



'Moving Forward and Gaining Ground: The Sterilisation of Women and Girls with Disabilities in Australia'

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Women With Disabilities Australia (WWDA)*

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Introduction

*Bella is 34 years old. Without her knowledge or consent, she became the victim of forced sterilisation at the age of 12 when her parents took her to hospital for what they told her was an operation to have her appendix removed. Nine years later, during a routine pelvic examination, Bella was told it was her uterus, not her appendix that had been removed. Thirteen years on from her discovery, Bella's grief and anger are still raw. The trust she had in her parents and hospital staff, she explains, was violated. "If they'd told the truth and asked me, I would have shouted 'No!'" "My sterilisation makes me feel I'm less of a woman when I have sex because I'm not normal down there," says Bella. "When I see other mums holding their babies, I look away and cry because I won't ever know that happiness."*¹

It was stories like Bella's that initiated, more than a decade ago, Women With Disabilities Australia's campaign to address the issues of forced sterilisation and reproductive rights of women and girls with disabilities.

Women With Disabilities Australia, known widely by our acronym 'WWDA', is the national peak body representing more than 2 million women and girls with disabilities in Australia. Our work is grounded in a human rights framework, which links gender and disability issues to a full range of civil, political, economic, social and cultural rights. Promoting the rights of women with disabilities to freedom from violence, exploitation and abuse and to freedom from torture or cruel, inhuman or degrading treatment are key policy priorities of our organisation.

For more than a decade, WWDA has been at the forefront of what is now becoming a global campaign against the practice of forced sterilisation of women and girls. Our long-standing, unwavering campaign to stop the forced sterilisation of disabled women and girls and promote their sexual and reproductive rights, is starting to yield 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.

This paper traces some of the key features of WWDA's campaign over more than a decade to stop the forced and coerced sterilisation of disabled women and girls in Australia. It discusses some of the critical issues in the consideration of forced sterilisation as a human rights issue, and looks at some of the key strategies

¹ Osfield, S. (2012) 'This girl has special needs and one day dreams of being a mum. Does anyone have the right to stop her having a baby?' In *marie claire* magazine, June 2012.

WWDA has employed to advance our efforts to promote the sexual and reproductive rights of disabled women and girls, on an equal basis with other women and girls.

What do we mean when we talk about forced sterilisation of disabled women and girls?

Systemic prejudice and discrimination against women and girls with disabilities continues to result in widespread denial of their right to experience their sexuality, to have sexual relationships and to found and maintain families. The right to bodily integrity and the right of a woman to make her own reproductive choices are enshrined in a number of international human rights treaties and instruments.² However, throughout the world, an alarming number of women and girls with disabilities have been, and continue to be, denied these rights through the practice of forced and coerced sterilization.³

Forced sterilisation refers to medical procedures which permanently remove an individual's ability to reproduce.⁴ It occurs when a person is sterilised after expressly refusing the procedure, without her knowledge or is not given an opportunity to provide consent. Coerced sterilisation occurs when financial or other incentives, misinformation, or intimidation tactics are used to compel an individual to undergo the procedure. Women and girls with disabilities are particularly vulnerable to forced sterilisations performed under the auspices of legitimate medical care or the consent of others in their name.⁵ The forced sterilisation of disabled women and girls is an act of unnecessary and dehumanising violence,⁶ a form of social control, and a violation of the right to be free from torture and other cruel, inhuman or degrading treatment or

² See for example: UN General Assembly, *Convention on the Rights of Persons with Disabilities*, 24 January 2007, A/RES/61/106, [Art.23]; UN General Assembly, *International Covenant on Civil and Political Rights*, 16 December 1966, 2200A (XXI), [Art.7, 17]; UN General Assembly, *International Covenant on Economic, Social and Cultural Rights*, 16 December 1966, 2200A (XXI), [Art.10]; UN General Assembly, *Convention on the Elimination of All Forms of Discrimination Against Women*, 18 December 1979, 34/180, [Art.16]; 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.94-96].

³ See for example: Brady, S., Briton, J., & Grover, S. (2001) *The Sterilisation of Girls and Young Women in Australia: Issues and Progress*. A report commissioned by the Federal Sex Discrimination Commissioner and the Disability Discrimination Commissioner; Human Rights and Equal Opportunity Commission, Sydney, Australia. Available online at: www.wwda.org.au/brady2001.htm; Brady, S. (2001) *The sterilisation of girls and young women with intellectual disabilities in Australia: An audit of Family Court and Guardianship Tribunal cases between 1992-1998*. Available online at: www.wwda.org.au/brady2001.htm; Ana Peláez Narváez, Beatriz Martínez Ríos, and Mercé Leonhardt Gallego, *Maternidad y Discapacidad* [available in Spanish] (Comité Representante de Personas con Discapacidad, Barclays Fundación, Ediciones Cinca, 2009), p.65; Human Rights Watch interview with Dr. Lalitha Joshi, gynecologist and President of the Down's Syndrome Association, Kathmandu, Nepal, March 30, 2011; Human Rights Watch (2011), *Futures Stolen: Barriers to Education for Children with Disabilities in Nepal*. Available online at: <http://www.hrw.org/reports/2011/08/24/futures-stolen>.

⁴ Dowse, L. (2004) 'Moving Forward or Losing Ground? The Sterilisation of Women and Girls with Disabilities in Australia'. Paper presented to the Disabled Peoples' International (DPI) World Summit, Canada.

⁵ 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

⁶ FIGO (International Federation of Gynecology and Obstetrics), *Contraceptive Sterilization Guidelines*, Recommendation 5. Available at: <http://www.figo.org/files/figo-corp/FIGO%20-%20Female%20contraceptive%20sterilization.pdf>.

punishment.⁷ Sterilisation disproportionately affects women and girls and is clearly a gendered issue. Whilst there may be instances where disabled men and boys are subject to sterilisation procedures, all cases that have come to the attention of relevant authorities in Australia (including Courts and Guardianship Tribunals) have involved the sterilisation of girls with intellectual disabilities.⁸ Similarly, there have been no instances in Australia where authorisations to sterilise have been sought for children without disabilities in the absence of a threat to life or health (WWDA).

Why are women and girls with disabilities still being sterilised?

Across the globe, forced sterilisation is performed on young girls and women with disabilities for various purposes, including eugenics-based practices of population control, menstrual management and personal care, and pregnancy prevention (including pregnancy that results from sexual abuse).^{9 10} The practice of forced sterilisation is itself part of a broader pattern of denial of human and reproductive rights of disabled women and girls which also includes systematic exclusion from appropriate reproductive health care and sexual health screening, limited contraceptive choices, a focus on menstrual suppression, poorly managed pregnancy and birth, selective or coerced abortion and the denial of rights to parenting.¹¹ These practices are framed within traditional social attitudes that characterise disability as a personal tragedy, a burden and/or a matter for medical management and rehabilitation.^{12 13}

The reasons used to justify forced sterilisations generally fall into four broad categories, all couched as being in the “best interests” of women and girls with disabilities:

- The genetic/eugenic argument
- For the good of the state, community or family
- Incapacity for parenthood
- Prevention of sexual abuse

⁷ 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]. See also UN Committee Against Torture (CAT Committee), *General Comment No. 2: Implementation of Article 2 by States Parties*, 24 January 2008, CAT/C/GC/2 [para.22]; UN General Assembly, *Rome Statute of the International Criminal Court* (last amended January 2002), 17 July 1998, A/CONF. 183/9 [Article 7(1)(g)].

⁸ Brady, S. (2001) *The sterilisation of girls and young women with intellectual disabilities in Australia: An audit of Family Court and Guardianship Tribunal cases between 1992-1998*. Available online at: www.wwda.org.au/brady2001.htm

⁹ Women With Disabilities Australia (WWDA), Human Rights Watch (HRW), Open Society Foundations, & International Disability Alliance (IDA)(2011) Op Cit.

¹⁰ Brady, S., Briton, J., & Grover, S. (2001), Op Cit.

¹¹ Dowse, L. and Frohmader, C. (2001) *Moving Forward: Sterilisation and Reproductive Health of Women and Girls with Disabilities*. Published by Women With Disabilities Australia (WWDA), Tasmania, Australia.

¹² Dowse, L. (2004) Op Cit.

¹³ Steele, L. (2008) Making sense of the Family Court’s decisions on the non-therapeutic sterilisation of girls with intellectual disability; *Australian Journal of Family Law*, Vol.22, No.1.

1. 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."*¹⁴

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. The residue of this type of thinking continues to have the potential for profound and alarming consequences for girls and women with disabilities.¹⁵

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.

2. 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.

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:

¹⁴ Re H [2004] FamCA 496 (20 May 2004)

¹⁵ Brady, S. & Grover, S. (1997) *The Sterilisation of Girls and Young Women in Australia - A legal, medical and social context*. Report commissioned by the Federal Disability Discrimination Commissioner for the Human Rights and Equal Opportunity Commission. Available online at: <http://www.wvda.org.au/brady.htm>

*"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."*¹⁶

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.¹⁷ For example, in authorising the sterilisation of a 12 year old girl in 2004, the Court accepted medical 'evidence' that caring for her was an *"onerous responsibility"* on her parents and that sterilisation would make the task of caring for her *"somewhat less onerous"*, including that it would *"make it easier for her carers if they had one less medication to administer."*¹⁸

In terms of the 'burden' on families of the care of girls and women with disabilities, lack of resources and appropriate education and support services, respite care, school and post-school options, see many families already struggling to manage the care of their girl or young woman with disabilities. Faced with the prospect of added personal care tasks in dealing with menstruation and in the limited availability or accessibility of specific reproductive health and training services (including those for menstrual management), families may well see sterilisation as the only option open to them.^{19 20} The denial of a young woman's human rights through the performance of an irreversible medical intervention with long term physical and psychological health risks is wrongly seen as the most appropriate solution to the social problem of lack of services and support.²¹ Evidence suggests however that menstrual and contraceptive concerns, even for women and girls with high support needs can be successfully met with approaches normally taken with non-disabled women.^{22 23 24} Indeed WWDA's research has found that when parents and carers are given appropriate support and resources the issue of sterilisation loses potency.²⁵

Medical professionals are often very influential in the decision to sterilise disabled women and girls. The propensity of Courts and parents to value medical opinion above all else – and in many cases elevating opinions and assertions to the status of fact - has the effect of reducing the 'best interests' of disabled women and girls to the 'best [and easiest and cheapest] ways' of controlling and managing their unruly

¹⁶ Re: Angela [2010] FamCA 98 (16 February 2010)

¹⁷ See: Between: the Attorney-General of Queensland and Parents Re S [1989] FamCA 80; (1990) FLC 92-124 13 Fam Lr 660 Children (22 November 1989)

¹⁸ Re H [2004] FamCA 496 (20 May 2004)

¹⁹ Dowse, L. and Frohmader, C. (2001) Op Cit.

²⁰ Dowse, L. (2004) Op Cit.

²¹ Dowse, L. and Frohmader, C. (2001) Op Cit.

²² Dowse, L. (2004) Op Cit.

²³ Brady, S. & Grover, S. (1997) Op Cit.

²⁴ Jones M. & Basser Marks L. (1997) Female and Disabled: A Human Rights Perspective on Law and Medicine in K. Petersen (ed) *Intersections: Women on Law, Medicine and Technology* Aldershot, Dartmouth: 49-71.

²⁵ Dowse, L. and Frohmader, C. (2001) Op Cit.

bodies.^{26 27 28} Yet these judgements are made from a particular perspective which we must all vigorously challenge – that the woman or girl with a disability is essentially the sum of her biology or her psychology and her human right to bodily integrity is less important than controlling her body and her behaviour.²⁹

A diagnosis of intellectual disability does not by itself constitute a clinical reason for sterilisation. The onset of menstruation is the same in girls with and without intellectual disabilities, and girls with intellectual disabilities present with the same types of common menstrual problems as the rest of the young female population.³⁰ Arguments for elimination of menstruation in girls and young women with disabilities are primarily about social taboos.^{31 32 33}

Sterilisation is not 'a treatment of choice' for non-disabled females who are approaching menstruation, who menstruate, or who experience menstrual problems. Like their non-disabled counterparts, women and girls with disabilities have the right to bodily integrity, the right to procreate, the right to sexual pleasure and expression, the right for their bodies to develop in a natural way, and the right to be parents.^{34 35 36}

3. 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. Women with disabilities are typically seen as child-like, asexual or over-sexed, dependent, incompetent, passive, and genderless³⁷ and therefore considered inadequate for the '*nurturing, reproductive roles considered appropriate for women*'.³⁸ For 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.³⁹ Such incapacity is automatically deemed to be an irremediable deficiency in the parent such that it cannot be overcome.

²⁶ Ibid.

²⁷ Brady, S. (2001) *The sterilisation of girls and young women with intellectual disabilities in Australia: An audit of Family Court and Guardianship Tribunal cases between 1992-1998*. At: http://www.hreoc.gov.au/disability_rights/sterilisation/disability_with_attitude.html

²⁸ Dowse, L. (2004) Op Cit.

²⁹ Dowse, L. and Frohmader, C. (2001) Op Cit.

³⁰ Brady, S. & Grover, S. (1997) *The Sterilisation of Girls and Young Women in Australia - A legal, medical and social context*. Report commissioned by the Federal Disability Discrimination Commissioner for the Human Rights and Equal Opportunity Commission. Available online at: <http://www.wwda.org.au/brady.htm>

³¹ Ibid.

³² Steele, L. (2008) Making sense of the Family Court's decisions on the non-therapeutic sterilisation of girls with intellectual disability; *Australian Journal of Family Law*, Vol.22, No.1.

³³ Brady, S., Briton, J. and Grover, S. (2001) *The Sterilisation of Girls and Young Women in Australia: Issues and Progress*. A report commissioned by the Federal Sex Discrimination Commissioner and the Disability Discrimination Commissioner; Human Rights and Equal Opportunity Commission, Sydney, Australia. Available online at: <http://www.wwda.org.au/brady2.htm>

³⁴ Women With Disabilities Australia (WWDA) (2007) *Policy & Position Paper: The Development of Legislation to Authorise Procedures for the Sterilisation of Children with Intellectual Disabilities*. Available at: <http://www.wwda.org.au/polpapist07.htm>

³⁵ New South Wales Council for Intellectual Disability (2006) *Submission on the Draft Model Bill to regulate the sterilisation of children with an intellectual disability*. Available online at: <http://www.wwda.org.au/sternswcid06.htm>

³⁶ Intellectual Disability Rights Service (IDRS) (2006) *Submission on the Draft Model Bill to regulate the sterilisation of children with an intellectual disability*. Available online at: <http://www.wwda.org.au/sterirds06.htm>

³⁷ In Women With Disabilities Australia (WWDA) (2009) *Parenting Issues for Women with Disabilities in Australia: A Policy Paper*. WWDA, Rosny Park, Tasmania. Available online at: <http://www.wwda.org.au/subs2006.htm>

³⁸ Ibid.

³⁹ Ibid.

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".⁴⁰

*"There is no prospect that will ever show any improvement in her already severely retarded mental state."*⁴¹

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.

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.⁴²

Like their non-disabled counterparts, women and girls with disabilities have a right to retain their fertility on an equal basis with others. Women with disabilities have a have a fundamental right to 'found a family', to experience sexual relationships; to experience parenthood and all that it entails; to decide 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. These rights are expressed in a number of international human rights treaties and instruments, and are clearly articulated in the UN Convention on the Rights of Persons with Disabilities (CRPD).⁴³

4. Prevention of Sexual Abuse

Sterilisation has been said to protect a woman from sexual abuse and the consequences of abuse.⁴⁴ 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.^{45 46} 'Inappropriate' behaviour, and 'good looks' are considered major determinants of sexual activity or abuse.⁴⁷

⁴⁰ Between: the Attorney-General of Queensland and Parents Re S [1989] FamCA 80; (1990) FLC 92-124 13 Fam Lr 660 Children (22 November 1989)

⁴¹ Ibid.

⁴² Women With Disabilities Australia (WWDA) (2009) Op Cit.

⁴³ UN General Assembly, *Convention on the Rights of Persons with Disabilities*, 24 January 2007, A/RES/61/106.

⁴⁴ Jones M. & Basser Marks L. (1997) Op Cit.

⁴⁵ Between: L and Gm Applicants and Mm Respondent and the Director-General Department of Family Services and Aboriginal and Islander Affairs Respondent/Intervener [1993] FamCA 124; (1994) FLC 92-449 17 Fam Lr 357 Family Law (26 November 1993)

⁴⁶ Re Elizabeth Suit [1989] FamCA 20 (3 May 1989)

⁴⁷ Brady, S. (2001) Op Cit.

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."*⁴⁸

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."*⁴⁹

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."*⁵⁰

Research has demonstrated that rather than protecting against sexual abuse, forced sterilisation can increase vulnerability to sexual abuse.⁵¹ We already know that sexual abuse of women and girls with disabilities occurs at very high rates in our communities.⁵² A young woman who has been sterilised is less likely to be taught about sexuality or sexual abuse because she cannot become pregnant. Sterilisation is quicker, easier and cheaper than sex education. Sterilisation can also inadvertently serve to cover up the sexual abuse of women with disabilities, since pregnancy is often the only clear evidence that sexual abuse has occurred. Others may know she has been sterilised and she may be seen as a safe target. On the other hand women who have been sterilised may also be assumed to be non-sexual and therefore not considered for sexual and reproductive health screening.^{53 54}

⁴⁸ In the Matter Of: Re Katie Number of Pages - 29 Children - Welfare of Child - Medical Procedures [1995] FamCA 130 (30 November 1995)

⁴⁹ Re A Teenager [1988] FamCA 17 (15 November 1988)

⁵⁰ Re Elizabeth Suit [1989] FamCA 20 (3 May 1989)

⁵¹ Sobsey, D. & Doe, T. (1991) cited in Dowse, L. and Frohmader, C. (2001) Op Cit.

⁵² Women With Disabilities Australia (2011) *Submission to the Preparation Phase of the UN Analytical Study on Violence against Women and Girls with Disabilities (A/HRC/RES/17/11)*. Available online at: <http://www.wwda.org.au/viol2011.htm>

⁵³ Dowse, L. and Frohmader, C. (2001) Op Cit.

Sterilisation will never overcome vulnerability to sexual abuse. Sexual assault is a problem for all young women, including young women with intellectual disabilities and it demonstrates the need for targeted and gendered educational, protective behaviour, and violence prevention programs. Women and girls with disabilities, like all women and girls, have a human right to live free from violence, abuse, exploitation and neglect.

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. In making judgements about best interests it is crucial that we are clear about whose best interests are really at stake.^{55 56} We need to be clear about whether 'best interests' is judged according to human rights principles or whether the judgement is about the 'best compromise between the competing interests' of parents, carers, service providers and policy makers. To really determine 'best interest' for women and girls with disabilities it is crucial to focus on the fact that a person will be subjected to an irreversible medical procedure with life-long consequences without informed consent.^{57 58}

The fact that a procedure may be ‘authorised’ or ‘lawful’ does not in any way obviate the reality that a woman with a disability, often a very young woman, undergoes a medical procedure to remove non-diseased parts of her body which are essential to her ongoing health.⁵⁹ The long-term negative social and psychological impact and effects on women with disabilities are somehow deemed insignificant. This blatant disregard for women and girls with disabilities is clearly evident in the cases that have proceeded to legal judgment in Australia, where, the opinion of the medical specialist is 'authoritative' and sterilisation is characterised as a 'simple' and 'common' procedure. In a technical sense it is portrayed as inconsequential and of minimum risk. In a social sense (from a medical perspective) it offers a final solution to a myriad of problems potentially encountered because of disability.⁶⁰ The social and psychological effects on the disabled female are irrelevant:

“There is unlikely to be any psychological impact of the procedure on H as she has no understanding of the nature of the procedure.”⁶¹

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

⁵⁴ Dowse, L. (2004) Op Cit.

⁵⁵ Dowse, L. and Frohmader, C. (2001) Op Cit.

⁵⁶ Dowse, L. (2004) Op Cit.

⁵⁷ Ibid.

⁵⁸ Dowse, L. and Frohmader, C. (2001) Op Cit.

⁵⁹ Ibid.

⁶⁰ Brady, Op Cit.

⁶¹ Re H [2004] FamCA 496 (20 May 2004)

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.⁶²

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

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

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

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

"For me it is about living with loss."

"I was sterilised at 17. Someone else made the decision for me. I didn't object because I had been led to believe that people with disabilities were worthless and that they were a burden on people and society. I felt that if I produced a child with a disability I would be producing a "bad" person."

"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."

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.^{63 64 65}

⁶² Dowse, L. and Frohmader, C. (2001) Op Cit.

⁶³ Dowse, L. and Frohmader, C. (2001) Op Cit.

⁶⁴ Strahan, F. (Ed)(1990) *On The Record - A Report on the 1990 STAR Conference on Sterilisation: 'My Body, My Mind, My Choice'*. Available online at: <http://www.wwda.org.au/record.htm>

⁶⁵ Women With Disabilities Australia (WWDA) (1999) *Presentation to the First Australian Tribunal on Women's Human Rights*. Available online at: <http://www.wwda.org.au/wrana.htm>

WWDA's Campaign – Gaining Ground

In Australia the issue of sterilisation has been the subject of debate since the early 1980s when it became evident that many women with disabilities were being sterilised without their consent and in many cases, without their knowledge. It was clear that this practice was happening with the informal consent of family, carers or doctors and without public scrutiny or accountability.^{66 67} In 1992, in a case now known as *Marion's Case*⁶⁸, an application was made to the High Court of Australia on appeal from the Family Court in relation to a teenage girl with an intellectual disability. The application was for a 'non-therapeutic'⁶⁹ surgical sterilisation in order to manage the young girl's menstruation and prevent pregnancy. The High Court found that fundamental questions of human rights such as the right to reproduce should be decided by the courts rather than by parents, carers or medical practitioners.⁷⁰ While this decision lent support to the rights of people with disabilities and has since assumed symbolic importance, subsequent judicial decisions and social practices have failed to give full effect to the promise of Marion's case.⁷¹ In reality considerations about forced sterilisation in Australia have remained effectively bogged down in an ongoing legalistic debate about who can authorise sterilisation, for whom, under what circumstances and within which jurisdiction.⁷² The main concern of public policy in the area has focused on piecemeal development of mechanisms, protocols and guidelines in an attempt to '*minimise the risk of unauthorised sterilisations occurring*'.⁷³ Fundamentally, the broader public policy debate about forced sterilisation of disabled women and girls, from a human rights perspective, and in keeping with Australia's international human rights obligations, have not taken place.⁷⁴

In 2001, WWDA completed a national government funded research project into sterilisation and reproductive health of women and girls with disabilities. Initially, the project was titled '*Sterilisation and Reproductive Rights of Women and Girls with Disabilities*' however funding was approved only on the proviso that the title of the project be changed to '*Sterilisation and Reproductive Health of Women and Girls with Disabilities*'. This small, one word difference spoke volumes about the underlying current in the national approach to reproductive issues for women and girls with disabilities in Australia.

⁶⁶ Dowse, L. and Frohmader, C. (2001) Op Cit.

⁶⁷ Dowse, L. (2004) Op Cit.

⁶⁸ Department of Health and Community Services v JWB and SMB (Marion's Case) [1992] HCA 15; (1992) 175 CLR 218 (6 May 1992). At: http://www.austlii.edu.au/au/cases/cth/high_ct/175clr218.html

⁶⁹ 'Non-therapeutic sterilisation' is sterilisation for a purpose other than to 'treat some malfunction or disease': Secretary, Department of Health and Community Services v JWB and SMB, 1992, 175 CLR 218; 106 ALR 385.

⁷⁰ Dowse, L. (2004) Op Cit.

⁷¹ Jones, M. and Basser Marks, L. (2000) Valuing People through Law: Whatever Happened to Marion? In M. Jones and L. A. Basser Marks (eds) *Explorations on Law and Disability in Australia*. Sydney, Federation Press.

⁷² Dowse, L. and Frohmader, C. (2001) Op Cit.

⁷³ Standing Committee of Attorneys-General (SCAG) (2004) *Issues Paper on the Non-Therapeutic Sterilisation of Minors with a Decision-Making Disability*. Available online at: www.wwda.org.au/scagpap1.htm

⁷⁴ Dowse, L. (2004) Op Cit.

WWDA's project reviewed and analysed international and national developments in the field and integrated this for the first time with the personal experience and perspectives of women and girls with disabilities who have experienced sterilisation and other denials of their rights to reproductive freedom.

The resulting report of the project, entitled *'Moving Forward'* recommended, amongst other things,⁷⁵ the banning of all sterilisations of girls under the age of 18 years and the prohibition of sterilisation of adults in the absence of informed consent, except in circumstances where there is a serious threat to health or life. Successive Australian Governments failed to substantially address and respond to any of the recommendations stemming from WWDA's national project. Instead, from 2003 to 2007, the Australian Government pushed ahead with a proposal to develop legislation aimed to regulate authorisation of sterilisation of minors with a 'decision-making disability' rather than prohibit this form of violence.⁷⁶ The Government disbanded this work in 2008, declaring that *'there would be limited benefit in developing model legislation'*⁷⁷ and advised WWDA that it had no intention of pursuing the issue of reform any further.⁷⁸ This was despite the fact that the Australian Government conceded that: a) girls with disabilities continue to be sterilised in Australia,⁷⁹ and b) *'unrecorded and unauthorised non-therapeutic sterilisations of young women with intellectual disabilities [are] being undertaken in Australia'*.⁸⁰

The Australian Government does not currently have a coherent national approach to sterilisation of women and girls with disabilities. Instead of developing universal legislation which protects their human rights and prohibits the sterilisation of women and children except in those circumstances where there is a threat to health or life, the Government has consistently taken the view that there are instances in which sterilisation can and should be authorised, as evidenced in its 2009 Report to the United Nations under the Convention on the Rights of the Child (CRC):

A blanket prohibition on the sterilisation of children could lead to negative consequences for some individuals. Applications for sterilisation are made in a variety of circumstances. Sometimes sterilisation is necessary to prevent serious damage to a child's health, for example, in a case of severe menstrual bleeding where hormonal or other treatments are contraindicated. The child may not be sexually active and contraception may not be an issue,

⁷⁵ The report also outlined a program of reconciliation; co-ordinated legislative and policy development; information, support and service models; consent considerations; approaches to reproductive health care and education; and data collection.

⁷⁶ Standing Committee of Attorneys-General (SCAG) Working Group (2006) *Draft 17: Children with Intellectual Disabilities (Regulation of Sterilisation) Bill 2006*. Available at: www.wwda.org.au/sterbill06.pdf

⁷⁷ Standing Committee of Attorneys-General (SCAG) *Communique* 28 March 2008.

⁷⁸ Hon Robert McClelland (Attorney-General) Correspondence to Women With Disabilities Australia (WWDA), 27 August, 2009.

⁷⁹ Australian Government (2009) *Response to the UNESCAP Questionnaire on the implementation of the outcome of the Fourth World Conference on Women (Beijing 1995)*. Available online at: www.unescap.org/ESID/GAD/Issues/Beijing+15/Responds_to_Questionnaire/Australia.pdf [See page 14].

⁸⁰ Australian Government (2006) *Sterilisation of Women and Young Girls with an Intellectual Disability - Report to the Senate*. Tabled by the Minister for Family and Community Services and the Minister Assisting the Prime Minister on the Status of Women, December 6, 2000. Available online at: www.wwda.org.au/senate.htm

*but the concern is the impact on the child's quality of life if they are prevented from participating to an ordinary extent in school and social life.*⁸¹

This approach has several extremely negative consequences for women and girls with disabilities in Australia. It clearly undermines their fundamental human rights; it takes no account of the social, cultural and economic conditions which drive the sterilisation agenda; it ignores the long-term physical and psychological health effects of sterilisation; it frames sterilisation as a medical/behavioural issue rather than an issue of human rights; and effectively makes authorisation easier rather than more difficult to obtain. This kind of approach once again relegates the voice of women and girls with disabilities to the margins of the debate.

In response to the Australian Government's apparent indifference to the issue, WWDA has reacted by progressively intensifying our campaign, pushing for domestic and international reforms to promote the sexual and reproductive rights of disabled women and girls, and calling on Governments to:

- develop and enact universal legislation which prohibits sterilisation of any child unless there is a serious threat to health or life;
- address the cultural, social and economic factors which drive the sterilisation agenda;
- commit resources to assist women and girls with disabilities and their families and carers to access appropriate reproductive health care; and,
- create the social context in which all women and girls are valued and respected.

Our campaign is starting to yield 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.

It is outside the scope of this Paper to detail the extent of the work WWDA's has undertaken on this issue over the past twelve years. We can however, highlight some of the key strategies we have used and some of the key outcomes we have achieved, in what has now become WWDA's international campaign to stop the forced sterilisation of disabled women and girls, and address their sexual and reproductive rights.

⁸¹ Australian Government (2008) *Fourth Report under the Convention on the Rights of the Child: Australia*, October 2008, 159, p31. Accessed online August 2009 at: http://www.ag.gov.au/www/agd/agd.nsf/Page/Humanrightsandantidiscrimination_ReportsundertheConventionontheRightsoftheChild

Key Strategies and Outcomes of WWDA's Campaign

1. Persistence

Perhaps one of our most important strategies has been our persistence on the issue. We have never wavered or given up on our campaign to stop the forced sterilisation of women and girls with disabilities. We have maintained a clear and consistent message through times of change in the political climate of our country and during times of uncertainty about our future. We have not compromised on our position and we have stubbornly refused to accept our Government's indifference and inaction on the issue. Instead, in those difficult times, we have found different ways of working and continually sought out different strategies to get our message out.

As the majority of our funding comes from government, there have been times, (particularly during the periods of conservative Government) when we have taken risks by challenging our Government's inaction on the issue. We spoke out publicly even though we had signed a funding contract with the government which contained a proviso that we not speak to the media without permission from the Government. Taking this course of action was a difficult decision for us, as we were fearful of losing our funding. But we considered it important to disseminate our message to as wide as possible a constituency and to gain support of women with disabilities and their allies. Regardless of the substantive issue, gaining public *recognition* of the rights of women with disabilities has always been high on our agenda.⁸² And we have survived. And our message is, never, ever give up. Persistence is critical.

2. Utilising the international human rights mechanisms

Australia is a signatory to seven core United Nations human rights treaties,⁸³ along with many declarations and other instruments. Over the years, WWDA has educated ourselves about the international human rights mechanisms, the machinery of the United Nations, and Australia's reporting obligations under those instruments it has ratified. And we are still learning.

Some years ago, we realised that if we wanted our Government to act on addressing the reproductive rights of women and girls with disabilities, including forced and coerced sterilisation, we needed to use all available mechanisms to support our position, including those available through the United Nations. Up until 2007,

⁸² Frohmader, C. & Meekosha, H. [forthcoming] Recognition, respect and rights: Women with disabilities in a globalised world. In *Disability and Social Theory*, Edited by Dan Goodley, Bill Hughes and Lennard Davis, London: Palgrave Macmillan.

⁸³ Commonwealth of Australia (2010) *Australia's Human Rights Framework*. Accessed online November 2011 at: [http://www.ag.gov.au/Humanrightsandantidiscrimination/Australiahumanrightsframework/Documents/HumanRightsFramework\[1\]PDF.pdf](http://www.ag.gov.au/Humanrightsandantidiscrimination/Australiahumanrightsframework/Documents/HumanRightsFramework[1]PDF.pdf)

this had been difficult, as the then Government, under the conservative leadership of Prime Minister John Howard, had little regard for the UN and had essentially disengaged from its reporting obligations under the international human rights instruments Australia had ratified.

However, with the installation of a federal Labor government in 2007, Australia set about repairing its relationship with the UN, with the new Government pledging to *'adhere to Australia's international human rights obligations, seek to have them incorporated into the domestic law of Australia and taken into account in administrative decision making.'*⁸⁴ It also committed to *"engage with the international community and lead by example to encourage other nations to review and continually improve their own human rights performance."*⁸⁵ WWDA latched onto statements such as these, and used them in our advocacy work on the issue.

Utilising the international human rights mechanisms, and getting our work recognised within the UN, has been critical to WWDA's campaign and to our successes. We have contributed to the development of Australia's NGO Shadow Reports to the UN, and have fought to ensure that the issues of concern to disabled women and girls have been given prominence in those Reports. We have provided the treaty monitoring bodies with draft recommendations for consideration in their official Concluding Observations on Australia's performance. In 2010, we wrote our own NGO Shadow Report to the Committee on the Elimination of Discrimination Against Women (CEDAW) and later that year, attended the 46th session of CEDAW as the NGO representative on the Australian delegation. We were able to speak directly to the Committee about forced sterilisation, violence against women with disabilities and other key issues of concern. Our sustained advocacy work with the treaty monitoring committees and reporting mechanisms has had significant impact and outcomes. WWDA's key message – *that the Australian Government enact national legislation prohibiting, except where there is a serious threat to life or health, 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* – has now been formally and consistently articulated by the United Nations to the Australian Government, through for eg: the Concluding Observations and Recommendations of the Committee on the Elimination of Discrimination Against Women (CEDAW) (2010);⁸⁶ the Human Rights Council Universal Periodic Review (2011);⁸⁷ and the Committee on the Rights of the Child (2006, 2012).

In addition to our advocacy with the various UN treaty monitoring bodies, we have also used other UN mechanisms to advance our campaign. For example, in 2010, we lodged a formal communication with the Commission on the Status of Women (CSW), detailing the ongoing practice in Australia of forced and

⁸⁴ Australian Labor Party (ALP) (2007) *ALP National Platform and Constitution 2007*, ALP, Barton, ACT.

⁸⁵ McClelland, Hon. R., and Smith, Hon. S. (2010) *'Reaffirming our commitment to international human rights obligations'*. Joint Media Release, 21 April 2010.

⁸⁶ Committee on the Elimination of Discrimination against Women (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>

⁸⁷ UN General Assembly Human Rights Council (2011) *Draft report of the Working Group on the Universal Periodic Review: Australia*, 31 January 2011, A/HRC/WG.6/10/L. 8 [para. 86.39]. The final document will be issued under the symbol A/HRC/17/10.

coerced sterilisation of women and girls with disabilities. In 2011, we made use of the UN Special Procedures, and lodged a formal complaint with four of the United Nations Special Rapporteurs, requesting urgent intervention from each of their offices simultaneously. This was an important step, because the Australian Government is compelled to formally respond – a process that is occurring currently.

We have also worked hard to utilise mainstream fora at the United Nations, in our endeavours to have the issue of forced sterilisation of women and girls with disabilities taken up as a major women's rights issue, rather than have it viewed solely as a 'disability' issue. We were fortunate this year to be able to organise and co-sponsor a *High level Panel on Women and Girls with Disabilities* at the 56th session of the Commission on the Status of Women (CSW) where we spoke passionately about the issue of forced sterilisation and demanded an end to the practice.

We still have much to learn about how to best use the machinery of the United Nations to advance our cause. But our efforts are paying off, and it is now becoming increasingly difficult for our Government to ignore the strong recommendations coming from the UN treaty monitoring committees in regard to the practice of forced sterilisation of women and girls with disabilities.

3. Maximising the virtual world

New communication technologies have been a vital part of WWDA's success as well as an essential part of maintaining contact with women with disabilities and their allies around the world. As a national body with very few resources, it is unlikely we would have been able to advance our campaign without the advent and widespread use of the Internet. The globalisation of communication has thrown up the means to contest, resist and oppose stigmatising and demeaning representations of women with disabilities.⁸⁸

We have spent more than 15 years methodically building up extensive email distribution lists, and have used these to regularly disseminate information about our campaign, and to seek support for our cause. We have often been surprised at the extent of the reach of our work – such is the power of the Internet in disseminating information quickly and widely. Importantly, it has also been an affordable option for WWDA – whilst we do not have the funding to be physically present at various national and international fora, including for eg: UN treaty monitoring events and key international Conferences – communication technologies have given us the opportunity of ensuring our message can still be presented and heard.

We have spent many years building up our website and have always ensured that our published resources and materials are free of charge and widely accessible to the broadest possible audience. This has been an important strategy in getting our messages out and engendering support for our cause. We have in recent

⁸⁸ Frohmader, C. & Meekosha, H. [forthcoming] Op Cit.

times established a presence on Facebook and this is proving to be a useful strategy in getting information out quickly and keeping women with disabilities informed of progress. Importantly, information on our Facebook site about forced sterilisation and WWDA's campaign to end the practice, has resulted in a number of women with disabilities contacting WWDA to share their stories of forced and coerced sterilisation, and to seek support from others.

4. Forming Strategic Alliances

Forming strategic alliances and establishing collaborative relationships with others has been crucial to WWDA's campaign. We have built a close and productive working relationship with our national human rights institution, and our work in the area of forced sterilisation and violence against women and girls with disabilities has been particularly well supported by our national Sex Discrimination Commissioner and our national Disability Discrimination Commissioner. Both these individuals have assisted WWDA by speaking out publicly in support of WWDA's position and by actively taking up the issue on our behalf with politicians, policy makers and the media.⁸⁹ We have also deliberately sought out sympathetic politicians and media personnel to work with as a way of increasing our momentum and putting pressure on our governments to undertake reforms in the area. For example, we recently worked with a freelance journalist on an investigative report for a popular national mainstream women's magazine.⁹⁰ We were able to clearly articulate WWDA's position in the context of Australia's human rights obligations and support this with the personal stories of women who had been affected. The publishing of this feature article generated extensive interest and also resulted in women with disabilities who had been sterilised contacting WWDA to share their stories, and to seek support and information.

We have formed a productive working relationship with the *Global Campaign to End Torture in Health Care*⁹¹, which has prioritised forced sterilisation as one of its three key action areas. For the past 18 months, WWDA has been a member of the Global Campaign's Working Group to Stop Forced and Coerced Sterilisation, which aims to stop the practice in different parts of the world and among different populations, including women and girls with disabilities. In 2011, as part of this work, WWDA collaborated with the Open Society Foundations, Human Rights Watch and the International Disability Alliance to publish an *International Briefing Paper on the Sterilisation of Women and Girls with Disabilities*.⁹² The Paper outlines various international human rights standards that prohibit forced sterilisation of women and girls with disabilities and offers several recommendations for improving laws, policies, and professional guidelines governing sterilisation practices. Being an active part of this global campaign and jointly collaborating on advocacy

⁸⁹ See: 'Concerns over sterilisation of girls with disabilities' at: <http://www.abc.net.au/pm/content/2012/s3430739.htm>

⁹⁰ Osfield, S. (2012) 'This girl has special needs and one day dreams of being a mum. Does anyone have the right to stop her having a baby?' In *marie claire* magazine, June 2012.

⁹¹ The Global Campaign is co-ordinated by the Open Society Foundations. See: <http://stoptortureinhealthcare.org>

⁹² 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

work, has undoubtedly raised the profile of the issue and helped to build the evidence base. Importantly, it has given WWDA a sense of solidarity and affirmed that we are not alone in our fight.

Our alliances with other international networks, such as the *International Network of Women and Girls with Disabilities (INWWD)* have been vital in keeping our campaign on the agenda as well as providing us with a mechanism to seek advice and support on various elements of our work in the area. The INWWD was established in 2008 and as a virtual community, is working collaboratively to develop and publish position statements and establish a presence within the United Nations treaty monitoring system and processes. Supporting the work of our sisters in similar organisations and networks, such as the European Disability Forum Women's Committee, the International Disability Alliance, Disabled People's International, DAWN Canada, and other emerging groups of women with disabilities throughout the world, has also been an important part of our efforts to advance the sexual and reproductive rights of women and girls with disabilities. This collective identity empowers us to speak out about our experiences *together* and take action to realise our rights and improve our lives as a group.⁹³

5. Maximising opportunities to have our voice heard

WWDA has continually sought out opportunities to speak out about the denial of sexual and reproductive rights for women and girls with disabilities. We are always somewhat limited by our lack of capacity – we are after all, an organisation of only two paid staff. However, the activism and goodwill of our members has enabled us to maximise many opportunities.

We speak on the issue at Conferences, forums and seminars; we meet with policy makers and politicians; we write questions to be asked of our Government in the Parliament. We provide input into the work of other organisations. We write and send endless letters and emails and copy them to anybody we think might be influential. We seek out avenues where we can be represented on relevant advisory structures and fora, such as our Government's National NGO Forum on Human Rights, and it's National Violence Prevention Advisory Panel.

We have worked hard to ensure that the issue of forced sterilisation is recognised as a form of violence, and that it is integrated into violence prevention policies and programs. An important part of this has been to establish collaborative relationships with NGO's in the women's and violence prevention sectors. We now have representation on some of the Management Committees of these NGO's and this has been a crucial part of our campaign. In reality, we have at times had to work just as hard arguing our case within these sectors, who have traditionally viewed our issues as being belonging in the realm of the disability sector alone.

⁹³ Frohmader, C. & Meekosha, H. [forthcoming] Op Cit.

However, we are making progress. A clear example of this is the Australian Government's recent review of its national Family Violence Legislation, which has seen for the first time ever, forced sterilisation defined in legislation as a form of violence against women. This significant development is directly attributable to the sustained advocacy work of our organisation. WWDA has been at the forefront of highlighting the intersectional nature of discrimination in Australia and has led the way on ensuring that mainstream fora incorporate a gendered perspective on disability.

6. Creating safe spaces

For years, women with disabilities have had to endure 'experts' speaking on our behalf and making decisions about us, without us. For WWDA, creating safe spaces for women with disabilities to be able to speak out and to work collectively on issues has been paramount. WWDA's National Project on Sterilisation back in 2001, was the beginning of our efforts to redress the exclusion of women and girls with disabilities from the debates about their sexual and reproductive rights. In many senses, our campaign has been about empowering women to reclaim their issue and in doing so, reclaim some control over their lives.

Very recently we were privileged to have the UN Special Rapporteur on Violence, Ms Rashida Manjoo, visit our country on a short study tour. Although not a formal fact finding mission, the Special Rapporteur kindly agreed to hold a *Roundtable on Violence Against Women With Disabilities*. The Roundtable was organised to enable women with disabilities to have a dialogue with the Special Rapporteur about the many forms of violence perpetrated against us and to discuss ways of working to redress this human rights violation. The impact of the stories our women shared had a profound impact on all involved and had a much greater immediacy than the words of 'experts'. The importance of creating safe and supportive environments for women with disabilities to share their experiences cannot be overstated. Many of our members have spoken out about their experiences of forced and coerced sterilisation and other infringements of their human rights, only on the proviso that their identity is not revealed publicly. Fear of recrimination and retribution, along with feelings of embarrassment, shame and guilt remain very real for many of the women concerned.

Creating safe spaces to talk about issues such as forced sterilisation, is also important in the context of the media and the broader public domain. We have learned the hard way that we need to be very careful about how we use the media, and indeed, how the media uses us. In 2010, for example, we spoke out in the media about forced sterilisation in response to the reported case of Angela, an 11 year old girl sterilised by authorisation of the Family Court. The backlash we received from members of the public, including from medical professionals as far away as the UK, was frightening. Comments such as these were sadly, very common:

*"I think this is a good ruling. Personally I think people with any medium level to high level disability should be completely sterilised to keep the gene pool clean."*⁹⁴

*"Carolyn Frohmader, go away and do something useful with your life - nobody needs your silly rights pushing. It's right for these people to be sterilised, that way we don't end up spending tax payer's money looking after children who cannot be supported or again need support."*⁹⁵

*"We have a family member who has an intellectual disability and I support this action. Until you have had to actually change another person's sanitary napkin and have sleepless nights worrying if they will be taken advantage of and raped/become pregnant, you have no right to judge actions like this!"*⁹⁶

*"Someone I know worked in a mental institution and she told me that the disabled often have very high sexual urges and they often do the deed with each other and then fall pregnant. It apparently results in lots of abortions so sterilisation is certainly a good option."*⁹⁷

We have learned to become more careful about the way we work with the media, and now weigh up carefully what outcomes we might achieve from such engagement. We have turned down many offers from the sensationalist TV talk show producers, who are eager to get the sound-bite for their program, but have no interest in learning about the sensitivities involved. We are also now much more careful about the safety of our women who are in the public space, ensuring that they are well equipped to deal with the media. Through our experiences, we have realised that we still need to build the capacity of our members and our staff to be more confident about engaging with the media.

7. Continually building on our work

Systemic advocacy can be slow and arduous process. Results don't come overnight and we have learned to keep picking ourselves up, dusting ourselves off, and pressing on with our work in this field. Continually building upon our work and maximising any opportunity to showcase and share that work, has been an integral part of our campaign. We are always looking for ways to improve our knowledge base and often we have learned more from our mistakes than from our successes. Over the past decade, we have built up our resources, publications, information and research on the sexual and reproductive rights of women and girls

⁹⁴ Comment 70 of 162 posted at 10:14 AM March 09, 2010; accessed online June 2012 at: <http://www.news.com.au/national/family-court-lets-couple-sterilise-disabled-daughter/story-e6frfkvr-1225838469430>

⁹⁵ Comment Posted online at 12:20 PM March 09, 2010. Accessed online June 2012 at: <http://www.heraldsun.com.au/news/family-court-gives-goupld-permission-to-sterilise-their-disabled-11-year-old-daughter/story-e6frf7jo-1225838629977>

⁹⁶ Comment 26 of 162 Posted online at 8:32 AM March 09, 2010 accessed online June 2012 at: <http://www.news.com.au/national/family-court-lets-couple-sterilise-disabled-daughter/story-e6frfkvr-1225838469430>

⁹⁷ Comment 113 of 162 Posted online at 12:13 PM March 09, 2010 accessed online June 2012 at: <http://www.news.com.au/national/family-court-lets-couple-sterilise-disabled-daughter/comments-e6frfkvr-1225838469430?pg=2>

with disabilities. Our website has become an important clearing-house and repository for historical and contemporary information on many issues of concern to women with disabilities, including sexual and reproductive rights. As many of you will know, WWDA's website is a collection of resource materials from around the world, and making these resources available and accessible to the broadest possible audience is important for our mutual understandings and learnings.

8. Monitoring developments

Through our extensive networks, alliances and collaborative relationships, we are able to keep abreast of developments occurring in the field of sexual and reproductive rights of women and girls with disabilities. For example, just recently, one of our members alerted us to the development of draft Mental Health legislation in the state of Western Australia, which proposed that children with mental health diagnoses could be sterilised without Court authorisation, provided they demonstrated '*sufficient maturity and understanding to make reasonable decisions*'⁹⁸ about themselves. WWDA acted swiftly, writing formally to the Western Australian Government insisting that this section of the proposed Act be immediately repealed in light of its contravention of many of the human rights instruments to which Australia is a signatory and, the fact that it patently infringed on disabled girls fundamental human right to bodily integrity. We then widely publicised these developments, and formally sent copies of our letter to various UN officials, including, among others, the High Commissioner for Human Rights and the Special Representative of the UN Secretary General on Violence Against Children. WWDA's action yielded immediate results, with the issue being reported internationally in various media, sections of the UN responding formally, our own Human Rights institution intervening, and finally, a concession from the Western Australian Government that the section of the proposed Act would be withdrawn.

Monitoring the outcomes of other countries UN reporting processes, particularly where forced sterilisation is specifically mentioned, enables us to use these developments in our own advocacy work. This assists us in building the evidence base around the widespread infringements of the sexual and reproductive rights of women and girls with disabilities, and importantly, places our work firmly in a globalised context.

⁹⁸ Government of Western Australia [Draft] *Mental Health Bill 2011*. Accessed online June 2012 at: http://www.mentalhealth.wa.gov.au/Libraries/pdf_docs/Discussion_Draft_for_Mental_Health_Bill_2011_v3.sflb.ashx

So where are we now? And what does the future hold?

Despite WWDA's sustained advocacy campaign for more than a decade, the Australian Government still has not developed or enacted national legislation prohibiting, except where there is a serious threat to life or health, 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. However, there is no question that our work is gaining momentum and gaining ground. The issue of forced and coerced sterilisation of women and girls with disabilities, and the broader issues of their sexual and reproductive rights, is now firmly back on the national agenda. And we have put it there. We are continuing to demand reform, and our calls for reform continue to be formally endorsed by the United Nations. Most recently, in June 2012, the Committee on the Rights of the Child, in reviewing Australia's latest CRC implementation report, expressed its *'serious concern that the absence of legislation prohibiting sterilisation is discriminatory and in contravention of article 23(c) of the Convention on the Rights of Persons with Disabilities.'* The Committee urged the Australian Government to:

'enact non-discriminatory legislation that prohibits non-therapeutic sterilization of all children, regardless of disability; and ensure that when sterilisation that is strictly on therapeutic grounds does occur, that this be subject to the free and informed consent of children, including those with disabilities'.⁹⁹

WWDA believes it is now only a matter of time before this occurs. We are getting closer every day. We are working closely with our Human Rights institution which is actively supporting us to progress our campaign. We have been successful in having the issue of forced sterilisation included in the Australian Government's current national Human Rights Action Plan, as a priority for action. We are generating media coverage about the issue and using our allies and supporters to keep the pressure on our politicians and our Government. We have developed a national Working Group on Forced Sterilisation, in order to progress our campaign and share the workload, and we are continuing to build relationships and networks internationally to strengthen our capacity for our work.

Although our priority has always been to see the development of national legislation prohibiting this form of violence against women and girls with disabilities, we are also working hard to ensure that the issue is

⁹⁹ Committee on the Rights of the Child (2012) *Consideration of reports submitted by States parties under article 44 of the Convention: Concluding observations: Australia*. Committee on the Rights of the Child, Sixtieth session, 29 May–15 June 2012; CRC/C/AUS/CO/4. Accessed online June 2012 at: http://www2.ohchr.org/english/bodies/crc/docs/co/CRC_C_AUS_CO_4.pdf

considered in the broader framework of sexual and reproductive rights. To this end, our campaign also centres on the urgent need for our Governments to:

- implement the recently adopted Guidelines on Female Contraceptive Sterilization, developed by the International Federation of Gynecology and Obstetrics (FIGO);
- provide redress to women and girls with disabilities who have been sterilised without their consent, including through the provision of financial compensation and an official apology, along with programs to support women with disabilities who are survivors of forced sterilisation;
- commission and fund national research on women with disabilities' right to reproductive freedom which addresses the incidence and long term effects of forced/coerced sterilisation and menstrual suppression practices for all women with disabilities and,
- develop policies, program and services which assist women and girls with disabilities and their families and carers to access appropriate reproductive health care.

Conclusion

The forced sterilisation of disabled women and girls is a grave violation of human rights and medical ethics. It is an act of unnecessary and dehumanising violence,¹⁰⁰ a form of social control, and a violation of the right to be free from torture and other cruel, inhuman or degrading treatment or punishment.¹⁰¹ 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.

This paper has sought to analyse some of the critical issues in the consideration of forced sterilisation as a human rights issue. It has sought to question why women and girls with disabilities are still being sterilised, and has highlighted the discriminatory views, assumptions and behaviours that underpin this barbaric practice and the debates that occur around it. The paper has also traced some of the key features of WWDA's campaign over more than a decade to stop the forced and coerced sterilisation of women and girls with disabilities and to promote their sexual and reproductive rights.

¹⁰⁰ FIGO (International Federation of Gynecology and Obstetrics), *Contraceptive Sterilization Guidelines, Recommendation 5*. Available at: <http://www.figo.org/files/figo-corp/FIGO%20-%20Female%20contraceptive%20sterilization.pdf>.

¹⁰¹ 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]. See also UN Committee Against Torture (CAT Committee), *General Comment No. 2: Implementation of Article 2 by States Parties*, 24 January 2008, CAT/C/GC/2 [para.22]; UN General Assembly, *Rome Statute of the International Criminal Court* (last amended January 2002), 17 July 1998, A/CONF. 183/9 [Article 7(1)(g)].