



# STERILISATION OF GIRLS WITH DISABILITY

## The State Responsibility to Protect Human Rights

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Involuntary, non-therapeutic sterilisation has existed in Australia since the 1800s as a form of eugenics. It has continued to target girls and women with disability to control fertility under the guise of 'health' and 'best interests'. Unlike therapeutic sterilisation non-therapeutic sterilisation of a female is a planned procedure with the intent of permanently removing reproductive capabilities. The procedure of non-therapeutic sterilisation on children has been denounced by the United Nations as a violation of numerous human rights treaties to which Australia is party. Unfortunately, Australia legally continues this harmful practice. The Australian Government has affirmed that involuntary, non-therapeutic sterilisation has health benefits for some girls, particularly in regards to menstruation, mood and behaviour management, and emotional relief. The government considers the current legislation to be living up to human rights obligations. However, despite the 'safeguards' in place, girls with intellectual disability continue to experience violations to their bodily integrity. In this paper, I will argue that Australian law should abide by its human rights obligations and protect girls with disability from sterilisation in all cases that are non-therapeutic.

The wellbeing of girls should be the primary consideration when considering non-therapeutic sterilisation. The transition from child to womanhood is an important milestone in a girl's life, and denying significant portions of this development can be both physically and mentally devastating. The female body should not be non-consensually interfered with, particularly whilst still adjusting to menstrual cycles and adolescent mood swings. Eliminating menstruation may provide some relief to carers, but is unlikely to change moods or behaviour - and the side effects could be harmful. Despite governmental opinion, Australia is recognised as failing to fulfil its human rights obligations and is discriminating against girls with disability. Not only is this affecting the girls, but the lack of support for parents pushes them to feel they must trade-off their children's rights. International governments have recognised the danger of continuing the practice, and have enforced legal prohibition. Certain governments have even begun providing compensation for past acts of eugenic sterilisation against girls with disability. Australia continues this legal and damaging act of discrimination, despite the progress made internationally toward protecting children from this harmful practice.

## 1. Background Information

### 1.1 Defining Terms

#### (a) Sterilisation

Sterilisation is a surgical operation or any other process that induces the permanent loss of reproductive capacity.<sup>1</sup> For women, the most common and effective procedures are the hysterectomy, bilateral oophorectomy, tubal ligation and endometrial ablation. The most common procedure for girls with disability is the *hysterectomy* - removing the uterus and ceasing menstruation, yet continuing ovulation. Both *bilateral oophorectomy* and *tubal ligation* may be used in conjunction with a hysterectomy. A *bilateral oophorectomy* removes both ovaries. For a young woman with functioning ovaries this is a particularly serious operation, as it will cause a sudden termination of hormone production and commence menopause. She will need to undertake long-term hormone replacement therapy.<sup>2</sup> *Tubal ligation* - blocking the female egg from proceeding down the fallopian tube - is less common as ovulation and menstruation will continue. A *total hysterectomy* may also be utilised, removing the uterus, ovaries, fallopian tube, cervix and upper vagina.<sup>3</sup>

#### (b) Therapeutic and non-therapeutic sterilisation

There are two primary reasons a woman will undergo a sterilisation procedure: therapeutic and non-therapeutic. Australian law has yet to provide a clear distinction, given the uncertain

boundary between the two and the numerous potential complications with menstruation. In *Marion's Case*, Justice Brennan defined medical treatment as therapeutic "when it is administered for the purpose of preventing, removing or ameliorating a cosmetic deformity, a pathological condition or a psychiatric disorder, provided the treatment is appropriate for and proportionate to the purpose for which it is administered."<sup>4</sup> Therapeutic has also been termed as "procedures that are necessary to 'save life' or prevent 'serious damage' to health."<sup>5</sup> In contrast, non-therapeutic treatment that has been described as a 'planned' procedure that is not required for medical reasons.

Despite the lack of clarity on this matter in medicine and in law, for the purpose of this paper:

**'Therapeutic sterilisation'** will be defined as a by-product of a life saving procedure performed in a medical emergency to prevent serious harm.

**'Non-therapeutic sterilisation'** will be defined as any planned procedure performed for any reason other than to save the patient's life.

#### (c) Disability

Girls with a disability who are subject to sterilisation are of varying ages and levels of capacity, but it is understood the primary targets are pre-pubescent or adolescent girls, who have intellectual disability, and 'impaired

1 'Sterilization', *Concise Medical Dictionary* (Oxford University Press, 8th ed, 2010) 1080.

2 Susan M Brady & Dr Sonia Grover, 'The Sterilization of Girls and Young Women in Australia: A Legal, Medical and Social Context', Submission to Human Rights and Equal Opportunity Commission, December 1997, 3(C).

3 Lorraine Pacey and the Women's Health Editorial Committee (eds), *Hysterectomy fact sheet* (Women's Health Queensland Wide Inc, 2011) 2.

4 *Secretary, Department of Health and Community Services v. J.W.B and S.M.B* (1992) 175 CLR 218, 269 ('*Marion's Case*').

5 Lesley Naik, Submission No 7 to the Senate Community Affairs Committee, *Senate Inquiry into Involuntary and Coerced Sterilization of People with Disabilities in Australia*, December 2012, 6.

capacity'.<sup>6</sup> Whilst these terms differ nationally and internationally, the World Health Organisation (WHO) has developed a broad definition for intellectual disability:

Intellectual disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning) [...] Disability depends not only on a child's health conditions or impairments but also and crucially on the extent to which environmental factors support the child's full participation and inclusion in society.<sup>7</sup>

There is no uniform test to determine incapacity. It has been defined as an "impairment of mental functioning such that a person is unable to understand, retain, and weigh up information so as to communicate a choice or preference."<sup>8</sup> In Australian law, states and territories have attempted to define 'capacity' to different degrees, for example in South Australia "'mental incapacity' means the inability for a person to look after his or her own health, safety or welfare or to manage his or her own affairs."<sup>9</sup>

Whilst 'disability' is "an umbrella term, covering impairments, activity limitations, and participation restrictions",<sup>10</sup> for the purpose of this essay the term 'disability' will

be used exclusively in reference to intellectual disability and any instigating or intersecting disabilities.

## 1.2 Parameters

This paper has certain parameters. There will be a specific focus on girls under the age of 18. Children and adolescents require more defensive rights and protective laws due to their vulnerability. This essay will not attempt to measure or explore the capability of a person - with or without a disability - to raise a child. Such a topic is a divisive and difficult issue of its own. Furthermore, while it is recognised that males with disability experience involuntary sterilisation, boys and men with disability will be excluded due to the overriding majority being performed on women and girls.

## 1.3 Justification

### (a) Historical context of eugenics

The history of 'eugenics' and 'fertility control' are closely linked. From the 1800's to early 1900's in Australia, migrants were selected based on economic situation, disability and/or race, and forced or coerced to take birth control or be sterilised under the guise of 'public health'.<sup>11</sup> In the early to mid twentieth century, psychiatrists began exploring the biological differences of the 'mentally defective' to prove it would be unwise to encourage continued fertility.<sup>12</sup> In the 1930's, Nazi Germany sterilised

6 Senate Community Affairs References Committee, *Inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia* (2013) 4 ('Senate Inquiry').

7 World Health Organisation Regional Office for Europe, *Definition: Intellectual Disability* (2018) <<http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability>>.

8 'Incompetence, (2) Incapacity', *Concise Medical Dictionary* (Oxford University Press, 8th ed, 2010) 559.

9 *Guardianship and Administration Act 1993* (SA) s 3.

10 World Health Organisation, *Disabilities* (2018) <<http://www.who.int/topics/disabilities/en/>>.

11 Susanne Klausen and Alison Bashford, 'Fertility Control: Eugenics, Neo-Malthusianism, and Feminism' in Alison Bashford and Phillippa Levine, *The Oxford Handbook of the History of Eugenics*, (Oxford University Press, 2010) 98, 104.

12 Matthew Thomson, 'Disability, Psychiatry, and Eugenics' in Alison Bashford and Phillippa Levine, *The Oxford Handbook of the History of Eugenics*, (Oxford University Press, 2010) 116-111.

“mentally and physically disabled people [and] women whose promiscuity was perceived as a symptom of mental deficiency”<sup>13</sup> as part of their goal to create a ‘pure race’. The stigma from the use of biological eugenic methods in World War Two decreased many sterilisation programs and tightened laws - but not all. Discriminatory views of people with disability - principally intellectual disability - as “unfit” to have reproductive rights continue today.

#### (b) Present vulnerability

Throughout history - and to the present day - persons with disability have been continually viewed as “lesser” or “inferior”, and therefore have been unjustly denied rights. Girls with disability are extremely susceptible to human rights violations due to their age, gender and disability. Girls with disability are 3 to 4 times more likely to experience violence than their peers without disability;<sup>14</sup> continue to be denied the right to make decisions about their own body;<sup>15</sup> and more than 70% of females with disability experience sexual violence at some point in their life.<sup>16</sup> Yet, no conclusive national studies or commissions have been undertaken to understand the true extent of involuntary sterilisation in Australia.

## 2. Developing Womanhood

Every girl - with or without disability - should be granted the time to biologically develop into a woman. It is both mentally and physically healthy to allow girls to acquire their sense of womanhood. Whilst not all stereotypes toward menstruation are positive, over history

the kinship of menstruation has constantly bonded young women. Femininity and what it means to be a woman should not be wholly linked to biology; however, many of our innate feelings toward ‘growing up’ do derive from bodily changes. Young women who have experienced sterilisation have exhibited many long-term health issues, and no girl child should be subject to this for non-therapeutic reasons.

For girls in general, sterilisation is rarely an appropriate procedure. If used, this is only as a last resort by-product of another surgery. The most common therapeutic reasons for performing a sterilisation surgery are all very unusual for a girl under 18 years. Diseases of the reproductive tract rarely affect young women; and treatment of cancer using chemotherapy has only a small and unlikely chance of resulting in sterilisation.<sup>17</sup> Common disorders in women requiring treatment, including dysmenorrhea, menorrhagia, and pre-menstrual syndrome, are rarely treated with surgery for girls. Menstrual irregularities and problems occur frequently in adolescent girls and are likely to be resolved naturally.<sup>18</sup> It has been found that “the onset of menstruation is the same for girls with and without intellectual disability, and girls with intellectual disability present with the same type of menstrual problems as the rest of the young female population”.<sup>19</sup> Therefore, most menstrual issues in girls with disability are not life threatening, do not require therapeutic

13 Klausen and Bashford, above n 11, 105.

14 WWDA Youth Network, ‘Position Statement 1: Violence’ (2017) *Women with Disabilities Australia* 3.

15 WWDA Youth Network, ‘Position Statement 2: Decision-Making’ (2017) *Women with Disabilities Australia* 3.

16 WWDA Youth Network, ‘Position Statement 4: Sexual & Reproductive Rights’ (2017) *Women with Disabilities Australia* 3.

17 Brady and Grover, above n 2, 26, a 10-year study of the Royal Children’s Hospital found no cases of a disease that lost function of both ovaries.

18 Ibid, 27.

19 Ibid, 28.

surgery, and will be rectified in time.

## 2.1 Menstruation

Societies and cultures all over the world continue to hold negative views about menstruation. However, the self-esteem and self-value of adolescent girls is increased when the process into womanhood is celebrated.<sup>20</sup> In Laura Fingerson's book *Girls in Power: Gender, Body, and Menstruation in Adolescence*, she explores the social perceptions of adolescent menstruation, varying from "it's messy, and it's gross"<sup>21</sup> to "[menstruation] makes us stronger"<sup>22</sup>. Her findings revealed that - whilst adolescent girls have unpredictable feelings toward menstruation itself - for all it affirmed their womanhood. Family and schools that promoted sexual and reproductive health positively and provided premenstrual preparation, helped make the transition more empowering. Part of this adolescent empowerment is not seeing their menstruation as 'medical'. Instead, girls want to make it their own - a part of them that is different from boys - and a shared bond with other girls.

A girl's menstrual status and experience can be an important focus of her everyday interactions. This is different from most adults' experiences, where menstruation is not as salient to their lives as it is to the lives of adolescents.<sup>23</sup>

Puberty, and the biological transformation from girl to woman is certainly a difficult time

for all females, with or without an intellectual disability. It is complicated coming to terms with changes - psychologically and physically - and monitoring those to appropriately engage socially. Hormones instigate changes to mood and behaviour, and young women must become familiar with menstrual hygiene, management, and taboos. Some girls cope better with this transition, principally due to appropriate preparation by parents, schools and community groups. Many parents of children with a disability have come out supporting their daughters' bodies and the celebration of becoming a woman.

Despite this, non-therapeutic sterilisation applications to the Family Court emphasize menstruation as a 'problem'. Girls presented to the courts often have little or no communication abilities<sup>24</sup> and cannot effectively communicate their menstrual pain, fatigue and physical discomfort.<sup>25</sup> The physical toll can be upsetting and excessively demanding on a girl's health. It is believed that removal of the uterus can reduce suffering; relieve "heavy and painful periods";<sup>26</sup> and increase the quality of life. Permanently stopping menstruation removes the personal care tasks associated with menstrual hygiene and management - particularly when the young woman refuses to wear menstrual pads. There are numerous alternatives to manage menstruation, primarily oral contraceptives and hormonal devices - most of which are very successful. However, certain girls may be unable to tolerate medication given orally or by injection. Others fear health

20 Laura Fingerson, *Girls in Power: Gender, Body, and Menstruation in Adolescence* (Albany State University of New York Press, 2006).

21 Ibid, 1.

22 Ibid.

23 Ibid, 148.

24 Name Withheld, Submission No 10 to Senate Community Affairs References Committee, *Inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia* (2013).

25 Brady and Grover, above n 2, 30.

26 *Re Angela* (2010) 43 Fam LR 98 [29].



care facilities, making it distressing for the young woman to return every 3 to 5 years to have a device replaced.<sup>27</sup>

The court's sterilisation applications require all reversible contraceptive options to be tried as an essential prerequisite to a permanent surgery. Unfortunately - as long as one option has been attempted - this step is often excused due to the exhausting nature of trying new pills or devices. In such cases, the court will rely on a health professional's opinion, stating that alternate options 'may not work'. Such opinions are troubling and discriminatory. Many women struggle at first to find an appropriate contraceptive option. This is particularly common in adolescences whilst the menstrual cycle is not yet 'regular' and the body is not fully developed. These issues are the same for young women with or without disability. Health professionals would never make the same judgment about girls without disability until all options had been tested.

## 2.2 Mood and Behaviour Management

Cases often cite 'mood swings' and 'behaviour' during menstruation as necessary reasons to sterilise. Whilst these symptoms can be linked to the menstrual cycle, Brady and Grover's study of legal sterilisation of young women, found that the behaviours described in sterilisation cases are too easily attributed to menstruation. They may in fact be "manifestations of stressful environments or

adolescence".<sup>28</sup> If the mood swings are based in biology (not environment) the only effective sterilisation option is a total hysterectomy, removing both ovaries. This will have negative ramifications, particularly for long-term health and wellbeing. Hormonal supplements for early menopause will need to be taken, which can also lead to numerous physical and psychological ailments. Likewise, for girls with epilepsy there will be no greater control over seizures unless the ovaries are removed, and even then there are no guarantees.<sup>29</sup>

Sterilization cases frequently rely on guardians providing evidence of a child's challenging behaviour. Parents have described escalated pre-menstrual mood swings and distress due to the inability to cope with menstruation.<sup>30</sup> Emotional reactions and "phobias" of blood are mentioned, with symptoms including screaming, crying and self-mutilation.<sup>31</sup> Inappropriate social behaviour during menstruation is described, such as menstrual smearing, and publically exposing soiled hygiene products.<sup>32</sup> These problematic behaviours have been acknowledged as impacts to social opportunities. Possible tantrums or public humiliation may prevent attendance at school or at community events.<sup>33</sup>

Behaviour and hygiene will not be magically "fixed" through an operation. Environment, hormones, mental and physical illness, and many other causes can alter mood. Programs to support the transition into womanhood -

<sup>27</sup> *Re Edith* (2014) FamCA 908, [28-30].

<sup>28</sup> Brady & Grover, above n 2, 32.

<sup>29</sup> *Ibid.*

<sup>30</sup> John and Merren Carter, Submission No 20 to Senate Standing Committee on Community Affairs, *The Senate Inquiry into Involuntary or Coerced Sterilisation of People with Disabilities in Australia*, February 2013.

<sup>31</sup> *Re Edith* (2014) FamCA 908.

<sup>32</sup> Name Withheld, Submission No 11 to Senate Community Affairs References Committee, *Inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia* (2013).

<sup>33</sup> John and Merren Carter, above n 30.

for both parents and daughters - are essential. It has been found that comprehensive and accessible programs to inform young women about sexual and reproductive health greatly assist in this transition. Whilst trying menstrual management programs is a prerequisite for sterilisation applications, it has become clear that limited funding goes into such programs. The program should ideally be commenced pre-menses and continued into adolescence, and must be employing a form of communication accessible to the girl. These should be participated in alongside behaviour management programs. Without these steps, it is difficult to tell if the program will ease menstrual anxieties and management - for the girls and for their parents.

### 2.3 Emotional Relief

Girls with disability are more susceptible to sexual abuse than girls without. Whilst it has been made clear that a court cannot approve a sterilisation on the grounds of potential sexual abuse, this is still frequently mentioned in cases as an 'additional' positive outcome. Guardians often fear the risk of their child being abused and becoming pregnant.<sup>34</sup> A pregnancy for any girl under 18 (through consensual or nonconsensual sex) is potentially emotionally and physically distressful. However, for a girl with disability, pregnancy is regarded as potentially dangerous as she may not understand the connections between sex, pregnancy and birth. Additionally, she may be unable to cope with the health impacts of pregnancy on body. Many parents consider their daughter unable to raise a child, and therefore the baby would need to be raised by them. Parents argue

that due to their age, and the need to care for their own child into adulthood, they would be unable to support a new baby. Therefore, the baby must be aborted or taken away by authorities. Neither of which are viewed as 'ideal' options. Despite the potential difficulties involved with a pregnancy, it is absolutely unconscionable to request the sterilisation of any child due to a potential pregnancy through sexual abuse. Sterilization of girls only masks the real issues - and perhaps even increases vulnerability to abuse without risk of being caught. The onus is on parents, guardians, carers, government and society to ensure these girls are not exploited or abused.

The significant role parents and guardians play in understanding a girl's situation should not go without recognition. These girls require full-time assistance, and parents articulate their exhaustion from the 'burden of care'<sup>35</sup> and the lack of support for them and their daughter. For parents, fear and anxiety play a large part in the decision to apply for sterilisation. There is a shared fear about the future: what will happen when they age and become less capable to care for their daughter? What will happen if they suddenly die? Will she be put in an institution? If so, will she be protected adequately? These fears are profuse, and sterilisation can be seen as having "one worry alleviated".<sup>36</sup>

The fears parents express are genuine and should be considered - but not put in front of the emotional welfare of the girl herself. The effects of sterilisation - particularly to a girl - can be severe, even when she does not fully comprehend the impact of the procedure. Research has shown that the postoperative

34 *Re Sarah* (1993) FamCA 124. Example from *Re Sarah*, "the parents, in particular, were concerned about the prospect of sexual abuse of Sarah, resulting in pregnancy."

35 See, e.g., *Re Edith* (2014) FamCA 908 [17], [44]; *Marion's Case* (1992) 175 CLR 218, 269 [16], [20], [50], [54]; *Submission No 10*, above n 24.

36 Name Withheld, *Submission No 6 to Senate Community Affairs References Committee, Inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia* (2013).



effects of sterilisation run deep. Young women are the most negatively affected, experiencing a fractured gender identity, and a loss of femininity and sisterhood, with one woman saying after her hysterectomy, “I feel less feminine. They have, in a way, removed what made me a woman, what distinguishes a man from a woman.”<sup>37</sup> Young women who are not mentally prepared are the most likely to be negatively affected by the surgery; and it is not only the sense of womanhood that is lost. The “feelings of sadness and hopelessness; less interest in activities; sleep disturbance; decreased libido; lack of energy; and thoughts of death or suicide”<sup>38</sup> can be overwhelming. Even women who have no intention of having children are still likely to grieve for their loss of reproductive capability.<sup>39</sup> Many such women have described feeling an emptiness; have pled for their uterus back; have “flooding memories in response to sudden reminders”; and “unwanted thoughts about surgery.”<sup>40</sup>

All girls have a right to enter womanhood; to experience the frustrations and joys; and to allow their body time to regulate. Sterilization may (or may not) be the best option medically for an adult, but there is no reasonable

medical need for a child to be denied the chance to develop into a woman.

### 3. Responsibility to Protect Rights

Australia has a legal obligation to implement appropriate laws and procedures to comply with the United Nations treaty principles. Non-therapeutic sterilisation of girls with disability is a violation of the human rights held by all children. By continuing the legal practice of these procedures, Australia violates its legal obligations enshrined in numerous UN Conventions to which it is a party, particularly the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)<sup>41</sup>; Convention on the Rights of Persons with Disabilities (CRPD)<sup>42</sup>; Convention on the Rights of the Child (CRC)<sup>43</sup>; Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT)<sup>44</sup>; International Covenant on Civil and Political Rights (ICCPR)<sup>45</sup>; International Covenant on Economic, Social and Cultural Rights (CESCR)<sup>46</sup>. Australia has obligations to uphold the sexual and reproductive rights of girls with disability, and prevent harmful practices and discriminatory treatment. Unfortunately, the government is failing to fulfil its human rights

37 Kari Nyheim Solbrække and Hilde Bondevik, ‘Absent organs - Present selves: Exploring embodiment and gender identity in young Norwegian women’s accounts of hysterectomy’ (2015) 10 *International Journal of Qualitative Studies in Health and Well-being* 1, 7. See also, Nancy B. Kaltreider, Anne Wallace and Mardi J. Horowitz, ‘A field study of the stress response syndrome: Young women after hysterectomy’ (1979) 242(14) *The Journal of the American Medical Association* 1499.

38 Lorraine Pacey and the Women’s Health Editorial Committee, above n 3.

39 Ibid 1.

40 Kaltreider, Wallace and Horowitz, above n 37, 1501.

41 *Convention on the Elimination of all forms of Discrimination Against Women*, opened for signature 18 December 1979, 1249 UNTS 1 (entered into force 3 September 1981) art 1, 2, 10, 12, 16 (‘CEDAW’).

42 *Convention on the Rights of Persons with Disabilities*, opened for signature 13 December 2006, 2515 UNTS 3 (entered into force 3 May 2008) art 5, 6, 7, 23, 25 (‘CRPD’).

43 *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) art 2, 4, 5, 18, 23 (‘CRC’).

44 *Convention Against Torture and other cruel, inhuman or degrading treatment or punishment*, opened for signature 10 December 1984, 1465 UNTS 85 (entered into force 26 June 1987) art 1, 16 (‘CAT’).

45 *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976) art 3, 24, 26 (‘ICCPR’).

46 *International Covenant on Economic, Social and Cultural Rights*, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976) art 2, 3, 12 (‘CESCR’).

obligations to provide support and services. This has led desperate parents to seek non-therapeutic sterilisation for their daughters. There is a clear violation of rights occurring - and an obvious solution to protect human rights and assist parents.

### 3.1 Sexual and Reproductive Rights

Non-therapeutic sterilisation of girls with disability is seen as a blatant violation of their sexual and reproductive rights. It is a prejudicial treatment that explicitly affects rights around family planning, health, sex and bodily integrity,<sup>47</sup> evident in CRPD article 23:

States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that [...] Persons with disabilities, including children, retain their fertility on an equal basis with others.<sup>48</sup>

It cannot be ignored that girls without disability, and boys with or without disability, do not undergo sterilisation unless in a life-saving situation. Therefore, Australia is expressly violating its human rights obligations by denying fertility to girls with disability.<sup>49</sup> The right to reproductive choice is ingrained in the human rights Conventions and is innately held by all women. Reproductive functions should be protected and bodily integrity must be respected. This is very clear in numerous

Conventions and therefore cannot be reinterpreted by State parties.

It has been contended by pro-sterilisation activists that the sterilisation procedure may provide the child with a more dignified life. Dr Wendy Bonython stated in the Senate Inquiry, “the right to produce and have a family are not the only human rights we recognise [...] There are other rights as well, including dignity and quality of life, that are just as important to the individual.”<sup>50</sup> With or without their fertility, girls with disability carry many additional burdens, including communicative, social, emotional and physical. Ceasing menstruation may increase self-reliance, active social participation and the mental and physical fulfillment of a ‘decent life’.<sup>51</sup> Whilst it would be eliminating one right, the increased enjoyment of other rights may better promote the entitlement written in Article 23 of the CRC, for a child “to be treated with dignity and respect.”<sup>52</sup>

By agreeing that certain rights may flourish if others are denied, the Australian Government is actively trading-off rights. All rights must be recognised on an equal basis. A higher value cannot be placed on one over another. Presently, a damaging judgement is being made on what a girl with disability does and does not ‘need’ in her life. The State has decided that she will gain a more socially inclusive, decent life with greater dignity and respect (‘needs’) if she loses her fertility (‘does not need’). Responding this way is discriminatory and therefore a violation of one of the foundational human rights principles.<sup>53</sup>

47 CRC art 24; CRPD art 17, 23 and 25; CEDAW art 10, 12 and 16; and CESC art 12

48 CRPD art 23 [1](c).

49 CEDAW preamble states, “The role of women in procreation should not be a basis for discrimination”.

50 Senate Inquiry, above n 7, 90 [4.22].

51 CRC art 23.

52 CRC General Comment No 9, 43(d).

53 Universal Declaration of Human Rights, GA Res 217A (III), UN GAOR, 3rd Session, 183rd plen mtg, UN Doc A/180 (10 December 1948) art 7, ‘All are equal before the law and are entitled without any discrimination to equal protection of

The state must provide assistance - through legislation, programs and services - to ensure all rights are fulfilled. Nobody's bodily integrity should be traded-off to retain other rights.

### 3.2 Parental Rights

The UN Committees have acknowledged that the desire to have girls with disability non-therapeutically sterilised, stems from a lack of support for parents and carers. They expressed concern about the State's failure to provide adequate assistance, including "different forms of respite care, such as care assistance in the home and day-care facilities directly accessible at community level."<sup>54</sup> This familial support is enshrined in in both the CRC<sup>55</sup> and CRPD.<sup>56</sup> By ratifying, the Australian Government acknowledged they would be obliged to provide "comprehensive information, services and support to children with disabilities and their families".<sup>57</sup>

There is a common impression that the government and society have "washed their hands of the responsibility"<sup>58</sup> of children with disability and their families. Sterilization and the right to fertility easily gain public attention and criticism of the parents. Yet parents and carers continue to struggle with inadequate assistance and poorly funded programs, facilities and services for their children. The application for their daughter's non-therapeutic sterilisation is more than an issue of menstrual suppression for families; it is a last resort due to the lack of support. Extra

pressure is placed on carers, parents and guardians; and this affects the fulfillment of their own human rights. Not only their rights as parents,<sup>59</sup> but also their right live free from discrimination, and to enjoy their highest attainable standard of physical and mental health.<sup>60</sup>

Every individual human has value and therefore his or her rights are of equal importance. A parent holds rights as both an individual and a carer. As a carer, the State must provide assistance to ensure that they are able to adequately fulfil their responsibility without diminishing their rights as an individual. Most parents seeking sterilisation of their child are doing so out of love. They view it (perhaps mistakenly) as the best option, due to the State's failure to live up to its other human rights responsibilities. In general, a parent does not wish to intentionally trade-off one of their child's rights for another. However, when lacking respite care and assistance, parents may view the benefits of sterilisation out weighing the loss. That is a horrific and preventable position to put both a parent and child into.

### 3.3 Discrimination

Non-discrimination and equality are the foundation of all human rights treaties. References toward non-discrimination, equal and dignified treatment and empowerment for children, women and people with disability, are embedded in all the aforementioned

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the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.'

54 Committee on the Rights of the Child, *General Comment No 9: The Rights of Children with Disabilities*, 43<sup>rd</sup> sess, UN Doc CRC/C/GC/9 (27 February 2007) VI [A](41).

55 CRC art 23.

56 CRPD art 23.

57 Ibid.

58 Name Withheld, Submission No 4 to Senate Community Affairs References Committee, *Inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia* (2013).

59 CRC art 5.

60 CESCR art 2 and 12.

treaties.<sup>61</sup> The State's responsibility to prevent discrimination is summed up in CRPD article 5: "States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds."<sup>62</sup> Due to their age, sex, and disability, girls with disability are highly exposed to discrimination. The CRC has discussed on numerous occasions the need for girls with and without disability to be treated equally. In their Concluding Observations, the CRC Committee urged Australia to

Enact non-discriminatory legislation that prohibits non-therapeutic sterilization of all children, regardless of disability; and to ensure that when sterilisation which is strictly carried out on therapeutic grounds does occur, that this be subject to the free and informed consent of children, including those with disabilities.<sup>63</sup>

Non-therapeutic sterilisation of a child is recognised as a harmful practice<sup>64</sup> due to the mental and/or physical suffering that accompanies the procedure, and it being grounded in discrimination. It is also recognised as a form of torture or other cruel, inhuman or degrading treatment or punishment. In its review, the CAT Committee recommended that Australia "enact uniform

national legislation prohibiting, except where there is a serious threat to life or health, the use of sterilization without the prior, free and informed consent of the person concerned."<sup>65</sup>

The Commonwealth Attorney-General's Department advised that it is Australian policy to become party to a United Nations treaty only once it has ensured "any necessary implementation action has been taken, either by the Commonwealth or by State or Territory Governments."<sup>66</sup> This includes undertaking a national analysis to guarantee all "legislation, policies and programs are in compliance with the immediately applicable obligations and substantially achieve implementation of the progressively realisable obligations"<sup>67</sup> under the treaty. The Australian Government firmly regards the State as complying with their obligations under the Treaties to which they are party. Yet, it has become evident that the Australian Government deems the human rights to bodily integrity and freedom from harmful practices as being only applicable if the individual has 'mental capacity'. This promotes a view that girls with disability do not have "full humanness,"<sup>68</sup> and simultaneously fails to recognise the procedure as an act of abuse and discrimination. Whilst it may be more economic in the short-term to discount the human rights of a limited number of girls, introducing adequate supports and services

61 CRC art 2 and 23; CRPD art 5, 6 and 7; CEDAW art 1 and 16; CAT art 1; CESCR art 2 and 3; and ICCPR art 3, 24 and 26.

62 CRPD art 5[2].

63 Committee on the Rights of the Child, *Consideration of reports submitted by States parties under article 44 of the Convention, Concluding Observations: Australia*, 60<sup>th</sup> sess, UN Doc CRC/C/AUS/CO/4 (28 August 2012) 14[58](f)

64 Committee on the Elimination of Discrimination Against Women and Committee on the Rights of the Child, *Joint general recommendation No. 31 of the Committee on the Elimination of Discrimination Against Women / general comment No. 18 of the Committee on the Rights of the Child on harmful practices*, UN Doc CEDAW/C/GC/31-CRC/C/GC/18 (14 November 2014) 5 [15], 'Harmful practices are persistent practices and forms of behaviour that are grounded in discrimination on the basis of, among other things, sex, gender and age, in addition to multiple and/or intersecting forms of discrimination that often involve violence and cause physical and/or psychological harm or suffering'.

65 Committee Against Torture, *Concluding observations on the combined fourth and fifth periodic reports of Australia*, UN Doc CAT/C/AUS/CO/4-5 (23 December 2014) [20].

66 *Senate Inquiry*, above n 6, 87 [4.13].

67 *Ibid.*

68 Linda Steele, 'Court Authorised Sterilisation and Human Rights: inequality, discrimination and violence against women and girls with disability' (2016) 39(3) *UNSW Law Journal* 1002.

is a more sustainable, effective, and humane option.

Australia has reported that adequate safeguards have been implemented to ensure any non-therapeutic sterilisation of a girl with disability is justified. One of these safeguards was put in place through the Senate Inquiry, to better abide by the CRPD. It established a replacement for the 'best interests' test - used in cases for non-therapeutic sterilisation of minors - with the more stringent 'best protection of rights' test.<sup>69</sup> This new legal test aims at regulating sterilisation cases through a human rights perspective - ensuring that only applications promoting the maximum positive outcomes for the person; their rights; their future; and their quality of life, will be considered. However, this test is merely a pragmatic middle ground, which still fails to recognise that this procedure is a discriminatory and harmful practice. The impartiality of this decision places the government in an ideal position, between fulfilling human rights obligations and appeasing certain social groups. This 'neutral ground' does not provide Australian children or their parent's adequate protection; it fails to live up to human rights obligations; and is nothing more than a politically appealing gesture.

The Australian Government claims that it has enforced legislation to abide by its human rights responsibilities, but instead interprets the treaty articles in the way it deems best. Committee observations and comments are made to guide a State on how the rights and articles should be understood and enforced. Yet, Australia continues to ignore the call to end non-therapeutic sterilisation of girls. Australia has traded-off certain rights in place of 'safeguards' to continue harmful practices

in a 'justified' manner; and traded-off equal treatment for the cheapest option.

#### 4. The Law Must Protect

Australian law fails to protect girls with disability from a practice that is widely viewed as discriminatory and harmful. By continuing, Australia is not only negating its responsibility to implement human rights into its legislation, but is also preserving a legal eugenics program. In States internationally, legislation has been effectively amended to ensure the prohibition of non-therapeutic sterilisation of children. Cases of eugenics from the past have become recognised as wrongful and victims have been compensated. Shockingly, these eugenic programs have many similarities to current Australian laws. Australia has a responsibility for the welfare of all citizens, yet specifically denies a girl with disability equal legal protection. Fortunately, harmful practices comparable to sterilisation have been outlawed in Australia. This demonstrates that potential alterations can be made to the existing legislation, if the Australian Government were willing to make a proactive change.

##### 4.1 Legislation

Many other States have demonstrated legislative efforts to eliminate forced sterilisation of children with disability. After a review by the Irish Human Rights Commission,<sup>70</sup> it was recommended that legislation regarding non-therapeutic sterilisation be amended to become compatible with the CRPD. The *Assisted Decision-Making (Capacity) Act 2015* was amended. It was not followed up with criminal sanctioning. However, it did provide explicit legislation that no person, including a State authority, can "give consent for a non-therapeutic sterilisation procedure

69 *Senate Inquiry*, above n 6, 130 [5.12].

70 Irish Human Rights Commission, *Observations on the Assisted Decision-Making (Capacity) Bill 2013* (2014).

to be carried out on a person who lacks capacity.”<sup>71</sup> Whilst laws on sterilisation vary in the United States of America, California has very strict legislation on the performance of sterilisation and informed consent. The California code recognises that:

A sterilization shall be performed only if the following conditions are met: (1) The individual is at least 18 years old at the time the consent is obtained. (2) The individual is able to understand the content and nature of the consent process.<sup>72</sup>

This law is reiterated in the California Probate Code, making it clear that neither a guardian nor an authority of the court may permit sterilisation of a minor.<sup>73</sup> A woman over 18 may be sterilised, but not without her full knowledge and consent - this includes suitable arrangements being made to effectively communicate all information.

Australia, like most other countries, maintains an opposition to total prohibition of non-therapeutic sterilisation of women and girls with disabilities. However, as previously mentioned, Australia has enforced measures to restrict applications for sterilisation. To create national uniformity and avoid inconsistencies, the *Protocol for Special Medical Procedures (Sterilisation)* (“The Protocol”) has been adopted in all Australian states and territories. The Protocol involves three phases: (1) The Application; (2) The Thresholds; (3) The Determination. For a child, one or both parents; a medical practitioner; or a person who can demonstrate great interest in the care and welfare of the child; can apply for her sterilisation. The application must provide proof of the child’s incapacity to consent to the procedure; establish that all alternative and

less invasive procedures have been explored; and provide medical advice that this is in the child’s best interests. Once the tribunal has received the application, two thresholds must be passed. First, lack of capacity must be assessed and determine that she is incapable - and will continue to be incapable - of making this decision herself. Second, the tribunal will assess whether sterilisation is required, and ensure that there is no less invasive option available. Finally, a hearing will be held and a decision made based on the information found in the application, evidence, and reports from health providers. All the applications must be go through the Family Court, or in certain States, a Tribunal. The Each State and Territory legislation has different definitions for ‘sterilisation’ and ‘capacity’, but all must apply tests to ensure the welfare of the child. Given the stringent nature of this process, many guardians have found it necessary to go overseas for a procedure. The fact that certain parents are using ‘medical tourism’ and going to countries like New Zealand and Thailand has been used to demonstrate that Australian regulations are not only tight, but also in the best interests of the child.

The explicit legislation in other States - including Ireland and California (US) - demonstrate that it is not only possible, but also positive to completely prohibit non-therapeutic sterilisation of minors. These States have been commended for encouraging the fulfilment of CRPD obligations in this regard. Their actions demonstrate genuine application of International Human Rights Law into legislation. Informed and independent consent is essential in both Ireland and California to ensure that legislation does not negatively target persons with disability. The fact that other States view

71 *Assisted Decision-Making (Capacity) Act 2015* (Ireland) 4[4].

72 *California Code of Regulations*, 22, CCR §§ 70707.3-70707.7 (1990)

73 *California Probate Code*, 5, Cal Prob Code §2356 (1999).



this procedure so seriously reflects poorly on the Australian Government, who is willing to continue the degrading treatment in the name of 'best interests'. Australia has set up a National Protocol to safeguard children, and this has provided additional challenges to prevent cases being approved. However - despite adding a level of difficulty - it has not necessarily 'protected' children. It is widely known that girls with disability are non-therapeutically sterilised under the guise of a 'therapeutic surgery'. This is illegal, but is not actively investigated, so no data on the prevalence has been collected. Likewise, parents are known to take their daughters overseas to have the procedure. There is no available data on this either, but it is legal. This is dangerous as girls can be legally taken to procure the operation in countries with even fewer safeguards.

#### 4.2 Case Law

Governments in other countries have begun accepting responsibility for their role in sterilising girls with disability. Between 1924 and 1979, Virginia and North Carolina (hereafter known as the "US Cases") had eugenic sterilization laws; primary targeting female children and adolescents deemed mentally or physically unfit to procreate. The *Virginia Sterilization Act 1924* stated that, "the health of the individual patient and the welfare of society may be promoted in certain cases by sterilisation of mental defectives under careful safeguard and by competent and conscientious authority"<sup>74</sup> and must be in "the best interests of the patients."<sup>75</sup> Eugenic Sterilisation in North Carolina similarly viewed

sterilisation to be for "the best interest of the mental, moral or physical improvement"<sup>76</sup> of the individual. The law was believed to be abiding with the constitution by not depriving life or liberty, and ensured the individual had "ample opportunity to be heard."<sup>77</sup> Despite both states considering the procedure to be in the 'best interests' of the individual, and that the appropriate 'safeguards' were in place, both State Governments have formally apologised and begun compensating the victims of the sterilisation laws. Similarly, in the case of *Leilani Muir v Alberta Government (1989)*, Muir sued for damages due to an unwanted and wrongful sterilisation when she was 14-years-old. Muir had been labelled a "mental defective - moron" and sterilisation was approved on the basis of her possibly transmitting her disability through procreation, and being incapable of parenthood. The Alberta Government was forced to pay damages as a punishment to the Province. Many forced sterilisation cases have applied to the European Court of Human Rights, most notably *Gauer and others v France (2008)*. In this case, five women with intellectual disabilities had been forcibly sterilised. The Court commented that the "forced sterilisation of women with disabilities, and the inadequacy of State responses to it, represent grave violations of multiple human rights."<sup>78</sup> The case verified that France was violating international human rights and has a "positive obligation to apply stringent and effective safeguards to protect persons with disabilities from forced sterilisation."<sup>79</sup>

In the 'Marion' Case, the High Court discussed and determined the role of the Family Court in sterilisation case authority. The High

74 *Virginia Sterilization Act 1924*

75 *Ibid.*

76 Secretary of Eugenics Board of North Carolina, *Eugenic Sterilization in North Carolina: Purpose, Statutory Provisions, Forms and Procedure* (1938) 8.

77 *Ibid.* 7.

78 *Gauer and Others v France* [2011] Eur Court HR (Application no 61521/08).

79 *Gauer and Others v France*, pt 1, para 2.

Court found that the procedure could not be lawfully authorised by a guardian without a court order, as it is a procedure involving “immediate and serious invasion of physical integrity with the resulting grave impairment of human dignity.”<sup>80</sup> Given the risks, it was decided that before Court authorisation, certain safeguards must be in place. The child must be tested for present and future capacity to consent; the procedure must be a ‘step of last resort’; and that the child’s best interests must be the primary consideration of the court. The Case of ‘Marion’ set forth a rigorous (and expensive) process to ensure safe authorisation. Many cases have followed - such as ‘Angela’ (2010) and ‘Edith’ (2014) - and the processes are normally considered and obeyed. Both ‘Angela’ and ‘Edith’ were brought to the Family Court of Australia; determined the girl incapable of decision-making; assumed the procedure was in her best interests; and had health professionals state their were minimal risks. However, whilst other menstrual suppression options were discussed, in both cases many had not been tried.

As demonstrated with the compensation of women in the US Cases, and the payment of damages to Muir, Western countries are coming to terms with the fact that forced non-therapeutic sterilisation of girls based on their disability is wrong. Even though the other procedures occurred over 40 years ago under the label of ‘eugenics,’ there are numerous similarities to present day Australia. The safeguards set out in the ‘Marion’ Case are very similar to those in the US Cases. In both Australia and the 1900s US, the procedures require the authorisation of the State; and the facts and grounds for non-therapeutic sterilisation must be presented to a special board. The best interests of the individual are the principle consideration, and the procedure

can only be forced if the individual has a disability making her incapable of consent. From this, it is clear to see that regardless of the safeguards put in place by the Australian Government, it is just a replication of wrongful laws. Justice Brennan admitted in the ‘Marion’ Case that the involuntary and non-therapeutic procedure seriously damaged human dignity. In other international cases - like those presented to the European Court of Human Rights - Brennan’s message has been echoed, and nations including France and Slovakia have been condemned for these acts. The safeguards put in place by the High Court of Australia may give the impression of fairness. However, history has made it clear that regardless of any legal processes or safeguards, women with disability - including Muir, Gauer and Others, and the victims in the US Cases - suffer from the pain and damage caused by involuntary, non-therapeutic sterilisation.

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80 ‘Marion’s Case’ (1992) 175 CLR 218, 322.

## Conclusion

So, should Australia make non-therapeutic sterilisation of girls with disability illegal? Yes. Australian law must abide by human rights obligations and protect our nation's daughters. Girl children are still young and vulnerable. They require time to develop into women and - if capable in adulthood - they can make informed reproductive choices. Through current law, girls with disability can continue to be sterilised for non-therapeutic reasons as long as guardians and health practitioners are able to demonstrate it is in her 'best interests'. This, however, is still a violation of human rights doctrines and observations. By persisting with this practice, girls with disability will not only continue to be discriminated against and denied bodily integrity; they will be exposed to terrible postoperative mental and physical health risks.

The wellbeing of a girl is strengthened if she has time to develop her sense of womanhood. Her body should be allowed time to regulate, she ought to have access to useful programs, and make consensual and informed decisions. Menstruation holds great importance to a young woman, both through physical development and due to its sociocultural importance. Unfortunately, menstruation can have 'side effects', including social taboos, irregular cycles, mood swings and menstrual cramps. However, these are not valid reasons to sterilise a girl. Whilst sterilisation will cease menstruation, programs to assist in menstrual management and behaviour management - for both girls and parents - would be far more mentally and physically effectual long-term. Fears about sexual abuse and pregnancy should not be ignored, but are insufficient and inappropriate reasons to forcibly sterilise. Ultimately, the procedure is on a girl's body and affects only her bodily integrity.

There is no acceptable non life-threatening reason to prevent a girl from developing into a woman.

By ratifying numerous UN treaties, Australia has a legal responsibility to protect the rights of girls with disability. Australia has received recommendations from UN treaty bodies to legally prohibit all non life-saving sterilisation of girls with disability, but continues to violate their sexual and reproductive rights. The government has an obligation to provide support and services to children with disability and their carers; however, adequate support has not been made available. This has resulted in sterilisation being rebranded as a way for girls with disability to experience greater enjoyment of other rights - such as social participation. However, changing the viewpoint does not solve the problem. Governments cannot freely exchange rights for the cheapest or easiest options. Instead of a rights trade-off, Australia must fulfil its obligations to provide adequate and accessible services, programs and support for girls with disability and their carers.

By failing to enact the appropriate laws, Australia is continuing a legal eugenics-style program. More progressive governments have successfully demonstrated how to incorporate the CRPD into legislation and legally prohibit this discriminatory and harmful practice against children. Similar governments have started accepting responsibility for the involuntary sterilisation practices against girls with disability. After the Case of 'Marion', Australia did put safeguards in place to protect the dignity of girls with disability, including a national protocol to restrict sterilisation applications. However this was a futile step forward.

As international cases have shown - regardless of safeguards - performing the procedure on a girl will cause suffering and damage. Law must be enforced to prevent the procedure on minors; a strict definition of 'therapeutic' should be written in legislation; and unwarranted surgeries should incur a penalty.

It is clear that girls with disability experience discrimination in many areas of life. Australia must take greater responsibility in fulfilling their human rights obligations to prevent all forms of discrimination and harm. This includes prohibition of non-therapeutic sterilisation on girls with disability. Whilst changing this law will not eliminate discrimination entirely, it certainly will demonstrate a serious effort toward equality and fulfilling UN treaty obligations.

Australia must actively work to create effective support services and programs to replace the 'quick fix' of sterilisation. Women with disability may decide - after being educated on non-therapeutic sterilisation - that they wish to undertake the procedure. That is their decision. However, a girl under the age of 18 should be allowed time to learn about her body; give her body time to develop and regulate; and then when she is older, she can make informed reproductive choices.

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