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The Involuntary or Coerced Sterilisation of People with Disabilities in Australia Senate Committee Inquiry

Intellectual Disability Rights Service Inc Submission to the Senate Standing Committee on Community Affairs.

Contents

1. General Comments 3

2. About the Intellectual Disability Rights Service (IDRS) 5

3. Terms of Reference (a): Types of Sterilisation Practices Used 5

3.1. Historical Context 6

3.1.1. Eugenics 6

3.1.2. For the good of the state, community or family 7

3.1.3. To mitigate the effects of, or prevent sexual abuse 7

Overarching Recommendation 1 8

1. Terms of Reference (b): Prevalence of Sterilisation Practices 9

1.1. Use and Recording of Sterilisations in Australia 9

1.1.1. Recommendation 9

2. Terms of Reference (c): Harmonisation of Regimes in Australia 10

2.1. Recommendation 12

2.2. Recommendation 12

3. Terms of Reference (d): Consent and Wishes of People with Disabilities 12

3.1. Steps to determine the wishes of person with disability 12

3.2. Best Interests Test 13

4. Terms of Reference (e): Impacts of sterilisation on people with disabilities 13

4.1. Breach of human rights 14

4.2. A step backwards 15

4.3. Denied the opportunity to parent 15

5. Terms of Reference (f): Australia's compliance with its international obligations as they apply to sterilisation of people with disabilities 18

5.1. UN Convention on the Rights of Persons with Disabilities 18

5.2. Convention on the Rights of the Child 20

5.3. International Covenant on Economic, Social and Cultural Rights 21

5.4. International Covenant on Civil and Political Rights 22

5.5. Women's Human Rights Instruments 23

5.6. Universal Periodic Review Recommendations 24

6. Terms of Reference (g): The Factors that Lead to Sterilisation Procedures Being Sought by Others 25

6.1. Programs to Support People with Disability 25

6.1.1. Recommendation 26

6.2. Educational Resources for the Community and Professionals on the Impact of Sterilisation 27

6.2.1. Recommendation 28

6.2.2. Recommendation 28

6.3. Recommendation 28

7. Terms of Reference (h): Any other related matter 28

7.1. Long term contraceptive devices 28

8. Conclusion and Recommendations Summary 30

1. General Comments

Thank you for the opportunity to make a submission to the Senate Standing Committee Inquiry into Involuntary or Coerced Sterilisation of People with Disabilities in Australia. The Intellectual Disability Rights Service has had a keen interest in this issue and we welcome the Committee's Inquiry.

This submission addresses key aspects of the Committee's Terms of Reference, and offers a raft of recommendations.

This submission aims to identify some of the underlying concerns that lead to carers sterilising people with intellectual disability, or coercing them into the procedure, and makes recommendations on how these concerns can be addressed.

Sterilisation refers to a surgical procedure that has the result of terminating the person's ability to reproduce.[1] Sterilisation can be performed for therapeutic or non-therapeutic reasons. Non-therapeutic sterilisation refers to sterilisation that is performed for reasons other than to treat a medical condition or disease.

Forced sterilisation refers to a process of sterilisation being performed upon a person without their consent. Coerced sterilisation refers to sterilisation where undue pressure or coercion has been placed upon the individual to undertake the procedure.[2]

In summary, the Intellectual Disability Rights Service (IDRS) strongly opposes involuntary or coerced non-therapeutic sterilisation of people with a disability, and it is this procedure that is the focus of this submission. IDRS would welcome uniform prohibition of these

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[1] Women with Disability Australia, Policy and Position Paper: 'The Development of Legislation to Authorise Procedures for the Sterilisation of Children with Intellectual Disabilities (June 2007) Women With Disability Australia, <http://www.wwda.org.au/polpapster07.htm>

[2] Ibid.

practices through the implementation of nationally consistent legislation. Further, IDRS opposes any move to adopt legislation which would see involuntary or coerced non-therapeutic sterilisation sanctioned or regulated in any way.

Alarmingly, IDRS is aware that despite current prohibitions on non-therapeutic sterilisation, it continues to occur in many guises.[3] There is no one single way in which this issue can be addressed, and it requires legislative and policy changes from governments. Further, IDRS believes things will not change until the issues and concerns that lead to carers of people with intellectual disability seeing the procedure as necessary and desirable are addressed. It is necessary that Government support be provided for educational campaigns directed to parents and carers of people with intellectual disabilities. Further, it is necessary that educational material be developed for people with intellectual disabilities focussing on educating individuals on their reproductive rights.

Involuntary or coerced sterilisation it is a breach of the human rights of people with intellectual disability and a discriminatory practice that identifies people with intellectual disability as a distinct group within society that can be sterilised, while others cannot. This suggests that people with intellectual disability deserve fewer rights than people without disabilities.[4] Involuntary or coerced non-therapeutic sterilisation contravenes Australia's obligations under a number of human rights conventions.

IDRS is a specialist service that assists clients with intellectual disabilities. Our submission focuses on the experience of people with intellectual disability. This submission also focuses on the non-therapeutic sterilisation of girls and women. While the non-therapeutic sterilisation of men is also an issue, anecdotal evidence strongly suggests that sterilisation

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[3] Anecdotally, IDRS is aware that some carers take the person with intellectual disability overseas to have the procedure performed.

[4] People with Disability Australia, People with Disability Australia: Submission on the Draft Model Bill to regulate the sterilisation of children with an intellectual disability (November 2006) Women With Disability Australia < http://www.wwda.org.au/sterpwda06.htm>.

of women, and in particular girls and young women under 18, is more commonly sought as it is associated with issues such as managing menstruation and contraception.

2. About the Intellectual Disability Rights Service (IDRS)

IDRS is a specialist legal advocacy service for people with intellectual disability in New South Wales. We work with and for people with intellectual disability to exercise and advance their rights. Of particular relevance to this Inquiry, IDRS:

- Provides legal advice and casework to people with intellectual disability
- Advocates for improvements to law and policies affecting people with intellectual disability
- Provides assistance to legal and other professionals supporting people with intellectual disability
- Provides information to service providers and the community about the rights of people with intellectual disability
- Runs a specialist service, *The Parent's Project*, for parents with intellectual disability who are at risk of having their children removed from their care or are involved in care and protection proceedings.

IDRS has a long history of active involvement with the issue of sterilisation of people with intellectual disability and welcomes the Government's Inquiry into the involuntary or coerced sterilisation of people with disabilities.

3. Terms of Reference (a): Types of Sterilisation Practices Used

It is generally noted by human rights NGOs, academics and much of the international community that forced sterilisation is properly characterised as a fundamental breach of

human rights.[5] This has been recognised by the Special Rapporteur on Torture and Other Cruel and Inhuman or Degrading Punishment as a 'violation to be free from torture and other cruel, inhuman or degrading punishment'.[6]

3.1.Historical Context

In the experience of IDRS, there are a number of factors leading to carers, and others, seeking sterilisation procedures for people with intellectual disabilities.

3.1.1. Eugenics

There is a view held that people with intellectual disabilities should be sterilised in order to prevent them from reproducing children who themselves will have a disability.

This view is problematic for two reasons. Firstly, this is not necessarily the case, as relatively few intellectual disabilities are genetic. Secondly, and more importantly in IDRS's view, such a fear is based on a discriminatory assumption that people who have disabilities are of lesser worth as human beings.

People with an intellectual disability are capable of enjoying a fulfilling life. The lower standard of living that many people with intellectual disability experience is due to a disabling environment (factors such as poverty, lack of access to support systems, negative attitudes of others) rather than something inherent to their biological makeup.

A second part to this argument is that people with intellectual disability are seen as incapable of parenting due to their disability. This is explored in more detail below.

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[5] Women with Disability Australia above n1.

[6] Radhika Coomaraswamy, *Report of the Special Rapporteur on Violence Against Women, its Causes and Consequences: Policies and practices that impact women's reproductive rights and contribute to, cause or constitute violence against women*, (55th Sess.), E/CN.4/1999/68/Add.4.

3.1.2. For the good of the state, community or family

The arguments here centre on the burden that women and girls with disability, and their potential offspring, place on the resources and services funded by the state and provided through the community.

The lack of support structures and services for women and girls with intellectual disability and their families and carers must not be taken as reason for sterilisation. Evidence suggests that when parents and carers are given appropriate support and resources the issue of sterilisation loses potency.[7]

Related justifications for sterilisation focus on the added burden menstrual care and contraceptive management place on overstretched families and carers.

Many have used the argument that sterilisation is effective in managing problems associated with menstruation such as hygiene, pad changing, and inappropriate behaviour (such as smearing). These issues can be overcome through menstrual management teaching, support and education.[8] The focus on menstruation as a burdensome bodily function that should be removed reflects discrimination against females in general. Arguably other bodily functions such as urination and defecation - are more 'burdensome' given that they occur every day of the year rather than the five days per month that menstruation occurs.[9]

3.1.3. To mitigate the effects of, or prevent sexual abuse

A suggested justification for sterilisation is that it can mitigate the effects of, or prevent, sexual abuse of women and girls with intellectual disability.

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[7] Women With Disability Australia, above n 1.

[8] Susan M Brady and Sonia Grover, The Sterilisation of Girls and Young Women in Australia: A legal, medical and social context (1997), p. 31.

[9] Susan Brady, 'Invasive and Irreversible: The sterilisation of intellectually disabled children (1996) 21 Alternative Law Journal 160, 162.

Sterilisation does not overcome the vulnerability of children and women with intellectual disability to sexual abuse. In fact, sterilisation might lead to additional vulnerability and repeated assault insofar as a girl or woman who cannot fall pregnant is arguably a safer target for a perpertrator of sexual assault because the abuse can go more easily undetected.[10] The vulnerability to sexual abuse of children and women with intellectual disabilities is a product of other factors such as social isolation, inadequate screening of support workers and carers, lack of educational and protective behaviour programs, and the failure to take seriously complaints made of sexual abuse due to the perceived unreliability of people with intellectual disabilities.[11]

Justice Brennan in *Re Marion* stated that "sterilisation should not be used to lighten the burden of the duty to protect intellectually disabled people from all kinds of abuse, much less to allow for their neglect. It is important to separate these issues: sterilisation in no way addresses the real problem of sexual abuse."[12]

Overarching Recommendation 1

That the Commonwealth enact legislation to prohibit sterilisation of all people, without a person's prior free and informed consent, except in circumstances where there is a fundamental or serious risk to the life or health and the individual is unable to provide consent. In those situations sterilisation should only be authorised by a competent decision maker in line with relevant legislation.

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[10] Susan M Brady and Sonia Grover, The Sterilisation of Girls and Young Women in Australia: A legal, medical and social context (1997), p. 32; Leanne Dowse and Carolyn Frohmader, Moving Forward: Sterilisation and reproductive health of women and girls with intellectual disabilities (2001), p. 17.

[11] Intellectual Disability Rights Service, Making a Statement: An exploratory study of the barriers facing women with intellectual disability when they make a statement to police about sexual assault. <www.idrs.org.au/pubs/statement.html>

[12] Department of Health and Community Services v JWB and SMB (Marion's Case) 106 ALR 385.

1. Terms of Reference (b): Prevalence of Sterilisation Practices

1.1. Use and Recording of Sterilisations in Australia

IDRS is aware of anecdotal evidence that suggests that sterilisation procedures are being undertaken outside of the existing regulatory framework. This includes carers taking individuals overseas to have such treatment done. It is concerning that since *Marion's Case* (1992)[13] ruled that Tribunal consent is required before a child can be sterilised. Despite even this safeguard in the law, it is clear from anecdotal evidence that sterilisations are still being performed without the consent of the relevant decision-making Tribunal.[14]

Specifically on the issue of sterilisation procedures authorised by Tribunals and Courts, very few bodies appear to release publically available figures on the specific nature of sterilisation applications sought.

Of the figures available, it is not clear as to the nature of these sterilisation applications and for what purpose these applications were brought, if they were unsuccessful or their outcomes.

1.1.1. Recommendation

It is recommended that Tribunals, Courts and other bodies given the power to authorise sterilisations, consistently report on the nature of all sterilisation applications.

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[13] Department of Health and Community Services v JWB and SMB (Marion's Case) 106 ALR 385.

[14] Brady, Britton and Glover, The Sterilisation of Girls and Young Women in Australia: issues and progress, Australian Human Rights Commission, 2001. Accessed at: http://humanrights.gov.au/disability_rights/sterilisation/index.html on 7 March 2013.

2. Terms of Reference (c): Harmonisation of Regimes in Australia

IDRS is a New South Wales specific Service and operates in that jurisdiction only. Whilst IDRS does not wish to comment in detail on the current legislative schemes of other States and Territories, it is noted that the current legal position in each jurisdiction varies in terms of both the legal tests used and the availability of forums.[15]

We note that there is inadequate protection domestically, at a State and Territory and Federal level to prohibit forced non-therapeutic sterilisation.

Presently, the issue of sterilisation is regulated by State and Territory Tribunals and Boards with respect of adults and in some jurisdictions, children. With respect to children, most applications are made before the Family Courts.

IDRS would support a nationally consistent legislative scheme, banning all types of forced non-therapeutic sterilisation (as recommended above), as well as providing for a consistent approach to judicial authorisation with respect to sterilisation to prevent serious damage or injury.

Other jurisdictions, notably the Commonwealth, operate on a 'best interests' test.[16] The present legal test before the Family Courts is whether the procedure is 'in the child's best interests' and there is no other less invasive procedure.[17] IDRS has concerns of the 'best interest test', namely that:

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[15] We note that in New South Wales, jurisdiction is held by both the Guardianship Tribunal and Family Law Courts (including Family Law Court and Federal Magistrates Court) in relation to decisions relating to sterilisation for both minors and the Tribunal with respect of adults. This is also the case in South Australia, Queensland and Tasmania with respect to concurrent jurisdiction. Victoria, the Australian Capital Territory, Western Australia and the Northern Territory all provide for such decisions to be made by the Family Law Courts with regards to minors only.

[16] *Department of Health and Community Services v JWB and SMB (Marion's Case) 106 ALR 385.*

[17] *Department of Health and Community Services v JWB and SMB (Marion's Case) 106 ALR 385.*

- The nature of the test takes into account a broad range of factors, including the views of carers, parents, doctors, support and health systems and other relevant considerations which may dominate decision making;
- As a part of this decision making process, increased weight may be given to certain factors within the 'best interests' mix. Such decisions may be impacted on underlying assumptions of persons with disabilities.
- The nature of the Family Court process is in essence adversarial and is not an appropriate jurisdiction to have such a matter decided;
- There is no right to have an independent children's representative;[18]
- The issues of what is in the child's best interests can be incredibly difficult to ascertain.

In New South Wales, presently the Guardianship Tribunal may make orders in relation to sterilisation where an individual cannot provide consent. Sterilisation is classed a 'special medical treatment', and as such the Tribunal can only make an order for the procedure per the test contained within the relevant legislation. The primary aspects of that test include that the Tribunal may only make the decision if it is satisfied that the treatment is necessary to save the patient's life, or to prevent serious damage to the patient's health.[19]

Re Marion , 412.

[18] Re Angela [2010] FamCA 98

[19] This test is contained in s 45 of the *Guardianship Act 1987*. See also s 175 of the *Children and Young Persons (Care and Protection Act) 1998* which provides that the Guardianship Tribunal must be satisfied the sterilisation is necessary to 'prevent serious damage to the child's psychological or physical health'.

IDRS considers the New South Wales test to offer substantial benefits. As discussed above, there are concerns with the best interests test presently adopted in the Commonwealth and other jurisdictions, and this approach removes the subjective elements of the best interests test. Further, as the right to bodily integrity is a fundamental human rights issue, sterilisation should only be performed if there is a suitably justifiable reason for doing so, namely there are serious health consequences from not undertaking the procedure.

2.1. Recommendation

It is recommended the Commonwealth Government propose a consistent legislative scheme with respect to sterilisation where consent cannot be provided. Such a scheme should regulate that sterilisation is not be performed unless the relevant decision maker is satisfied that the treatment is necessary to save the patient's life, or to prevent serious damage to the patient's health.

2.2. Recommendation

The issue of nationally consistent legislation regarding the issue of sterilisation as raised above is raised at the Standing Council on Law and Justice (SCLJ) and other relevant intergovernmental meetings to discuss the implementation of law reform.

3. Terms of Reference (d): Consent and Wishes of People with Disabilities

3.1.Steps to determine the wishes of person with disability

As discussed above, it is a fundamental human right that medical treatment not be undertaken unless the individual provides free, prior informed consent. In IDRS' experience, this right of individuals with intellectual disabilities is often brushed aside and doctors may bypass the individual and use a substituted decision making

process, without thoroughly testing the person's current or potential capacity to make their own decision about treatment.

Anecdotally, IDRS is aware that doctors may only consult carers in relation to people with intellectual disability when it comes to medical consent and the patient is not asked their wishes. The impact and consequences of certain procedures, especially when it comes to the issue of serious medical procedures such as tubal ligations is not explained to the patients. Of further concern is the lack of explanation as to the possible alternatives to such treatment which may not be adequately explained. With those aspects lacking, it is difficult to see how any such decision could be considered an informed choice.

There are barriers in relation to fully explaining the impact, consequences and alternatives of medical treatment, especially when it comes to decisions about reproductive issues. This can be challenging and time consuming and doctors are often ill-equipped to provide an adequate opportunity for an informed choice.

It can be very difficult to achieve an assessment of a person's capacity to consent without considerable cost. Also it should be noted that a person's capacity to consent is not static. Information and education can enhance the ability of a person with intellectual disability to decide about their own medical treatment.

3.2.Best Interests Test

IDRS has concerns about the 'best interests test' being used and the impact of this on allowing for consent to be adequately provided, as detailed above.

4. Terms of Reference (e): Impacts of sterilisation on people with disabilities

Sterilisation permanently prevents an individual from being able to reproduce. In the High Court case, *Re Marion* (1991),[20] all seven High Court judges recognised sterilisation as a most serious procedure involving the 'immediate and serious invasion of physical integrity with the resulting grave impairment of human dignity'[21] (Brennan J at 322) and 'the destruction of a natural human attribute and the removal of an integral part of complete human personality'.[22] (Deane J at 331).

IDRS has worked with women with intellectual disability who have experienced clear grief related to the loss of the possibility of having children due to sterilisation at an early stage in their adulthood. The personal impact of sterilisation on women with intellectual disability is commonly overlooked.

4.1. Breach of human rights

Involuntary or coerced sterilisation for non-therapeutic reasons is a breach of an individual's human rights, as set out in a number of international human rights treaties to which Australia is party. People with intellectual disabilities are not exempt from the protections provided by these treaties.

Allowing involuntary or coerced sterilisation of people with intellectual disability would be a breach of Australia's international human rights obligations and an infringement on the rights of people with intellectual disability.

The human rights treaties relevant to this discussion are set out below in response to Terms of Reference (f).

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[20] Department of Health and Community Services v JWB and SMB (Marion's Case) 106 ALR 385.

[21] Department of Health and Community Services v JWB and SMB (Marion's Case) 106 ALR 385 per Brennan J at 24 Re Marion [1992] HCA 15.

[22] Department of Health and Community Services v JWB and SMB (Marion's Case) 106 ALR 385 per Deane J at 10 Re Marion [1992] HCA 15.

4.2. A step backwards

Involuntary or coerced sterilisation of people with disabilities, for non-therapeutic reasons, reflects and reinforces outdated, negative and discriminatory beliefs about people with intellectual disability.

The practice sits at odds with the disability rights movements globally, which through the introduction of the UNCRPD has seen the rights of people with intellectual disability explicitly recognised and protected.

It also conflicts Australia's practices of inclusion for people with intellectual disability. Since the 1980s, institutions for housing people with intellectual disabilities have largely been closed down and people with intellectual disability live in the community, attend mainstream schools and have increasing employment opportunities. Allowing involuntary or coerced sterilisation of people with disabilities for non-therapeutic reasons reinforces a view that people with intellectual disability may be denied certain rights held by people without disabilities. It suggests that people with intellectual disability as less worthy, eternal children, incapable of being parents and burdensome on society.

4.3. Denied the opportunity to parent

Widespread prejudicial attitudes that people with intellectual disabilities are "eternal children" and therefore cannot raise children of their own, or be effective parents leads to pressure to sterilise girls and women with disability to prevent pregnancy.

Some of the parents assisted by IDRS' *Parent's Project* have been encouraged by Community Services or their doctors to abort foetuses, upon finding out they are pregnant, or encouraged to have tubal ligations after the birth of their child.

There is no presumption in law that people with intellectual disability are not fit to be parents. To the contrary, the *Children and Young Persons (Care and Protection Act) 1998* (NSW), being the legislation governing child protection in New South

Wales, specifically states that a parent's or primary care-giver's disability alone is not a ground for making an order that a child is in need of care and protection.[23]

IDRS acknowledges that the removal of children from parents is sometimes necessary to ensure the health, safety and well-being of the children. However, we are concerned at the trends around child removal from parents with intellectual disability. Parents with intellectual disability make up less than 1% of the parenting population, yet approximately 10% of cases before the NSW Children's Court.[24] Through our work, and the research in this area, it is clear that this trend largely reflects the prejudicial view that people with intellectual disability are incapable of parenting.

This view is contrary to research around parents with intellectual disability which demonstrates that there is a general consensus that IQ score is a poor predictor of parenting adequacy.[25] Many people with intellectual disability can and do parent effectively particularly when they have adequate preparation for parenting, access to appropriate supports and the backing of family and friends.[26] The problem for parents with intellectual disability is overcoming the presumption of incapacity they face at every turn[27].

Sterilisation fails to acknowledge the reproductive rights and parenting ability of people with intellectual disability. It does not allow for investment in preparing people with intellectual disability for parenting or for investment in support systems to assist parents

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[23] Children and Young Persons (Care and Protection Act) 1998 (NSW) s.71(2)(a)

[24] David McConnell, Gwynnyth Llewellyn, Louisa Ferronato 'Parents with a disability and The NSW Children's Court (2000), University of Sydney.

[25] David McConnell, Gwynnyth Llewellyn, 'Stereotypes, Parents with intellectual disability and Child Protection. (2002) 24(3) Journal of Social Welfare and Family Law. 297-317

[26] S McGaw, T Scully, & C Pritchard, Predicting the unpredictable? Identifying high-risk versus low-risk parents with intellectual disabilities. (2010) 34 Child Abuse & Neglect, 699-710; C McGaha, Development of Parenting Skills in Individuals with Intellectual Impairment: An Epigenetic Explanation. (2002) 17:1 Disaiblity & Society , 81-91

[27] Llewellyn, G., & McConnell, D. (2005). You have to prove yourself all the time: People with learning disabilities as parents. In G. Grant, P. Goward, M. Richardson & P. Ramcharan (Eds.), *Learning Disability: A life cycle approach to valuing people*. (pp. 441-467). New York: Open University Press.

with intellectual disability. As for result, the ability of people with intellectual disability to parent becomes diminished, child removal from parents with intellectual disability becomes a self-fulfilling prophecy and the argument becomes strengthened for the non-therapeutic sterilisation of people with intellectual disability to prevent pregnancy.

This can be directly contrasted to the approach taken to other families identified as 'vulnerable' or 'at risk'. 'At risk families' are commonly those that experience domestic violence, or where the mother is very young or has mental health, drug or alcohol issues. For these families, we begin by acknowledging their parenting capacity and investing in specialist support services to support them in their parenting role. Only where these systems fail do we resort to removing the children from their parents' care.

Involuntary or coerced non-therapeutic sterilisation should not be a substitute for the provision of adequate services and support for people with intellectual disability who are, or may become, parents.

Case Study

When Kay found out she was pregnant she went to Community Services to ask what she would need to do to keep this child. Kay had four other children each removed from her soon after birth.

Kay was told that they would removed this baby at birth and she should consider having a termination. Kay contacted IDRS for legal advice and support. IDRS contacted the Community Services Case Manager to request a meeting. The Manager replied by email "We can meet but it will not change our view … I am concerned about the time factor here if Kay is to still have an option of termination."

Kay decided not to terminate the pregnancy. She was in her second trimester and working hard to be as ready to prove she was capable of caring for this baby. She had approached services and was attending programs. One day Kay rang IDRS buoyed following a phone

conversation with the manager at Community Services. The conversation went as follows "It's looking more positive …[the manager] can see I'm doing good. She said if I have a tubal ligation at the time bub is born they would consider letting her "keep this one".

5. Terms of Reference (f): Australia's compliance with its international obligations as they apply to sterilisation of people with disabilities

Involuntary or coerced non-therapeutic sterilisation is a breach of a number of international treaties listed below. Australia is a party to these treaties and therefore under international obligation to prohibit these practices.

5.1. UN Convention on the Rights of Persons with Disabilities

Australia signed the UN Convention on the Rights of Persons with Disabilities (UNCRPD) on 30 March 2007 and ratified it on 17 July 2008. The UNCRPD aims to protect the rights and dignity of people with disabilities.

There is no Article of the UNCRPD that specifically addresses sterilisation. However, the involuntary or coerced sterilisation of people with disabilities would be a breach of the following Articles of the UNCRPD:

Article 23, Respect for home and the family, obliges state parties to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships.

Article 23 reinforces the right of people with disabilities to found and maintain a family, decide freely and responsibly on the number and spacing of children, access reproductive

and family planning education and retain fertility on an equal basis with others.

Article 1 sets out the purpose of the UNCRPD, being to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Article 3 General principles, respect for inherent dignity, individual autonomy including the freedom to make one's own choices, non-discrimination, full and effective participation and inclusion in society and respect for the evolving capacities of children with disabilities.

Article 4 General obligation, promotes the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability.

Article 5 Equality and non-discrimination, recognises that all people are equal before the law and are entitled without any discrimination to equal protection, and equal benefit of the law.

Article 6 Women with disabilities, recognises that women and girls with disabilities are subject to multiple discrimination and that States should take measures to ensure full development and empowerment of women and full and equal enjoyment by women of all human rights and fundamental freedoms.

Article 7 Children with disabilities, requires State parties to take measures to ensure that children with disabilities have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children.

Article 12 Equal recognition before the law, reaffirms the right of persons with disabilities to recognition everywhere as persons before the law, to enjoy legal capacity on an equal basis with others and to have access to the support required to exercise legal capacity.

Article 17 Protecting the integrity of the person, recognises that every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others

Article 25 Health, recognises that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.

5.2. Convention on the Rights of the Child

Australia signed the Convention on the Rights of the Child (CROC) on 22 August 1990 and ratified it on 19 December 1990. CROC sets out the basic rights of children.

CROC is relevant to the discussion on non-therapeutic sterilisation as this practice is commonly sought when women with disabilities are under 18, and menstruation and contraception first become an issue.

Article 2 states that children with disabilities should enjoy the rights set out in CROC on an equal basis with others.

Article 6 sets out the rights of the child to life and development.

Article 19 provides children with protection from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation including sexual abuse.

Article 23 specifically concerns children with disabilities and states that children with disabilities should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and allow the child to actively participate in the community.

The Committee on the Rights of the Child (CRC) has identified forced sterilisation of girls with disabilities as a form of violence.[28] The CRC noted that State parties to CROC are expected to prohibit by law the forced steril isation of children with disabilities, stating:

"*the Committee is deeply concerned about the prevailing practice of forced sterilisation of children with disabilities, particularly girls with disabilities. This practice, which still exists, seriously violates the right of the child to her or his physical integrity and results in adverse life-long physical and mental health effects. Therefore, the Committee urges States parties to prohibit by law the forced sterilisation of children on grounds of disability*." [29]

The CRC has also explained that the principle of the "best interests of the child" cannot be used to justify practices which conflict with the child's human dignity and right to physical integrity.[30]

5.3. International Covenant on Economic, Social and Cultural Rights

The International Covenant on Economic, Social and Cultural Rights (ICESCR) aims to ensure the protection of economic, social and cultural rights.

Australia signed the ICESCR on 18 December 1972 and ratified it on 10 December 1975.

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[28] UN Committee on the Rights of the Child (CRCCommittee), General comment No. 13 (2011): Article 19: The right of the child to freedom from all forms of violence, 17 February 2011, CRC/C/GC/13 [paras.16, 21]. Set out in HRW paper on sterilisation of women and girls with disabilities.

[29] Human Rights Watch, Sterilization of Women and Girls with Disabilities, November 2011 <http://www.hrw.org/news/2011/11/10/sterilization-women-and-girls-disabilities> Human Rights Watch.

[30] CRC Committee General Comment No. 13[at para.61] states: "The Committee emphasizes that the interpretation of a child's best interests must be consistent with the whole Convention, including the obligation to protect children from all forms of violence. It cannot be used to justify practices, including corporal punishment and other forms of cruel or degrading punishment, which conflict with the child's human dignity and right to physical integrity. An adult's judgment of a child's best interests cannot override the obligation to respect all the child's rights under the Convention." Set out in HRW paper on sterilisation of women and girls with disabilities.

Article 10 concerns the right to family life and requires State Parties to provide protection and assistance to the family.

The UN Committee on Economic, Social and Cultural Rights stated,
"Women with disabilities also have the right to protection and support in relation to motherhood and pregnancy. As the Standard Rules state, persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood … Both the sterilization of, and the performance of an abortion on, a woman with disabilities without her prior informed consent are serious violations of article 10 (2)."[31]

5.4. International Covenant on Civil and Political Rights

The International Covenant on Civil and Political Rights (ICCPR) commits State Parties to respect the civil and political rights of individuals.

Australia signed the ICCPR on 18 December 1972 and ratified it on 13 August 1980.

Article 7 prohibits torture, cruel, inhuman or degrading treatment.

Article 17 prohibits unlawful interference with rights and family.

Article 24 provides special protection for children.

The Committee Against Torture has recommended that States take urgent measures to investigate promptly, impartially, thoroughly and effectively all allegations of involuntary

[31] Human Rights Watch above 29.

sterilisation of women, prosecute and punish the perpetrators, and provide the victims with fair and adequate compensation.[32]

5.5. Women's Human Rights Instruments

Australia signed the Convention on the Elimimation of Discrimination against Women (CEDAW) on 17 July 1980 and ratified it on 28 July 1983.

Article 16 of CEDAW concerns the rights to family life. As part of eliminating discrimination against women, Article 16 states that women should have the right to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.

The Committee on the Elimination of Discrimination against Women has considered forced sterilisation a violation of a woman's right to informed consent, infringing on her right to human dignity and physical and mental integrity.[33] The Committee has clarified that except where there is a serious threat to life or health, the practice of sterilisation of girls, regardless of whether they have a disability, and of adult women with disabilities in the absence of their fully informed and free consent, should be prohibited by law.[34]

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[32] UN Committee Against Torture (CAT Committee), *Concluding Observations*: Slovakia, para 14, U.N. Doc. CAT/C/SVK/CO/2(2009); Czech Republic, para 6(n), U.N. Doc.CAT/C/CR/32/2.

[33] Committee on the Elimination of Discrimination Against Women (CEDAWCommittee) (1999), *General recommendation No. 24: Article 12 of the Convention(women and health),*A/54/38/Rev.1, chap. I;[para.22]. HRW paper.

[34] CEDAW Committee(2010) *Concluding observations of the Committee on the Elimination of Discrimination Against Women: Australia.*CEDAW Forty-sixth session, 12 – 30 July 2010. CEDAW/C/AUS/CO/7. See: http://www2.ohchr.org/english/bodies/cedaw/cedaws46.htm..

The United Nations Special Rapporteur on violence against women has asserted that forced sterilisation is a method of medical control of a woman's fertility. It violates a woman's physical integrity and security and constitutes violence against women.[35]

The United Nations Special Rapporteur on torture has emphasised that forced sterilisation of women with disabilities may constitute torture or cruel or inhuman treatment, and that forced sterilisation constitutes a crime against humanity when committed as part of a widespread or systematic attack directed against any civilian population.[36]

The *Beijing Declaration and Platform for Action (BPA)* identifies forced sterilisation as an act of violence and reaffirms the rights of women, including women with disabilities, to found and maintain a family, to attain the highest standard of sexual and reproductive health, and to make decisions concerning reproduction free from discrimination, coercion, and violence.[37]

5.6. Universal Periodic Review Recommendations

Australia received a range of recommendations from a number of countries during its first Universal Periodic Review in 2011, that Australia review its policy and legislative provisions with regard to forced sterilisation.[38]

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[35] Radhika Coomaraswamy (1999), *Report of the SpecialRapporteur on Violence Against Women, its Causesand Consequences: Policies and practices that impactwomen's reproductive rights and contribute to, cause orconstitute violence against women*, (55th Sess.), E/CN.4/1999/68/Add.4 (1999), [para.51].

[36] UN Human Rights Council, *Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development: Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, Manfred Nowak, 15 January 2008, A/HRC/7/3,[paras.38, 39].

[37] United Nations, *The Beijing Declaration and the Platform for Action:* Fourth World Conference on Women, Beijing, China, 4-15 September 1995; A/CONF.177/20/Add.1.[paras. 95-96].

[38] United Nations, *Universal Periodic Review – Australia*, 27 January 2012 <http://www.ohchr.org/EN/HRBodies/UPR/PAGES/AUSession10.aspx>,United Nations Office of the High Commissioner for Human Rights.

6. Terms of Reference (g): The Factors that Lead to Sterilisation Procedures Being Sought by Others

Presently, people with intellectual disabilities find it difficult to gain access to reproductive information and know about their rights and be fully informed. This lack of education impacts, in a real way, the ability for people with disabilities to provide informed consent in relation to any medical procedure regarding their contraceptive health.

For example, whilst there are Family Planning Organisations in each State and Territory offering reproductive and sexual health education services, in the experience of IDRS and its clients, these services lack the experience of specialist skill in providing information to parents with intellectual disabilities in an accessible and targeted format.

6.1.Programs to Support People with Disability

IDRS notes the importance and availability and effectiveness of services and programs to support people with disabilities in managing their reproductive and sexual health needs. Article 23 of the Convention on Rights of People with Disabilities reinforces the right of people with disabilities to found and maintain a family, decide freely and responsibly on the number and spacing of children, access reproductive and family planning education and retain fertility on an equal basis with others.

It is difficult for people with intellectual disabilities to find any service relating to sexual and reproductive health issues, including:

- Sexual health and reproductive health education services;
- Specialist counselling services relating to sexual health issues; and
- Counselling around decisions relating to parenting and the consequences of

having children.

IDRS considers that measures currently in place to ensure that education around these areas are available and appropriate are presently inadequate.

In IDRS' experience, where women with intellectual disability possess the capacity to make informed contraceptive choices, it seems that too often, contraceptive options are not being clearly explained to them. UK research has shown that of women with intellectual disabilities who participated in the research, few felt they had been given information appropriate to their needs.[39]

Further overseas research found that doctors of women with intellectual disability rarely discussed contraception prescriptions with them. [40] One third of women in did not know anything about any contraception other than what they had used themselves. Most others knew only of the pill and Depo-Provera, another long term contraceptive device. Most women were unaware of how contraception worked, and half lacked basic knowledge about reproduction. This was despite the predominately mild level of their intellectual disabilities.

6.1.1. Recommendation

That funding be provided for education strategies, campaigns and programs be put in place to develop targeted programs for people with intellectual disabilities about:

- their reproductive and sexual health rights,;
- contraception options and specifically the impact of long term contraception; and
- the impact of measures such as surgical sterilisation options.

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[39] Michelle McCarthy, 'Prescribing Contraception to women with intellectual disabilities: GPs attitudes and practices' (2011) 29(4) *Sexuality and Disability*, 339.

[40] HM Van Schrojenstein Lantman-de Valk, F Rook and MA Maaskant, 'The use of contraception by women with intellectual disabilities' (2011) 55(4), *Journal of Intellectual Disability Research,* 434.

6.2. Educational Resources for the Community and Professionals on the Impact of Sterilisation

Too often the issues around sexual health and reproductive rights are not openly discussed when it comes to people with intellectual disabilities. The issues are never spoken about and carers and family members often are unsure how to raise these very sensitive and delicate issues.

IDRS contends that there is a lack of educations resources available for professionals on the impact of sterilisation, and long term contraceptive devices.

It is important that doctors, including general practitioners, are adequately trained and resourced to provide information to clients with intellectual disabilities. Further, it is imperative that doctors attempt to seek consent from the patient directly and not just the carers.

IDRS considers that there is limited understanding in the medical community, especially among doctors, of the support services that can assist people with intellectual disabilities with respect of their reproductive rights and sexual health.

Case Study:

Julie was to have her baby delivered by caesarean section the Obstetrician proposed she have her tubes tied at the same time. The registrar was left to organise the consent forms for surgery. The registrar was concerned that Julie was unable to give medical consent due to her cognitive impairment. The registrar discussed her concerns about the mother's capacity to give informed medical consent with the Obstetrician and questioned whether they should apply to the NSW Guardianship Tribunal. The Obstetrician response was "Don't complicate it …consider that we will be doing a community service!"

6.2.1. Recommendation

That each sexual and reproductive health service providers be required to show that they have appropriate knowledge and skills to be able to provide reproductive information to people with disabilities.

6.2.2. Recommendation

That all members of the wider community including nurses, doctors, advocates and parents be provided with information on how best to discuss issues around reproductive and sexual rights with people with disabilities.

6.3. Recommendation

That training be provided to supported accommodation workers in relation to sexual rights of people with disabilities.

7. Terms of Reference (h): Any other related matter

Whilst surgical sterilisation is the major focus of this inquiry, IDRS is aware that long-term contraceptive devices are frequently administered to people with intellectual disability. Whilst access to these long term contraceptive devices should be available to people with disability in the same way as any other person, it is important to recognise that the misuse of such contraceptive devices may have the same impact of surgical sterilisation if a person with a disability is permanently kept on the device.

7.1. Long term contraceptive devices

There are a range of long term contraceptive devices presently used and include:

- Depot injections (such as Depo-Provera) are given every 3 months. They work by preventing ovulation.;

- Contraceptive implants (such as Implanon) are inserted under the skin on the inside of the upper arm. They work by releasing progesterone which prevents ovulation. They work for three years (though can be removed at any time), after which they must be removed and can be replaced if desired.
- An IUS (such as Mirena) is placed in the uterus and releases progesterone which changes the cervical mucus, preventing fertilisation and implantation. It also makes menstruation lighter, shorter and prevents period pain. It can remain in place for up to five years.
- A 'copper IUD' (such as ParaGard) is also placed in the uterus, but does not release hormones. Most types last for five years, though some can last for ten. They can make periods heavier, last longer, and increase period pain.

IDRS supports the right for all persons to access such important long-term contraceptive devices. These devices provide a relatively easy, non-invasive and reversible alternative for managing menstruation and controlling reproductive health.

IDRS is however concerned that if not properly regulated long-term contraceptive devices may be used as 'de facto sterilisation'. This may occur where carers place individuals who are unable to provide consent on such devices and keep them on such devices for no other reason than an attempt to prevent pregnancy.

This 'just in case' rationale is akin to some of the reasons carers historically have sought sterilisation procedures for those they have cared for. This "just in case" mentality fails to take into account the side-effects of many forms of contraception. Depo-Provera injections, for example, increase a person's risk of osteoporosis. They are particularly damaging when used in adolescence, a time when bone density is ordinarily gained. It is of interest to note that only 3% of the general population chooses to use Depo-Provera, while it made up

34.2% of contraception used by those with intellectual disability in certain research studies.[41]

Presently the Commonwealth has no regulatory power over the use of long term contraceptive devices and it is essentially a State and Territory issue. In New South Wales, the use of these contraceptive devices can be consented to by a 'person responsible', which in most cases is the person's unpaid carer.[42] Given the long-term nature of these devices and current evidence pointing to their overuse, the consent of a 'person responsible' may not provide adequate protection to those who cannot consent themselves.

IDRS recommends that there be some level of oversight by an independent decision maker, such as Court or Tribunal, in situations where an individual is unable to provide consent and has been placed on a long-term contraceptive device.

8. Conclusion and Recommendations Summary

IDRS recommends:

1. That the Commonwealth enact legislation to prohibit sterilisation of all people, without a person's prior free and informed consent, except in circumstances where there is a fundamental or serious risk to the life or health and the individual is unable to provide consent. In those situations sterilisation should only be authorised by a competent decision maker in line with relevant legislation.

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[41] See Michelle McCarthy, 'Contraception and Women With Intellectual Disabilities' (2009) 22 *Journal of Applied Research in Intellectual Disabilities,* 339.

[42] Generally, the person responsible is the person's guardian appointed under an instrument or other Order. In situations where there is no appointed guardian, it may also include one's spouse, a friend, or other person who has close care of the person. Further, the person responsible may also be the Minister or Director General of the Department of Family and Community Services in the case of children who are in care. See *Guardianship Act 1987* s.33A.

2. That Tribunals, Courts and other bodies given the power to authorise sterilisations, consistently report on the nature of all sterilisation applications.
3. The Commonwealth Government propose a consistent legislative scheme with respect to sterilisation where consent cannot be provided. Such a scheme should regulate that sterilisation is not be performed unless the relevant decision maker is satisfied that the treatment is necessary to save the patient's life, or to prevent serious damage to the patient's health.
4. The issue of nationally consistent legislation regarding the issue of sterilisation as raised above is raised at the Standing Council on Law and Justice (SCLJ) and other relevant intergovernmental meetings to discuss the implementation of law reform.
5. That funding be provided for education strategies, campaigns and programs be put in place to develop targeted programs for people with intellectual disabilities about:
   - their reproductive and sexual health rights,;
   - contraception options and specifically the impact of long term contraception; and
   - the impact of measures such as surgical sterilisation options.
6. That each sexual and reproductive health service providers be required to show that they have appropriate knowledge and skills to be able to provide reproductive information to people with disabilities.
7. That all members of the wider community including nurses, doctors, advocates and parents be provided with information on how best to discuss issues around reproductive and sexual rights with people with disabilities.
8. That training be provided to supported accommodation workers in relation to sexual rights of people with disabilities.

If you wish to discuss any of the comments in this submission, please do not hesitate to contact Janene Cootes or Margaret Spencer

Please note we are willing to give evidence at a public hearing.

Yours sincerely,