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

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[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?

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[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’.
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> 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:
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> - 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

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[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

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[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

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[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

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[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

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[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

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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.