



“The Sterilisation of Women and Girls with Disabilities in Australia: Violating the Human Right to Health”

Paper written by Carolyn Frohmader and presented by Karin Swift on behalf of Women with Disabilities Australia (WWDA) at the 7th Australian Women’s Health Network Conference, Sydney, 8 May, 2013

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NB: This paper and accompanying Powerpoint presentation is based on WWDA’s Submission to the Senate Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia. WWDA’s Submission, entitled *‘Dehumanised: The Forced Sterilisation of Women and Girls with Disabilities in Australia’* (ISBN: 978-0-9876035-0-0) is available for download in PDF and Word versions, from the WWDA website at: <http://www.wwda.org.au/senateinquiry2012.htm>

About Women With Disabilities Australia (WWDA)

Women With Disabilities Australia (WWDA)¹ is the peak non-government organisation (NGO) for women with all types of disabilities in Australia. WWDA is run by women with disabilities, for women with disabilities, and represents more than 2 million disabled women in Australia. WWDA’s work is grounded in a rights based framework which links gender and disability issues to a full range of civil, political, economic, social and cultural rights. Promoting the reproductive rights of women and girls with disabilities, along with promoting their rights to freedom from violence and exploitation, and to freedom from torture or cruel, inhuman or degrading treatment are key policy priorities of WWDA.²

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Winner, National Violence Prevention Award 1999
Winner, Tasmanian Women’s Safety Award 2008
Certificate of Merit, Australian Crime & Violence Prevention Awards 2008
Nominee, French Republic’s Human Rights Prize 2003
Nominee, UN Millennium Peace Prize for Women 2000

¹ For more detailed information on Women With Disabilities Australia (WWDA), go to: <http://www.wwda.org.au>

² See WWDA’s *Strategic Plan 2010 – 2015* at: <http://www.wwda.org.au/stratplan.htm>

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Much has happened since an earlier version of this paper was first presented in June, 2012 when WWDA was invited to present the Keynote Address on *'Sexual and Reproductive Rights of Women and Girls with Disabilities'* at the International Women with Disabilities Conference, held in Madrid. The Conference was hosted by the Spanish Committee of Representatives of Persons with Disabilities. WWDA was invited to showcase, on the international stage, our organisations internationally lauded work in the area of the sexual and reproductive rights of women and girls with disabilities. Specifically, the Conference organisers requested that WWDA *"present the excellent and significant work you are doing in the fight against forced sterilisation and coerced abortion of women and girls with disabilities."*

Since then, the Senate Inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia has been announced and is due to report in June this year.

WWDA was instrumental in advocating for this Senate Inquiry and did much work in the lead up to, and during the period submissions were called for. As well as writing a comprehensive organisational submission to the Inquiry (on which this paper is based), WWDA also attended several Senate Inquiry Hearings and supported women with disabilities to share their lived experience on the issue. We also worked hard to support other organisations and individuals in submitting to the Inquiry, and have worked closely with the Senate Committee for the past year.

It was unfortunate that WWDA received several calls from women's organisations, including women's health organisations, who said they weren't going to put in a submission to the Inquiry as they felt this was WWDA's issue. Involuntary or coerced sterilisation is an issue that affects many women worldwide, including Roma women and other poor and marginalised women. The involuntary or coerced sterilisation of any woman, regardless of disability, is everyone's issue.

Earlier this year the United Nations declared that forced sterilisation constitutes torture. The right to be free from torture is one of the few absolute and non-derogable human rights, and

as such is binding on all States, irrespective of whether they have ratified specific treaties.³

The UN Special Rapporteur on Torture has recently clarified that:

Forced interventions [including involuntary sterilization], often wrongfully justified by theories of incapacity and therapeutic necessity inconsistent with the Convention on the Rights of Persons with Disabilities, are legitimized under national laws, and may enjoy wide public support as being in the alleged “best interest” of the person concerned. Nevertheless, to the extent that they inflict severe pain and suffering, they violate the absolute prohibition of torture and cruel, inhuman and degrading treatment.

The UN Special Rapporteur on Torture has made it clear that the failure of the State to exercise due diligence to intervene to prevent torture and provide remedies to victims of torture ‘facilitates and enables non-state actors to commit acts impermissible under [the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment] with impunity,’ and its indifference or inaction provides a form of encouragement and/or de facto permission.

The UN Committee Against Torture has also confirmed that States have a heightened obligation to protect vulnerable and/or marginalised individuals from torture and cruel inhuman and degrading treatment and to:

‘adopt effective measures to prevent public authorities and other persons acting in an official capacity from directly committing, instigating, inciting, encouraging, acquiescing in or otherwise participating or being complicit in acts of torture.’

In March this year I attended the 57th meeting of the United Nations Commission on the Status of Women, the principal global policy-making body dedicated exclusively to gender equality and advancement of women. This year’s priority theme focussed on the Elimination of all forms of violence against women and girls. We were able to advocate for some inclusive language around women and girls with disabilities in the Agreed Conclusions, a global policy document articulating principles and actions to address and prevent violence against women. We were successful in achieving two specific paragraphs on disability in the Agreed Conclusions:

This and all other references in this paper are cited from Frohmader, C, (2013) ‘Dehumanised: The forced sterilisation of women and girls with disabilities in Australia’ Submission to the Senate Inquiry into Forced and Coerced Sterilisation of People with Disabilities in Australia. WWDA, Rosny Park, Tasmania. Available online at: <http://www.wwda.org.au/senateinquiry2012.htm>

(gg) Take all appropriate legislative, administrative, social, educational and other measures to protect and promote the rights of women and girls with disabilities as they are more vulnerable to all forms of exploitation, violence and abuse, including in the workplace, educational institutions, the home, and other settings;

This paragraph is important as it makes specific mention of the fact that women and girls with disabilities are more vulnerable to violence; acknowledges the different settings women and girls with disabilities experience violence in; and that violence has a broader context than just domestic and family violence.

The next paragraph is:

(aaa) Condemn and take action to prevent violence against women and girls in health care settings, including sexual harassment, humiliation and forced medical procedures, or those conducted without informed consent, and which may be irreversible, such as forced hysterectomy, forced caesarean section, forced sterilization, forced abortion, and forced use of contraceptives, especially for particularly vulnerable and disadvantaged women and girls, such as those living with HIV, women and girls with disabilities, indigenous and afro-descendent women and girls, pregnant adolescents and young mothers, older women, and women and girls from national or ethnic minorities.

WWDA's campaign to address the issues of forced sterilisation and reproductive rights of women and girls with disabilities began more than a decade ago. For more than 12 years, WWDA has been at the forefront of what has now become a global campaign (for which WWDA has been repeatedly recognised and acknowledged) against the practice of forced and coerced sterilisation of women and girls.

This presentation today traces some of the key features of WWDA's campaign to stop the forced and coerced sterilisation of disabled women and girls in Australia.

Australia is a country that prides itself on values and principles which provide the basis for a free and democratic society, including for example: the equal worth, dignity and freedom of the individual; equality under the law; equality of opportunity; equality of men and women; and the right of its citizens to participate fully in the economic, political and social life of the nation. However, these entitlements remain a distant goal for many women and girls with disabilities. In contemporary Australia, many are denied the most fundamental rights and freedoms, they are not treated with dignity and respect, they remain profoundly more

disadvantaged than their male counterparts; are systematically denied opportunities to develop, gain an education and live a full and meaningful life. They experience multiple forms of discrimination, and widespread, serious violation of their human rights.

Viewed as "undesirable" and as potential threats to society, women with disabilities have often been isolated in institutions and otherwise prevented from fully participating in society.

The right to bodily integrity and bodily autonomy, including the right of a woman to make her own reproductive choices, are enshrined in a number of international human rights treaties and instruments to which Australia is a party. However, women and girls with disabilities in Australia have failed to be afforded, or benefit from, these provisions in international human rights law. Instead, systemic prejudice and discrimination against them continues to result in widespread denial of their right to make decisions about their own bodies, experience their sexuality, have sexual relationships, and found and maintain families.

In Australia there are women and girls with disabilities who have been and continue to be, denied these and other fundamental human rights through the ongoing Government sanctioned practice of 'forced/involuntary' and 'coerced' sterilisation.

Forced sterilisation – that is, sterilisation in the absence of the free and informed consent of the individual concerned - including instances in which sterilisation has been authorised by a third party, without that individual's consent - is an act of violence, a form of social control, and a clear and documented violation of the right to be free from torture. Forced sterilisation of girls and women with disabilities is internationally recognised as a harmful practice based on tradition, culture, religion or superstition. Perpetrators are seldom held accountable and women and girls with disabilities who have experienced this violent abuse of their rights are rarely, if ever, able to obtain justice. Successive Australian Governments have not acknowledged this pervasive practice, nor expressed regret, nor offered redress to the women and girls affected.

Forced sterilisation breaches every international human rights treaty to which Australia is a party. Legal authorisation of forced sterilisation procedures directly implicate the Australian Government in the perpetration of torture against disabled women and girls. Any law which authorises forced sterilisation is a law which authorises violence against women, the

consequence of which is severe pain and suffering, including *'drastic and emotionally painful consequences that are un-ending'*.

For more than twenty years, women with disabilities and their allies have been demanding successive Australian Governments show national leadership and undertake wide ranging reforms to stop the forced and coerced sterilisation of women and girls with disabilities, and develop policies and programs that enable disabled women and girls to realise their human rights on an equal basis as others. These recommendations to the Australian Government for action have been strongly echoed, supported and re-iterated by several international human rights treaty monitoring bodies and mechanisms since 2005. For example, In June 2012, the Committee on the Rights of the Child, in its *Concluding Observations on Australia* expressed its serious concern that the absence of legislation prohibiting non-therapeutic sterilisation of girls and women with disabilities is discriminatory and in contravention of the CRC. Furthermore, the Committee clearly identified non-therapeutic sterilisation as a form of violence against girls and women, and recommended that the Australian Government develop and enforce strict guidelines to prevent the sterilisation of women and girls who are affected by disabilities and are unable to consent.

That Australian Governments have chosen to ignore the voices of disabled women, as well as clear recommendations from the United Nations and international medical bodies, clearly demonstrates that disabled women and girls are not considered by our Governments as worthy of all that it means to be fully human.

No group has ever been as severely restricted, or negatively treated, in respect of their reproductive rights, as women with disabilities.

The practice of forced sterilisation is itself part of a broader pattern of denial of human and reproductive rights of Australian disabled women and girls which also includes systematic exclusion from appropriate reproductive health care and sexual health screening, forced contraception and/or limited contraceptive choices, a focus on menstrual suppression, poorly managed pregnancy and birth, selective or coerced abortion and the denial of rights to parenting. These practices are framed within traditional social attitudes that continue to characterise disability as a personal tragedy, a burden and/or a matter for medical management and rehabilitation.

When we examine the rationale used to justify the forced sterilisation of disabled women and girls in Australia, we find they include themes such as eugenics/genetics; for the good of the State, community or family; incapacity for parenthood; incapacity to develop and evolve; prevention of sexual abuse; and discourses around “best interest”.

The Genetic/Eugenic Argument - This line of argument is based on the fear that disabled women will re/produce children with genetic ‘defects’. For example, in 2004, the Family Court of Australia authorised the sterilisation of a 12 year old intellectually disabled girl with Tuberous sclerosis, a genetic disorder with a 50% inheritance risk factor. Although one out of two people born with tuberous sclerosis will lead ‘normal’ lives with no apparent intellectual dysfunction, the Court accepted evidence from a medical specialist that sterilisation was in the best interests of the young girl because:

“the result will be complete absence of menstruation and this will undoubtedly be of benefit to H who already appears to have substantial difficulties with cleanliness..... As a by-product of an absence of her uterus H will never become pregnant. Given the genetic nature of her disorder and the 50% inheritance risk thereof, this would in my view be of great benefit to H.”

Consider these recent alarming responses to newspaper articles on Sterilisation:

- *“.....Personally I think people with any medium level to high level disability should be completely sterilised to keep the gene pool clean.”*
- *“The severity of disability needs to be considered, as well as the genetic likelihood of the disability being passed on.”*
- *“The government shouldn't have to support unwanted babies let alone disabled children having disabled children.”*

This reasoning is clearly grounded in eugenic ideology and in the broad views that society holds of disability as a personal tragedy or a medical problem. However, there is clear evidence to indicate that the causes of impairment are overwhelmingly social and environmental (including war, poverty and environmental degradation) and only a small number are related to genetic causes.

Sterilisation is not 'a treatment of choice' for non-disabled women and girls with genetic disorders.

For the good of the state, community or family - arguments here centre on the 'burden' that disabled women and girls and their potentially disabled children place on the resources and services funded by the state and provided through the community. A related and commonly used argument, is the added burden of care that menstrual and contraceptive management places on families and carers. The 'burden' of parents having to deal with menstrual management of their disabled daughters is often used as a valid justification when Australian Courts authorise the sterilisation of disabled females - even before the onset of puberty.

In a recent case, the Family Court of Australia authorised the sterilisation of an 11 year old girl with Rett Syndrome. The application was made by the young girl's mother to prevent menstruation. No independent children's lawyer was appointed to advocate for the girl, as the judge determined it would be of 'no benefit'. In accepting "*without hesitation*" the evidence of Dr T, an Obstetrician and Gynaecologist, the judge said:

"Undoubtedly and certainly of significant relevance is that there are hygiene issues which must fall to the responsibility of her mother because Angela cannot provide for herself..... the operation would certainly be a social improvement for Angela's mother which in itself must improve the quality of Angela's life."

'Bad and unruly behaviour' associated with menstruation is another dimension in applications for, and authorisations of sterilisation of young disabled girls and women:

"Dr Py. records that "staff" at the ward in which Sarah resides, have told him that she becomes a problem during her menstrual period as she has no concept of personal care, cleanliness or propriety."

Sterilisation is not 'a treatment of choice' for non-disabled females who are approaching menstruation, who menstruate, or who experience menstrual problems.

Incapacity for parenthood – Widely held societal attitudes that disabled women cannot be effective parents mean there is pressure to prevent pregnancy in disabled women, particularly women with intellectual disabilities. The label of intellectual disability per se is mistakenly taken for prima facie evidence of likely parental incapacity or risk of harm to the

child. Such incapacity is automatically deemed to be an irremediable deficiency in the parent such that it cannot be overcome.

My son was removed from my care when he was born by the department of child safety. They hadn't assessed my abilities as a parent nor did they tell me they were going to take away my son before I gave birth. They didn't trust me and said that they wanted to prevent me from harming my baby, even when I had done nothing wrong. No support has ever been provided to help me be a parent of my son. We got an independent assessment done and it showed that even though I have a mild intellectual impairment, my behavioural functioning is normal. Even now, I only see him every Friday and he stays overnight once a fortnight."

There is ample evidence that many women with disabilities successfully parent happy children within our communities. There is no clear relationship between competence or intelligence and good parenting – in fact, more than six decades of research has demonstrated that intellectual disability per se is an unreliable predictor of parenting performance.

Incapacity to Evolve - The determination of capacity is inextricably linked to the exercise of the right to autonomy and self-determination. To make a finding of incapacity results in the restriction of one of the most fundamental rights enshrined in law, the right to autonomy. Millions of people with disabilities are stripped of their legal capacity worldwide, due to stigma and discrimination, through judicial declaration of incompetency or merely by a doctor's decision that the person "lacks capacity" to make a decision. Deprived of legal capacity, people are assigned a guardian or other substitute decision maker, whose consent is deemed sufficient to justify forced treatment.

Incapacity is often used as a valid justification for Court authorisation of sterilisation of disabled females. Incapacity in this context, is considered to be a fixed state, with no consideration given to the possibility of capacity evolving over time:

"Those who are severely intellectually disabled remain so for the rest of their lives".

"There is no prospect that will ever show any improvement in her already severely retarded mental state."

Views such as these fail to acknowledge the fact that 'incapacity' can very often be a function of the environment and a lack of support for the individual concerned. Research has shown

that information, experience, environment, social and cultural expectations, and levels of support can dramatically impact the development of a disabled persons capacity to form a view.

Prevention of sexual abuse - Sterilisation has been said to protect a woman from sexual abuse and the consequences of abuse. Indeed, vulnerability to sexual abuse is a major theme in many of the applications seeking court authorisation for sterilisation of disabled women and girls in Australia. 'Inappropriate' behaviour, and 'good looks' are considered major determinants of sexual activity or abuse.

For example, in the case of Re Katie, prevention of sexual abuse was part of the rationale for the authorisation of Katie being sterilised at the aged of 16:

"It is highly unlikely that Katie will ever have the capacity to understand and voluntarily enter into a sexual relationship..... It is however well documented that disabled children are particularly vulnerable to sexual abuse and Katie is quite an attractive girl."

Similarly, in a case where the Court authorised the sterilisation of a 14 year old girl prior to the onset of menstruation, the judge stated:

"it is unlikely she will have any form of relationship involving sexual intercourse. She could, of course, be the victim of a sexual assault and with her normal physical development and attractive looks that cannot be discounted."

In yet another case, the child's 'behaviour' with men was a consideration in authorising her sterilisation:

"Ever since Elizabeth was a very young child, she was prone to run to men. If her mother takes her out she will go to any man, including strangers. On many occasions in public when the mother has not been holding Elizabeth tightly, she has run over to a man who is a complete stranger and taken his arm. She shows no fear and would happily go off with any man. She has to be physically restrained from chasing after men in public and throwing her arms around them."

Research has demonstrated that rather than protecting against sexual abuse, forced sterilisation can increase vulnerability to sexual abuse.

As highlighted earlier, the reasons used to justify forced sterilisations are often couched in the language of being in the “best interests” of the disabled female.

Successive Australian Governments have continued to use the ‘best interest’ argument to justify the torture of women and girls with disabilities by forced sterilisation, asserting that sterilisation is only ever carried out as a ‘last resort’ and when it is in the girl or woman’s ‘best interests’.

The best interest approach has, in effect, been used to perpetuate discriminatory attitudes against women and girls with disabilities, and has only served to facilitate the practice of forced sterilisation. When analysing the applications to Courts and Tribunals for sterilisation of disabled women and girls in Australia to date, it is clear that the best interest approach has in reality, very little to do with the young girl or woman, and more to do with the ‘best interests’ of others, particularly families and caregivers. As can be seen in these examples:

- *“The interests of Katie are inextricably linked with the ability of her parents to cope with the burdens of Katie's care.”*
- *“The operation would certainly be a social improvement for Angela's mother which in itself must improve the quality of Angela's life.”*
- *“Not only would S be unable to care appropriately for herself it would also be difficult for others to care for her as a result of menstruation.”*

The UN *Committee on the Rights of the Child* (CRC) has made it clear 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. The UN Special Rapporteur on Torture has also made it clear that ‘best interest’ and ‘medical necessity’ are no justification for forced/involuntary sterilisation of disabled women and girls.

The impact of forced sterilisation on women and girls with disabilities reaffirms that forced and coerced sterilisation has long-lasting physical, psychological and social effects and causes severe mental pain and suffering, extreme psychological trauma, including depression and grief. It also demonstrates that for women with disabilities, the issue of forced sterilisation encompasses much broader issues of reproductive health, including for example: support for choices and services in menstrual management, contraception, abortion, sexual health

management and screening, pregnancy, birth, parenting, menopause, sexuality, violence and sexual assault prevention and more.

Crucially, the voices of the women and girls with disabilities who have been the subject of Court and Tribunal applications, judgements, laws and debates, have not been heard.

It is through organisations such as WWDA, that women with disabilities have been afforded the right and the opportunity to speak their history and have their voices heard. And in stark contrast to the views of medical specialists and judges, the women have spoken about the long-term negative social and psychological impact and effects of being sterilised. They have spoken about sterilisation as a life sentence, as loss and betrayal, and as a violation of their right to choose what happens to their bodies.

"It has resulted in loss of my identity as a woman, as a sexual being."

"I haven't had the chance to grieve the loss of a part of me that should have been mine to choose whether I keep it or not".

"I feel upset because I can't have children. I feel I should have been able to make the decision."

"I worry about the future health effects like osteoporosis and other problems."

"I have been denied the same joys and aspirations as other women."

"I was sterilised at the age of 18 without my consent. I still feel devastated by what happened because I will never be able to have children."

"After trying to have a baby for a long time I finally found out I had been sterilised when I was 14 living in an institution."

"For me it is about living with loss."

"The psychological effects are huge – it takes away your feelings of womanhood."

The voices and stories of women with disabilities who have been sterilised and experienced other violations of their reproductive rights, carry the message that we must listen to women and learn from them so that healing can take place for those already affected and safeguards can be put in place to prevent others being denied their human rights.

Forced sterilisation is a violation of human rights and the practice contravenes every international human rights treaty to which Australia is a party. In examining human rights treaty monitoring bodies responses to the practice of forced sterilisation around the world it is clear that Australia's apathy and indifference to the issue sees it lagging behind the rest of the developed world, at the expense of the human rights of disabled women and girls.

The Australian Government is obliged to exercise due diligence to: prevent the practice of forced and coerced sterilisation from taking place; investigate promptly, impartially and effectively all cases of forced sterilisation of women and girls with disabilities; remove any time limits for filing complaints; prosecute and punish the perpetrators, and, provide adequate redress to all victims of forced or coerced sterilisation. Nothing less is acceptable.

Given the magnitude of the issue of forced sterilisation of women and girls with disabilities, there is a wide-ranging and extensive raft of actions required to address the breadth and scope of issues involved. I will now touch on just some of the key recommendations WWDA has made to the Australian Government, through the current Senate Inquiry, whilst acknowledging that much more intensive work is required. Underpinning all WWDA's recommendations is the principle that women and girls with disabilities must be at the forefront of any and all consultative and decision-making processes.

- Enact national legislation prohibiting, except where there is a serious threat to life, the use of sterilisation of girls, regardless of whether they have a disability, and of adult women with disabilities in the absence of their fully informed and free consent.
- Establish and adequately resource a National Task Force to develop a Policy and Framework for Transitional Justice and Redress to address the forced and coerced sterilisation of women and girls with disabilities in Australia.
- Develop specific measures of rehabilitation and recovery in consultation with those affected;
- Issue a formal apology that identifies the discriminatory actions, policies, culture and attitudes that result in forced and coerced sterilisation of people with disabilities

- Provide financial reparation to women and girls with disabilities who have been forcibly sterilised.
- Undertake legislative reforms to replace regimes of substitute decision making for people with disabilities with supported decision-making
- Commission and fund a three year national research study on women and girls with disabilities' right to reproductive freedom
- Recognise, support and strengthen the role of women with disabilities organisations, groups and networks in efforts to fulfil, respect, protect and promote their human rights, and to support and empower women with disabilities, both individually and collectively, to claim their rights.

WWDA's campaign is yielding results, with the issue now receiving international attention, intervention and action from the machinery of the United Nations, other NGO's, advocates, the media, researchers and politicians. Importantly, it is also empowering more women to come forward, to speak out about their experiences, to gain strength, to recognise their own needs for personal autonomy, and perhaps most importantly, develop a sense of personal worth.

The forced sterilisation of disabled women and girls is a grave violation of human rights and medical ethics. This paper has made it clear that, for disabled women and girls, forced and coerced sterilisation encompasses much broader issues of sexual and reproductive health, including for example: support for choices and services in menstrual management, contraception, abortion, sexual health management and screening, pregnancy, birth, parenting, menopause, sexuality, violence and sexual assault prevention and more.

Addressing these issues is not just the responsibility of WWDA, or the disability sector. The women's health movement has an equal responsibility to actively work with disabled women in addressing and preventing violations of their sexual and reproductive health rights.

This is consistent with the objectives of the women's health movement, which include, for example:

- promoting a social view of women's health

- providing support for women to participate in all decision making which affects health and wellbeing
- working towards securing women's control over and responsibility for their own sexual health and reproduction
- promoting equitable access to services for all women, including women with disabilities.

We therefore encourage the women's health movement to recognise the immense harm done to disabled women and girls who have been forcibly sterilised and experienced other violations of their reproductive rights, and work collaboratively with us to not only demand redress and justice for all those affected, but also to take all measures necessary, including focused, gender-specific measures, to ensure that disabled women and girls experience full and effective enjoyment of all their human rights on an equal basis as others.

Thank you.