

# **Australian Institute on Intellectual and Developmental Disabilities**



## **The involuntary or coerced sterilisation of people with disabilities in Australia**

Submission to the Senate inquiry into the involuntary or coerced  
sterilisation of people with disabilities in Australia.

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## **AIIDD Background**

The Australian Institute on Intellectual and Developmental Disabilities (AIIDD) operates as the information, research and development arm of NCID. The AIIDD is entering into a new and exciting phase that will see it expand its current role of delivering information to people with intellectual disability, their families, service providers and the broader community.

The AIIDD aims to support high level, high quality, independent analysis and strategic policy advice in order to improve the effectiveness of disability service systems, and help sharpen the focus of groups advocating for reform and improvement.

The activities of the AIIDD include:

### **Policy Research Briefs**

The purpose of the AIIDD's Policy Research Briefs is to establish what is known and not known about an issue utilising and synthesising extant research, then to define the most productive areas of possible research.

### **Roundtables**

The AIIDD aims to provide high-level forums where research is discussed and debated with the aim of proposing policy principles and program directions, furthering the research agenda and fostering new partnerships between participants.

### **Research and Development**

The AIIDD aims to commission evidence-based research independent of the political agenda that will advance the discussions, debate and ultimately the policies affecting Australians with intellectual disability and their families. Key priority areas include unmet need, accommodation support, employment, inclusive education, family skills development and leadership.

## Introduction

Involuntary sterilisation of people with disabilities in Australia should not be legalised or forced. Systematic discrimination and animosity against women and girls with disabilities continue to flourish through prevailing denial of basic human rights to experience sexual relationships, experience love and make decisions concerning parenthood<sup>1</sup>. It is dehumanising to force compulsory sterilisation upon people with intellectual disability; therefore existing policies regarding sterilisation must be reconsidered and reformulated into legislative acts that constitute and protect human rights, the power of choice and centre on the best interest of people with intellectual disability.<sup>2</sup>

According to the Australian Bureau of Statistics, “just under one in five (18.5%) Australians had a disability in 2009”<sup>3</sup> and, by 2099, “it is estimated that approximately 4 million people will have a severe/profound core activity limitation in Australia - more than triple the current number”<sup>4</sup>. These figures illustrate the importance of addressing concerns now, so that more Australians will not suffer from discrimination regarding sexual health and the power of choice.

The Australian Institute on Intellectual and Developmental Disabilities supports the position that women (and men) with an intellectual disability should be supplied with appropriate and sufficient medical information and assistance in order to aid decision-making regarding sterilisation. The crucial step into adulthood and possible parenthood is an important issue; therefore, the opportunity for an in-depth education must be readily available for all persons. Increased awareness and education about the issues associated with adulthood and parenthood may or may not lead to a decision of sterilisation, but that decision is for the individual with intellectual disability to make.<sup>5</sup> AIIDD advises the Australian Government to advocate its human rights commitments and successfully achieve national legislation, which would prohibit forced sterilisation on girls and young women, regardless of those individuals having a disability or not.<sup>6</sup>

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1. WWDA, (March, 2013). Dehumanized: The Forced sterilisation of women and girls with disabilities in Australia. Women with Disabilities Australia. Submission no.49.

3. ABS, (2, May, 2011). One in five Australians with a disability - media release. Australian Bureau of Statistics. Accessed from <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4125.0main+features3130Jan%202013>

4. PWC, (Nov 2011). Disability expectations - investing in a better life, a stronger Australia. PWC - People with Disabilities Australia. <http://www.pwc.com.au/industry/government/assets/disability-in-australia.pdf>

5. Family Planning NSW - Reproductive Sexual Health, (Feb, 2013). Senate inquiry into involuntary or coerced sterilisation of people with disabilities in Australia. Submission 25

6. Family Court of Australia, (1998). A question of right treatment. The Family Court and Special Medical Procedures for Children, an introductory guide for use in Victoria. Accessed from

[http://www.familycourt.gov.au/wps/wcm/resources/file/eba9c049d2a7cc1/Question\\_of\\_right\\_treatment.pdf](http://www.familycourt.gov.au/wps/wcm/resources/file/eba9c049d2a7cc1/Question_of_right_treatment.pdf)

6. Family Court of Australia, (1998). A question of right treatment. The Family Court and Special Medical Procedures for Children, an introductory guide for use in Victoria. Accessed from

[http://www.familycourt.gov.au/wps/wcm/resources/file/eba9c049d2a7cc1/Question\\_of\\_right\\_treatment.pdf](http://www.familycourt.gov.au/wps/wcm/resources/file/eba9c049d2a7cc1/Question_of_right_treatment.pdf)

Women with intellectual disability have the right to make clear decisions regarding their own choice of contraception, gynecological care and overall health, therefore involuntary or coerced sterilisation is not an option. The AIIDD is aware that some girls and young women may be deemed incapable of making such decisions. In these cases, the AIIDD recommends an in-depth analysis be conducted on the individual in question, to accurately determine the extent of their decision-making capabilities. An analysis must also be undertaken through appropriate courts of law – such as the Family Court of Australia or the High Court of Australia – on the individual’s primary carer, family member or legal guardian, to deliberate on whether the primary carer has the person with disability’s best interest at heart.<sup>7</sup>

Throughout this submission, concerns over human rights, power of choice, ideologies of eugenics and sexual health of people with intellectual disability are deliberated upon. The urgency of reform regarding sterilisation policies is crucial in meeting the equal rights and freedom of choice for people with intellectual disability. Women with disabilities are more vulnerable to domestic violence, sexual assault and rape. Reform will not only improve the wellbeing of those with disabilities, but will provide women and men with disabilities with options regarding sexual health, contraception, abortion and family/parenting education and support.<sup>8</sup>

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7. Family Court of Australia, (1998). A question of right treatment. The Family Court and Special Medical Procedures for Children, an introductory guide for use in Victoria. Accessed from

[http://www.familycourt.gov.au/wps/wcm/resources/file/eba9c049d2a7cc1/Question\\_of\\_right\\_treatment.pdf](http://www.familycourt.gov.au/wps/wcm/resources/file/eba9c049d2a7cc1/Question_of_right_treatment.pdf)

8. Queensland Government, (2013). Topic: Sexual Health and Disability. Accessed from

[http://access.health.qld.gov.au/hid/InfectionsandParasites/SexuallyTransmittedDiseases/sexualHealthAndDisability\\_ap.asp](http://access.health.qld.gov.au/hid/InfectionsandParasites/SexuallyTransmittedDiseases/sexualHealthAndDisability_ap.asp)

## Terminology

***Sterilisation*** refers to the irreversible medical procedure in which a woman's ability to menstruate and rights to reproduce are taken away.<sup>9</sup> Sterilisation surrounds "the primary purpose of which is to render an individual incapable of procreating without impairing his or her capacity to engage in sexual activity"<sup>10</sup>.

***Involuntary (or forced) sterilisation*** refers to the medical procedure where the person with disability is not involved in the decision-making process and has not given their free and informed consent<sup>11</sup>. In past decades, involuntary sterilisation was performed for various 'social' reasons, eg. eugenics-based population control, menstrual management, pregnancy prevention of those considered not capable of being an adequate parent<sup>12</sup>.

***Coerced Sterilisation*** occurs when persuasive tactics are used to persuade individuals to undergo the sterilisation procedure. Incentives such as financial gains, misinterpretation regarding the procedure, pressure, intimidation and bribery are some ways in which coerced sterilisation is influenced<sup>13</sup>.

Non-voluntary sterilisation procedures are used to eliminate issues such as unplanned pregnancy, abortion, menstruation and incompetent parenting. Primarily, they eradicate the free choice and human right to conceive, reproduce and become a parent<sup>14</sup>. As such, the AIIDD believes education and counseling should be the norm, as increased assistance in decision-making will provide people with intellectual disability with the confidence to voice their human rights, equality and freedom of choice.

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9. Veatch, R., Haddad, A. (27 Feb, 2008). Case Study in Pharmacy Ethics. Oxford University Press, USA.

10. CSEP, (24 Sep, 2011). Sterilization of Persons who are mentally retarded. American Association for Intellectual and Developmental Disabilities. Accessed from <http://ethics.iit.edu/ecodes/node/3713>

11. Human Rights Watch, (10 Nov, 2011). Sterilization of women and girls with disabilities. A briefing paper. Accessed from <http://www.hrw.org/news/2011/11/10/sterilization-women-and-girls-disabilities>

12. Sifris, R. (2010). Conceptualizing involuntary sterilisation as 'severe pain or suffering' for the purposes of torture discourse. Accessed from <http://www.corteidh.or.cr/tablas/r25754.pdf>

13. Kasiva, F. (2012). Robbed of Choice, Forced and coerced sterilisation experiences of women living with HIV in Kenya. A publication by African Gender and Media Initiative. Accessed from <http://kelinkkenya.org/wp-content/uploads/2010/10/Report-on-Robbed-Of-Choice-Forced-and-Coerced-Sterilization-Experiences-of-Women-Living-with-HIV-in-Kenya.pdf>

14. Women With Disabilities Australia (WWDA), Human Rights Watch (HRW), Open Society Foundations, International Disability Alliance (IDA) (2011) Sterilization of Women and Girls with Disabilities: A Briefing Paper (November). Available online at: [http://www.wwda.org.au/Sterilization\\_Disability\\_Briefing\\_Paper\\_October2011.pdf](http://www.wwda.org.au/Sterilization_Disability_Briefing_Paper_October2011.pdf)

## Highlighted Issues

### Human Rights Abuse

An individual's reproductive rights are established in the United Nations 1968 International Conference on Human Rights<sup>15</sup> and are further enshrined in a number of international human rights treaties and instruments to which Australia is a party. The World Health Organization expanded that:

“Reproductive rights rest on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. They also include the right of all to make decisions concerning reproduction free of discrimination, coercion and violence.”<sup>16</sup>

These are rights to which all women are entitled – the right to control their own reproductive functions and to make choices in regard to reproduction, free from coercion or violence.<sup>17</sup> However, women and girls with disabilities in Australia have failed to be afforded, or benefit from, these provisions in international human rights law. In the case of forced sterilisation of people with disabilities, the denial or ignorance of these rights seems to imply a belief that, whilst every person is a human being, not every human being is a person, and that in order for these rights to apply, one must meet a ‘person’ criteria in order to be entitled to their protection.<sup>18</sup>

Creativity and intelligence are described as ‘what makes us human’,<sup>19</sup> consequentially resulting in the belief that a lack of, or lesser of, these qualities gives the impression of ‘less than human’. Based on these criteria, those with disabilities have been dehumanised to the point that they are not recognised as having the same needs or wants as ‘normal’ human beings and, therefore, not privy to the same rights. Because of this continued perception within society, women with disabilities continue to be isolated from society at large by the current governing policies; an action that prevents any chance of developing a public view that allows them to have an equal place in

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15 Freedman, Lynn P.; Isaacs, Stephen L. (1993). "Human Rights and Reproductive Choice". *Studies in Family Planning* (Population Council) **24** (1): 18–30.

16 Cottingham, J. "Who Report- Using human rights for sexual and reproductive health: improving legal and regulatory frameworks" <http://www.who.int/bulletin/volumes/88/7/09-063412/en/>. Accessed 24 May 2013

17 Amnesty International "Realizing Sexual and Reproductive Rights" <https://www.amnesty.org/en/library/asset/ACT35/006/2012/en/10fd8a1f-7360-4a3d-b21e-7a11882d7d88/act350062012en.pdf> . Accessed 24 May 2013.

18 Carter, J. (2011) "Being a person" <http://www.firstthings.com/onthesquare/2011/01/being-a-person>. Accessed 24 May 2013.

19 Mickens, R. "American Museum of Natural History-What Makes Us Human?" <http://www.amnh.org/exhibitions/past-exhibitions/human-origins/what-makes-us-human>. Accessed 24 May 2013.

society.<sup>20</sup> As a result of this division, there are Australian women with disabilities who have been, and continue to be, denied human rights through the government's lack of action regarding involuntary sterilisation.

The right to be free from torture is a human right awarded to all. It is jus cogens,<sup>21</sup> binding on all States, whether a country has ratified their particular policy regarding the matter or not.<sup>22</sup> The UN Special Rapporteur on Torture clarified that the State cannot deny this right:

“[involuntary sterilization is]...inconsistent with the Convention on the Rights of Persons with Disabilities...inflict severe pain and suffering, they violate the absolute prohibition of torture and cruel, inhuman and degrading treatment.”<sup>23</sup>

Forced sterilisation is torture.<sup>24</sup> The implication that the Australian Government sanctions ‘forced sterilisation’ through their current inability to take adequate preventative measures, allows the continued torture of Australian citizens. The consequence is the prolonged suffering of the victim<sup>25</sup>, such as “severe emotional and physical stress”<sup>26</sup> and continued “interference with a person’s reproductive health status and involves many aspects of personal integrity, including physical, psychological, emotional, spiritual and family wellbeing.”<sup>27</sup>

## Sexual Abuse

In Australia, women and girls with disabilities are at higher risk of sexual exploitation<sup>28</sup> and abuse than the greater female society. Those who justify enforced sterilisation argue that it is necessary to ensure women with disabilities cannot conceive as a result of assault. Whether a person with severe intellectual disability is able to give adequate consent to intercourse is an ongoing issue of consideration in Australia. It should be noted that, under the Crimes Act 1900, a person does not consent to sexual intercourse:

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20 Roos, P. (1975) Psychological Impact of Sterilization on the Individual; *Law and Psychology Review*, Issue 45, pp.45-54.

21 International Criminal Tribunal for the Former Yugoslavia, *Prosecutor v. Furundzija*, Case IT-95-17/1-T; Judgement, 10 December 1998.

22 Méndez, Juan. E. (2013) UN.Doc A/HRC/22/53, Op Cit., See also: Sifris, R. (2010) Conceptualising involuntary Sterilisation as ‘Severe Pain or Suffering for the Purposes of Torture Discourse. *Netherlands Quarterly of Human Rights*, Vol.28/4, pp.523-547.

23 Méndez, Juan. E. (2013) UN.Doc A/HRC/22/53, Op Cit.

24 Méndez, Juan. E. (2013) UN.Doc A/HRC/22/53, Op Cit., Nowak, M. (2008) UN Doc. A/HRC/7/3; Op Cit.

25 Sifris, R. (2010) Op Cit.

26 Alexandra Minna Stern [STERILIZED in the Name of Public Health: Race, Immigration, and Reproductive Control in Modern California](#) *Am J Public Health*. 2005 July; 95(7): 1128–1138

27 “ECHR decisions re Slovakia: forced sterilization of Roma women” <http://reprohealthlaw.wordpress.com/2012/07/31/echr-decisions-re-slovakia-forced-sterilization-of-roma-women/>. Accessed 24 May 2013.

28 Hallahon, L (2003) ‘Time to Stop the forced Sterilisation of girls and women with disability’ <http://theconversation.com/time-to-stop-the-forced-sterilisation-of-girls-and-women-with-disability-9812>. Accessed 23 May 2013.



- (a) “if the person does not have the capacity to consent to the sexual intercourse, including because of age or cognitive incapacity.”<sup>29</sup>

There is a seemingly pervasive view in Australia that sterilisation will result in the prevention of sexual abuse of women and girls with disabilities. Examples from foreign contexts can be applied to the Australian setting. In the case ‘re S’ in the United States<sup>30</sup>, the girl in question was described as having a ‘mental age of no greater than 1 year old’, which would likely never change. In justifying his decision to allow the 14-year-old girl to be sterilised, the judge stated:

“Although I agree that the risk of pregnancy, on its own, is not of sufficient likelihood as to indicate a need to submit her to a sterilisation procedure, I would not dismiss the probability of sexual intercourse occurring”.

Yet the reasoning that forced sterilisation will reduce the risk of women and girls with disabilities being taken advantage of and sexually abused – and reduce the trauma faced by these vulnerable people – is an approach that is fundamentally wrong. This approach of enforcing sterilisation as a preventative measure for dealing with the results of abuse leaves unfortunate implications on the values that current legislation places on the protection of girls and women with disabilities – namely, as they cannot keep these women safe from the initial assault, current policy will instead protect them from becoming pregnant as a result of that assault.<sup>31</sup> Justice Brennan, in ‘re JWB’ [“Marion's Case”],<sup>32</sup> commented on this:

“Where it is desirable to avoid the risk of pregnancy, the risk may be avoidable by means which involve no invasion of the girl's personal integrity. Those who are charged with responsibility for the care and control of an intellectually disabled girl ... have a duty to ensure that the girl is not sexually exploited or abused... It is unacceptable that an authority be given for the girl's sterilisation in order to lighten the burden of that duty, much less to allow for its neglect... Such a situation bespeaks a failure of care, and sterilisation is not the remedy for the failure.”

Evidence also suggests that, even in these tragic circumstances, the emotional impact of pregnancy is hardly uniform for all women with disabilities; for some, the event would rightly be traumatic and have a negative effect on the rest of their lives while, for others, motherhood could be

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29 CRIMES ACT 1900 - SECT 61HA

30 Attorney-General (QLD) v. Parents, In re S. (1989) AFC. Fed Law Rep. 98:41-56. (Nov 22 1989)

31 Hallahan, L (2003) ‘Time to Stop the forced Sterilisation of girls and women with disability’ <http://theconversation.com/time-to-stop-the-forced-sterilisation-of-girls-and-women-with-disability-9812>. Accessed 23 May 2013.

32 *Department of Health Community Services v JWB SMB* [1992] HCA 15; (1992) 175 CLR 218 (6 May 1992)

considered something to celebrate and look forward to, regardless of circumstances. Brennan explored this, emphasising that:

“... (It is) forgotten that pregnancy and motherhood may have a significance for some intellectually disabled girls quite different from the significance attributed by other people. Though others may see her pregnancy and motherhood as a tragedy, she, in her world, may find in those events an enrichment of her life.”

## **Parenting Issues**

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.

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 ‘child-like’. This bias has become a significant issue in social policy as more parents with disability have their children removed from them. Persons with intellectual disability may only represent one to two percent of the population, but they make up 10 percent of those fighting in court to regain guardianship of their own children<sup>33</sup>. AIIDD believes in the right of people with disability to care for their own children while void of negative assumptions about their capabilities. This is cited in the Convention on the Rights of Persons with Disabilities (CRPD), where Article 6 states “Parties should ensure the full and equal enjoyment by them of all human rights and fundamental freedoms”. As such, AIIDD does not support the involuntary sterilisation of girls and young women, but does enforce the idea that girls with intellectual disability be given the opportunity to grow into a woman, like any other girl.

The right to have a family is outlined in several international treaties, including the Universal Declaration on Human Rights (UDHR) (1948, article 16), International Covenant on Civil and Political Rights (ICCPR) (1976, Article 23) and International Covenant on Economic, Social and Cultural Rights (1976, Article 10).<sup>34</sup> With first presumptions based within these rights, each individual must be assessed on their parental skills on a case-by-case analysis, where cognitive

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33 Renwick, E. 2004, ‘*Child removals from intellectually disabled parents 'inhumane'*’, ABC News, Australia, 24 October 2004.

34 United Nations 2006, ‘*Convention on the Rights of Persons with Disabilities*’  
<http://www.un.org/disabilities/convention/conventionfull.shtml>

limitations vary from individual to individual<sup>35</sup>. It is emphasised, though, that parents with disabilities should not be stereotyped and discriminated against based on their limitations. In the Convention on the Elimination of Discrimination against Women 1981 (CEDAW), Article 16 states:

“The same rights and responsibilities as parents, irrespective of their marital status, in matters relating to their children; in all cases the interests of the children shall be paramount.<sup>36</sup> Unless the parent is a danger, they should have the same rights as any other individual to parent their children as long as it is in ‘the best interests of the child’.”<sup>37</sup>

AIIDD argues that people with disabilities should be educated and informed to gain a full understanding of what options they have and given the opportunity to provide their own informed consent. This would mean more education and support services to ensure people with disabilities have the same knowledge as anyone else, while also meeting their individual personal needs and differences.

## **Gynaecological Health**

Menstrual and contraceptive management are listed as two of the main justifications for sterilisation in girls and young women with intellectual disability in Australia. In the court of law, sterilisation is deemed acceptable if it is “determined to be in the child’s best interests after alternative and less invasive procedures have all failed or it is certain that no other procedure or treatment will work”<sup>38</sup>. As it has been discovered though, arriving at the decision to commit to a procedure of sterilisation is not a decision made by one person alone, and there remains contestation about just how much of a say people with disabilities have on that decision. As such, there is evidently a need for appropriate and specialised support services for people with disabilities in terms of education and health care so that inclusive and informed decision-making may be achieved. As the issues of menstrual management and contraceptive management are different in nature, they should be treated as such.

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35 Frohmader, C. 2009, ‘Parenting Issues for Women with Disabilities in Australia,’ WWDA, Australia.

<http://www.wwda.org.au/parentingpolicy/paper09.pdf>

36 Lamont, A. Bromfield, L. 2009, ‘Parental intellectual disability and child protection: Key Issues’, Australian Institute of Family Studies: Child Family Community Studies.

37 United Nations 1981, ‘Convention on the Elimination of Discrimination against Women,’

<http://www.un.org/womenwatch/daw/cedaw/text/econvention.htm#article16>

38 Brady, S. M and Grover, S. (1997). The Sterilisation of Girls and Young Women in Australia. Retrieved 23 May 2013 from [http://www.humanrights.gov.au/sites/default/files/content/disability\\_rights/hr\\_disab/Sterilization/sterilis.doc](http://www.humanrights.gov.au/sites/default/files/content/disability_rights/hr_disab/Sterilization/sterilis.doc).

Menstrual management refers to a “range of strategies that a woman might use during her menstrual cycle” in order to be comfortable with her menstrual fluid, “manage her menstruation hygienically, with dignity and privacy” and to experience a normal menstrual cycle<sup>39</sup>. A key point made by Burbidge, Butler and Tracy (2003) is that all women must manage their menstrual cycle utilising the same options, regardless of disability. The difference that does remain, though, is that women with disabilities generally require more assistance in this area. For women with high support needs, specific management strategies can be implemented to help address menstrual management. Such tactics include having a consistent carer with whom the woman with disability feels comfortable to assist her and in using alternative hygiene products if a woman is incontinent of urine and/or faeces<sup>40</sup>. In terms of seeking additional assistance or information in this area, women with disabilities and carers can consult with medical practitioners, family planning centers and academic references.

According to one survey of community-dwelling women, around 40 percent of women with intellectual disability were not asked about their gynecological needs by a healthcare professional<sup>41</sup>. This indicates an ideology of a sub-classification of the needs of women with disabilities with regards to general gynecological health care and the recognition of their sexuality. There exists a lack of access to information and programs for women with disabilities when it comes to managing their own gynecological health. This judgment is made in relation to Article 25 of the Convention on the Rights of Persons with a Disability<sup>42</sup>. Article 25(a) states that healthcare professionals must “provide persons with disabilities with the same range, quality and standard of free or affordable health care and programs as provided to other persons, including in the area of sexual and reproductive health and population-based public health programs”. Education contained within such programs would include that of contraceptive choice. It was determined in a recent study at the Gynaecology clinic at the Centre for Adolescent Health, Royal Children’s Hospital in Melbourne that only two of 107 young women required “surgical approaches to manage their menstrual problems or contraceptive-related issues”.<sup>43</sup> Information, advice and medical management were sufficient for the remaining patients. The conclusions of that report were that young women with

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39 Burbidge, M., Butler, J. and Tracy, J. (2003). (Revised). Retrieved 24 May 2013 from <http://www.cddh.monash.org/assets/menstrual-management-guide-staff.pdf>.

40 Burbidge, M., Butler, J. and Tracy, J. (2003). (Revised). Retrieved 24 May 2013 from <http://www.cddh.monash.org/assets/menstrual-management-guide-staff.pdf>.

41 Wilinson, J. (2008). Primary Care for Women with Intellectual Disabilities. *Journal of the American Board of Family Medicine*. Vol.21(3). pp. 215-222. Retrieved 24 May 2013 from <http://jabfm.org/content/21/3/215.full>.

42 Disability Representative, Advocacy, Legal and Human Rights Organisations. (2012). *Disability Rights Now: Civil Society Report to the United Nations Committee on the Rights of Persons with Disabilities*. Retrieved 24 May 2013 from [http://doc.afdo.org.au/CRPD\\_Civil\\_Society\\_Report\\_PDF](http://doc.afdo.org.au/CRPD_Civil_Society_Report_PDF)

43 Grover, S. R. (2002). Menstrual and Contraceptive Management in Women with an Intellectual Disability. *Medical Journal of Australia*. vol.176(3), pp. 108-110. Retrieved 28 May 2013 from <https://www.mja.com.au/journal/2002/176/3/menstrual-and-contraceptive-management-women-intellectual-disability>

intellectual disability had, in most cases, similar menstrual and contraceptive needs and management strategies to women without intellectual disability. It can be determined, then, that the use of involuntary or coerced sterilisation procedures for women with intellectual disability is both inhumane and reflective of a lack of adequate care and information on the part of the healthcare practitioner and carer.

## **Conclusion**

AIIDD believes the current state of disability legislation does yet protect people with disabilities, especially young girls and women, from involuntary sterilisation. People with intellectual disability should have the same rights as those without a disability, which is clearly enshrined in numerous international treaties, including the Universal Declaration of Human Rights (1948).

AIIDD acknowledges the importance of everyone to have equal opportunities in all aspects of life, including the right to grow up and experience adolescence like any other individual going through puberty. Mensuration does not have to be a problem. This issue should be approached by reaching out to those with an intellectual disability and teaching them through tailored educational programs. By doing so, appropriate help and support can be given to individuals with disabilities and their families and carers.

Pregnancy and motherhood for individuals with intellectual disability should be celebrated, not perceived as a negative situation. It has been pointed out that involuntary and coerced sterilisation does not necessarily prevent sexual behaviour. Instead, precautions should be undertaken by providing family planning assistance and contraception given as an option.

AIIDD does not agree with involuntary sterilisation and finds it to be a criminal act, punishable before the law. There is a need for greater awareness of involuntary or coerced sterilisation in society and the long-term effects of such a procedure should be known to all.

Stereotypes of people with intellectual disability can be far from the truth; they are able to have a stable family life, raise children and lead meaningful lives as anyone else in the community. It is time the Australian government and wider society acknowledged this in order to prevent any further harm to people with intellectual disability.

## **Recommendations**

### **1.0 Research**

Further research must be undertaken to determine the capabilities of an individual with an intellectual disability and whether their level of cognitive functioning allows them to understand social relationships.

1.1 As a leading nation in medical research, more studies should be undertaken to look at the capabilities and/or difficulties for parents with disabilities to care for their child.

1.2 A national report on the views of people with disabilities on involuntary sterilisation<sup>44</sup>.

1.3 The impact of sterilisation on girls and young women, including long-term effects, must be investigated and reported.

### **2.0 Legislative Reform**

Reforms to Australian legislation must be enforced to stop the practice of involuntary and coerced sterilisation on people with disabilities.

2.1 Australia's legislation should comply with international law, including the prohibition of involuntary and coerced sterilisation.

2.2 Amend the *Crimes Act 1900* and include involuntary sterilisation as a punishable offence for those who participate in such an act.

2.3 It should also be outlined in the *Disability Act 2006* that people with intellectual disability should have the same right to have a family, despite cognitive limitations, as long as they have an adequate support system.

2.4 The Law should outline that sterilisation should be a last resort and only used for medical reasons. Consent should also be provided by the individual beforehand.

### **3.0 Representation**

People with disabilities should have the same rights as individuals without a disability.

3.1 People with disabilities can participate in representative and advocacy groups who actively work in the development, implementation and policy-making process to ensure Australia is fulfilling its human rights' obligations to all citizens.

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<sup>44</sup> United Nations 1981, 'Convention on the Elimination of Discrimination against Women,' <http://www.un.org/womenwatch/daw/cedaw/text/econvention.htm#article16>

3.2 An independent association or board able to investigate families and uncover any exploitation, sexual or physical abuse experienced by people with disabilities.

#### **4.0 Education and Training**

Everyone has the right to education.

4.1 Greater education surrounding sex and reproduction for people with disabilities to have a greater understanding of human development.

4.2 An on-going education and skills program for people with intellectual disability and their families.

#### **5.0 Support Services and Accessibility**

A range of support services be made available and readily accessible to help families with children with disabilities or parents with intellectual disability gain appropriate and adequate information.

5.1 Parenting support services should be in place for parents with disabilities to gain help and information on having children and caring for them.

5.2 Support groups should be established in areas of high need that are close to homes and readily accessible.

5.3 Ensure DisabilityCare Australia (previously National Disability Insurance Scheme) funds go towards supporting parents with disabilities and their families Australia-wide as soon as possible.

#### **6.0 Justice**

An apology made to all those already affected by involuntary or coerced sterilisation procedures.

## Appendix

### *Key areas of Law that Affect Persons with Intellectual Disability*

In order to understand the current legal framework surrounding the sterilisation of children, a brief summary of key Acts, Declarations and Conventions included within the report is listed below.

Key contributions to the development and evolution of legal framework can be attributed to the Reports on Consent to Sterilisation of Minors by the Law Reform Commission of Western Australia and the Family Law Council's Report to the Attorney General Sterilisation and Other Medical Procedures on Children (Brady & Grover 1997).

### **Australian Human Rights Commission (AHRC) Act 1986**

The Australian Human Rights Commission Act 1986 (Cth) is designed "to make provision in relation to human rights and in relation to equal opportunity in employment, and for related purposes"<sup>45</sup>. Section 3 of the Act offers a definition of discrimination, with the Australian Human Rights Regulations 1989 (Cth) providing scope and clarification on what constitutes discrimination. These pieces of legislation work together to better protect the human rights of people living with a disability – past, present or future. Protection of human rights ensures people can "live free from fear, harassment or discrimination"<sup>46</sup>. It is also noted that several conventions and declarations are present within the Act that are of particular relevance to the area of disability rights policy.

### **Declaration of the Rights of the Child**

This declaration is contained within Schedule 3 of the AHRC Act 1986 and specifically addresses the need for special safeguards and care for children under the age of eighteen<sup>47</sup>. The declaration was also adopted by UN General Assembly Resolution 1386 (XIV) of 10 December 1959<sup>48</sup>. Principle 5 addresses the needs of children with disabilities, stating "the child who is physically, mentally or socially handicapped shall be given the special treatment, education and care required by his particular condition"<sup>49</sup>.

### **Convention of the Rights of the Child**

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45 Australian Government (2010). Australian Human Rights Commission Act 1986. Retrieved 23 May 2013 from <http://www.comlaw.gov.au/Details/C2010C00865>.

46 ACTU Worksite. (2009). What is the Australian Human Rights Commission? Retrieved 23 May 2013 from <http://www.worksite.actu.org.au/fact-sheets/what-is---the-australian-human-rights-commission.aspx>.

47 Australian Government (2010). Australian Human Rights Commission Act 1986. Retrieved 23 May 2013 from <http://www.comlaw.gov.au/Details/C2010C00865>.

48 United Nations Cyber School Bus. (n.d.). Declaration of the Rights of the Child. Retrieved 23 May 2013 from <http://www.un.org/cyberschoolbus/humanrights/resources/child.asp>.

49 Australian Government (2010). Australian Human Rights Commission Act 1986. Retrieved 23 May 2013 from <http://www.comlaw.gov.au/Details/C2010C00865>.



This convention came into force on 2 September 1990 and is an addition to the Declaration on the Rights of the Child<sup>50</sup>. Article 3 states that the best interests of the child should be the primary consideration in all public and private aspects, such as in the court of law, welfare institutions and legislative bodies (Ibid). Article 3(3) also states that State Parties have a responsibility to ensure institutions and services are caring for the protection of children in various areas, including health. The convention is seen as being complimentary to the Geneva Declaration of the Rights of the Child 1924 and the Declaration of the Rights of the Child adopted by the General Assembly on 20 November 1959 (Ibid).

### **Declaration on the Rights of Mentally Retarded Persons**

The Declaration on the Rights of Mentally Retarded Persons lies under Schedule 4 of the AHRC Act 1986<sup>51</sup>. This declaration proclaims that “the mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings” (Ibid). The Declaration also proclaims “the mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential” (Ibid). Points 6 and 7 of this Declaration are of vital importance to the current debate surrounding sterilisation:

- 6) “The mentally retarded person has a right to protection from exploitation, abuse and degrading treatment. If prosecuted for any offense, he shall have a right to due process of law with full recognition being given to his degree of mental responsibility.
- 7) Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities” (Ibid).

### **Declaration on the Rights of Disabled Persons**

The Declaration on the Rights of Disabled Persons refers to the “dignity and worth of the person”<sup>52</sup>. Point 10 is of particular interest to the sterilisation discussion, declaring the right of disabled

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50 United Nations Human Rights. (n.d.). Convention on the Rights of the Child. Retrieved 23 May 2013 from <http://www.ohchr.org/en/professionalinterest/pages/crc.aspx>.

51 Australian Government (2010). Australian Human Rights Commission Act 1986. Retrieved 23 May 2013 from <http://www.comlaw.gov.au/Details/C2010C00865>.

52 Australian Government (2010). Australian Human Rights Commission Act 1986. Retrieved 23 May 2013 from <http://www.comlaw.gov.au/Details/C2010C00865>.

persons to be “protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature” (Ibid).

### **Convention on the Rights of Persons with Disabilities**

Australia became a signatory to the Convention on the Rights of Persons with Disabilities on 30 March 2007, ratifying the Convention on 17 July 2008 and additionally signing the option protocol on the 21 August 2009<sup>53</sup>. This convention came into effect in Australia 20 September 2009 (2010). The convention looks to secure the rights of people with disabilities and set out a code of implementation<sup>54</sup>. Article 6, which ensures “the equal rights and advancement of women and girls with disabilities”, and article 7, which protects children with disabilities, is of particular importance in the discussion of disability rights<sup>55</sup>. Article 17 is also pertinent, which states “countries must protect the physical and mental integrity of persons with disabilities, just as for everyone else”<sup>56</sup>.

### **Disability Discrimination Act 1992**

The Disability Discrimination Act 1992 protects the rights of people living with a disability from discrimination in all facets of their life, including employment, education, sporting, health and in the community at large. This Act acknowledges the “overall benefits to the community and the economy that flow from participation by the widest range of people”<sup>57</sup>. For example, women with disabilities should not be restricted to the provision of goods, services and facilities because of their disability. In the case of menstrual or contraceptive management, women with disabilities should not have a different set of options for services available to them than those without a disability.

### **Guardianship and Administration Act 1986**

The Guardianship and Administration Act 1986 is a core piece of legislation that “governs when a medical research procedure can be performed on a person aged 18 years or older who has a disability (that is, an intellectual impairment, mental disorder, brain injury, or physical disability or dementia), where that person is incapable of deciding whether to consent to the procedure”<sup>58</sup>.

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53 United Nations Enable. (n.d.). Convention and Optional Protocol Signatures and Ratifications. Retrieved 24 May 2013 from <http://www.un.org/disabilities/countries.asp?navid=17pid=166>

54 United Nations. (2006). Convention on the Rights of Persons with Disabilities: The Convention in Brief. Retrieved 24 May 2013 from <http://www.un.org/disabilities/convention/convention.shtml>

55 Australian Human Rights Commission. (n.d.). Legislation. Retrieved 23 May 2013 from <http://www.humanrights.gov.au/our-work/legal/legislation>.

56 United Nations. (2006). Convention on the Rights of Persons with Disabilities: The Convention in Brief. Retrieved 24 May 2013 from <http://www.un.org/disabilities/convention/convention.shtml>

57 Australian Human Rights Commission. (n.d.). A Brief Guide to the Disability Discrimination Act. Retrieved 24 May 2013 from <http://www.humanrights.gov.au/brief-guide-disability-discrimination-act>.

58 Department of Health Victoria, Australia. (2012). Health Legislation: Guardianship and Administration Act. Retrieved 24 May 2013 from <http://www.health.vic.gov.au/legislation/guardian-and-admin-act.htm>