered an alternative interpretation of the scope and effect of Article 12 of the Convention on the Rights of Persons with Disabilities. The Australian Human Rights Commission concluded that Article 12 allows for appropriate substituted decision-making:

> Article 12 of the CRPD requires States Parties to support persons with disability to exercise their own legal capacity, and to ensure that any measures which allow for legal capacity to be exercised on behalf of a person with a disability are checked by adequate safeguards to prevent abuse, and particularly 'are free of conflict of interest'.[36]

5.27 On this basis, substituted decision-making by courts and tribunals was held to serve a legitimate purpose. However, the role of courts and tribunals was seen as limited to instances where persons are without the capacity to give, or to withhold, consent. It was argued that third parties cannot legitimately assume the decision-making powers of persons who are capable of deciding for themselves. As the Office of the Adult Guardian stated, '[i]t is only where the person lacks the necessary cognitive capacity that society has the right to intervene in relation to that person's decision-making.'[37] For persons with disabilities who are nonetheless able to exercise legal capacity, the Office of the Adult Guardian held that 'they should be treated in exactly the same way as any member of the Australian community'.[38] Similarly, the Adult Guardian of Queensland and the Public Advocate of Queensland submitted:

> [i]t is only where an individual lacks capacity to exercise those rights and make those decisions that there is any justification for intervention in their lives.[39]

5.28 There appeared to be a one possible exception to this view. Australian Lawyers for Human Rights submitted that compliance with international recommendations and best practice requires both the individual's consent and court authorisation:

> ALHR believes that the only way to improve laws and practices governing sterilisation is to comply with the…recommendations made by the CEDAW Committee, CRC Committee and the UPR (Universal Periodic Review) process. This requires legislative prohibition of the sterilisation of children, particularly girls, regardless of whether they have a disability, and adults without free and informed consent *and an order from a competent court or tribunal* [emphasis added].[40]

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35 Catholic Social Services Victoria, *Submission 39*, p. 3.

36 Australian Human Rights Commission, *Submission 5*, p. 10.

37 Mr Kevin Martin, Adult Guardian, Office of the Adult Guardian, *Committee Hansard*, 27 March 2013, p. 28.

38 Mr Martin, Office of the Adult Guardian, *Committee Hansard*, 27 March 2013, p. 28.

39 Adult Guardian of Queensland and the Public Advocate of Queensland, *Submission 19*, p. 1.

40 Australian Lawyers for Human Rights, *Submission 41*, p.7.

5.29 When the committee spoke to women with disabilities, some questioned whether there were situations where substituted decision-making was legitimate:

> I think the reason I am here is that when I was involved with the advocacy movement there were a lot of things about women with disabilities being sterilised…my biggest problem is that I cannot see where a support worker or parent can make a decision for a woman with a disability.[41]

Views on consent, wishes and tribunal procedure

5.30 One submitter, Professor Susan Hayes, Professor of Behavioural Sciences in Medicine, Sydney Medical School, University of Sydney, noted with approval current steps taken by courts and tribunals to determine the wishes and capacity of persons with disabilities.[42] However, this view was not commonly shared by submitters to the inquiry. Accordingly, several recommendations were made to improve court and tribunal practice.

5.31 Submitters identified a need for greater awareness and recognition of the reality that capacity can develop over time with appropriate support. Indeed, it was submitted that there is a clear link between capacity and the degree and nature of support provided. A lack of support can be mistakenly correlated with a lack of capacity. For example, Women with Disabilities Australia (WWDA) criticised an approach that fails to recognise, or to consider, that capacity may change with time and circumstance:

> One of the other things is a problem around the notion that she will never have capacity, as if 'capacity' is a fixed state, and that she will never be able to handle her menstruation or that there will never be any kind of thing that will work…So when it comes to women and girls with disabilities, there is this weird notion of capacity as a fixed state and also that there will be no other options in the future.[43]

5.32 WWDA warned that the view of capacity as a fixed state can deny legal autonomy on the basis of a stereotypical, discriminatory understanding of disability, instead of an individual's circumstances or potential:

> Views such as these fail to acknowledge the fact that 'incapacity' can very often be a function of the environment and more often than not, a lack of support for the individual concerned.[44]

5.33 The link between capacity and support services was highlighted by other submitters to the inquiry. Family Planning New South Wales also recognised that '[m]any people who have an intellectual disability can make decisions about their reproductive and sexual health but may need support in the decision-making

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41 Donna, *Committee Hansard*, 30 January 2013, p. 2.

42 Professor Susan Hayes, *Submission 47*, p. 3.

43 Ms Frohmader, Women With Disabilities Australia, *Committee Hansard*, 11 December 2012, p. 14.

44 Women With Disabilities Australia, *Submission 49*, p. 38.

process.'[45] Similarly, Family Planning Victoria, while maintaining that there may be a segment of Australians with disabilities without legal capacity, noted the relevance of support services:

> [P]eople with a disability need age-appropriate information and education delivered in a developmentally-appropriate way, and support so that they can make their own choices.[46]

5.34 Sexual Health and Family Planning Australia concurred:

> Many people who have a disability, including those with intellectual disabilities, are capable of making decisions about their sexual and reproductive health, *if provided with developmentally appropriate information and unbiased guidance*.[47]

5.35 The National Council on Intellectual Disability (NCID) spoke not only of the relevance of appropriate support services but also of societal attitudes:

> NCID believes in the developmental model, which means having high expectations for each person. To achieve this we must provide support education based on individual needs and learning style of each person. We know that people with intellectual disability can and do grow and develop through life's ages and stages when given access to powerful, potent and precise intervention when appropriate in their lives.[48]

5.36 Sexual Health and Family Planning Australia further argued that steps to determine capacity are based on the assumption that a person with a disability receives appropriate support:

> The steps to determine free and informed consent and "best interest" are broadly based on the following assumed abilities of the disabled individual and/or their guardian to understand the facts involved, understand the choices, weigh up the consequences of the choices, understand how the consequences affect them [and] communicate their decision.[49]

5.37 Sexual Health and Family Planning Australia pointed out that the kinds of support services that may assist a person with a disability to understand the facts involved, the options available, and the consequences of their choices may not be provided:

> SH&FPA is concerned that these steps [to determine capacity] are predicated on there being adequate active support and education services to allow individuals to fully understand the connections between fertility, menstruation management, sexual activity, pregnancy, parenting with a disability and the full range of available options. It is our view that at

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45 Dr Bateson, Family Planning New South Wales, *Committee Hansard*, 27 March 2013, p. 10.

46 Family Planning Victoria, *Submission 58*, p. 4.

47 Sexual Health and Family Planning Australia, *Submission 52*, p. 3.

48 National Council on Intellectual Disability, *Submission 77*, p. 9.

49 Sexual Health and Family Planning Australia, *Submission 52*, p. 3.

> present, there are insufficient support structures to help individuals, their carers, the courts and the state to make these decisions in a fully informed way.[50]

5.38 It was further submitted that greater awareness of the nature of capacity requires courts and tribunals, and other relevant third parties, to be alert to subtle forms of coercion. Some people with an intellectual disability have been trained to be so compliant and acquiescent by carers and service providers that they need to be taught the concept of independent decision-making. Catholic Women's League Australia supported 'the promotion of the idea of informed consent, even when the person concerned has some experience of disability'. However, the organisation was concerned that 'the principles of informed consent, which include freedom from fear and all those other factors, are not being respected when it comes to the carers of disabled people or the disabled people themselves.'[51] The New South Wales Council for Intellectual Disability advised that subtle forms of 'coercion' can include a desire on the part of an individual with disability to obtain their carers' approval:

> [W]hen we talk about free and informed consent, it is the really tricky area with a lot of people with intellectual disability who are just used to doing whatever it takes to please.[52]

5.39 PWDA submitted that the circumstances in which an individual provides consent, or otherwise exercises their legal capacity, must be carefully and critically considered:

> Ostensibly it might appear as if a person is consenting but in fact we know from the stories from the women and the men we talk to that they have been coerced into it. So, it is not their informed choice to have this occur.[53]

5.40 The Office of the Adult Guardian advised that great care needs to be taken when assessing an individual's legal capacity:

> When it comes to consider the role of that particular individual in exercising the right that everyone else in the community possesses, there is a necessity for great care to be taken to ensure that the inability of that person to properly express and display decision in relation to them is indeed a decision.[54]

5.41 Accordingly, the quality of capacity assessments was questioned. The New South Wales Council for Intellectual Disability advised that there is a lack of

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50 Sexual Health and Family Planning Australia, *Submission 52*, p. 3.

51 Mrs Anna Maria Krohn, Bioethics Convenor, Catholic Women's League Australia, *Committee Hansard*, 27 March 2013, p. 44.

52 Mr Simpson, New South Wales Council for Intellectual Disability, *Committee Hansard*, 11 December 2012, p. 20.

53 Ms Therese Sands, Co-Chief Executive Officer, People with Disability Australia, *Committee Hansard*, 11 December 2012, p. 4.

54 Mr Martin, Office of the Adult Guardian, *Committee Hansard*, 27 March 2013, p. 28.

uniformity in the procedures adopted by State and Territory tribunals, and the quality of assessments is variable:

> I think just about all the legislation in some way calls for the views of the person to be obtained but what that means in practice would be a variable issue. Similarly, with capacity assessments, the quality of assessments that someone lacks capacity may vary. I think it is only in New South Wales that the legislation requires that there be a written statement of reasons explaining why the tribunal is satisfied that the person lacks capacity and the sterilisation should be approved.[55]

5.42 Ms Colleen Pearce, Public Advocate, Office of the Public Advocate, Victoria, also questioned whether safeguards that apply in one jurisdiction apply across the board, commenting that 'safeguards that exist in Victoria are one thing, and there are concerns…that the kinds of safeguards we have in place here are not replicated elsewhere.'[56]

5.43 Differences in tribunal practice have been noted in previous inquiries. Reporting in 2001 to the Australian Human Rights Commission, Susan Brady, John Britton, and Sonia Grover noted with approval the practice existing in some state and territory jurisdictions of providing a questionnaire to expert medical witnesses to clarify the information the court is seeking.[57] Evidence presented to this inquiry was silent on whether this practice is currently in use by all tribunals or the Family Court.

5.44 These concerns with tribunal procedures were, unsurprisingly, not shared by participants in the tribunal process. The Office of the Public Advocate (OPA) provided a detailed overview of the measures taken to minimise the risk of coercion and to maximise the level of support provided. The OPA advised that officers seek to develop a relationship with the person with a disability independent of the person's carers, family or friends. To avoid the risk of pressure or influence, OPA officers attempt to meet individually with the person. The committee was further informed that OPA officers also meet with medical advisers, social workers and others involved in the application to obtain information about the person's wishes. It was put to the committee that:

> the process will never be perfect, but there is a definite activity taken by [the OPA] office and by the tribunal itself to ascertain the real wishes of the individual as best we possibly can.[58]

5.45 The Northern Territory Government advised that section 7 of the *Mental Health and Related Services Act* directs that the person receive information and advice

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55 Mr Simpson, New South Wales Council for Intellectual Disability, *Committee Hansard*, 11 December 2012, p. 2.

56 Ms Colleen Pearce, Public Advocate, Office of the Public Advocate, Victoria, *Committee Hansard*, 11 December 2012, p. 6.

57 Susan Brady, John Britton, Sonia Grover, *The sterilisation of girls and young women in Australia: issues and progress*, p. 44.

58 Mr Martin, Office of the Adult Guardian, *Committee Hansard*, 27 March 2013, p. 30.

about the proposed treatment and adequate time to consider the information provided.[59] The New South Wales Government advised that it approves the procedures applied by the Guardianship and Administration Board to ascertain the person's wishes and capacity to consent. Such procedures reportedly include independent investigations by the Public Guardian and reports by health care providers.[60] The Adult Guardian of Queensland and the Public Advocate of Queensland supported procedures adopted by the Queensland Civil and Administrative Tribunal (QCAT) to ascertain the person's wishes.[61]

5.46 It was also questioned whether procedures to obtain medical advice are adequate. The committee was advised that ascertaining whether a person has capacity to provide or withhold consent can be quite an involved process. It is not a process to be rushed. As the Intellectual Disability Rights Service Inc. advised:

> Consent on decisions about sterilisation procedures should be made by the woman herself where ever possible…[T]hat involves usually a lengthy procedure of doctors liaising with the person to gauge their understanding, hopefully increasing their understanding of the decision that they need to make. I think it is a real misnomer that it is a one-off interaction between a doctor and patient and that the doctor can then decide that this person cannot make a decision for themselves. It needs to be a fairly in-depth process the doctor would go through to make that judgement. It also needs to be based on full information and information about alternatives for the person to weigh up if they are able to weigh up those options…Coercion can be very subtle.[62]

5.47 It was submitted that the process by which medical practitioners evaluate capacity to consent is subjective. The committee was informed that there is no widely accepted, easily administered standardised assessment of capacity to provide free and informed consent.[63] Based on their experience providing training programs to health professionals, Family Planning Victoria questioned whether there is sufficient expertise within the medical profession to properly ascertain wishes or capacity to consent:

> [D]uring our experience training health professionals and offering secondary consultation, it has become evident that many health professionals do not feel confident communicating with people with disabilities, particularly around sexual and reproductive health issues. It also appears that many health professionals do not consider, and in some

59 Northern Territory Government, *Submission 34*, p. 5.

60 New South Wales Government, *Submission 57*, pp. 2–3.

61 Adult Guardian of Queensland and the Public Advocate of Queensland, *Submission 19*, p. 7.

62 Ms Cootes, Intellectual Disability Rights Service Inc, *Committee Hansard*, 27 March 2013, p. 18.

63 Family Planning Victoria, *Submission 58*, p. 6.

> cases do not respect, the sexual and reproductive health rights of people with disabilities.[64]

5.48 Other submitters also questioned whether there is sufficient expertise within the medical community to advise on proposed sterilisation procedures. The Office of the Public Advocate, Victoria argued that there is a need for greater disability awareness and understanding among the medical profession:

> We think that an important topic is educating medical professionals. We do a lot of it already but we would love to do more of it, and we would love for medical professionals to be required to do some of it. We are really keen to hear any suggestions you have at the national level by which we can encourage this to occur.[65]

5.49 This view was shared by Family Planning Victoria:

> [M]any people with disability who fit into the first category [of having the capacity or potential capacity to consent] are treated as if they fall into the second [of lacking capacity to consent and therefore requiring a substitute decision–maker]. Medical practitioners require more specific support regarding the assessment of a person's capacity to consent to determine which of these categories accurately describes an individual's level of capacity.[66]

5.50 In response to these and related concerns, Sexual Health and Family Planning Australia argued that a comprehensive education strategy is required:

> Therefore steps to determine capacity (both for individuals with a disability as well as their carers) must include a nationally endorsed, up-to-date set of education strategies, tools and resources which can be freely and easily accessed and used by health professionals, parents, support workers, and other relevant stakeholders.[67]

5.51 The New South Wales Centre for Disability questioned not only medical expertise but also the extent of disability awareness and the influence of personal values:

> I am a little bit sceptical about the list [of experts] that medical colleges can come up with, because the fact that someone does a lot of this kind of work does not necessarily mean that their values are appropriate.[68]

5.52 Evidence from the medical community was provided by the Australian Medical Association, the Royal Australian College of Physicians, the Royal Australian and New Zealand College of Obstetricians and Gynaecologists, the

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64 Family Planning Victoria, *Submission 58*, p. 5.

65 Dr Chesterman, Office of the Public Advocate, Victoria, *Proof Committee Hansard*, 11 December 2013, p. 14.

66 Family Planning Victoria, *Submission 58*, p. 4.

67 Sexual Health and Family Planning Australia, *Submission 52*, p. 3.

68 Mr Simpson, New South Wales Council for Intellectual Disability, *Committee Hansard*, 11 December 2012, p. 12.

Australian Association of Developmental Disability Medicine Inc. (the AADDM), and the Royal Children's Hospital, as well as individual medical practitioners. Of these, the Australian Medical Association, the Royal Australian College of Physicians and the Royal Australian and New Zealand College of Obstetricians and Gynaecologists did not comment on the expertise or training of doctors and other relevant medical staff in disability matters. In contrast, the AADDM noted that expertise among general practitioners may be lacking, stating that '[m]any GPs do not feel comfortable relating to a female with ID (intellectual disability) who has difficulty communicating or is prone to aggressive outbursts'.[69] Both the Royal Children's Hospital and the AADDM concluded that there is a need for increased training of medical professionals.[70] This issue was considered in chapter 2.

5.53 Evidence provided by the medical community shed further light on the procedures used to determine a person's legal capacity. The Royal Children's Hospital advised that there are extensive guidelines provided by medical boards and medical training programs. Accordingly, it was submitted that '[f]rom our perspective, there is no need for a legal framework that reiterates' these guidelines.[71] The Royal Children's Hospital also noted that '[c]linicians with some experience in working with young women with disability are well aware of the need to try to establish the wishes of the young woman herself'.[72] However, it was further noted that this is not required by medical policy but rather by ethical principle. The hospital's evidence brought into question whether the steps taken by the medical community to ascertain the person's wishes are adequate. The hospital noted that '[a]t RHC, the young women with disabilities tend to be in the more severely disabled spectrum with limited capacity for medication and limited self-care abilities'.[73] The committee was not provided information about the steps taken to ascertain the wishes of these women. Rather, the committee was advised that steps are taken to try to establish factors relevant to the women's quality of life.[74]

5.54 The Australian Medical Association noted that decision making capacity is not static and can be subject to change. The Association also commented that where a person is considered to lack decision-making capacity, 'the patient should be encouraged to participate in the decision-making process as much as possible'. However, the committee was not provided advice about procedures and protocols in place to help facilitate the person's involvement or the doctor's assessment of capacity.[75]

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69 Australian Association of Developmental Disability Medicine Inc., *Submission 59*, p. 3.

70 Australian Association of Developmental Disability Medicine Inc., *Submission 59*, pp. 3–4; Royal Children's Hospital, *Submission 69*, p. 2.

71 Royal Children's Hospital, *Submission 69*, p. 6.

72 Royal Children's Hospital, *Submission 69*, p. 6.

73 Royal Children's Hospital, *Submission 69*, p. 6.

74 Royal Children's Hospital, *Submission 69*, p. 6.

75 Australian Medical Association, *Submission 53*, p. 2.

5.55 Submitters also questioned whether the courts and tribunals are appropriately scrutinising and evaluating the medical evidence received. Reporting in 1997, the Australian Human Rights Commission commented on an apparent trend among Australian courts to 'uncritically accept medical evidence to the exclusion of other relevant expertise'.[76] Similar concerns were raised with the committee. Ms Linda Steele advised that 'the medicalisation of sterilisation has ramifications for evidence and procedure'.[77] It was argued that the consideration by a court or tribunal of whether sterilisation is medically necessary leads to a general acceptance of medical advice.[78] WWDA agreed:

> The propensity of Courts and parents to value medical opinion above all else–and in many cases elevating opinions and assertions to the status of fact–has the effect of reducing the 'best interests' of disabled women and girls to the 'best [and easiest, quickest and cheapest] ways' of controlling and managing their unruly bodies and 'behaviour'.[79]

5.56 It was also questioned whether courts and tribunals have access to a sufficient breadth of medical advice. Mr Simpson observed that:

> To me the other issue that comes with the tribunal—or should come with the tribunal one way or the other, whether it is through the tribunal's own initiative or through involving a public advocate—is ensuring that there is balanced evidence in front of the tribunal and, unless the case is extremely clear, ensuring that a second opinion is obtained from Dr Grover or the like—someone who is known to the public advocate or the tribunal as having the relevant expertise.[80]

5.57 Submitters also argued that there are further measures that could be taken to ensure that the person's wishes are before the tribunal and are given due weight. Access to legal representation was a key feature of this debate. Similar issues arose in relation to children's proceedings.

Participation and legal representation – adults and children

5.58 As noted in chapter 3, the United Nations' Human Rights Committee has concluded that legal representation is a crucial and necessary part of court or tribunal hearings to determine a person's capacity. Commenting in particular on the situation in Lithuania, the committee recommended that:

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76 Australian Human Rights Commission, *The sterilisation of girls and young women in* Australia, 1997, p. 17; citing G. Carlson, M. Taylor, J. Wilson, and J. Griffen, *Menstrual Management and Fertility Management for Women who have Intellectual Disability and High Support Needs: Analysis of Australian Policy*, (2nd ed), 1994, Department of Social Work and Social Policy , University of Queensland.

77 Ms Linda Steele, *Submission 44*, pp. 11–12.

78 Ms Linda Steele, *Submission 44*, pp. 11–12.

79 Women With Disabilities Australia, *Submission 49*, p. 47.

80 Mr Simpson, New South Wales Council for Intellectual Disability, *Committee Hansard*, 11 December 2012, p. 12.

> [t]he State party should ensure free and effective legal representation to individuals in all proceedings regarding their legal capacity, including actions to have their legal capacity reviewed. It also should take appropriate measures to facilitate legal support to persons with disabilities in all matters impacting on their physical and mental health.[81]

5.59 Evidence before the committee indicated that procedures for legal representation differ across the jurisdictions. The AGAC advised that the *Protocol for Special Medical Procedures (Sterilisation)* provides guidance for tribunals considering the appointment of representation for the person.[82] Specifically, clause 5.21 advises that tribunals may consider appointing a representative, known as a separate representative. The protocol does not specify the intended role of the separate representative. Nor does it state that a separate representative is to be a legal representative.[83]

5.60 For proceedings concerning adults with disabilities, practices vary across the states and territories. For example, in the ACT the tribunal must appoint a representative.[84] However, this is not necessarily a legal role.[85] In contrast, the Northern Territory Government advised that there two options for legal representation, namely, the appointment of a legal representative or legal counsel. Both are government funded positions. The committee was further advised that legal counsel operate similarly to the Independent Children's Lawyers appointed in Family Court proceedings.[86]

5.61 The New South Wales Government advised that separate legal representation, provided by Legal Aid New South Wales, will be appointed for both adult and child sterilisation cases. The separate representative's role is to meet with the person to obtain their views and wishes, to the extent this is possible; review the evidence available and obtain any further relevant evidence; and present their independent conclusion to the tribunal about whether the application should be granted.[87] The Adult Guardian of Queensland and the Public Advocate of Queensland advised that the appointment of a legal representative for a child who is the subject of a sterilisation application is mandatory. A legal representative must be appointed in each case. The representative is to act in the child's best interests; have regard to any

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81 Human Rights Committee, *Consideration of reports submitted by States Parties under article 40 of the Covenant, Concluding observations adopted by the Human Rights Committee at its 150 session, 9–27 July 2012–Lithuania*, p. 4, http://www2.ohchr.org/english/bodies/hrc/hrcs105.htm (accessed 7 May 2013).

82 Australian Guardianship and Administration Council, *Submission 28*, p. 4.

83 Australian Guardianship and Administration Council, *Submission 28*, Attachment 1, *Protocol for Special Medical Procedures (Sterilisation)*, cl. 5.21.

84 *Guardianship and Management of Property Act 1991* (ACT), s. 70(2).

85 Correspondence received from the Australian Capital Territory Civil and Administrative Tribunal, 12 May 2013, p. 2.

86 Northern Territory Government, *Submission 34*, pp. 3, 5.

87 New South Wales Government, *Submission 57*, p. 5.

expressed views or wishes of the child; and, to the greatest extent practicable, present the child's views and wishes to the tribunal.[88] The committee was informed that the tribunal has the authority to order that all parties provide information to the child's representative, thus making clear Parliament's intention for the child representative, and by extension the tribunal, to have complete access to all necessary information concerning the child.[89]

5.62 For children's cases, submitters focused on procedures for the appointment of an Independent Children's Lawyer in the Family Court of Australia. The role of an Independent Children's Lawyer (an ICL) is specified in Division 10, Part 7 of the *Family Law Act 1975*. As noted in chapter 3, an ICL does not represent the children's views but forms an independent opinion of what is in the child's best interests.[90] Section 68L of the Act states that the court may appoint an ICL if it appears to the court that the child's interests ought to be independently legally represented. The Family Court confirmed that, in accordance with section 68L, the appointment of an ICL is at the court's discretion.[91] In *Re K* (1994) FLC 92-461, the Full Court of the Family Court held that the circumstances in which it would be appropriate for an ICL to be appointed include:

> [a]pplications in the court's welfare jurisdiction relating in particular to the medical treatment of children where the child's interests are not adequately represented by one of the parties.[92]

5.63 Submitters were critical of the courts' discretion, arguing that it undermines a safeguard that should be available in each case.[93] Academics, disability advocates, and members of the medical profession were united in the view that an ICL should be appointed for every application for court approval of a proposed child sterilisation procedure. Dr Wendy Bonython, Assistant Professor, School of Law, University of Canberra, submitted that an ICL is an essential part of identifying 'the fine-grained details' of a child's best interests:

> There is a very real risk that, if you do not have an independent lawyer whose job is specifically to assess what the best interests of the child are, evidence that is important may simply be missed or left out. If judges do not have access to information they cannot make the best decision possible under the circumstances. I would say that they do need independent representation–not just somebody acting in the role of the contradictor like a Human Rights Commission or someone from the Public Advocate–an

88 Adult Guardian of Queensland and the Public Advocate of Queensland, *Submission 19*, p. 7.

89 Adult Guardian of Queensland and the Public Advocate of Queensland, *Submission 19*, p. 7.

90 *Family Law Act 1975*, s. 68LA.

91 Attorney–General's Department, answer to question on notice, 19 April 2013 (received 14 May 2013).

92 Attorney–General's Department, answer to question on notice, 19 April 2013 (received 14 May 2013).

93 See, for example, Mr Simpson, New South Wales Council for Intellectual Disability, *Committee Hansard*, 11 December 2012, p. 2.

> independent legal adviser who is applying the best interest tests, considering them in the context of the facts, and is completely divorced from any other confounding factors based on family dynamics and relationships that may be present.[94]

5.64 Representatives of the Royal Children's Hospital also submitted that there is a need for independent legal representation for children, noting with concern that an ICL was not appointed in the family law case *Re Angela*.[95] Accordingly, it was recommended that the court's discretion to appoint an ICL in child sterilisation cases should be removed. Appointment should be mandatory.[96] Australian Lawyers for Human Rights linked the failure to provide an ICL with a failure to ensure that the child 'has a voice' in proceedings that impact their welfare.[97]

5.65 Additionally, while highlighting the importance of legal representation for children, the expertise of Independent Children's Lawyers was questioned. Dr Susan Hayes identified a need for 'more thorough and extensive' training for lawyers who represent adults or children in sterilisation cases.[98] The Queensland Centre for Intellectual and Development Disability, the Queenslanders with Disabilities Network and Queensland Advocacy Inc. submitted that legal representatives should receive training in disability matters, including alternatives to sterilisation.[99] The New South Wales Council for Intellectual Disability commented:

> In relation to ensuring that there is another voice for the child or for the person with a disability, if the Public Advocate is involved you have an expert rights based body. If you are relying on separate representative lawyers from Legal Aid, as I think may happen in other parts of Australia, you are not necessarily getting anybody who has the expertise.[100]

5.66 The committee sought, but did not receive information concerning the qualifications of persons appointed to act as an ICL.[101] In contrast, the committee was informed that a child's legal representative for proceedings before QCAT 'must be a lawyer with experience in dealing with children with impairment'.[102]

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94 Dr Wendy Bonython, Assistant Professor, School of Law, University of Canberra, *Committee Hansard*, 27 March 2013, p. 63.

95 Royal Children's Hospital, *Submission 69*, p. 6.

96 See, for example, Dr Wendy Bonython, *Submission 22*, Recommendation 6, p. 4.

97 Australian Lawyers for Human Rights, *Submission 41*, p. 3.

98 Professor Susan Hayes, *Submission 47*, p. 4.

99 Qld Centre for Intellectual and Developmental Disability, Queenslanders with Disabilities Network, and Qld Advocacy Inc, *Submission 37*, p. 3.

100 Mr Simpson, New South Wales Council for Intellectual Disability, *Committee Hansard*, 11 December 2012, p. 11.

101 Attorney–General's Department, answer to question on notice, 19 April 2013 (received 14 May 2013).

102 Adult Guardian of Queensland and the Public Advocate of Queensland, *Submission 19*, p. 7.

5.67 In response to these concerns, Chief Justice Diana Bryant of the Family Court of Australia advised that the appointment of an ICL may not be appropriate in every case. The Chief Justice considered that despite the title of 'Independent' Children's Lawyer, an ICL 'is not going to necessarily be giving an objective view'.[103] The Chief Justice advised that in considering what is in the best interests of the child, an ICL may concur with the views of a party to the proceedings. The Chief Justice agreed with the proposition that a child's voice can be represented by a third party, such as a contradictor.[104] However, the committee notes that there is a legislative requirement under the *Family Law Act 1975* (Cth) for ICLs to act independently. Objectivity and impartiality appear to be an implicit part of their duties as specified under section 68LA of the Act.

5.68 In addition to the legal representation of children, it was further put to the committee that adults should also be provided representation.[105] However, some submitters, such as the Royal Children's Hospital, were silent on the issue of whether this representative should be a legal representative.[106]

5.69 Alternatively, it was submitted that it would be appropriate to include disability advocates in child and adult sterilisation cases. The Queensland Centre for Intellectual and Development Disability, the Queenslanders with Disabilities Network and Queensland Advocacy Inc. argued that it would be appropriate for disability advocates to be parties to sterilisation cases to 'provide informed and independent representation'. The organisations advised that additional resources would be required for disability advocacy services to undertake this role.[107] The Chief Justice of the Family Court advised that 'it would not be appropriate for rights–based organisations to be involved'.

> The information regarding rights and so forth should inform other people in making decisions. We get ultimately the evidence that comes from doctors, parents, psychiatrists and psychologists who have thought about all of these issues at an earlier stage. So one would have hoped that all of the issues about rights, difficulties and problems would have been considered—particularly where hospitals are involved.[108]

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103 The Hon. Diana Bryant, AO, Chief Justice, Family Court of Australia, *Proof Committee Hansard*, 27 March 2013, p. 60.

104 The Hon. Diana Bryant, AO, Chief Justice, Family Court of Australia, *Proof Committee Hansard*, 27 March 2013, p. 61.

105 Mr Simpson, New South Wales Council for Intellectual Disability, *Committee Hansard*, 11 December 2012, p. 11.

106 Royal Children's Hospital, *Submission 69*, p. 2; Associate Professor Sonia Grover, Gynaecologist, Royal Children's Hospital, *Committee Hansard*, 11 December 2012, p. 11.

107 Qld Centre for Intellectual and Developmental Disability, Queenslanders with Disabilities Network, and Qld Advocacy Inc., *Submission 37*, p. 3.

108 The Hon. Diana Bryant, AO, Chief Justice, Family Court of Australia, *Proof Committee Hansard*, 27 March 2013, p. 60.

The 'best interests' test

5.70 The use and application of the 'best interests' test was a key topic for submitters to the inquiry. Currently, the best interest test is not in use in every jurisdiction. In jurisdictions where a best interest test is in use, there are variations in the criteria to determine whether a sterilisation procedure would be in a person's best interests. As one submitter noted:

> The very fragmented nature of the legislative and common law system that we have at the moment means that you could have different tests being applied all over the place.[109]

5.71 Of the four jurisdictions that have legislated for child sterilisation procedures, New South Wales has not adopted a best interests test. However, Dr Bonython, University of Canberra, advised that there have been cases in New South Wales where the tribunal has taken a broad view of the legislation and, accordingly, applied a best interests test.[110] In the remaining jurisdictions, Queensland, Tasmania and the Commonwealth (including Western Australia operating under Commonwealth law), sterilisation may be authorised if in the child's best interests. However, while these three jurisdictions all use a best interests test, the criteria that define best interests differ. For adults, a best interests test applies in five jurisdictions. However, again the criteria used to determine whether this test is satisfied differ throughout the jurisdictions.

The best interests of the child - definition

5.72 For Commonwealth cases, 'child's best interests' is defined by section 60CC of the Family Law Act. However, the definition relates to family arrangements such as who the child is to live with and spend time with. The court is also to consider factors outlined in *Re Marion (No. 2)* (1994) FLC 92–448 and Division 4.2.3 of the Family Law Rules. The criteria that apply for Commonwealth cases are outlined in detail in chapter 3.

5.73 In Queensland, sterilisation is taken to be in the child's best interest if one or more of the following applies:[111]

- The sterilisation is medically necessary;
- The child is, or is likely to be, sexually active and there is no method of contraception that could reasonably be expected to be successfully applied; or
- If the child is female, the child has problems with menstruation and cessation of menstruation by sterilisation is the only practicable way of overcoming the problems.

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109 Dr Bonython, School of Law, University of Canberra, *Committee Hansard*, 27 March 2013, p. 65.

110 Dr Bonython, School of Law, University of Canberra, *Committee Hansard*, 27 March 2013, p. 65.

111 *Guardianship and Administration Act 2000* (QLD), ss 80D(1)(a).

5.74 Additionally, the court must be satisfied that all of the following criteria apply:[112]

- The child's impairment results in a substantial reduction of the child's capacity for communication, social interaction and learning; and
- The child's impairment is, or is likely to be, permanent and there is a reasonable likelihood, when the child turns 18, the child will have impaired capacity for consenting to sterilisation; and
- The sterilisation cannot reasonably be postponed; and
- The sterilisation is otherwise in the child's best interests.

5.75 In contrast, in Tasmania 'best interest of the child' is determined according to the following factors:[113]

- The wishes of that person, so far as they can be ascertained; and
- The consequences to that person if the proposed treatment is not carried out; and any alternative treatment available to that person; and
- Whether the proposed treatment can be postponed on the ground that better treatment may become available and whether that person is likely to become capable of consenting to the treatment.

Criteria to determine whether a procedure would be in the best interests of the adult

5.76 For sterilisation cases involving adults, a best interests test is used in the Australian Capital Territory, the Northern Territory, Tasmania, Victoria, and Western Australia. In New South Wales, sterilisation may only be approved if the tribunal is satisfied that the treatment is necessary to save the adult's life or to prevent serious damage to the person's health.[114] In Queensland, the legislation does not include a best interests test. However, the list of factors that the tribunal is to consider share elements of the best interests test used in children's cases. Factors include whether the procedure is medically necessary; whether the person is, or is likely to be, sexually active; whether there are other methods of contraception that could reasonably be expected to be successfully applied; and whether the sterilisation cannot reasonably be postponed.[115] South Australia adopts a hybrid approach, whereby sterilisation may be authorised if therapeutically necessary or if certain other factors are satisfied.[116]

5.77 In the remaining jurisdictions, the best interest tests are not uniform but are defined differently throughout the relevant State and Territory legislation. Details of ACT, Northern Territory and Victorian legislation are provided by way of contrast. In

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112 *Guardianship and Administration Act 2000* (QLD), ss 80D(1)(b)–(e).

113 *Guardianship and Administration Act 1995* (Tas), s. 45.

114 *Guardianship Act 1987* (NSW), s. 45.

115 *Guardianship and Administration Act 2000* (QLD), s. 70.

116 *Guardianship and Administration Act 1993* (SA), s. 61.

the Australian Capital Territory, to determine whether a procedure is in the adult's best interests, the tribunal must consider the person's wishes, insofar as they can be ascertained; the likely consequences if the procedure is not carried out; the availability of alternative treatments; and whether the treatment can be postponed as better treatments may become available.[117] In the Northern Territory, while a threshold for authorising a procedure is whether the procedure is in the person's best interests, 'best interests' is not explicitly defined the legislation.[118] In Victoria, to determine whether sterilisation would be in the person's best interests, the tribunal is to consider the person's wishes and the wishes of any relative; the consequences if treatment is not carried out; the nature and degree of any risks associated with the treatment; and whether the treatment is to be carried out only to promote and maintain the person's health and well-being.[119] By considering the views of relatives, the Victorian legislation explicitly incorporates the opinions, and potentially the needs and circumstances, of carers and family members.

Criticisms of the best interests test

5.78 The merits of the best interests test as the basis for authorising a sterilisation procedure were strongly debated. Opinion was divided on whether the best interests test is not only appropriate for sterilisation cases but suitably defends a person's human rights.[120] The strong opposition to the use of the best interest test is evident in WWDA's statement that the test has been 'successively used to justify the torture of women and girls with disabilities' and to 'perpetuate discriminatory attitudes'.[121] Best interests tests were criticised on two grounds.

International law

5.79 First, it was submitted that use of a best interests test is prohibited under international law. WWDA contended that the international human rights framework is 'very clear that best interests can no longer be used as an argument'.[122] People with Disability Australia likewise commented that due to the presence of best interests tests in Commonwealth, state and territory legislation 'there is no synergy' between Australia's domestic law and international law.[123]

5.80 As explored in chapter 3, the committee was advised of comments by United Nations' committees regarding best interests tests. This included the advice of the Australian Women Against Violence Alliance that the United Nations' Committee

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117 *Guardianship and Management of Property Act 1991* (ACT), s. 70.

118 *Adult Guardianship Act* (NT), s. 21.

119 *Guardianship and Administration Act 1986* (VIC), s. 38.

120 See, for example, Ms Cootes, Intellectual Disability Rights Service Inc, *Committee Hansard*, 27 March 2013, p. 18.

121 Women With Disabilities Australia, *Submission 49*, p. 44.

122 Ms Frohmader, Women With Disabilities Australia, *Committee Hansard*, 11 December 2012, p. 27.

123 Ms Sands, People with Disability Australia, *Committee Hansard*, 11 December 2012, p. 6.

on the Rights of the Child has stated that 'the interpretation of the child's interests must be consistent with the whole Convention, including the obligation to protect children from all forms of violence.'[124] Similarly, WWDA submitted:

> The committee on the rights of the child has spelt out that you cannot sterilise a child with a disability using the language of 'best interest'—it is not in their best interest.[125]

5.81 The Human Rights Committee has questioned the use of 'best interests' tests, advising that 'international human rights standards…prohibit the coerced treatment of people suffering from intellectual disabilities, regardless of arguments of their "best interests"'.[126] Such statements formed the basis of the argument that the best interest test is prohibited under international law.[127]

5.82 Amnesty International Australia also submitted that a best interest test is contrary to international law, reporting that:

> [c]laims that forcing or coercing women and girls into sterilisation is in their best interests contradict the general principles of respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons set out in Article 3(a) of the CRDP [Convention on the Rights of Persons with Disabilities].[128]

5.83 People with Disability Australia argued that Australia's interpretation of the best interests test differs from what was intended under the Convention:

> So under the convention, if the concept of involuntary or coerced sterilisation is a form of violence, then how could it ever be in the best interests of a child to authorise it? So the concept of involuntary and coerced sterilisation is different according to our obligations under international human rights and often the best interests, as applied here, actually allows for the authorisation of what we would call 'legal violence'—and it has been called that in some other submissions as well.[129]

5.84 However, the recommendations of United Nation's committees, and the resulting interpretation of Australia's international law obligations, were not supported by all submitters to the inquiry. The Commonwealth Attorney–General's Department advised that the use of the best interest test is, in the Government's view, consistent

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124 Australian Women Against Violence Alliance, *Submission 49*, pp. 1–2.

125 Ms Frohmader, Women With Disabilities Australia, *Committee Hansard*, 11 December 2012, p. 6.

126 Office of the United Nations High Commissioner for Human Rights, *Thematic study on the issue of violence against women and girls and disability*, 30 March 2012, p. 10.

127 See, for example, Ms Frohmader, Women With Disabilities Australia, *Committee Hansard*, 11 December 2012, p. 6.

128 Amnesty International Australia, *Submission 48*, p. 44.

129 Ms Sands, People with Disability Australia, *Committee Hansard*, 11 December 2012, p. 6.

with Australia's international obligations.[130] The scope and effect of international law is considered in chapter 4 of this report.

5.85 Dr Wendy Bonython provided a counterpoint to the view that a best interests test is contrary to human rights principles. Dr Bonython noted that Article 7 of the Convention on the Rights of the Child requires the child's best interests to be a primary consideration in all actions concerning children with disabilities.[131] Dr Bonython further argued that sterilisation may be necessary to protect a person's rights:

> Sterilisation of people lacking capacity should be extremely rare; however, there may be some circumstances under which it is in the best interests of the person concerned, and, rather than denying that person their best chance of living a life of dignity and meaning by categorically banning the procedure, this submission instead argues that appropriate safeguards should be put in place to ensure that it truly is in their best interests.[132]

5.86 The Adult Guardian of Queensland and the Public Advocate of Queensland made a similar point, stating:

> It would seem that society has a tendency to assume that an individual would not choose sterilisation rather than applying an equilateral perspective that considers that both choices are ones that may be rightly made by an individual if they are in a situation where such a decision is being considered. The right to choose as well as the best interests of the person (taking into account all short and long term circumstances) must both be considered.[133]

5.87 In contrast with the concerns with the use of a best interests test, a number of submitters supported its use. In particular, the best interests test was supported by members of the judiciary and the legal profession, the medical profession, and carers of persons with disabilities. Dr Bonython submitted:

> [l]egislation should, at a minimum, contain a 'best interests' test based on Nicholson CJ's guidelines, considering not just the person's medical welfare, but also their psychological, educational, and social best interests.[134]

5.88 This view was endorsed by the Chief Justice of the Family Court, who noted that consideration of a particular child's best interests can differ from a broader rights-based discussion:

> I would only add that our role is to make a decision that is in the best interests of the child in a particular case, and that is what we do. Rights

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130 Attorney–General's Department, answer to question on notice, 19 April 2013 (received 14 May 2013).

131 Dr Wendy Bonython, *Submission 22*, p. 22.

132 Dr Wendy Bonython, *Submission 22*, p. 2.

133 Adult Guardian of Queensland and the Public Advocate of Queensland, *Submission 19*, p. 2.

134 Dr Wendy Bonython, *Submission 22*, Recommendation 5, p. 37.

> based issues, as I say, are separate. They sometimes coincide but sometimes they do not. I do not think I can say any more than that.[135]

5.89 This emphasis on the circumstances of the particular child was also cited by members of the medical profession in support of the use of the best interests test. Dr Irwin Farris commented:

> I would argue that taking into consideration the whole context of the patient and her situation it should be possible for an independent authority such as a Guardianship Board, to conclude that it is the best interests of the patient that a sterilisation procedure be performed.[136]

5.90 Similarly, Ms Janine Truter, private capacity, submitted that is the best interest test promotes equality and equal access to medical treatment:

> [A] person who is not disabled, or a disabled person with some decision-making ability can consent to their sterilisation in their own best interests. Those who can't give valid consent would lose this option, or the option to have someone make the decision on their behalf, under any proposed laws to make sterilisation illegal.[137]

5.91 The best interests test was contrasted with the criteria used in New South Wales. Carers, for example Professor John and Mrs Merran Carter, expressed concern with the New South Wales framework, arguing that it has led to unfair and overly restrictive outcomes. Accordingly, the Carters recommended the New South Wales legislation be amended to introduce a best interests test. Such a test, it was submitted, should consider factors such as the person's quality of life, ability to be independent, medical reasons for the proposed procedure and the suitability and availability of any alternatives.[138]

5.92 There was, however, a limit to the support for the use of the best interests tests. Dr Bonython was critical of Family Court decisions that have authorised sterilisation of a minor before menstruation:

> To pre-emptively authorise sterilisation of a minor before menstruation begins is inconsistent with the concept of it being a 'step of last resort'. The risk that a girl might be traumatised, as a consequence of being exposed to a phenomenon that she is yet to encounter is too remote to justify the procedure. Furthermore, it prematurely deprives her of the right to attempt to manage any issues which may- not necessarily will- manifest in a less invasive way.[139]

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135 The Hon. Diana Bryant, AO, Chief Justice, Family Court of Australia, *Committee Hansard*, 27 March 2013, p. 61.

136 Dr Irwin Faris, *Submission 8*, p. 1. See also Royal Australian College of Physicians, *Submission 17*, p. 2.

137 Ms Janine Truter, *Submission 18*, p. 4.

138 Professor John and Mrs Merren Carter, *Supplementary Submission*, p. 1.

139 Dr Wendy Bonython, *Submission 22*, p. 37.

Amorphous, undefined and slanted to give weight to the views and needs of carers

5.93 Submitters also argued that the best interest test is a malleable concept that can fail to address the needs and human rights of persons with disabilities. There appeared to be widespread concern that best interests tests are amorphous, and therefore do not provide adequate safeguards. The Intellectual Disability Rights Service Inc. characterised the best interests test as 'very loose'.[140] People with Disability Australia agreed with comments by former justice of the High Court of Australia, Brennan J, that 'in the absence of legal rules or a hierarchy of values' the best interests test is discretionary and flexible, being subject to the values and experiences of the decision-maker.[141] A similar point was made by the OPA, Victoria and the New South Wales Council for Intellectual Disability.[142] Mr Simpson, New South Wales Council for Intellectual Disability commented:

> [a] lot of the trouble is that the combination of the best interests test is so much in the eye of the beholder, with the beholder perhaps being an elderly judge. I think that is problematic.[143]

5.94 Several submitters argued that best interests tests have been used to justify decisions based on inappropriate considerations such as preventing pregnancies resulting from sexual abuse, notions that persons with disabilities are incapable of parenting, eugenic arguments and arguments that sterilisation would benefit the state, the community, and the family.[144] Analysis by WWDA was commonly cited in support of these concerns.[145] Predominantly, it was argued that a best interests test may allow the courts and tribunals to elevate the needs of the carer above the needs, wishes and interests of the person with disability. This view was held by a broad spectrum of submitters to the inquiry, including disability advocates and the Australian Human Right Commission. Disability Discrimination Commissioner Mr Graeme Innes considered best interests tests to be susceptible to a 'slewed' interpretation, one that prioritises the interest of parents and carers:

> The justification for the views that you talked about is based on a slewed interpretation of best interests. It is really based on the assertion that the best interests of children or adults with disability and the best interests of

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140 Ms Janene Cootes, Executive Officer, Intellectual Disability Rights Service Inc., *Committee Hansard*, 27 March 2013, p. 18.

141 People with Disabilities Australia, *Submission 50*, p. 15.

142 Dr Chesterman, Office of the Public Advocate, Victoria, *Committee Hansard*, 11 December 2013, p. 14; Mr Simpson, New South Wales Council for Intellectual Disability, *Committee Hansard*, 11 December 2012, p. 14.

143 Mr Simpson, New South Wales Council for Intellectual Disability, *Committee Hansard*, 11 December 2012, p. 14.

144 See, for example, Ms Sands, People with Disability Australia, *Committee Hansard*, 11 December 2012, p. 3.

145 See, for example, Australian Lawyers for Human Rights, *Submission 41*, p. 4; Australian Women's Health Network, *Submission* 44, p. 2; Catholic Women's League Australia Inc., *Submission 32*, p. 5.

> parents and carers can be weighed on an equal footing. International human rights law makes it clear that that is just not the case and that the primary issue to take into account is the best interests of the adult or child with a disability. Whilst the interests of parents and carers are important they do not rate at the level of the best interests of the child or adult with disability. There is an obvious reason for that—that is, the person whose bodily integrity is being impacted upon is an adult or child with a disability so of course their best interests would have to be paramount.[146]

5.95 The Queensland Centre for Intellectual and Developmental Disabilities concurred:

> Leaving decision-making in the hands of professionals—be it the Family Court of Australia or guardianship boards, who have little experience or knowledge of living with disability and whose framework derives from a utilitarian perspective—will only result in the decisions we see occurring today: that 'therapeutic' is defined as being in the best interests of a triangle of stakeholders—family, medical profession and care organisations—rather than the individual.[147]

5.96 While supporting a best interests approach, Dr Bonython cautioned against considering the views, needs and wishes of parents and carers as a key factor when reaching a decision.[148] Queensland Advocacy Inc agreed:

> Therefore, the test of 'best interests' requires careful consideration and analysis. Frequently, there is a tendency to give substantial weight to the 'best interests' of other parties, particularly family members and services.[149]

5.97 It is notable that the AGAC's *Protocol for Special Medical Procedures (Sterilisation)* directs tribunals to distinguish between the best interests of the person and the interests of the person's carers.[150]

5.98 However, not all submitters to the inquiry took exception to the inclusion in a court or tribunal's deliberation of the needs and wishes of the carer. Ms Janine Truter, private capacity, submitted:

> The carer is crucial to the best interests of the person with a decision-making disability. To disregard their role and emotional investment, as well as the best interests of the decision-making disabled person, is astonishing.[151]

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146 Mr Graeme Innes, Disability Discrimination Commissioner, Australian Human Rights Commission, *Committee Hansard*, 27 March 2013, p. 37.

147 Ms Miriam Taylor Gomez, Education Coordinator, Queensland Centre for Intellectual and Developmental Disabilities, *Committee Hansard*, 11 December 2012, pp. 19–20.

148 Dr Wendy Bonython, *Submission 22*, pp. 10–11.

149 Queensland Advocacy Inc, *Submission 65*, p. 7.

150 Australian Guardianship and Administration Council, *Submission 28*, p. 1.

151 Ms Janine Truter, *Submission 18*, p. 3.

5.99 Ms Truter argued that calls for courts and tribunals to not consider the needs and wishes of parents are based on an unrealistic and inappropriate assumption that parents and guardians do not properly support the welfare of persons in their care. It was submitted that calls for sterilisation to be banned other than in circumstance where the person is capable of providing free and informed consent incorrectly assumes that a prohibition is needed to protect disabled persons from their carers or guardians.[152] Chief Justice Diana Bryant of the Family Court of Australia advised that it is legally permissible to consider the views and needs of parents and carers, if this would help inform the court of the overall circumstances and facts relevant to the child:

> It is important to remember that although the best interests of the child is the paramount consideration, it is not the sole determinant. It is well established at law that all relevant circumstances in each individual case should be taken into account in arriving an outcome that is in the child's best interests. In some sterilisation cases, the appreciable easing of the burden on the parents as primary carers has been found to be a relevant factor.[153]

The introduction of a 'but for' test

5.100 The 'but for' test was submitted as an alternative to a 'best interests' test. Ms Lesley Naik provided the following explanation of the purpose and practical application of a 'but for' test:

> The ‘but for’ test in the context of sterilisation recognises that a child’s intellectual disability often changes the equation that indicates a case for or against sterilisation. It therefore isolates the distinctive feature of these children, which is their intellectual disability, and compels the removal of that distinctive feature from the decision–making process. In practical terms, it asks ‘but for’ the child’s intellectual disability would the outcome of the clinical decision be any different?[154]

5.101 Various submitters advised that the United Nations special rapporteur on torture 'has recently reiterated that the law should never distinguish individuals on the basis of capacity or disability in order to permit sterilisation'.[155] It was argued that by removing any consideration of the presence and effects of disability, a 'but for' test complements this recommended approach. In short, submitters argued that a 'but for' test is a necessary safeguard to prevent discrimination.

5.102 In defence of the proposition that 'there is discrimination within the law itself that results in the delineation of people with disability as a distinct class of legal subjects', Ms Linda Steele submitted that to fail to adopt a 'but for' is to 'render an

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152 Ms Janine Truter, *Submission 18*, p. 3.

153 The Hon. Diana Bryant, AO, Chief Justice, Family Court of Australia, *Submission 36*, p. 4.

154 Ms Lesley Naik, *Submission 7*, p. 7.

155 Ms Linda Steele, *Submission 44*, p. 3; Women With Disabilities Australia, *Submission 49*, p. 39.

individual *fundamentally* different and *incomparable* to someone without a disability.'[156] Queensland Advocacy Inc similarly argued that a 'but for' test removes discrimination, and in doing so promotes equality before the law:

> As an option of last resort, it should not be offered on a discriminatory basis. Therefore, it is crucial to consider whether sterilisation would be offered to a person without a disability in the same circumstances or given the same medical indications.[157]

5.103 Associate Professor Sonia Grover, Gynaecologist, Royal Children's Hospital, agreed, stating '[w]e should not be doing a sterilising procedure if we would not be doing it on somebody who did not have a disability.'[158] People with Disability Australia also supported a 'but for' test on the grounds that it promotes human rights and equality:

> In making decisions about an application for authorisation of purported therapeutic sterilisation, PWDA argues that the "but for" criterion is the most protective of human rights. That is, in determining an application for authorisation of a procedure that will result, either directly or indirectly in sterilisation, the court or tribunal must determine if the procedure would be authorised in the same or similar circumstances in relation to a person without disability. If the procedure would not be authorised in relation to a person without disability, it ought not be authorised in relation to a person with disability.[159]

5.104 Further, Queensland Advocacy Inc argued that a 'but for' test is necessary to counter, and to expose, cultural prejudice:

> Sterilisation is currently performed on a discriminatory basis, in particular being performed on very young women and girls, men and boys, where the culturally valued norm is for young people never to be sterilised. Thus, it is important to ask whether sterilisation would be proposed "but for" the disability.[160]

Reported difficulties with a 'but for' test

5.105 However, difficulties were also identified with the use of a 'but for' test. Accordingly, the test was not supported by all submitters to the inquiry. Rather than promoting equality, it was submitted that the test actually diminishes access to legal and medical remedies that may have otherwise been available but for the use of the 'but for' test.

> [S]ome commentators and judges have taken the view that it is inappropriate to apply the comparator test - asking whether the same order

156 Ms Linda Steele, *Submission 44*, pp. 14–16.

157 Queensland Advocacy Inc, *Submission 65*, p. 6.

158 Associate Professor Sonia Grover, Gynaecologist, Royal Children's Hospital, *Committee Hansard*, 11 December 2012, p. 9.

159 People with Disabilities Australia, *Submission 50*, p. 17.

160 Queensland Advocacy Inc, *Submission 65*, p. 6.

> would be granted in respect of a person without a disability- because of the enormity of the disability affecting the people the orders are being sought.
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> In P v P (2), the Court rejected the use of the 'but for' or comparator, test in applications for authorisation, stating:
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> "In our view it is illusory and misleading to even attempt to equate her position and to do so entirely shifts the focus of the enquiry away from where it should be, i.e. whether it is in her best interests that the procedure be performed."[161]

5.106 The Chief Justice of the Family Court also noted the conclusions of the Full Court of the Family Court in *P & P & Legal Aid Commission of New South Wales & Human Rights and Equal Opportunity Commission*. Specifically, the court's concern that the 'but for' test is actually discriminatory was highlighted:

> [T]he test is whether or not it would be in the best interests of the child to have the procedure performed, taking into account all relevant facts and circumstances. Professor Grover is effectively advancing what has been described as the but for test. The test has been rejected by the Full Court of the Family Court…The Full Court said the following:
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> "We disagree with the concept of such a test in these cases. While it may be superficially attractive to impose this sort of test upon the basis that it is non-discriminatory and equates the intellectually handicapped person with the non-intellectual handicapped, upon analysis it has the opposite effect.
>
> To apply it is, in our view, conceptually incorrect. We consider it is both unrealistic and contrary to the intention of the majority judgement in Marion's case to deal with a particular aspect of the child's needs and capacities as though it existed in isolation from other needs and capacities."[162]

5.107 Implicit in this judicial reasoning is support for the view that a person with disabilities cannot be viewed as part of a larger class of persons, but must be considered with reference to their individual life circumstances. This is evident in a New South Wales case cited by WWDA, in which the tribunal held that:

> Ms BAH's disability is clearly central to the Tribunal's deliberations in this matter. But for Ms BAH's intellectual disability, the Tribunal would not have given consideration to the proposed treatment.[163]

5.108 However, there was a concern among some submitters that an individual focus legitimises discrimination and ill treatment. As Ms Linda Steele submitted:

> The absolute distinction made on the basis of disability between people with and without disability, and the additional characterisation of these in terms of normality and abnormality…means that individuals with disability

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161 Dr Wendy Bonython, *Submission 22*, p. 23.

162 The Hon. Diana Bryant, AO, Chief Justice, Family Court of Australia, *Submission 36*, p. 5.

163 *BAH* [2009] NSWGT 8 (28 July 2009), as cited in Women With Disabilities Australia, *Submission 49*, pp. 39–40.

> can be legitimately subject to a form of violence that would be incomprehensible to people without disability. Moreover, the focus on an individual's best interests isolates them from comparison.[164]

The 'but for' test and the medical profession

5.109 It was further suggested that a 'but for' test may be appropriate for use by the medical profession. Both the OPA and Ms Lesley Naik identified that the test could be used as a threshold consideration to determine whether it would be inappropriate to proceed with the proposed sterilisation procedure without court or tribunal approval. As the OPA submitted:

> When parents and professionals are considering the sterilisation of a child, they should ask themselves whether they are only considering this procedure because of the child's disability (the 'but for' test). If this procedure would not be considered for a child without a disability then judicial authority has to be obtained as it must be a non-therapeutic procedure that is being considered.[165]

5.110 In support of this proposal, the OPA cited the work of Ms Lesley Naik.[166] In evidence before this inquiry, Ms Naik reported that the '"but for" test may be a useful practical tool to assist medical practitioners to apply the legal test for determining whether sterilisation requires court authorisation'.[167]

Committee view

5.111 As the committee has recommended in the previous chapter, substituted decision-making must only occur where appropriate supported decision-making has not resulted in persons having the capacity to decide for themselves. The laws, practices and procedures of relevant courts and tribunals must recognise that they are a venue of last resort to be accessed only after all appropriate supported decision-making options have been explored. Accordingly, the courts and tribunals exist to serve persons without legal capacity, even with the assistance of supported decision-making. The committee's analysis has revealed that Australia is failing to ensure that substituted decision-making only occurs where appropriate, and with all necessary safeguards. More can, and must, be done to defend the rights of persons with disabilities.

5.112 Aspects of court and tribunal procedure must be changed. Giving effect to this change will require amendments to the Commonwealth, state and territory laws that regulate court procedure. Implementing the recommended changes in every jurisdiction will lead to greater uniformity in the laws, practices and procedures that regulate access to sterilisation procedures for persons with disabilities. In chapter 7,

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164 Ms Linda Steele, *Submission 44*, pp. 14–16.

165 Office of the Public Advocate, *Submission 14*, p. 7.

166 Office of the Public Advocate, *Submission 14*, p. 7.

167 Ms Lesley Naik, *Submission 7*, p. 6.

the committee will consider whether additional consistency and uniformity across jurisdictions is required.

Amend legislation to ensure that courts and tribunals do not interfere with a person's ability to decide for themselves

5.113 In the first instance, for cases concerning adults, state and territory legislation should be amended to explicitly state that it is presumed that persons with disabilities have the capacity to make their own decisions unless objectively assessed otherwise. The committee was particularly struck by the compelling evidence before this inquiry that capacity is not static. Capacity can evolve with time and support. Accordingly, incapacity cannot be assumed even where a guardianship order is in place. It must be tested in every instance when major or irreversible decisions, such as sterilisation, are being considered.

Recommendation 8

5.114 The committee recommends that state and territory legislation regulating the sterilisation of adults with disabilities be amended to explicitly state that it is presumed that persons with disabilities have the capacity to make their own decisions unless objectively assessed otherwise. The legislation should be amended to specify that it cannot be presumed that persons are without legal capacity in relation to the proposed special medical procedure, including a sterilisation procedure, even where there is an existing guardianship order in place.

Recommendation 9

5.115 The committee recommends that Commonwealth, state and territory legislation regulating the sterilisation of adults with disabilities be amended to explicitly state that a court or tribunal does not have authority to hear an application for an order approving a proposed special medical procedure, including a sterilisation procedure, where the person with a disability has legal capacity.

5.116 The committee considers that there is merit in introducing one definition of capacity to apply in every jurisdiction. A person's rights to autonomy and bodily integrity should not vary depending on the state or territory in which they live. The committee particularly recommends the definition of capacity under the Australian Guardianship and Administration Council's *Protocol for Special Medical Procedures (Sterilisation)*.

Recommendation 10

5.117 The committee recommends that each Australian jurisdiction use the same definition of capacity, to ensure that a person's rights to autonomy and bodily integrity do not vary according to, and are not dependent on, the jurisdiction in which they live.

A best protection of rights test

5.118 The committee recognises that the application of a best interests test is a contentious subject. After careful consideration the committee reached three conclusions.

5.119 First, while a test that considers the person's interests is to be preferred over an outright ban on sterilisation, the test should be focussed on the protection of their rights, rather than on their 'best interests'. The main arguments regarding this issue were discussed in the previous chapter. The committee accepts the evidence that was provided by many submitters showing that, as currently applied, 'best interests' tests are currently at risk of 'a slewed interpretation'.[168]

5.120 The committee believes that the language of 'best interests' is not the most appropriate in this context. The committee believes that the appropriate test is of whether an action represents the best available protection and fulfilment of a person's rights. This should include recognition that a person with a disability should have the same right to access medical procedures in pursuit of quality of life as does a person without a disability.

5.121 Second, the committee concluded that a 'best protection of rights' test must be stringent – current criteria are insufficient to safeguard the rights of persons with disabilities as applied in some cases. Specifically, accounting for someone's best interests must include:

- Protection of their rights.
- Maximising future options and choices.
- Decisions to be made on the basis of the best support services available, not whatever services happen to have been provided in the past, which witnesses (including people with disabilities, their parents, and guardians) have frequently told the committee have been inadequate. This is particularly important in the context of the roll-out of Disability Care Australia services.

5.122 The committee urges jurisdictions, in adopting a best protection of rights test, to be vigilant and ensure it is not undermined by inappropriately broad interpretations of what constitute 'therapeutic' cases not requiring tribunal or court consideration. The problem of ambiguity in the interpretation of 'therapeutic' was discussed in an earlier chapter, and will be considered further by the committee in a later report on intersex issues.

5.123 The committee emphasises that, in moving away from the best interests test, it is still of the view that the procedural safeguards and considerations identified in the Australian Guardianship and Administration Council's 2009 *Protocol* (discussed in chapters 3 and 5) should be retained. Thus, for example, there should continue to be a requirement that less invasive procedures must have been considered and, where appropriate, tried, before more invasive or permanent procedures are undertaken.

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168 Mr Graeme Innes, Disability Discrimination Commissioner, Australian Human Rights Commission, *Committee Hansard*, 27 March 2013, p. 37.

5.124 Third, the committee agreed with the Full Court of the Family Court, that a 'but for' test should not be adopted by courts and tribunals. Committee members have been exposed to a wide range of issues in the context of disability, both within and beyond the current inquiry, and both within and outside their parliamentary responsibilities. That range of experience leads the committee to the view that a disability cannot be treated as an isolated feature of a person, which may be conceptually separated from the rest of their being. They are not defined by their disability, but neither is the disability a separable thing. Accordingly, courts should not construct tests as if it were possible to separate them. The committee is also concerned that a 'but for' test requires life without disability to be taken as the 'norm', and disability is then defined as deviance from that norm. Every person should be treated as equal, and the committee believes that a best protection of rights test, underpinned by a strong understanding and protection of equal rights, is the better approach.

5.125 The committee notes, however, that there is considerable merit in Ms Naik's suggestion that a 'but for' test could assist doctors to clarify their thinking about circumstances in which cases require court consideration, and this should be considered further by those responsible for training and development of medical professionals working in the field.

Recommendation 11

5.126 The committee recommends that all jurisdictions adopt in law a uniform 'best protection of rights' test, replacing current 'best interests' tests, that makes explicit reference to the protection of the individual's rights; and the maintenance of future options and choices.

Recommendation 12

5.127 The committee recommends that, in those cases where the need for supports has a bearing on the assessment of interests, regard should be had to best support services available, rather than the deficit in services provided in the past.

Recommended changes to court and tribunal procedures

5.128 An irreversible medical procedure should not be authorised on the basis of temporary circumstance. Similarly, an irreversible procedure should not be authorised due to a failure to provide a person with the support he or she needs to understand the proposed procedure and to convey their wishes. Sterilisation should not occur due to failure on the part of courts and tribunals to facilitate supported decision-making. Accordingly, consideration should be given to whether procedures have sufficient flexibility to accommodate individual needs.

5.129 In every case, consideration must be given to whether the court or tribunal has before it all necessary information. From the evidence provided to this inquiry, the committee considers that there are key parties that should be present in each case. These include the person, to the fullest extent that he or she is able to personally participate in proceedings; his or her parents, guardians or carers; independent representatives for the person with a disability; independent medical experts; and

independent expert advocates for the needs and rights of the individual who is the subject of the proceeding.

Independent representation

5.130 It is essential that, in proceedings to determine capacity, all appropriate support is given. Support should be free from conflicts of interest, assumptions and undue pressure. Family members or carers are essential to the process and should have a right to be heard, but they are not independent of their relative. An independent third party should be appointed in each case. Accordingly, the committee urges relevant courts and tribunals to carefully consider their procedures and practices. Courts and tribunals should facilitate the persons' participation in proceedings in a manner appropriate for that person.

5.131 None of the costs of this representation in court should be borne by the person or their family.

Recommendation 13

5.132 The committee recommends that the states and territories ensure that independent representation is provided for people with disabilities. Representation should be independent; while family or guardians should have a right to be involved, an independent representative should not be a member of the person's family or a caregiver.

Recommendation 14

5.133 The committee recommends that the costs of legal representation for adults should be covered by the relevant legal aid commission. state and territory governments should review legal aid funding arrangements to ensure that there are adequate funds to meet the costs of providing a legal representative for persons with disabilities in special medical procedure cases, including sterilisation cases.

5.134 For children's cases, the committee agrees with the opinions of several submitters to the inquiry that a legal representative must be appointed for each child in every child sterilisation case. While the focus of submitters was on the appointment of Independent Children's Lawyers in Commonwealth child sterilisation cases, the necessity of appointing a legal representative for children applies regardless of the jurisdiction in which the matter is heard. A legal representative tasked with conveying the child's wishes to the court and providing an independent assessment of the child's best interests must be appointed in every case. Independent Children's Lawyers are a critical part of ensuring a child's voice is heard. While parents are often the fiercest advocates for their children they are of necessity not independent, and the committee received evidence on a range of cases, both within and outside the legal system, where parents were not always able to advocate for, or were confused about, the best interests of their children. Consistent with the current duties of an Independent Children's Lawyer as specified in the Family Law Act, Independent Children's Lawyers should act independently and objectively, and convey to the court the child's views while providing an independent assessment of the child's best interests.

5.135 For Commonwealth cases, the committee understands that the Commonwealth government funds state and territory legal aid commissions to deliver legal aid services for Commonwealth cases in accordance with agreed principles and priorities.[169] Funding arrangements may need to be reviewed to ensure that there are sufficient funds to meet the costs of appointing an Independent Children's Lawyer in child sterilisation cases. State and Territory governments may likewise need to review funding arrangements to ensure that a legal representative can be appointed in state and territory child sterilisation proceedings.

Recommendation 15

5.136 The committee recommends that a legal representative be appointed in each child sterilisation case regardless of the jurisdiction in which the matter is heard. Commonwealth, state and territory legislation should be amended as necessary to ensure that the appointment of a legal representative of the child is mandatory in each sterilisation case.

Recommendation 16

5.137 The committee recommends that legal aid be provided to cover the costs incurred by the child's legal representative. The committee recognises that governments may need to revise current legal aid funding arrangements to ensure that there are sufficient funds to meet the costs of children's representatives in sterilisation cases.

5.138 The committee is particularly concerned with the lack of evidence regarding the training required to be appointed as an Independent Children's Lawyer. Appropriate training is a fundamental part of providing appropriate safeguards. An inadequate understanding of the nature and effects of disability compromises the legal representative's ability to make an informed decision in the case, and to work with the child to convey the child's wishes. A lack of understanding also has the potential to compromise the child's participation in proceedings.

5.139 Accordingly, the committee recommends that the Commonwealth and State and Territory governments work with legal aid commissions and relevant law societies to develop mandatory training courses for legal practitioners seeking to be appointed as a child representative in any case. As a necessity, training must include modules about children's capacity to communicate and to make decisions, and about disability awareness.

Recommendation 17

5.140 The committee recommends that Commonwealth, state and territory governments work with legal aid commissions and relevant law societies to develop training courses for legal practitioners about children's legal capacity,

169 See: Council of Australian Governments, N*ational partnership agreement on legal assistance services*, http://www.federalfinancialrelations.gov.au/content/npa/other/legal_assistance_services/national_partnership.pdf (accessed 9 July 2013).

techniques to communicate, and the varying effects and nature of disability. Successful completion of such courses should be mandatory before being appointed to represent a child.

Independent advocates

5.141 The committee considers that there is a role in both children's and adults' sterilisation proceedings for the court and tribunal to be assisted by persons who specialise in disability matters. In particular, the committee recognises the expertise of Public Advocates in communicating with persons with disabilities, and assessing the kinds of support needed to provide the person the best chance to develop capacity or to convey their wishes to the court. It is their expertise in all aspects of disability that separates disability advocates from members of the medical profession.

5.142 The committee notes the view of Chief Justice Diana Bryant that the courts would not be served by generic arguments about disability management or human rights. Courts and tribunals would be better served by advice that is tailored and specific to the individual. This approach also respects the person as an individual rather than as a stereotype or social or legal construct. However, the committee considers that a person skilled and experienced in working closely with persons with disabilities can provide a valuable support and advice to the court about the kind of procedures that the person needs in order to effectively engage with the court and tribunal, as well as the medical and legal support that may be of benefit to the person.

5.143 The committee recommends that Commonwealth, state and territory legislation be amended to provide the right for public advocates, such as the Office of the Public Advocate, to be a party to child or adult sterilisation cases. The Commonwealth and the state and territory governments should work with advocacy services to meet the advocate's costs. The cost should not be borne by the families in the proceedings.

Recommendation 18

5.144 The committee recommends that Commonwealth, state and territory legislation be amended to provide the right to public advocates, such as the Office of the Public Advocate, to be a party to child or adult sterilisation cases.

5.145 While mentioned only in passing, the committee is concerned by evidence provided by the Family Court of Australia that independent advocates or third parties, such as child welfare authorities, and the Australian Human Rights Commission, can (and do) decline the court's invitation to become a party to a child sterilisation case. In the committee's view, these agencies are ideally suited to the role of contradictor. Alternatively, where these agencies are in agreement with one or more of the parties, their involvement gives independent verification of the necessity, or lack of necessity, of the proposed procedure.

5.146 The committee understands that the Commonwealth Attorney–General's Department is currently considering whether Commonwealth laws and procedures provide appropriate support for persons in sterilisation cases. Evidence before the committee did not explain the apparent reluctance on the part of child welfare authorities, public advocates and agencies such as the Australian Human Rights

Commission to participate in child sterilisation proceedings. The committee considers that this matter is of primary importance. The Commonwealth Attorney–General's Department should consult with relevant agencies to determine the reasons for any reluctance and measures that can be taken to address identified concerns.

Medical advice

5.147 The committee particularly notes concerns that insufficient time may be allocated to medical practitioners to determine the person's capacity and what is medically necessary to safeguard and to improve the person's quality of life. The committee notes with approval practices existing in some jurisdictions of providing questionnaires to medical experts appearing in sterilisation cases. Questionnaires and information packs should be commonplace in each jurisdiction, and should seek the medical practitioner's advice about the processes the practitioner recommends in order to appropriately determine the capacity, wishes and medical needs of the person with a disability. In the interest of procedural fairness, sterilisation cases should be conducted without undue delay. However, courts and tribunal should be responsive to medical advice about what processes are appropriate in the particular case.

5.148 The committee recognises the concerns of a number of submitters that expertise in disability matters may be lacking among the medical professionals appointed in sterilisation cases. An appropriate response to this concern requires input not only from the medical profession but also the courts and tribunals. In the first instance, courts and tribunal should include in information packs and questionnaires details of the factors that the courts and tribunals are not authorised to consider, such as outdated and paternalistic attitudes to disability, eugenic arguments or assessments of the person's current or hypothetical future capacity to care for children. This material should present a factual up-to-date explanation of disability rights and of abilities. Additionally, legislation in each jurisdiction should be amended to require the input of more than one medical practitioner. Applicants should be required to provide reports from the person's treating doctor, but the court or tribunal should also have available to it the opinion of a specialist in the relevant area of medicine not involved in the person's care and with no interest in the outcome of the hearing. At least one of the medical practitioners must be independent, that is, the medical practitioner must not have any substantive previous involvement with the patient and the case.

Recommendation 19

5.149 The committee recommends courts and tribunals develop information packs and questionnaires to provide guidance for medical experts in sterilisation cases. The information packs should specify the factors that courts and tribunals consider under the relevant legislation, and should also note issues that the courts and tribunals are not authorised to consider such as outdated and paternalistic attitudes to disability, eugenic arguments or assessments of the person's current or hypothetical capacity to care for children. Questionnaires should seek the medical expert's advice about the procedures that could usefully be adopted in the particular case to facilitate both a robust medical assessment and the person's participation in proceedings.

5.150 As noted, to address concerns about the expertise of medical professionals, input will also be required from the medical community. The committee notes the advice provided by submitters to the inquiry that there is a need for additional training programs for medical professionals involved in child or adult sterilisation cases. The completion of training courses about the nature and effects of disability should be a prerequisite for medical practitioners providing evidence in adult or child sterilisation cases.

Chapter 6

Family Court of Australia

6.1 The previous chapter discussed a range of matters that are relevant to all legal jurisdictions where sterilisation matters, either in relation to children or adults, are considered. There was, in addition, debate during the inquiry about the appropriate role and effectiveness of the Family Court of Australia (the Family Court). There was some concern that the Family Court is an inappropriate forum for the child sterilisation proceedings.[1] The Family Court was characterised as unnecessarily adversarial, unnecessarily expensive, and without the necessary expertise to adjudicate child sterilisation cases.

An adversarial process?

6.2 The Qld Centre for Intellectual and Developmental Disability, Queenslanders with Disabilities Network, and Qld Advocacy Inc. agreed that combative court proceedings direct attention away from the needs of the child:

> They are usually adversarial in their approach with the respective parties becoming locked into winning. This can mean that families do not have the opportunity to hear information which could under other circumstances, change their minds.[2]

6.3 The committee heard from both individuals and organisations who argued that the Family Court's procedures are adversarial. Mr Jim Simpson, Lawyer, New South Wales Council for Intellectual Disability, submitted that the families who seek orders from the Family Court 'are locked into an adversarial system'.[3] It was argued that the apparent adversarial nature of Family Court proceedings detracts from its capacity to appropriately hear child sterilisation cases. As the Office of the Public Advocate (the OPA) submitted, the apparent adversarial process 'significantly weakens the ability of the Court to provide effective oversight of ethically complex medical treatment decisions concerning children'.[4]

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1 See, for example, Office of the Public Advocate, *Submission 14*, pp. 7–8.
The committee was not advised of any concerns with the Family Court of Western Australia relating to child sterilisation cases. However, it is noted that the issues raised about the Family Court of Australia may be relevant to the Family Court of Western Australia to the extent that the Family Court of Western Australia applies the provisions of the *Family Law Act 1975* and the mirror provisions in the Western Australian *Family Court Act 1997*.

2 Qld Centre for Intellectual and Developmental Disability, Queenslanders with Disabilities Network, and Qld Advocacy Inc, *Submission 37*, Attachment 3, p. 21.

3 Mr Jim Simpson, Lawyer, New South Wales Council for Intellectual Disability, *Committee Hansard*, 11 December 2012, p. 18.

4 Office of the Public Advocate, *Submission 14*, pp. 7–8.

6.4 As the OPA recognised,[5] such concerns reflect the view of the High Court of Australia in the 1992 decision in *Marion's Case*, in which the High Court questioned whether 'strictly adversarial' court procedures are appropriate for child sterilisation cases:

> [T]here is less likelihood of (intentional or unintentional) abuse of the rights of children if an application to a court is mandatory, than if the decision in all cases could be made by a guardian alone. In saying this we acknowledge that it is too costly for most parents to fund court proceedings, that delay is likely to cause painful inconvenience and that the strictly adversarial process of the court is very often unsuitable for arriving at this kind of decision.[6]

Analysis of Family Court procedures

6.5 While the Family Court procedures were criticised, those procedures were, with the exception of information provided by the Chief Justice of the Family Court of Australia and the Commonwealth Attorney-General's Department, not outlined. While it was commonly asserted that the Family Court processes are adversarial, the committee was not provided with detailed analysis of the procedures.

6.6 In contrast, one submitter, Dr Wendy Bonython, Assistant Professor, School of Law, University of Canberra, noted that the High Court's characterisation of the Family Court as adversarial has been criticised. Commenting in 1996, former Chief Justice of the Family Court, the Hon. Alastair Nicholson AO RFD QC, highlighted that the High Court failed to take into account the capacity of the Family Court to 'act as an inquisitorial forum'.[7]

6.7 Subsequent to this, in 2006 the *Family Law Act 1975* was amended to require the Family Court to adopt a less adversarial, that is, a more inquisitorial, approach in all children's cases. This requirement extends to applications for orders authorising child sterilisation procedures. Known as the less adversarial trial (LAT), LAT proceedings were introduced to ensure that:

> proceedings are managed in a way that considers the impact of the proceedings themselves (not just the outcome of the proceedings) on the child. The intention is to ensure that the case management practices adopted by courts will promote the best interests of the child by encouraging parents to focus on their parenting responsibilities.[8]

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5 Office of the Public Advocate, *Submission 14*, p. 7.

6 Mason C.J., Dawson, Toohey and Gaudron JJ, *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (1992) 66 ALJR 300 (*Re Marion*), at 54.

7 Dr Wendy Bonython, *Submission 22*, p. 7.

8 Family Law Amendment Bill (Shared Parental Responsibility) Bill 2005, *Explanatory Memorandum*, p. 3.

6.8 LAT cases are required to be conducted with as little formality, undue delay and legal technicality as possible.[9] Accordingly, the formal rules of evidence under the *Evidence Act 1995* do not automatically apply.[10] Judicial officers are required to actively direct the proceedings,[11] which can take the form of a dialogue between the presiding judicial officer and the parties.[12] The child may also participate in the proceedings.[13] As the Family Court advised:

> [a] less adversarial trial is focused on the children and their future, flexible to meet the needs of particular situations, expected to cost less and reduce the time spent in court, and is less formal and less adversarial than a traditional trial.[14]

6.9 In evidence before the committee, Ms Diana Bryant AO, Chief Justice of the Family Court of Australia, emphasised the less adversarial nature of child sterilisation cases. The committee was provided with an example of the procedures adopted in a case in which the Chief Justice presided:

> Alex No. 2...was done in a less adversarial format. We did Alex No. 2 in my chambers, actually, rather than the court room. We had everybody sitting around and people asked questions of doctors and so forth, without it being a formal setting. These are different types of cases and we do try to deal with them in a less adversarial way.[15]

The cost of Family Court proceedings

6.10 It was further reported that the cost of Family Court proceedings presents a barrier for families wishing to seek court approval for a sterilisation procedure. According to the OPA, costs are a 'significant disincentive' for seeking Family Court orders.[16] This view was reflected in evidence provided by individual families. Commenting on their experience, one family estimated that Family Court proceedings would cost approximately $10 000. As the family commented, such costs are unrealistic:

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9 *Family Law Act 1975*, s. 69ZN.

10 *Family Law Act 1975*, s. 69ZN; The Hon. Diana Bryant, AO, Chief Justice, Family Court of Australia, *Submission 36*, p. 10.

11 *Family Law Act 1975*, ss. 69ZN(4).

12 *Family Law Rules 2004*, r. 16.08.

13 The Hon. Diana Bryant, AO, Chief Justice, Family Court of Australia, *Submission 36*, p. 11.

14 The Hon. Diana Bryant, AO, Chief Justice, Family Court of Australia, *Submission 36*, p. 9.

15 The Hon. Diana Bryant, AO, Chief Justice, Family Court of Australia, *Committee Hansard*, 27 March 2013, p. 58.

16 Office of the Public Advocate, *Submission 14*, p. 7.

> I then had to engage a solicitor at my own expense and was advised that it would cost approximately $10 000 to present my application to the Family Court. Unfortunately, my family is not in a position to do this.[17]

6.11 The committee heard that for this family the high costs of Family Court proceedings were prohibitive, and effectively denied the family access to options otherwise available under Commonwealth law:

> I can assure you that parents go overseas because this subject is taboo, because the court system is too complicated and too expensive. Who has $10 000 to apply to the Family Court to do something to better their child's health?...We have been on one wage for 16 years because I look after my daughter. We have sacrificed. I don't have $10 000. I would love to because she is suffering every day. I'm disappointed in the system.[18]

6.12 Court costs were also noted with concern by the Royal Australian and New Zealand College of Obstetricians and Gynaecologists, which similarly highlighted that the costs of court proceedings may be unrealistic for families caring for children with disabilities:

> The College notes with dismay that families applying through a court system may suffer financially when they may already be resource poor and those limited resources are needed to care for a child with a severe disability.[19]

6.13 The high cost of child sterilisation procedures was acknowledged by the Chief Justice of the Family Court:

> I cannot say exactly what the charge is. It is not an inexpensive procedure. They are required to seek court ratification of a decision, then they are going to generally have legal advice. They are going to have to prepare affidavits, get medical evidence or get affidavits from the medical practitioners—and there are a number of those—plus psychiatrists and so forth. So while, in the end, the process itself is less adversarial, I accept that it is not an inexpensive process.[20]

6.14 Concerns with the capacity of parents to fund court proceedings were noted by the High Court of Australia in *Re Marion*, in which the court commented that 'it is too costly for most parents to fund court proceedings'.[21] Reporting two years following *Re Marion*, the Family Law Council also commented on the high cost of Family Court proceedings. The Council recommended that the cost of legal

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17 Mrs Louise Robbins, Private capacity, *Committee Hansard*, 27 March 2013, p. 47.

18 Mrs Louise Robbins, Private capacity, *Committee Hansard*, 27 March 2013, p. 52.

19 Royal Australian and New Zealand College of Obstetricians and Gynaecologists, *Submission 30*, p. 2.

20 The Hon. Diana Bryant, Family Court of Australia, *Committee Hansard*, 27 March 2013, p. 59.

21 Mason C.J., Dawson, Toohey and Gaudron JJ, *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (1992) 66 ALJR 300 (*Re Marion*), at 54.

representation for the child and the child's parent or guardian, and all other costs associated with the application, should be met by the Commonwealth government. The recommendation responded to concerns that the cost of accessing options available under the Commonwealth law far exceeds the cost of applications to state and territory Guardianship Boards.[22] In 2001, the Human Rights and Equal Opportunity Commission also noted with concern the cost of Family Court proceedings.[23] However, court costs were not included among the key areas of reform that the Commission identified.[24]

6.15 The committee was advised that government assistance to meet the cost of court proceedings, known as 'legal aid', is available in certain circumstances. Legal aid grants are administered by State and Territory legal aid commissions funded under the National Partnership Agreement on Legal Assistance Services. According to information provided by the Commonwealth Attorney-General's Department, the Agreement establishes the legal aid service priorities for Commonwealth law matters. In the area of family law, priorities include assistance for children and the appointment of Independent Children's Lawyers (ICLs).[25] However, with the exception of funding to meet the costs of the ICL, to be eligible to receive a grant of legal aid a family would be required to pass a means and merits test.[26] Neither the Commonwealth Attorney-General's Department nor State and Territory Legal Aid Commissions actively record data on the number of Independent Children's Lawyers appointed for child sterilisation cases or other cases involving special medical procedures.[27]

Expertise of Family Court judicial officers

6.16 It was also questioned whether the justices of the Family Court possess the necessary expertise and training to adjudicate child sterilisation cases. A number of grounds were identified.

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22 Family Law Council, *Sterilisation and other medical procedures on children*, 1994, paragraphs 5.16; Recommendation 4(i).

23 Susan Brady, John Britton, Sonia Grover, *The sterilisation of girls and young women in Australia: issues and progress*, A report jointly commissioned by the Sex Discrimination Commissioner and the Disability Discrimination Commissioner at the Australian Human Rights Commission, 2001, p. 50.

24 Susan Brady, John Britton, Sonia Grover, *The sterilisation of girls and young women in Australia: issues and progress*, A report jointly commissioned by the Sex Discrimination Commissioner and the Disability Discrimination Commissioner at the Australian Human Rights Commission, 2001, pp. 57–59.

25 Attorney-General's Department, answer to question on notice, 19 April 2013 (received 14 May 2013).

26 Ms Cathy Rainsford, Assistant Secretary, Family Law Branch, Attorney-General's Department, *Committee Hansard*, 31 May 2013, p. 15.

27 Attorney-General's Department, answer to question on notice, 31 May 2013 (received 2 July 2013).

Exposure and capacity to build expertise

6.17 As the Family Court acknowledged,[28] the court hears relatively few child sterilisation cases. OPA argued that this lack of exposure to child sterilisation cases undermines the Family Court's capacity to build expertise in child sterilisation matters.[29] The argument was articulated by Dr John Chesterman, Manager of Policy and Education, OPA, Victoria:

> The cases are relatively rare, and that is one of the real problems—that you have a judge suddenly sitting in on a very ethically complex matter with no experience in that kind of area.[30]

6.18 Commenting in 1994, the Family Law Council drew a distinction between the expertise of Guardianship Boards in disability matters and the proficiency of the Justices of the Family Court of Australia in child sterilisation cases.[31] While noting the 'high degree' of expertise in disability matters existing within the Guardianship Boards, the Council concluded that it was essential that 'specifically designed awareness programs' be developed for the Justices of the Family Court hearing cases involving applications for medical procedures.[32] Accordingly, the Council recommended that sterilisation cases be heard only by specially trained justices.[33] Similar themes emerged in a 2001 report, commissioned by the Australian Human Rights Commission, into the sterilisation of persons with disabilities in Australia. The report highlights that members of state and territory tribunals are appointed for their specialist knowledge and experience with people with disabilities, and concludes that this specialist knowledge 'is part of the "equipment" of the tribunal and places it in a position where it can independently assess evidence put before it from both a professional and personal perspective'.[34]

6.19 Over a decade on, the Attorney-General's Department (the Department) advised that the capacity to appropriately respond to family law issues is a key determinant of whether a person is suitable to be appointed as a Justice of the Family

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28 The Hon. Diana Bryant, Family Court of Australia, *Committee Hansard*, 27 March 2013, p. 57.

29 Office of the Public Advocate, *Submission 14*, p. 7.

30 Dr John Chesterman, Manager of Policy and Education, Office of the Public Advocate, Victoria, *Committee Hansard*, 11 December 2013, p. 13.

31 Family Law Council, *Sterilisation and other medical procedures on children*, 1994, paragraphs 5.36–40.

32 Family Law Council, *Sterilisation and other medical procedures on children*, 1994, paragraphs 5.24; 5.40.

33 Family Law Council, *Sterilisation and other medical procedures on children*, 1994, Recommendation 4.

34 Susan Brady, John Britton, Sonia Grover, *The sterilisation of girls and young women in Australia: issues and progress*, A report jointly commissioned by the Sex Discrimination Commissioner and the Disability Discrimination Commissioner at the Australian Human Rights Commission, 2001, p. 44.

Court. As the Department advised, section 22 of the *Family Law Act 1975* (Family Law Act) directs that a person shall not be appointed unless he or she, by reason of training, experience and personality, is suitable to deal with family law matters. The Department also noted that there is no requirement for the judicial officers to attend training programs. Judicial training is a matter for the courts.[35] The Department did not directly engage with concerns with the training or expertise of Family Court justices in child sterilisation and disability matters. It was, however, submitted that any departmental involvement in the training of federal judicial officers could be seen as infringing the doctrine of separation of powers.[36]

6.20 In response to concerns with the expertise of Family Court justices, the Family Court of Australia also highlighted the expectation that Family Court justices have the capacity to 'negotiate the difficulties and complexities' of family law cases.[37] Chief Justice Diana Bryant submitted that, as family law is a specialist area, it is probable that presiding justices would have been exposed to sterilisation cases prior to being appointed to the Family Court bench.[38]

6.21 The committee was further informed that the Family Court has access to third-party advice. Relevant to sterilisation cases, Chief Justice Diana Bryant noted that the Family Court has authority to obtain input from State and Territory child welfare departments, the Australian Human Right Commission, the OPA or its equivalents, and medical experts.[39] As has been discussed, the court may also have before it the advice of an Independent Children's Lawyer. The Chief Justice further advised that where parties are in agreement the court may, where appropriate, invite a contradictor to provide a counterview.[40] However, the Chief Justice also noted that there have been cases where organisations have declined the court's invitation to become a party to the case.[41]

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35 Attorney-General's Department, answer to question on notice, 19 April 2013 (received 14 May 2013).

36 Mr Daniel Abraham, Assistant Secretary, Human Rights Policy Branch, Attorney-General's Department, *Committee Hansard*, 31 May 2013, p. 14.

37 The Hon. Diana Bryant, AO, Chief Justice, Family Court of Australia, *Submission 36*, p. 8.

38 The Hon. Diana Bryant, AO, Chief Justice, Family Court of Australia, *Committee Hansard*, 27 March 2013, p. 59.

39 The Hon. Diana Bryant, AO, Chief Justice, Family Court of Australia, *Submission 36*, p. 8.

40 The Hon. Diana Bryant, AO, Chief Justice, Family Court of Australia, *Committee Hansard*, 27 March 2013, p. 58. Parties to proceedings include the people who may institute proceedings, which include the child's parents, the child, child's grandparents, or any other person concerned with the child's welfare care or development (see *Family Law Act 1975*, s. 69C). In addition, the court may in the late the persons to be party to the proceedings, including State and Territory child welfare officers (see *Family Law Act 1975*, s. 91B).

41 The Hon. Diana Bryant, AO, Chief Justice, Family Court of Australia, *Committee Hansard*, 27 March 2013, p. 58.

6.22 Pursuant to the *Family Law Rules 2004* (Family Law Rules), evidence before the court for applications for court approval of a special medical procedure must include evidence from a medical, psychological or other relevant expert witness. This evidence is to include an assessment of the likely long-term physical, social and psychological effects if the proposed procedure is, or is not, carried out and must establish whether the procedure is necessary for the child's welfare.[42] The evidence must also indicate whether the child, if capable of making an informed decision about the procedure, agrees to the proposed procedure. If the child is incapable of making an informed decision, the evidence also needs to establish the probability of whether the child will be able to make an informed decision within the time in which the procedure should be carried out or within the foreseeable future.[43]

6.23 Given the depth of advice available to the court, and the presiding justices' experience with complex matters, the Chief Justice concluded:

> Family Court judges are optimally placed to make informed and responsible decisions about individual special medical procedure applications and to arrive at a decision that is in the best interests of the child in all the circumstances.[44]

Ideology and judicial reasoning

6.24 It was further contended that Family Court decisions are based on personal ideology rather than objective, rights-based criteria. Speaking to the committee, Ms Carolyn Frohmader, Executive Director, Women With Disabilities Australia (WWDA), argued that '[y]ou only have to look back through the Family Court judgments that have been made to see the value judgements'.[45] WWDA advised that its analysis reveals that Family Court decisions are based on genetic/eugenic arguments; theories that sterilisation is for the good of the state, the community, or the family; arguments that disabled persons are without the capacity for parenthood; the notion that persons with intellectual disabilities are incapable of developing the capacity for self-determination; and to minimise the risk of sexual abuse.[46]

6.25 People with Disabilities Australia (PWDA) agreed.[47] PWDA shared the view that Family Court decisions are based on personal values:

> Other examinations of Family Court decision-making also reveal that prejudicial assumptions and values about girls and young women with disability are embedded in reports to the Court and in final judgements. Not

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42 *Family Law Rules 2004*, r. 4.09.

43 *Family Law Rules 2004*, r. 4.09.

44 The Hon. Diana Bryant, AO, Chief Justice, Family Court of Australia, *Submission 36*, p. 8.

45 Ms Carolyn Frohmader, Executive Director, Women With Disabilities Australia, *Committee Hansard*, 27 March 2013, p. 4.

46 Women With Disabilities Australia, *Submission 49*, pp. 30, 38.

47 People with Disabilities Australia, *Submission 50*, p. 16.

> surprisingly, Family Court judgements have overwhelmingly found that non-therapeutic sterilisation is appropriate in the circumstances of the case.[48]

6.26 Similar concerns were raised by Ms Miriam Taylor, Queensland Centre for Intellectual and Development Disability, University of Queensland, and Ms Linda Steele, Lecturer, Faculty of Law, University of Wollongong. Ms Taylor submitted that the judgements of the Family Court Australia are 'based on a whole lot of assumptions that there is a devalued status for young women in particular with intellectual disabilities and quite severe physical disabilities'.[49] Ms Steele also commented on the status of persons with disabilities. It was submitted that given the scope of the court's child welfare jurisdiction, 'individuals who are the subject of sterilisation applications can only be known within its jurisdiction as children and in terms of their relationship to their parents'. Accordingly, Ms Steele argued:

> this has the effect of freezing time in terms of that person's individual life course, and easily folds into the construction of people with intellectual disability as eternal children.[50]

6.27 In support of the view that Family Court decisions are based on idiosyncratic, personal ideology, WWDA provided nine case examples. Of the nine cases, five predate the May 1992 High Court of Australia's decision in *Re Marion*. Accordingly, while representative of the history of the Family Court and illustrative of its evolution in responding to sterilisation matters, the cases do not represent current law or practice. Of the remaining four cases, two predate the commencement of the Family Law Rules in 2004. However, rule 4.09 of the Family Law Rules replicates Order 23B, which existed prior to the introduction of the Family Law Rules.

6.28 Of the post *Re Marion* cases, WWDA highlighted ideological statements in the evidence before the court. However, the views of parties to the proceedings were equated with the opinions of the presiding judicial officers. For example, in support of the proposition that Family Court judgements are based on genetic or eugenic arguments, WWDA provided an extract of the judgement in *Re H* [2004] FamCA 496. The extract is itself an extract of a summary of medical evidence presented during the proceedings:

> A laparoscopic hysterectomy will be associated with a relatively short stay in hospital and significantly less post-operative pain (and therefore easier management) than a formal laparotomy. The result will be complete absence of menstruation and this will undoubtedly be of benefit to H who already appears to have substantial difficulties with cleanliness following defecation and micturition. As a by–product of an absence of the uterus H will never become pregnant. Given the genetic nature of her disorder and

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48 People with Disabilities Australia, *Submission 50*, p. 16.

49 Miriam Taylor, Queensland Centre for Intellectual and Development Disability, University of Queensland, *Proof Committee Hansard*, 30 January 2013, p. 6.

50 Ms Linda Steele, *Submission 44*, p. 23.

> the 50% inheritance risk thereof, this would in my view be of great benefit to H.[51]

6.29 While the court may accept views into evidence, it does not follow that the court gives weight to, or agrees with opinions, offered. Indeed, the fact that the judgement records the evidence says nothing about the views of the court itself. It is notable that the court's reasons in *Re H* do not cite eugenic arguments, or the statement of the medical expert quoted above. Rather, in accordance with rule 4.09 of the Family Law Rules, the court weighed the benefits and likely risks of carrying or not carrying out the procedure to determine whether the procedure would be in the best interests of the child. The listed benefits do not include eugenic considerations.

6.30 An analysis of the reasons for Family Court decisions in sterilisation cases does, however, give weight to WWDA's argument that sterilisation may be authorised 'for the good of the family'. For example, in *Re H* and *Re: Angela* [2010] FamCA 98, the court linked the best interests of the child to the interests of the parents. This matter was further explored in Chapter 5.

6.31 WWDA's submission also highlighted the need for greater direction for persons preparing evidence for sterilisation cases. Reporting in 1994, the Family Law Council concluded that there are four situations in which sterilisation should never be authorised. These include scenarios in which sterilisation is proposed for eugenic reasons. In contrast, WWDA's analysis highlighted that, regardless of the weight given to such views by the court, such considerations may underlie applications for child medical procedures such as sterilisation.

Committee view

6.32 In conducting its inquiry, the committee sought to establish the nature, and the appropriateness, of the procedures that operate in sterilisation cases. As a primary forum for the exercise of the Commonwealth jurisdiction in child sterilisation matters, it was clear from the material before the committee that the Family Court is regularly criticised by non-government organisations. However, it is equally clear that the precise nature of Family Court procedures is not widely and comprehensively understood. Criticisms were not always founded on a clear analysis of the Family Court's procedural rules or legislative framework. The lack of any reference to the less adversarial trial (LAT), in particular, raises doubt about the validity of the concerns. The committee does not accept that Family Court procedures in sterilisation cases are conventionally adversarial. However, the committee does encourage officers of the Family Court of Australia to consider whether state and territory procedures can be adapted to further strengthen non-adversarial procedures for Commonwealth child sterilisation cases.

6.33 Evidence before the committee did highlight two areas of concern.

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51 Prof T, *Re H* [2004] FamCA 496, 49; as cited, in part, in Women With Disabilities Australia, *Submission 49*, p. 32.

Training and expertise of members of the judiciary

6.34 All participants in child and adult sterilisation cases must have sufficient expertise in disability matters. The committee is concerned with the lack of evidence about the training and expertise of officers of the Family Court of Australia in disability matters. The committee accepts evidence that presiding officers are proficient in family law issues. However, the committee considers that child sterilisation is a special category of matter that does not fall neatly within the broader family law framework.[52] Additional knowledge, skills, and experience are required. Accordingly, the committee urges the Family Court of Australia to develop training courses in child disability matters, and to make participation in such courses mandatory for any judicial officer who may hear special medical procedure cases.

6.35 The committee notes the approval among not only the submitters to this inquiry but within previous inquiries of the skills and expertise of members of state and territory tribunals. The committee encourages state and territory tribunals to continue prioritising training in disability matters.

Recommendation 20

6.36 The committee recommends that the Family Court of Australia gives strong consideration to the evidence gathered by this inquiry about the absolute necessity of ensuring that judicial officers participating in special medical procedure cases have appropriate skills and expertise in disability matters. The committee urges the Family Court of Australia to develop training courses about disability matters and to ensure that such courses are completed by any judicial officer who may hear cases concerning special medical procedures.

6.37 Currently under the Family Law Act, the Court may seek external assistance. A general power to do this lies in section 102B:

> In any proceedings under this Act (other than prescribed proceedings), the court may, in accordance with the applicable Rules of Court, 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.

6.38 'Assessor' is not defined in the Act. The Family Law Rules provide for procedures for either the parties to a case to seek the appointment of an assessor, or for the Court to appoint an assessor at its own initiative.[53] There are also detailed provisions on the obtaining of expert evidence, in particular from a 'single expert witness'.[54] Division 4.2.3 of the Rules, as outlined in chapter 3 of this report, imposes particular requirements on the form of applications to the Court for a sterilising

52 This matter is also taken up in the next chapter.

53 *Family Law Rules 2004*, Part 15.4, especially r. 15.38(3).

54 *Family Law Rules 2004*, Part 15.5.

medical procedure. This must 'include evidence from a medical, psychological or other relevant expert witness' on certain matters.

6.39 It is clear to the committee from evidence received during this inquiry that there is a range of views and practices among medical professionals and other experts in the field, in respect of sterilisation and menstrual management for people with disability, as well as for intersex people. Reliance on the advice of a single expert carries with it the risks that that particular person's views may or may not be consistent with best practice or evidence, in both medical and non-medical matters. This is particularly acute in cases where there is no contradictor (no party to the case with a different view to the other party or parties), cases in which, as Chief Justice Diana Bryant pointed out, the Court has to proceed with caution.[55]

6.40 The committee concluded that there should be greater expert discussion of cases in this area, and that the Family Court, as well as other jurisdictions, could benefit from drawing on that discussion. This could be achieved by the establishment of an advisory committee of experts in the field, which could regularly discuss best practice, and provide advice to courts upon request, including on specific case information placed before the committee. The scope of the committee would be to discuss best practice and provide advice in relation to sterilisation procedures and related matters, sometimes referred to as special medical procedures.

6.41 The committee should include individuals expert in medical and in psychological care, but must also include non-medical expertise in relation to disability care, and non-medical expertise in relation to disability rights. There are a number of existing organisations that could assist in identifying appropriate members for the committee, but the committee is intended to be expert in nature, and not representative of interests or views. Organisations that could assist in identifying suitable members include:

- Australian Human Rights Commission
- Royal Australian and New Zealand College of Obstetricians and Gynaecologists
- Australasian Paediatric Endocrine Group
- Sexual Health and Family Planning Australia
- National Council on Intellectual Disability
- Women With Disabilities Australia
- Australian Guardianship and Administration Council

6.42 The advisory committee would be established by the Commonwealth government, and would be supported through the Department of Health and Ageing. The Family Court would then be able to appoint it as an assessor under existing

55 The Hon. Diana Bryant, AO, Chief Justice, Family Court of Australia, *Submission 36*, p. 7.

Family Law Rules. As the rules state, it would be strictly advisory: 'The court is not bound by any opinion or finding of the assessor'.[56]

6.43 This mechanism will allow the Family Court to, as a matter of routine, draw on the best information available, and to minimise the risks associated with choosing a single expert to provide evidence. At the same time, by utilising the committee as an assessor, it would avoid introducing a multiplicity of experts into the court's proceedings.

6.44 While recommending the establishment of this advisory committee in the context of providing more effective support to the Family Court, the committee could potentially provide similar assistance to other jurisdictions. This would be a matter for discussion with the Standing Committee on Law and Justice, and with the Australian Guardianship and Administration Council.

Recommendation 21

6.45 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.

The cost of sterilisation procedures

6.46 The cost of accessing Family Court proceedings is likely to be out of the reach of families whose resources are dedicated to supporting a child with a disability. Where the cost of accessing the legal system is excessive, the system becomes inaccessible. Accordingly, the committee endorses the recommendation first made by the Family Law Council in 1994 for child sterilisation cases to be funded through legal aid. Families' access to legal aid in child sterilisation cases should not be subject to means or merits testing, and should not be limited by funding caps.

Recommendation 22

6.47 The committee recommends that legal aid should be provided to cover the costs incurred by the parents or guardians in child sterilisation cases. The legal aid grant should not be subject to capping or to a means or merits test.

Should jurisdiction for child sterilisation cases be retained within the Family Court of Australia?

6.48 Concerns with the operation and expertise of the Family Court in child sterilisation cases have raised the question of whether it is appropriate for the Family

56 *Family Law Rules 2004*, r. 15.39(4).

Court to continue hearing these cases. The committee concluded that, at present, it would not be appropriate for the jurisdiction to be removed. As the Commonwealth court, the Family Court facilitates consistency in policy and practice for children regardless of where they live. Accordingly, Family Court decisions can act as a benchmark for consistency and uniformity for all Australian children. The committee does however acknowledge the excellent work of the Australian Guardianship and Administration Council in preparing and endorsing the 2009 *Protocol for Special Medical Procedures (Sterilisation)*, which is also intended to ensure consistency across jurisdictions.[57]

6.49 As the committee's survey of jurisdictions in chapter 3 has shown, there is variation in practice across the states and territories, including matters such as the circumstances under which procedures will be approved. Given the current inconsistency throughout the State and Territory legislation, the committee is concerned that were the Family Court jurisdiction to be removed, protections of the child's rights will vary to some extent according to where the child lives. The committee is particularly concerned about the rights of children in the states and territories that have not legislated to regulate child sterilisation cases.

6.50 However, the committee does recognise the valuable expertise in state and territory tribunals, and the strong protections of rights in place in many cases. The committee recognises that the specialisation of tribunals may deliver stronger understanding of cases in some circumstances. It also notes the argument that tribunals may be cheaper or more accessible for families.

6.51 The committee concluded that this is a matter that needs to return to the agenda of the Standing Council on Law and Justice, which dealt with some aspects briefly in the mid-2000s. There needs to be ongoing review of the effectiveness with which all jurisdictions are managing applications for sterilising procedures, and the extent to which rights are being protected. The Standing Council's deliberations will provide an opportunity to consider whether there may be benefits to further changes to the scope or operation of the various jurisdictions.

Recommendation 23

6.52 The committee recommends that the matter of the scope and operation of the relevant courts and tribunals be placed on the agenda of the Standing Council on Law and Justice for ongoing review.

6.53 The committee suggests that the Standing Council may wish to refer aspects of the matter for more detailed examination by other specialist organisations. During the course of review, the Standing Council should consult with the Australian Law Reform Commission and the Australian Human Rights Commission as well as the tribunals and the Australian Guardianship and Administration Council.

57 Australian Guardianship and Administration Council, *Submission 28*, p. 2.

6.54 The committee also has a concern that there are cases which should be reaching tribunals or courts, but which are being labelled as 'therapeutic' by medical professionals and are not being adequately scrutinised. This is also a matter to which the Standing Council should give consideration.

Recommendation 24

6.55 The committee recommends that the Standing Council on Law and Justice obtain information about the frequency and nature of 'therapeutic' sterilisation cases being conducted, and compare the circumstances of those cases with 'non-therapeutic' cases that have been authorised by courts or tribunals.

Chapter 7

Legislation: uniformity, offences, and data collection

7.1 As has been noted in previous chapters, there are aspects of Australian law and policy regulating the sterilisation of persons with disabilities that are consistent across jurisdictions. All states and territories have court or tribunal-based procedures for considering applications to sterilise an adult. All have some form of test in place that can be considered a 'best interests' test. Jurisdictions have agreed to the *Protocol for Special Medical Procedures (Sterilisation)*, described in Chapter 3.

7.2 Despite these similarities, however, there are significant differences, and some weaknesses, in the current system. For example some jurisdictions have processes to consider applications for children and some do not; the guidelines endorsed by the Australian Guardianship and Administration Council are not mandatory; there is uncertainty around what constitutes 'therapeutic' cases, and therefore uncertainty about the scope of the jurisdiction of courts and tribunals; and the criteria being applied are not the same in every state or territory. Data collection and availability, as well as being poor, highlights differences across the jurisdictions.

Are sterilisation procedures happening at the same rate across Australia?

7.3 The committee sought information from all states and territories about how widespread sterilisation orders actually were. It looked at other information, where available, about the nature of cases and their outcomes.

7.4 Some of the relevant data was provided in submissions from New South Wales and Tasmania. Other jurisdictions received a letter from the committee in March or April 2013, seeking information about sterilisation procedures authorised in that jurisdiction. This text is representative of what was sought:

> The committee seeks data regarding the number of applications for sterilisation orders for adults and children with disabilities in the past decade, and the number of such orders granted during this time.
>
> The committee invites the Tribunal to provide any additional information that the Tribunal considers relevant to the terms of reference, including an analysis of the kinds of disabilities specified in the applications and whether sterilisation is for therapeutic or non-therapeutic purposes. The committee would be interested in any relevant decisions that demonstrate the approach taken by the Tribunal in adjudicating applications for sterilisation orders.[1]

7.5 The committee was grateful for the assistance of jurisdictions in helping to assemble the information, but the results of this process raised significant concerns for the committee.

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1 Committee correspondence to the ACT Civil and Administrative Tribunal, 28 March 2013.

Sterilisation cases in each jurisdiction

7.6 The Australian Capital Territory (ACT) provided an extremely detailed analysis of its case files, for which the committee is very grateful. The ACT Civil and Administrative Tribunal (ACTCAT) can make decisions regarding prescribed medical procedures for adults, and these may include abortion, sterilisation, contraception, but also transplants and some treatments for mental illness. The scope of its operation is thus slightly broader than in some other jurisdictions. The tribunal reviewed 21 years of case files, from 1992 to 2012, and identified 55 that involved contraception or sterilisation. Of these, 48 were for women and 7 for men, all but one of those for males being for medications to reduce libido. There were 13 applications for reproductive sterilisation, meaning fewer than one per year, and four of these were for therapeutic reasons. Of the remaining nine, three were for contraception and six for menstrual management; all were approved (except one which was withdrawn).[2]

7.7 The ACT was the only jurisdiction that provided detailed analysis of every relevant case. The committee looked at all the cases where sterilisation was sought and granted. In all cases, either the subject of the proposed procedure was asked their views and they were supportive, or the subject was assessed as unable to express their view. There was no case where views were sought, the person objected, but the procedure was agreed to.[3]

7.8 The New South Wales Government supplied information about applications to the Guardianship Tribunal for sterilisation of both children and adults. In the six years from July 2006 to June 2012, the Tribunal considered 39 applications for sterilisation. Eight were withdrawn; of the remaining 31, 14 were consented to and 17 were dismissed. Applications were overwhelmingly for adults: there were only 2 applications for children, one of which was withdrawn and the other consented to.[4]

7.9 The response from the Northern Territory Department of Health's Adult Guardianship office produced a surprising result. The Northern Territory scheme has jurisdiction only for adults under guardianship orders. The Northern Territory advised that there had not been a single case prior to April 2013,[5] when the committee sent its correspondence, but that in the seven weeks between the committee's letter arriving and the government finalising its response, the Local Court had received and approved three applications for the insertion of contraceptive devices. There had been no applications for permanent sterilisation.[6]

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2 Correspondence received from the Australian Capital Territory Civil and Administrative Tribunal, 12 May 2013, pp. 6–7.

3 Correspondence received from the Australian Capital Territory Civil and Administrative Tribunal, 12 May 2013, pp. 8–14.

4 New South Wales Government, *Submission 66*, p. 2.

5 The committee's letter asked for information over the preceding decade, and the committee assumes that this is the period covered by the Northern Territory's response.

6 Correspondence received from the Northern Territory Executive Office of Adult Guardianship, 21 May 2013, p. 2.

7.10 Queensland reviewed its case data for the years 2006 to 2012 inclusive. In that period, 19 applications relating to adults were received. Of those, two were ongoing, while four had been withdrawn during the process. Of the remaining 13, 11 were approved and two were dismissed. There were four applications in relation to children over the same period, of which one was withdrawn. Notably, all four involved a child who had become an adult by the time the process was concluded, and all three that proceeded to a decision were approved.[7] There appeared to be no applications involving younger children. The QCAT provided examples of its decisions (in which applicants are given letter-based codes). It observed of the three case examples: 'Both HGL and TN involved consideration of applications based on menstrual management while CEN involved consideration of methods of contraception'.[8]

7.11 The brief response from the Guardianship Board of South Australia indicated that it had received 12 applications between August 2006 and April 2013. Ten were approved.[9] The committee was not advised whether the remaining two were declined, withdrawn or were still under consideration.

7.12 Tasmania's Guardianship and Administration Board (TGAB) provided information through the Tasmanian Government's submission. It indicated that the TGAB had received around one application per annum in the last decade, for sterilisation of both children and adults. However, around half the applications were withdrawn 'when less invasive measures met the concerns of the applicants'.[10] The government's submission gave some details of four of the cases. One was refused as alternative procedures had not been adequately tried and the person was very young. The other three cases highlight the complex nature of the factors that have to be considered. In all three cases, the persons themselves wanted a sterilising procedure conducted (for very diverse reasons) but, as each had an intellectual disability that prevented them from fully understanding the consequences of the surgery, the Board had to be involved. In all three cases the Board agreed to the procedure.[11]

7.13 The Victorian Civil and Administrative Tribunal's response provided information quite different to the pattern in any other state or territory. From financial year 1999-2000 to the present there have been 1188 applications relating to adults considered by the tribunal. This extremely high figure is primarily accounted for by the fact that, prior to July 2006, applications had to be made in cases of medical research. Thus the scope of the Tribunal's responsibilities was historically different to elsewhere. Since that requirement has been removed, the Victorian tribunal has considered 102 applications in a six and a half year period. This number, however,

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7 Correspondence received from the Queensland Civil and Administrative Tribunal, 3 May 2013, pp. 3–4.

8 Correspondence received from the Queensland Civil and Administrative Tribunal, 3 May 2013, p. 4.

9 Correspondence received from the Guardianship Board South Australia, 3 May 2013.

10 Tasmanian Government, *Submission 57*, p. 2.

11 Tasmanian Government, *Submission 57*, pp. 3–4.

includes procedures for the termination of a pregnancy as well as sterilisation procedures. Data limitations meant that Victoria was unable to break the figures down any further.[12]

7.14 The State Administrative Tribunal of Western Australia responded to the committee's query, and began by noting some of the differences between Western Australia's system and that in some other states, particularly New South Wales. It indicated that there were only small numbers of applications, and that five had been considered in the last ten years. Of those five, three had been approved and two dismissed. The Tribunal supplied the statements of reasons for some of the cases, including one of those dismissed. It appeared that, in that case, one of the reasons that the person's parent had sought an order was their fear of the consequences of sexual abuse. The tribunal had rejected this as a relevant reason, and concluded '[t]he proposed procedure is not necessary from a medical or behavioural point of view and cannot be justified for menstrual management'.[13]

7.15 The Family Court of Australia, as noted in Chapter 3, has jurisdiction in a range of relevant cases, including those pertaining to children. The Chief Justice provided information to the committee in relation to cases heard by the Court. She identified 27 cases heard by the court involving 'applications to perform hysterectomies on young people with disabilities'. However almost all were during the 1990s, and there have been only two judgements on such cases in the 13 years since 2000. The committee understands that in both those cases, sterilisation was authorised.[14]

7.16 The table below summarises the very incomplete data available, excluding that from the Family Court, which is not state or territory-specific. The figures are seldom directly comparable, and can be treated as indicative only.

12 Correspondence received from the Victorian Civil & Administrative Tribunal (VCAT), 28 May 2013.

13 AD [2007] WASAT 123, paras 100, 101.

14 The committee understands the two cases to be *Re: Angela* [2010] FamCA 98 (16 February 2010) and *Re: H* [2004] FamCA 496 (20 May 2004).

Table 7.1: The number of sterilisation applications considered by State and Territory tribunals

Jurisdiction	Time period	Applications	Withdrawn	Approved	Dismissed	Applications per unit population[15]
ACT	21 years	13	1	12	0	1.55
NSW	6 years	38	8	14	17	0.87
NT	10 years	3	0	3	0	1.50
QLD	6 years	21	5	14	2	0.76
SA	7 years	12	NK	10	NK	1.01
TAS	10 years	c. 10	c. 5	c. 3	c. 1	2.00
VIC	6.5 years	102	NK	NK	NK	2.75
WA	10 years	5	0	3	2	0.20

Notes: NK = Not known. Rates calculated using ABS 2012 state and territory population estimates. Victorian sample commences after the exclusion from tribunal jurisdiction of applications for medical research.

7.17 The apparent discrepancies in practice revealed by the preceding information are also implicit in data received from State and Territory legal aid commissions. At the committee's request, the Commonwealth Attorney-General's Department asked state and territory legal aid commissions to report on the number of child sterilisation cases that received legal aid funding.[16] The department asked the commissions two questions:

- How many special medical procedure cases has the legal aid commission funded?
- How many Independent Children's Lawyers (ICLs) have been appointed in special medical procedure cases?

7.18 The committee received the following responses, through the Attorney-General's Department:

15 (Number of applications divided by number of years), divided by jurisdiction population in millions.

16 Commonwealth Attorney-General's Department, Answers to questions on notice, 31 May 2013 (received to July 2013).

Table 7.2: Estimates of the number of Commonwealth child sterilisation cases that have received legal aid funding

LACTas (Tasmania)	Only funded one in the past 3 years that I can recall. Possibly two in the past 5.
LSCSA (South Australia)	1 ICL appointment this financial year. The parties are not in receipt of legal aid. Can't recall any other matter in the past few years.
LANSW (New South Wales)	Around 1 or 2 each year. We generally try to keep them in-house.
LAWA (Western Australia)	We have had no sterilisation cases to my knowledge for many years. We are able to advise on how many in the last 12 months but not over a longer period as we do not report against this. We have had 12 gender dysphoria cases in 2012/13 (these are classed as special medical procedures).
LAQ (Queensland)	We have had a look through our systems however we do not capture this data to a sufficient resolution to report.
VLA (Victoria)	The Victorian protocol is for an ICL to be appointed in every special medical case. We are not aware of any appointments for sterilisation matters in recent years. We have also checked our records for matters funded as "special medical procedure" and can find no reference to any sterilisation matters.
LAACT (Australian Capital Territory)	Cannot recall funding any in the past few years.
NTLAC (Northern Territory)	1 case in last 22 years.

7.19 It is difficult to interpret the data. It is at times unclear whether a commission is referring to legal aid funding for one or more of the parties to the case or for the appointment of an ICL. What is clear, however, is that each jurisdiction's approach to data management differs. At times, data was provided on the basis of supposition, prefaced with statements such as 'to my knowledge' or 'I recall'. As the number of cases that received funding were not compared with the number of cases for which a funding application was received but refused, it is also difficult to build a picture of the similarities and differences across jurisdictions. One thing does, however, stand out – there is a lack of uniformity, and a lack of data to determine the practices that exist across the Commonwealth, the states, and the territories.

7.20 Nowhere was a lack of uniformity in data and practice more starkly illustrated for the committee than in a discussion about vasectomies in young men. As has been seen above, the number of cases being considered by courts and tribunals is of the order of perhaps two dozen per annum, and that figure is likely to include some cases that lie outside the committee's terms of reference, including terminations and procedures for people with mental illness. However, the committee received evidence from Professor Sonia Grover and her colleagues at Royal Children's Hospital,

Melbourne, who had extracted Medicare data about vasectomies in boys and men aged 15 to 24. They did emphasise some qualifications on the information:

> These procedures may not be being performed in young men with disabilities, but it would be relatively uncommon for a sterilising procedure to be performed in a male of this age. Some of these procedures may for medical reasons and may be unilateral – ie not sterilising.[17]

7.21 The data however was troubling; the most recent decade of figures is below:

Table 7.3: Medicare data on vasectomies in males age 15 to 24

Year	NSW	VIC	QLD	SA	WA	TAS	ACT	NT	**Total**
2003	9	10	22	1	0	0	2	0	**44**
2004	9	5	23	0	4	0	3	0	**44**
2005	7	7	22	0	4	1	0	1	**42**
2006	9	5	25	0	9	3	0	0	**51**
2007	10	6	20	2	5	0	4	0	**47**
2008	6	5	23	1	8	1	0	0	**44**
2009	13	1	21	1	3	0	2	0	**41**
2010	8	3	21	3	7	0	2	0	**44**
2011	4	7	15	0	1	0	2	0	**29**
2012	9	4	22	0	8	0	1	0	**44**
Total	**84**	**53**	**214**	**8**	**49**	**5**	**16**	**1**	**430**

7.22 It is possible that these represent normal vasectomies undertaken by choice, but it would be unusual to undertake this procedure at such a young age. It is possible that some of these reflect sterilising procedures being undertaken without court or tribunal authorisation. The figures for Queensland are out of all proportion to that state's population and suggest an aberrant medical practice of some kind, whether or not in connection with men with disability.

Committee view

7.23 Data on cases appeared to be very uneven, while the ability of jurisdictions to extract data regarding cases was limited and the task labour-intensive. The figures

17 Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne, *Submission 69*, p. 13.

suggest a number of features that warrant attention, and some of these issues have been covered in previous chapters:

- The rate of applications varies wildly between states and territories. While the Victorian figure is known to be high because it includes abortion applications that are not counted in at least some other jurisdictions, there is still an order of magnitude range from least to most frequent, once the different population sizes of the jurisdictions are taken into account.
- There are significant differences in the frequency with which applications are withdrawn, ranging from half the applications in Tasmania, to none in Western Australia, and almost none in the ACT.
- There are even more significant differences in the rates at which applications are dismissed, ranging from a slight majority in New South Wales, to none in the ACT.

7.24 The data indicates that it cannot be assumed that Australians will receive the same outcome, and undertake the same legal journey, irrespective of where they live. Their experiences may differ significantly according to the jurisdiction in which they reside. The data available suggests that there is great scope for creating more consistent processes and outcomes across jurisdictions.

Recommendation 25

7.25 The committee recommends that data about adult and child sterilisation cases be recorded, and reported, in the same way in each jurisdiction. Data records should include the number of applications made for a special medical procedure, the kind of special medical procedures specified in the application, the categories of parties to the proceedings (for example, parents, medical experts, public advocates), and the outcome of the case.

Recommendation 26

7.26 The committee recommends that the Department of Human Services investigate the pattern of vasectomy in young males, including the apparently high number occurring in Queensland, and provide information to the Standing Council on Law and Justice if it has reason to believe the figures include sterilisations of men with disability.

The argument for uniform legislative and procedural requirements

7.27 One submitter to the inquiry, Dr Wendy Bonython, commented on the need for more consistent outcomes and processes across jurisdictions. According to Dr Bonython, given the lack of uniformity across jurisdictions '[t]he law as it currently exists with respect to sterilisation of minors is a jurisdictional disaster'.[18]

7.28 Focusing on children's cases, Dr Bonython advised that the existence of both Commonwealth and State and Territory laws regulating the sterilisation of children can lead to 'forum shopping'. While, as the Family Law Council has previously noted,

18 Dr Wendy Bonython, *Submission 22*, p. 33; Law Institute of Victoria, *Submission 79*, p. 20.

orders of Commonwealth courts cannot be overturned by a by state or territory court or tribunal,[19] families who are dissatisfied with the outcome of a proceeding before a state or territory court or tribunal may try to circumvent the tribunal's ruling by subsequently seeking orders from the Family Court of Australia:

> Either an applicant doesn't obtain the order they sought in the Supreme Court, so tries their luck in the Family Court; or a disgruntled party, having unsuccessfully argued against the order being granted, then applies for an ex tempore injunction from the Family Court to invalidate the Supreme Court order, pending a hearing in the Family Court. It is worth emphasising that the two courts are operating in separate hierarchies, and so both are exercising original jurisdiction; argument would have to be heard de novo [from the beginning], thereby increasing delay, expense and, potentially, the trauma associated with court proceedings for all involved, including the child. This is clearly unacceptable.[20]

7.29 As Dr Bonython's advice implies, the existence of multiple jurisdictions operating under different laws creates the potential for like cases to receive different outcomes. In their submission to this inquiry, the Law Institute of Victoria noted this possibility and accordingly argued that the same criteria should apply in each jurisdiction.[21]

Standing Committee of Attorneys–General

7.30 The need for uniformity has previously been considered by the Commonwealth and the State and Territory governments. The matter was considered by the Standing Committee of Attorneys–General (SCAG) following the release of a 1997 report by the Australian Human Rights Commission, which indicated there was a high incidence of coerced or involuntary sterilisations of Australians with a disability.[22] SCAG did not publicly release the 2004 discussion paper or the 2006 draft model legislation. The documents were, however, released to 'select relevant stakeholders' for comment. The Commonwealth Attorney–General's Department advised that stakeholders included legal and medical associations, state and federal human rights commissions, health and human services, religious organisations and the judiciary.[23]

7.31 People with Disabilities Australia advised that there were concerns with the draft model legislation:

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19 Family Law Council, *Sterilisation and other medical procedures on children*, November 1994, paragraph 3.30; *P v P* (1994) 120 ALR 545.

20 Dr Wendy Bonython, *Submission 22*, p. 33.

21 Law Institute of Victoria, *Submission 79*, p. 30.

22 Commonwealth Attorney-General's Department, Answers to questions on notice, 19 April 2013 (received 14 May 2013).

23 Commonwealth Attorney-General's Department, Answers to questions on notice, 19 April 2013 (received 14 May 2013).

> While PWDA supported the development of a nationally consistent approach to the issue, we expressed our strong opposition, along with WWDA and other disability organisations to the emphasis of the SCAG on the elaboration of the circumstances and principles under which involuntary or coerced sterilisation can be authorised, rather than on prohibition of this human rights abuse.[24]

7.32 Dr Bonython also implied that the draft legislation was contentious:

> The Standing Committee of Attorneys–General have considered it. They sort of got ready to do something, and then they kind of backed away a bit and it became a bit topical. So really we are not that much further towards a consistent, transparent system than we were back when the High Court really first came to grips with it in the Marion case.[25]

7.33 While SCAG did not publicly release submissions received, a number were published on stakeholder websites and are available through a general Internet search. The submissions indicate that the object of achieving uniformity, particularly to prevent forum shopping, received support. However, there were concerns with aspects of the draft model legislation. For example, the Multicultural Disability Advocacy Association did not support the draft bill. The association was concerned that the legislation would relax safeguards already existing in New South Wales.[26] Women With Disabilities Australia opposed the draft model legislation on the grounds that it would leave open the possibility of child sterilisation:

> It was with extreme regret that, in late 2006, WWDA discovered that the Standing Committee of Attorneys-General (SCAG), had ignored WWDA's pleas to respect the fundamental human rights of women and girls with disabilities, and had proceeded to draft national, uniform legislation which sets out the procedures that jurisdictions could adopt in authorising the sterilisation of children who have an intellectual disability.[27]

7.34 The proposal for uniform legislation was removed from the SCAG agenda in 2008. As recorded in the SCAG minutes, officially the item was removed as SCAG no longer considered uniform legislation to be necessary:

> Further work and research since April 2007 has revealed that…[t]here are existing processes in place in each jurisdiction to authorise sterilisation procedures, which appear to be working adequately in light of recent

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24 People with Disabilities Australia, *Submission 49*, p. 10.

25 Dr Wendy Bonython, private capacity, *Committee Hansard*, 27 March 2013, p. 64.

26 Multicultural Disability Advocacy Association, *Comments on draft model bill*, http://www.mdaa.org.au/service/systemic/06/cidbill.html (accessed 9 July 2013).

27 Women With Disability Australia, *Systematic advocacy on the unlawful sterilisation of minors with disabilities (2003 – 2008)*, http://www.wwda.org.au/steriladv07.htm (accessed 9 July 2013).

> improvements in treatment options and education initiatives. There would be limited benefit in developing model legislation.[28]

7.35 The committee sought clarification of what work had been done since the item was removed from the SCAG agenda:

> Senator BOYCE: …In terms of the sterilisation of minors, the Standing Council of Attorneys-Generals back in 2008 said they would continue the promotion of ongoing awareness of the non-surgical alternatives to manage the menstruation and contraceptive needs of intellectually disabled people. Can you tell me what the Commonwealth is doing in this regard? The promotion of ongoing awareness, is what we are talking about.
>
> …
>
> Mr Abraham: The standing council did not make a decision to monitor ongoing activity in relation to that by the jurisdiction, so we are not in a position to indicate to the committee what the states have done.
>
> Senator BOYCE: So how would we ever know if that measure was implemented?[29]

7.36 The Attorney-General's Department agreed to review this issue further with Victoria, the lead jurisdiction on the matter. It subsequently provided further advice, confirming that there was no information about activities after 2008:

> Victoria advised they not aware of SCAG or SCLJ undertaking any further work on the recommendations from the March 2008 meeting. Victoria advise that it was up to each jurisdiction to undertake follow up action. The item did not attract any formal reporting or monitoring requirements.
>
> States and Territories had not provided examples of steps taken in their jurisdictions to promote ongoing awareness or to review their tribunals at the time of deadline for the questions on notice.[30]

7.37 The committee does note however the work of the Australian Guardianship and Administration Council at around that same time, and in response to SCAG's review of the Commonwealth, state and territory laws regulating sterilisation of persons with disabilities.[31] AGAC is made up of 'the Public Guardians, Adult Guardians and Public Advocates, the Boards and Tribunals who deliberate upon applications under guardianship and administration legislation and the State Trustees or Public Trustees'.[32] In March 2009 it agreed and released the Protocol for Special Medical Procedures (Sterilisation).

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28 Commonwealth Attorney-General's Department, Answers to questions on notice, 19 April 2013 (received 14 May 2013).

29 *Committee Hansard*, 31 May 2013, p. 9.

30 Commonwealth Attorney-General's Department, Answers to questions on notice, 19 April 2013 (received 14 June 2013)

31 Australian Guardianship and Administration Council, *Submission 28*, Attachment 1, *Protocol for Special Medical Procedures (Sterilisation)*, cl. 1.5.

32 Australian Guardianship and Administration Council, *Submission 28*, p. 1.

7.38 In response to this committee's questions, the Commonwealth Attorney–General's Department advised that the Commonwealth government has subsequently recommitted to working with the states and territories on the regulation of sterilisation of women and girls with disabilities. This commitment forms part of the 2012 National Human Rights Action Plan, released on 10 December 2012. The department further advised that discussions with State and Territory Ministers have not commenced.[33] The department advised that this initiative is in response to Recommendation 39 of the United Nations Universal Periodic Review of Australia in 2011, which recommended Australia:

> Comply with the recommendations of the Committee on the Rights of the Child and the Committee on the Elimination of All Forms of Discrimination against Women concerning the sterilization of women and girls with disabilities (Denmark); enact national legislation prohibiting the use of non-therapeutic sterilization of children, regardless of whether they have a disability, and of adults with disability without their informed and free consent (United Kingdom); repeal all legal provisions allowing sterilization of persons with disabilities without their consent and for non-therapeutic reasons (Belgium); abolish non-therapeutic sterilization of women and girls with disabilities (Germany).[34]

Uniform legislation – implications for the Family Law Act 1975

7.39 Two representatives of the legal sector, Dr Wendy Bonython and the Law Institute of Victoria, noted that legislative change may be required to address current issues with the regulation of the sterilisation of children.[35] At the Commonwealth level, the relevance of the *Family Law Act 1975* for child sterilisation cases was considered in 1994 by the Family Law Council. As explored in Chapters 3 of this report, the Family Law Act does not contain any specific provisions about child sterilisation cases. The Family Court of Australia applies the general principles regarding the best interests and the welfare of the child in Part 7 of the Act, as well as rules that the court has made to govern applications for special medical procedures.

7.40 Reporting in 1994, the Family Law Council recommended '[t]here should be a new division in the Family Law Act regulating sterilisation of young people.'[36] As Council noted, there was concern that the principles in Part 7 are of limited relevance to child sterilisation cases. Part 7 is primarily concerned with the procedures and principles for the court to apply for cases involving parental responsibility for the

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33 Commonwealth Attorney-General's Department, Answers to questions on notice, 19 April 2013 (received 14 May 2013).

34 Human Rights Council, *Report of the Working Group on the Universal Periodic Review – Australia*, 24 March 2011, paragraph 86.39, http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G11/122/90/PDF/G1112290.pdf?OpenElement (accessed 8 July 2013).

35 Dr Wendy Bonython, *Submission 22*, p. 33; Law Institute of Victoria, *Submission 79*, p. 20.

36 Family Law Council, *Sterilisation and other medical procedures on children*, 1994, Recommendation 1(a).

child and who the child will live with and spend time with. Consequently, its relevance for child sterilisation cases is questionable:

> Council…agrees that the proposed provisions on sterilisation of children should be contained in a separate division of the Family Law Act. In Council's view, the adoption of this approach will make it quite clear that distinct conditions apply in relation to sterilisation of children and a separate Act is not considered necessary to achieve this objective.

Committee view

7.41 Court or tribunal procedures must establish a robust framework for the defence of persons with disabilities. Uniform legislation would ensure that a child and an adult with disabilities receive the same protections regardless of the jurisdiction in which they reside. It is of concern to the committee that it cannot be guaranteed that a person with a disability will receive the same treatment and the same outcome irrespective of where they live. As explored in both this and previous chapters, there are marked differences in the way each jurisdiction operates. As the committee has previously noted, chief differences include the requirements and procedures to assess capacity as a threshold issue, provisions for the adult or a child to participate in proceedings, the availability of legal representation or a non-legal advocate, and the criteria considered when determining whether to grant a sterilisation order.

7.42 The committee has already made a series of recommendations to ensure a robust framework of the defence of persons with disabilities in sterilisation cases (see chapter 5). This framework would be compromised by differences across jurisdictions, and should not depend on whether an order is sought from a State or Territory tribunal or from the Family Court. Legislation, and related court and tribunal procedure, should provide a consistent defence of the rights of persons with disabilities. This safety net is compromised where like cases produce different outcomes.

7.43 Accordingly, the committee recommends that the Council of Australian Governments oversee the development of uniform model legislation. This legislation should take into account the committee's recommendations to improve court and tribunal practice and procedure, which include recommendations about the circumstances in which court or tribunal authorisation is needed, the tests courts and tribunals are to apply when considering an application for a sterilisation order, the participation of persons with disabilities in proceedings, and access to legal representation and advocacy support (see chapter 5). Based on the model legislation, a new division of the Family Law Act should be created to specifically establish the factors to be considered in child sterilisation cases as opposed to children's cases under Part 7 of the Act.

Recommendation 27

7.44 The committee recommends that the Council of Australian Governments oversee the development of uniform model legislation to regulate the sterilisation of persons with disabilities. Based on this model, a new division of the *Family Law Act 1975* (Cth) should be created.

Further proposed legislative amendment – the need for uniform offences

7.45 A broad range of submitters advocated that any regulations to prohibit, or to otherwise circumscribe, the sterilisation of persons with disabilities need to be underpinned by offences that would act as a deterrent against non-compliance.[37] Two categories of offences were proposed:

- an offence of performing a sterilisation without authorisation; and
- an offence of aiding, abetting or procuring the unauthorised sterilisation of an Australian with a disability, both within Australia and overseas.

The offence of performing a sterilisation procedure without authorisation

7.46 This category of offence would, in reality, apply exclusively to the medical profession. Such an offence, it was argued, is needed to discourage the medical profession from proceeding without requisite approvals. The offence would act as both a deterrent and a signpost that in most circumstances the medical profession does not have the authority to authorise the sterilisation of a person with a disability. The committee was provided with anecdotal evidence that the practice of sterilisation without necessary authorisations is continuing. Women with Disabilities Australia (WWDA) advised that the organisation:

> …had reports from the Tasmanian Guardianship Board to say that they are seeing an increase in applications for sterilisation procedures on women with intellectual disabilities once they turn 18 and they say that the doctors get really frustrated because they do not understand why they have to even go through the process. They said that it appears that the applications are being sought solely for the purpose of prevention of future pregnancy. I am not saying that they are being granted; I am saying that they have noticed an increase in the number of applications.[38]

7.47 Data compiled by the Australian Human Rights Commission in 1997 and 2001 was cited in support of the proposition that the medical profession is continuing to perform sterilisation procedures on persons with disabilities without proper authorisation. For example, Qld Centre for Intellectual and Developmental Disability, Queenslanders with Disabilities Network, and Qld Advocacy Inc. provided the committee with a report which, on the basis of the Australian Human Rights Commission's work, concluded that 'unauthorised sterilisations still continue to be done into the 21st century.'[39]

7.48 However, the accuracy of these concerns was disputed. Associate Professor Sonia Grover, a gynaecologist at Royal Children's Hospital, described the complex

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37 See, for example, Australian Human Rights Commission, *Submission* 5, Recommendation 4; Office of the Public Advocate, *Submission 14*, Recommendation 13; People with Disability Australia, *Submission 50*, pp. 12; 34.

38 Ms Carolyn Frohmader, Executive Director, Women With Disabilities Australia, *Committee Hansard*, 11 December 2012, p. 8.

39 Qld Centre for Intellectual and Developmental Disability, Queenslanders with Disabilities Network, and Qld Advocacy Inc., *Submission 37*, Attachment 3, p. 10.

process that would have to be undertaken in order to perform an unauthorised sterilisation without attracting suspicion, if it was being reported as a different type of operation:

> If we are going to propose that people are tying tubes in theatre—because it has to be done in the operating theatre under a general anaesthetic—and if somebody is saying, 'This woman has gone to theatre for an appendectomy but they are tying tubes instead,' then I would say: the people who work in the coding department are not in theatre; you cannot line them up and get them to tell the right story, and they are going to look for the appendectomy specimen to be able to code this as having been done as an appendectomy. Sure you could put clips on the tubes at the same time, having done the appendectomy, but that requires all the nursing staff in theatre to write down that they did not pull the clips out. So it requires a whole string of people to risk their careers. So I am not sure that there are many people who would be prepared to risk their careers or, for that matter, that a hospital would risk being closed down, presumably, if they are doing a procedure they have not got permission to do…So there may be problems but I am not sure that the size of the problem of what is happening in Australia is as big as all that.[40]

7.49 On the other hand, the committee heard evidence from a woman with a disability who had a different experience:

> Miriam: There are paediatric surgeons who are willing to do that. I have been in the presence, in a medico legal forum, only it is 20 years ago now. But the practice would continue. In 1992, we ran a medico legal forum with the High Court. We had a number of very eminent lawyers and Supreme Court and High Court judges there. In their presence were two paediatric surgeons who admitted to doing it – in the best interests of the parents. They would record it as an appendectomy. Of course that is under private health insurance. In Medicare it would be harder to follow.[41]

7.50 During the hearing at which the above evidence was received, a current health professional observed that they understood how the practice could be allowed to continue, as it would in reality be difficult for other staff to question the surgeon in theatre.[42]

7.51 It was suggested that, if occurring, unauthorised procedures may be the result of a lack of understanding of legal requirements. Ms Lesley Naik attributed any incidence of unauthorised procedures to uncertainty amongst the community about when authorisation is needed. This uncertainty, it was argued, 'raises a serious doubt

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40 Associate Professor Sonia Grover, Gynaecologist, Royal Children's Hospital *Committee Hansard*, 11 December 22, p. 4.

41 Miriam, *Proof Committee Hansard*, 30 January 2013, p. 7.

42 Woman A, *Proof Committee Hansard*, 30 January 2013, p. 7.

regarding the clarity of law in this area'.[43] Professor Grover also commented on uncertainty within the medical community about legal requirements:

> We do still get straight-out requests regarding hysterectomies. They are often from people who do not know. I get horrified when it happens. We still get doctors writing us occasional letters. I was thinking as I came in here that we have recently done a survey of GPs and paediatricians. The work has not actually been published yet. We were asking them a few questions about how comfortable GPs and paediatricians felt about fixing young women's health related problems. Of the 300 GPs and paediatricians, 12 of them mentioned hysterectomy early in the menstrual management issue for intellectually disabled young women. There is no doubt that there are gaps and there is no doubt that these families need resources. It breaks my heart to be called in late when they have struggled for years. I take my hat off to these families.[44]

Existing offences

7.52 As outlined in chapter 3 of this report, the offence of performing a sterilisation procedure without all necessary approvals already exists in a number of jurisdictions. For example, in South Australia, a medical practitioner commits an offence subject to a $10 000 fine or imprisonment two years is performing a sterilisation without the tribunal's consent. A medical practitioner does not commit an offence if the unauthorised sterilisation was performed in response to a medical emergency.[45] In the Northern Territory, proceedings for professional misconduct may be taken against a medical practitioner who performs a major medical procedure without court authorisation.[46]

7.53 In Tasmania, a person who carries out unauthorised special treatment commits an offence liable to imprisonment for a period not exceeding one year or a fine not exceeding 10 penalty units or both.[47] However, it is not an offence to carry out special medical treatment if the medical practitioner considers that, as a matter of urgency, the treatment is necessary to save the person's life or to prevent serious damage to person's health.[48] It is also an offence to purport to give consent to special medical treatment. A person who gives unlawful consent to treatment is guilty of an offence subject to a fine not exceeding 20 penalty units.[49] In New South Wales, a person who

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43 Ms Lesly Naik, *Submission 7*, pp. 2–3.

44 Associate Professor Grover, Royal Children's Hospital, *Committee Hansard*, 11 December 22, p. 4.

45 *Guardianship and Administration Act 1993*, s. 61.

46 *Adult Guardianship Act*, ss. 21(2) Note.

47 *Guardianship and Administration Act 1995*, s. 38.

48 *Guardianship and Administration Act 1995*, s. 40.

49 *Guardianship and Administration Act 1995*, s. 42.

performs an unauthorised sterilisation of a person with a disability is liable to a maximum penalty of seven years imprisonment.[50]

7.54 In the Australian Capital Territory, a medical practitioner who performs an unauthorised sterilisation does not commit an offence if he or she obtained consent for the procedure but did not know, and could not be recently expected to know, that the person who provided consent did not have the authority to do so.[51]

7.55 Dr Bonython advised that medical practitioners who perform a sterilisation procedure without appropriate approvals commit 'a trespass against the person', and therefore may also be liable to a penalty under civil law.[52] However, the value of penalties under civil law was questioned. Ms Lesley Naik submitted that civil remedies are a poor substitute for criminal sanctions:

> [C]ivil law enforcement measures are ill suited to providing a remedy for achieving deterrence in light of the barriers intellectually disabled children are likely to face in accessing justice.[53]

7.56 These examples illustrate the lack of uniformity in the existing offences. Differences affect the scope of the offences, that is, what actions and circumstances they cover, what the practitioner had to know or intend, and the penalties attached. As Ms Lesley Naik pointed out, the lack of consistency results in certain people being 'afforded less legal protection against unauthorised sterilisation' and is 'particularly unsatisfactory in light of Australia's international human rights obligations'.[54]

Offence of procuring an unauthorised sterilisation procedure within or outside Australia

7.57 WWDA gave an account of a mother who, in 2003, allegedly admitted her daughter to hospital under the mother's name in order to secure a sterilisation procedure.[55] It was submitted that these kinds of attempts to procure, or otherwise assist with the performance of, unauthorised sterilisation procedures should be subject to a criminal penalty. For example, PWDA submitted that relevant legislation should 'make it an offence to procure, or seek to procure, an involuntary or coerced sterilisation, and to assist or aid and abet such a procedure.'[56]

7.58 The committee received evidence that indicated that there is an established practice among some families of taking children outside Australia to obtain special medical procedures such as sterilisation. This may be because they are not confident

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50 New South Wales Government, *Submission 66*, p. 4.

51 *Guardianship and Management of Property Act 1991*, s. 69.

52 Dr Wendy Bonython, *Submission 22*, p. 10.

53 Ms Lesly Naik, *Submission 7*, p. 8.

54 Ms Lesly Naik, *Submission 7*, p. 8.

55 Ms Frohmader, Women With Disabilities Australia, *Committee Hansard*, 11 December 2012, p. 6.

56 People with Disabilities Australia, *Submission 49*, p. 35.

of the effectiveness of Australian tribunals and courts; or because they lack the money to pay for court processes. The grandmother of a child with a disability wrote:

> We don't want to have to take M overseas to get what we know to be the best outcome for her. Travel by aircraft would cause extreme stress for her and discomfort for other passengers; however, if we must, it may have to happen.[57]

7.59 Professor Carter, the father of a woman with a moderate to severe intellectual disability, observed:

> Some—and I gave an example in our submission—have reached the stage of thinking that the only way they can get this done is to go overseas and have a hysterectomy done there. We put in an example of somebody going to New Zealand. But there are other examples. Traditionally, it has been Thailand and New Zealand. But I heard recently about somebody who went to India to get it done.[58]

7.60 Another parent stated:

> I can assure you that parents go overseas because this subject is taboo, because the court system is too complicated and too expensive. Who has $10,000 to apply to the Family Court to do something to better their child's health? If the system was more family friendly, if the system was more open, these people would not need to go overseas.[59]

7.61 The Carters also noted that there were instances where a person went overseas in order to circumvent Australian tribunal decisions:

> We are aware of instances where parents have taken their daughters to Thailand or New Zealand to have a hysterectomy because their request to have a hysterectomy performed in Australia was rejected by the Guardianship Tribunal.[60]

7.62 Accordingly, there was support for the offence of procuring, aiding or abetting an unauthorised sterilisation procedure applying not only within Australia but also to circumstances where a person with a disability is taken overseas for the purpose of obtaining an unauthorised sterilisation. The Law Institute of Victoria argued that an offence should be created:

> The LIV suggests that a clause be included in the legislation to the effect that an adult or minor with a disability from Australia whose parent, carer or guardian intends to have a forced sterilisation procedure performed must not be removed from the Commonwealth of Australia.[61]

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57 Name withheld, *Submission 10*, p. 4.

58 Professor Carter, *Committee Hansard*, 27 March 2013, p. 49.

59 Mrs Robbins, *Committee Hansard*, 27 March 2013, p. 52.

60 Dr and Mrs John and Merren Carter, *Submission 20*, p. 3.

61 Law Institute of Victoria, *Submission 79*, p. 23.

7.63 The Human Rights Commission made a similar recommendation.[62] In addition, the Law Institute of Victoria recommended that a system be put in place to allow the Australian Federal Police to put a child on the Airport Watch List as a preventative measure where necessary.[63]

7.64 Existing offences under State and Territory legislation relating to female genital mutilation (FGM) were put forward as a model that could be adopted to deter persons from taking persons with disabilities oversees for sterilisation procedures.[64] For example, the *Crimes Act 1900* (NSW) contains an offence of aiding, abetting, or procuring a person to perform an FGM act on another person. This offence carries a penalty of imprisonment for seven years.[65] This offence applies even where the action occurs outside New South Wales. It is sufficient that the person who commits the offence is usually resident in New South Wales or that the offence was committed against a New South Wales resident. The Australian Government has advised that such offences apply to attempts to remove an Australian from Australia for the purpose of procuring a FGM procedure.[66]

Committee view

7.65 The committee concludes that actions should never be taken to circumvent tribunal or court decisions, and that, as the provider of submission 10 pointed out, such actions will in any case often cause stress for all involved. The financial savings are likely to be limited, suggesting that the main motivation is fear of the courts and tribunals, or an unwillingness to abide by a tribunal decision. The solution lies in ensuring those processes are accessible and fair. Deliberately circumventing the protections that Australian law seeks to extend to people with disabilities is wrong.

7.66 The committee therefore agrees that each jurisdiction should enact offences for performing, or for procuring, an unauthorised sterilisation procedure. Consistent with legislation currently existing in some jurisdictions, it should be a defence if the medical practitioner acted in good faith or otherwise did not know, and could not be reasonably expected to know, that court or tribunal authorisation was required. The committee is concerned by anecdotal evidence that suggests that persons may be taking people with disabilities oversees for the purpose of obtaining a sterilisation procedure. Accordingly, the committee agrees that the offence of procuring or aiding and abetting an unauthorised sterilisation procedure should apply to circumstances where Australians travel overseas for this purpose. Offences relating to FGM appear to be a useful model.

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62 Australian Human Rights Commission, *Submission 5*, p. 4.

63 Law Institute of Victoria, *Submission 79*, pp. 23–24.

64 Australian Human Rights Commission, *Submission* 5, p. 13.

65 *Crimes Act 1900* (NSW), s. 45.

66 Australian Government, *Female genital mutilation*, http://www.smarttraveler.gov.au/tips/female-genital-mutilation.html (accessed 11 July 2013).

Recommendation 28

7.67 The committee recommends that each jurisdiction enact legislation prohibiting the performance or procurement of unauthorised sterilisation procedures. State and Territory legislation should also make it an offence to take, attempt to take, or to knowingly assist a person to take, a child or an adult with a disability oversees for the purpose of obtaining a sterilisation procedure.

Senator Rachel Siewert

Chair

APPENDIX 1

Submissions and Additional Information received by the Committee

Submissions

1 Name Withheld

2 Name Withheld

3 Mr Geoff Bird

4 Name Withheld

5 Australian Human Rights Commission

6 Name Withheld

7 Ms Lesley Naik

8 Dr Irwin Faris

9 Name Withheld

10 Name Withheld

11 Name Withheld

12 Name Withheld

13 Name Withheld

14 Office of the Public Advocate

15 Name Withheld

16 Miss Lynne Bertram

17 Royal Australasian College of Physicians

18 Ms Janine Truter

19 Adult Guardian and Public Advocate of Queensland

20 Dr and Mrs John and Merren Carter

21 University of Sydney

22 Dr Wendy Bonython

23 Organisation Intersex International Australia

24 Name Withheld

25 Family Planning NSW

26 Name Withheld

27 Name Withheld

28 Australian Guardianship and Administration Council

29 Name Withheld

30 Royal Australian and New Zealand College of Obstetricians and Gynaecologists

31 Confidential

32 Catholic Women's League Australia Inc.

33 Name Withheld

34 Northern Territory Government

35 Advocacy for Inclusion

36 Ms Diana Bryant AO

37 Qld Centre for Intellectual and Developmental Disability, Queenslanders with Disabilities Network, and Qld Advocacy Inc.

38 Women's Health West

39 Catholic Social Services Victoria

40 Australian Women's Health Network

41 Australian Lawyers for Human Rights

42 STAR Victoria

43 Name withheld (received via Women With Disabilities South Australia)

44 Ms Linda Steele

45 Name Withheld

46 Name Withheld

47 Professor Susan Hayes

48 Amnesty International Australia

49 Women With Disabilities Australia

50 People with Disability Australia

51 Name Withheld

52 Sexual Health and Family Planning Australia

53 Australian Medical Association

54 Androgen Insensitivity Support Group Australia Inc.

55 Name Withheld

56 Australian Catholic Bishops Conference

57 Tasmanian Government

58 Family Planning Victoria

59 Australian Association of Developmental Disability Medicine Inc.

60 National LGBTI Health Alliance

61 Associate Professor Lee Ann Basser

62 Name Withheld

63 Name Withheld

64 Name Withheld

65 Queensland Advocacy Incorporated

66 NSW Government

67 Intellectual Disability Rights Service Inc.

68 Miss Stella Young

69 Department of Paediatric and Adolescent Gynaecology at Royal Children's Hospital, Melbourne

70 Women's Legal Services NSW

71 Name withheld (received via Women With Disabilities South Australia)

72 Name withheld (received via Women With Disabilities South Australia)

73 Ms Tammy Burke

74 Name Withheld

75 Ms Susan Lamrock

76 Mrs Cynthia Hughes

77 National Council on Intellectual Disability

78 Mental Health Law Centre (WA) Inc.

79 Law Institute of Victoria

80 Australian Women Against Violence Alliance

81 Mr Robert Greenfield

82 Department of Human Services

83 Name Withheld

84 Australian Institute on Intellectual and Developmental Disabilities

85 A Gender Agenda

86 Ms Zoe Brain

87 Mr Senthorun Raj

88 Australasian Paediatric Endocrine Group

89 Mr Bayne MacGregor

90 Confidential

91 Mr Alastair Lawrie

Form Letters

1 Form Letter Type 1, received from approximately 23 individuals

Additional Information

1 Article by Ruby Grant, received 11 March 2013

2 Agreed Conclusions from the UN Commission of the Status of Women (CSW) 57th session, from Women With Disabilities Australia, received 20 March 2013

3 Information, tabled by Family Planning NSW, Sexual Health and Family Planning Australia and Family Planning Victoria, at Sydney public hearing 27 March 2013

4 Extract from Norplant Meets the New Eugenicists: the Impermissibility of Coerced Contraception, tabled by Intellectual Disability Rights Service Inc, at Sydney public hearing 27 March 2013

5 Women's Studies International Forum journal article by Michelle McCarthy, tabled by Intellectual Disability Rights Service Inc, at Sydney public hearing 27 March 2013

6 Swiss National Advisory Commission on Biomedical Ethics, 'On the management of differences of sex development', tabled by Organisation Intersex International Australia, at Sydney public hearing 28 March 2013

7 Anne Tamar-Mattis, 'Report to the Inter-American Commission on Human Rights: Medical Treatment of People with Intersex Conditions as a Human Rights Violation', tabled by Organisation Intersex International Australia, at Sydney public hearing 28 March 2013

8 Victoria, Department of Health, 'Decision-making principles for the care of infants, children and adolescents with intersex conditions', tabled by Organisation Intersex International Australia, at Sydney public hearing 28 March 2013

9 Organisation Intersex International Australia, 'Response to Victorian Health Department framework document', tabled by Organisation Intersex International Australia, at Sydney public hearing 28 March 2013

10 Report from the Parliamentary Assembly of the Council of Europe Committee on Social Affairs, Health and Sustainable Development, from Women With Disabilities Australia, received 30 April 2013

11 Advice by Emeritus Professor Ivan Shearer, 24 May 2013

12 Report of a 2005 Human Rights Investigation into the medical "normalization" of intersex people, from Organisation Intersex International Australia, received 3 June 2013

13 Discrimination Generated by the Intersection of Gender and Disability report, by the European Parliament, from Women With Disabilities Australia, received 6 June 2013

14 National LGBTI Health Alliance policy statement on the Victorian Department of Health approach to intersex young people, from Organisation Intersex International Australia, received 12 July 2013

Correspondence

1 Correspondence received from the Chief Judge of the Family Court of Western Australia, 15 April 2013

2 Correction from Australian Human Rights Commission to evidence given at Sydney public hearing 27 March 2013

3 Correspondence received from the State Administrative Tribunal Western Australia, 2 May 2013

4 Correspondence received from the Queensland Civil and Administrative Tribunal, 3 May 2013

5 Correspondence received from the Guardianship Board South Australia, 3 May 2013

6 Correspondence received from the Australian Capital Territory Civil and Administrative Tribunal, 12 May 2013

7 Correspondence received from the Northern Territory Executive Office of Adult Guardianship, 21 May 2013

8 Correspondence received from the Victorian Civil & Administrative Tribunal (VCAT), 28 May 2013

9 Correspondence received from Organisation Intersex International Australia, 12 July 2013

Answers to Questions on Notice

1 Answer to Question on Notice received from Queensland Centre for Intellectual and Development Disability, 27 March 2013

2 Answers to Questions on Notice received from Office of the Adult Guardian Queensland, 11 April 2013

3 Answers to Questions on Notice received from People With Disability Australia, 12 April 2013

4 Answers to Questions on Notice received from Australian Human Rights Commission, 1 May 2013

5 Answers to Questions on Notice received from Attorney-General's Department, 14 May 2013

6 Answers to Questions on Notice received from Attorney-General's Department, 14 June 2013

7 Answers to Questions on Notice received from Attorney-General's Department, 2 July 2013

APPENDIX 2

Public Hearings

Tuesday, 11 December 2012

Parliament of Victoria, Melbourne

Witnesses

Office of the Public Advocate, Victoria
CHESTERMAN, Mr John, Manager of Policy and Education
PEARCE, Ms Colleen, Public Advocate

Women With Disabilities Australia
FROHMADER, Ms Carolyn, Executive Director

Royal Children's Hospital
GROVER, Associate Professor Sonia, Gynaecologist

New South Wales Council for Intellectual Disability
SIMPSON, Mr Jim, Lawyer

Wednesday, 30 January 2013

Brisbane

Witnesses

Department of the Senate
McINALLY, Mr Gerry, Principal Research Officer

Jen, Private capacity
Karin, Private capacity
Fran, Private capacity
Donna, Private capacity
Rachael, Private capacity
Sharon, Private capacity
Anne, Private capacity
Julie, Private capacity

Petra, Private capacity
Debra, Private capacity
Miriam, Private capacity
Sue, Private capacity
Woman A, Private capacity

Friday, 1 February 2013

Sydney

Witnesses

BOWDEN, Mr Matthew, Advocate
Woman A, Private capacity
Woman B, Private capacity
Woman C, Private capacity
Woman D, Private capacity

Tuesday, 19 February 2013

Adelaide

Witnesses

Katherine, Private capacity
Kristen, Private capacity
Sue, Private capacity
Naomi, Private capacity
Margie, Private capacity

Wednesday, 27 March 2013

Cliftons, Sydney

Witnesses

Family Planning New South Wales
BATESON, Dr Deborah, Medical Director
CHIVERS, Ms Jane, Senior Project Coordinator
HARDY, Mr Rob, Education Officer, Senior Health Promotion

BONYTHON, Dr Wendy Elizabeth, Private capacity

Family Court of Australia
BRYANT, Hon. Diana, AO, Chief Justice

CARTER, Miss Sophie, Private capacity
CARTER, Mrs Merren, Private capacity
CARTER, Professor John, Private capacity

Intellectual Disability Rights Service Inc.
COOTES, Ms Janene, Executive Officer
SPENCER, Dr Margaret, Coordinator, Parents Project

Women With Disabilities Australia
FROHMADER, Ms Carolyn, Executive Director
MEEKOSHA, Associate Professor Helen, Member, Past President, WWDA Representative on Human Rights

Family Planning Victoria
HAMILTON, Ms Lauren Anne, Psychologist, Disability and Sexuality Service

Australian Human Rights Commission
INNES, Mr Graeme, Disability Discrimination Commissioner
RICCI, Ms Cristina, Senior Policy Officer

KNIGHT, Ms Kathryn Elizabeth, Private capacity

Catholic Women's League Australia
KROHN, Mrs Anna Maria, Bioethics Convenor

Centre for Disability Research and Policy, University of Sydney
LLEWELLYN, Professor Gwynnth, Director

Office of the Adult Guardian
MARTIN, Mr Kevin James, Adult Guardian

Advocacy for Inclusion
RYAN, Ms Christina, General Manager
READ, Ms Ellen, Policy Officer

ROBBINS, Mrs Louise Anne, Private capacity

People with Disability Australia
SANDS, Ms Therese, Co-Chief Executive Officer

Queensland Centre for Intellectual and Developmental Disabilities
TAYLOR GOMEZ, Ms Miriam, Education Coordinator

Thursday, 28 March 2013

Cliftons, Sydney

Witnesses

National LGBTI, Health Alliance
ANSARA, Mr Y Gavriel, Health Policy Officer

Androgen Insensitivity Syndrome Support Group Australia
HART, Ms Bonnie, President
PERRIN, Ms Sandra L, New South Wales Representative
BRIFFA, Councillor Tony Muliett, Committee Member

Organisation Intersex International Australia
WILSON, Gina, President
CARPENTER, Morgan, Secretary

Woman A, Private capacity

Woman B, Private capacity

Woman C, Private capacity

Woman D, Private capacity

Friday, 31 May 2013

Parliament House, Canberra

Witnesses

Attorney-General's Department

MANNING, Mr Greg, First Assistant Secretary, International Law and Human Rights Division
ABRAHAM, Mr Daniel, Assistant Secretary, Human Rights Policy Branch
RAINSFORD, Ms Cathy, Assistant Secretary, Family Law Branch
SHERBURN, Ms Anna, Director, Human Rights Projects Section, Human Rights Policy Branch
BALLANTYNE, Ms Tracy, Principal Legal Officer, Family Law Policy and Legislation Section, Family Law Branch