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

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.