Women With Disabilities Australia (WWDA)

Presentation to the National Roundtable
"Political Participation, Inclusion and Decision Making"

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Introduction

My name is Karin Swift. I am the President of Women With Disabilities Australia (WWDA), the peak NGO for women with all types of disabilities in Australia. Our 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. WWDA is internationally recognised as a leader in the field of gender and disability, and is increasingly in demand to showcase our critically acclaimed work on the national and international stage, and support and mentor groups and organisations in developing countries. WWDA is pleased to be invited here today to the "Political Participation, Inclusion and Decision Making Roundtable" organised by the Disability Rights Research Collaboration at the University of Sydney. We thank you for this opportunity.

The Convention on the Rights of Persons with Disabilities (CRPD) entered into force in Australia in 2008. At Article 6, it prioritises women with disabilities as a group warranting specific attention, obliging Governments to take positive actions and measures to ensure that disabled women and girls enjoy all human rights and fundamental freedoms. The need to incorporate a gender perspective in all efforts to promote the human rights of people with disabilities is expressly stated in the CRPD.

Australia is also a signatory to six other core international human rights treaties, all of which create obligations to promote gender equality and denounce discrimination against women, including women with disabilities. Gender equality has long been recognised both as a human right and a core development goal. Discrimination against women and girls impairs progress in all other areas of development, and remains the single most widespread driver of inequalities in today's world. Although the Australian Government has consistently articulated its commitment to meeting its obligations under the treaties it has ratified, women and girls with disabilities are yet 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 and grave violations of, their human rights and fundamental freedoms.

Our discussions today are focusing on political participation, inclusion and decision-making, with particular attention on Articles 12, 19, 29, 30 and 33 of the CRPD. Access to decision-making, political participation and representation are essential markers of gender equality. But women and girls with disabilities in Australia are often excluded from, and denied opportunities to participate in decision-making about issues that affect our lives and those of our families, community and nation. Today I will touch on some of the ways this exclusion manifests, and will also highlight the kinds of reforms that are required to create full and meaningful participation and inclusion for disabled women and girls. I will also briefly highlight some activities WWDA has been involved with at an international level as a Civil Society Organisation to promote the participation, inclusion and representation of women with disabilities.

Participation, inclusion and decision-making

Participation of disabled women as citizens is at the basis of the recognition of their dignity. For women and girls with disabilities, participation in social and political life and ensuring an adequate standard of living depends on their access to fundamental social structures such as education, employment, health care, housing, and free enjoyment of the most fundamental human rights, such as the right to sexuality and reproduction and freedom from all forms of violence.

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However, regardless of country or culture, disabled women and girls all over the world, do not have access to the social structures to enable them to enjoy an adequate standard of living. Many are denied the most fundamental rights and freedoms to enable their participation in social and political life on an equal basis as others. They are not treated with dignity and respect, they remain profoundly more disadvantaged than their male counterparts; and are systematically denied opportunities to develop, gain an education and live a full and meaningful life. Instead, they continue to experience multiple forms of discrimination, and widespread, serious violation of their human rights.³

Denial of these rights and freedoms is predicated on the assumption - usually implicit - that there are degrees of being human, and that only the "fully human" are entitled to enjoy the advantages of society and the full protection of its laws. Women with disabilities have typically been perceived as sub-human - lacking such basic human needs as the need for love, intimacy, identity and freedom. Dehumanising conditions - such as those which still pervade many state institutions - have been rationalised on the basis that women with disabilities do not have the same needs and feelings as the "fully human", and hence that they do not need privacy, personal property, recognition, intimacy or freedom of choice. 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.

Although there has been progress in women’s participation in decision-making globally, the representation of women with disabilities in political and public life remains negligible in most societies, including Australia. In some areas, discriminatory and traditional attitudes and practices at the local level limit the space for participation of women with disabilities in political and economic decision-making within their communities. The CEDAW Committee in both its 2006 and 2010 Concluding Observations [Australia] has expressed its concerns at the slow progress in ensuring the equal participation of women with disabilities in leadership and decision-making positions, in public and political life as well as their equal access to education, employment and health. The Committee has re-iterated that the measures taken by the Australian Government to enhance the participation of women with disabilities in public life remains inadequate. The Committee continues to be concerned that Australia does not favour adoption of temporary special measures in the form of compulsory targets and quotas to address the under-representation of women with disabilities in decision-making bodies, in political and public life and the persistent inequality of their access to education, employment opportunities and health care services. The CEDAW Committee has also explicitly recognised that violence against disabled women and girls, and denial of their sexual and reproductive rights, severely limit the opportunities for the participation of women and girls with disabilities in public life. In so doing, the Committee has called on the Australian Government to address these issues.

**CRPD Article 12: Equal Recognition Before the Law**

Article 12 of the CRPD mandates States Parties to recognise that persons with disabilities enjoy legal capacity on an equal basis with others. This means that an individual’s right to decision-making should not be replaced by decision-making of a third party, but that each individual without exception has the right to make their own choices and to direct their own lives, whether in relation to living arrangements, medical treatment, or family relationships. Yet women and girls with disabilities are often denied these choices - due to stigma and discrimination, through judicial declaration of incompetency or merely by a third party’s decision that the individual ‘lacks capacity’ to make a decision.

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.⁴

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For example, ‘incapacity’ is very often used as a valid justification for violations of the sexual and reproductive rights of women and girls with disabilities, through practices such as forced sterilisation, forced contraception, forced abortion, denial of information and education on sexual and reproductive rights, and the denial of maternity, parenting and parental rights. Women with disabilities the world over are discouraged or actively denied the opportunity, to bear and raise children. They have been, and continue to be perceived as asexual, dependent, recipients of care rather than care-givers, and generally incapable of looking after children. Alternatively, women with intellectual disabilities in particular may be regarded as overly sexual, creating a fear of profligacy and the reproduction of disabled babies, often a justification for their sterilisation. These perceptions, although very different, result in women with disabilities being denied the right to reproductive autonomy and self-determination. Recent Australia data demonstrates that a parent with a disability (usually a mother) is up to ten times more likely than other parents to have a child removed from their care, with the child removed by authorities on the basis of the parent’s disability, rather than any evidence of child neglect.

The right to participate in all decision-making processes that affect sexual and reproductive health and development is a basic right of all women, including women and girls with disabilities. Yet, more often than not, many women and girls with disabilities are excluded from participating in decisions that affect their lives on a daily basis, including as active partners in their own sexual and reproductive health care. They are further excluded and ignored in sexual and reproductive health policy, service and program development, including information and education resources.

Australia’s reservation to the CRPD (Article 12, 17, 18) has in fact exacerbated the pervasive violations of the human rights of disabled women and girls, and been used by the Australian Government as a justification to deny disabled women and girls their sexual and reproductive rights. For example, although the monitoring bodies of the core international human rights treaties (including the CRPD) have all found that forced/ involuntary and coerced sterilisation clearly breaches multiple provisions of the respective treaties, the Australian Government has determined that Australia’s obligations are shaped by its reservations made at the time Australia entered into the Convention. Australia’s consent to the provisions of the CRPD was not without caveats. In entering to the treaty, Australia declared its view that the CRPD allows for substituted decision-making and compulsory medical treatment. The recently released report of the Senate Inquiry into Involuntary Sterilisation of People with Disabilities in Australia, used Australia’s reservation to the CRPD to reject the United Nations (and WWDA’s) recommendation 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.’ Instead, the Senate Inquiry Report stipulated that:

In those cases where there is not capacity for consent, and no reasonable prospect that it may develop, laws and procedures may permit the sterilisation of persons with disabilities, but the circumstances in which this may occur must be narrowly circumscribed, and based on the protection and advancement of the rights of the person.

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7 Ibid.
9 This happens in two main ways: a) the child is removed by child protection authorities and placed in foster or kinship care; and b) a Court, under the Family Law Act, may order that a child be raised by the other parent who does not have a disability or by members of the child’s extended family. See: Victorian Office of the Public Advocate (OPA) (2012) OPA Position Statement: The removal of children from their parent with a disability. http://www.publicadvocate.vic.gov.au/research/302/
In early 2013, the UN Special Rapporteur on Torture [and other cruel, inhuman or degrading treatment or punishment], in addressing reproductive rights violations under the torture framework, clarified that forced sterilisation of people with disabilities, regardless of whether the practice is legitimised under national laws or justified by theories of incapacity and therapeutic necessity, violates the absolute prohibition of torture and cruel, inhuman and degrading treatment. The Special Rapporteur further clarified that the grounds on which a medical procedure can be performed without a person’s free and informed consent should be the same for persons with or without a disability. Yet the Senate Inquiry dismissed this, by arguing that the recommendations contained in the Special Rapporteur’s Report “do not include explicit calls for the prohibition of sterilisation without informed consent.” If the Australian Government accepts the recommendations of the Senate Inquiry, it will mean that the Australian Government remains of the view that it is an acceptable practice to sterilise girls and women with disabilities, provided that they lack capacity and that the procedure is in the “best interests”.

CRPD Article 19: Living Independently and Being Included in the Community

One of the biggest barriers to women with disabilities living independently and being included in the community, is the significant systemic failures in legislation, regulatory frameworks, policy, administrative procedures, availability and accessibility of services and support, to prevent and address violence against women and girls with disabilities. Underlying these systemic failures is an entrenched culture throughout all levels of society that devalues, stereotypes and discriminates against women and girls with disabilities, and invariably perpetuates and legitimises not only the multiple forms of discrimination perpetrated against them, but also the failure of governments and other actors to recognise and take action on these violations.

Multiple and intersecting forms of discrimination contribute to and exacerbate violence against women and girls with disabilities. Although women with disabilities experience many of the same forms of violence all women experience, when gender and disability intersect, violence has unique causes, takes on unique forms and results in unique consequences. For many women with disabilities, identification and recognition that violence in their lives is a problem or a crime remains a significant issue. They may have difficulties in recognising, defining and describing the violence; have limited awareness of strategies to prevent and manage it; and lack the confidence to seek help and support. Frequently they do not report the violence, they often lack access to legal protection; law enforcement officials and the legal community are ill-equipped to address the violence; their testimony is often not viewed as credible by the courts; and they are not privy to the same information available to non-disabled women.

Human rights treaty monitoring bodies and special procedures have urged States Parties to address all forms of violence against women and girls with disabilities. For example, in 2010, the CEDAW Committee made very strong recommendations regarding the need for urgent action by Australian governments to address the abuse and violence experienced by women with disabilities living in institutions or supported accommodation. The Australian Government concedes that violence against women with disabilities in Australia is ‘widespread’, that women with disabilities, particularly

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15 Community Affairs References Committee, OpCt. at: para. 3.31, p61.
intellectual disabilities, are extraordinarily vulnerable to violence and abuse, and that disabled women experience significant barriers in accessing domestic violence services and support.\textsuperscript{21} Women and girls with disabilities who live in institutions are at particular and significant risk of violence. Yet violence against women and girls with disabilities, (particularly those who live in institutions) remains largely outside the increasing public debate and policy responses to violence against women.

**CRPD Article 33: National implementation and monitoring**

Human rights standards elucidate the freedoms and entitlements that the Australian Government and other duty bearers must guarantee in order to be answerable to women and girls with disabilities whom their decisions affect. The principles of non-discrimination and equality, participation, and access to information are essential in this context. These cross-cutting norms are expected to guide the State and other duty bearers in their implementation of human rights, including those set out in the CRPD.\textsuperscript{22}

The *participation* of women with disabilities in all areas of public life remains woefully inadequate.\textsuperscript{23} States and other duty bearers must ensure the active, free, informed and meaningful participation of women and girls with disabilities at all stages of the design, implementation, monitoring and evaluation of decisions and policies affecting them, including for example, those relating to sexual and reproductive rights, and prevention of violence. This requires *capacity-building and human rights education* for women and girls with disabilities, and the *establishment of specific mechanisms* and institutional arrangements, at various levels of decision-making, to overcome the obstacles that women and girls with disabilities face in terms of effective participation.\textsuperscript{24}

The empowerment of women with disabilities is achieved principally through women with disabilities coming together to share their experiences, gaining strength from one another and providing positive role models. Women and girls with disabilities, their representative organisations and networks, must be *empowered with sufficient resources, training and opportunities* to effectively participate in shaping and monitoring the policies that affect them, at the national, regional and international levels. Organisations and groups of women with disabilities play a critical role in raising awareness of, and working to address the violations, denials and infringements of their human rights.\textsuperscript{25} In Australia, WWDA is the only national representative CSO for women and girls with disabilities, but with a total workforce of one paid employee and an annual budget of $163,000, WWDA's capacity to promote the participation and inclusion of disabled women and girls, is obviously significantly hampered. *Financial and political support* is therefore urgently needed for the establishment and maintenance of organisations, groups and networks of women with disabilities at international, national, regional and local levels.

Fulfilling the right to *information* is a key prerequisite for the active, free, informed, relevant and meaningful participation of women and girls with disabilities. Yet many women and girls with disabilities are denied the right to seek, receive and impart information about decisions affecting their lives. They are far less likely than their non-disabled counterparts to receive general information or information that is gender and disability-specific, particularly relating to issues such as sexual and reproductive rights, and prevention of violence. They are denied access to information as to how their human rights and freedoms can be enforced and violations remedied. Women with disabilities have limited, if any, input into the development of relevant policies, services and programs, including information and education resources.\textsuperscript{26} Information must therefore be available to women and girls.

\textsuperscript{21} In Frohmader, C. (2011) Op Cit.
with disabilities in a timely, comprehensive, accessible and understandable way so that it can be used to enable women with disabilities to realise their human rights, and to hold duty bearers accountable if those rights are violated.27

As rights-holders, women and girls with disabilities must be in a position to exercise and enforce their human rights, particularly their sexual and reproductive rights, including seeking and receiving effective remedy and redress through impartial, transparent, and prompt processes. Enforcement is critical to setting out clear incentives for those exercising authority to respond to women and girls with disabilities (whose sexual and reproductive rights have been violated by their actions), in a fair, open, timely and efficient manner.

Access to justice and equal recognition before the law are essential to the preservation and advancement of the human rights of women and girls with disabilities. Historically and to this day, many legal systems restrict the legal capacity of women with disabilities solely because of their disability. Women with disabilities experience significant barriers to access to justice, including for example: inaccessibility of courthouses, inaccessible procedures, stereotypes about women with disabilities which operate to exclude or discount their testimony; problems accessing legal representation and protection; assumptions that women with disabilities lack credibility, lack of accessible information and processes, and much more.28

For women with disabilities to fully benefit from the rights enshrined in international human rights treaties and standards, they must have legal capacity and access to justice. States have an obligation to afford full and fair access to the justice system regardless of either a person’s disability or gender.

Promoting accountability for implementation and monitoring of the CRPD

The international human rights normative framework, including the international human rights treaties and their optional protocols, and the general comments and recommendations adopted by the bodies monitoring their implementation, provide the framework to delineate the respective obligations and responsibilities of governments and other duty-bearers in relation to the human rights of women and girls with disabilities. It also provides the framework for civil society organisations such as WWDA to hold Governments accountable for the human rights treaties and instruments they have ratified. It is outside the scope of this paper to detail the many strategies WWDA has employed over the years to promote and indeed demand, accountability from Governments and other duty bearers in relation to the participation, inclusion and representation of women with disabilities. We can however, highlight some of the key strategies we have used and some of the key outcomes we have achieved.

1. Persistence
Regardless of the substantive issue, gaining public recognition of the human rights of women with disabilities, and the violations of these rights, has always been high on our agenda. 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 successive Government’s indifference and inaction on various issues, such as forced sterilisation and violence against women with disabilities. Instead, in difficult times, we have found different ways of working and continually sought out different strategies to get our message out.

2. Utilising international human rights mechanisms
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. Utilising the international human rights mechanisms, and getting our work recognised within the UN, has been critical to WWDA’s work and to our successes. We have:

- contributed to the development of Australia’s NGO Shadow Reports to the UN and written our own Shadow Reports to the UN, which have been formally tabled by both the CEDAW Committee and the CRPD Committee as stand-alone NGO Shadow Reports for Australia;
- participated in UN Treaty Bodies reviews of Australia and other key UN forums, and undertaken direct lobbying and advocacy of Treaty Body Committee members and UN mechanisms;
- lodged formal complaints to Commission on the Status of Women (CSW) and the UN Special Rapporteurs;
- been commissioned by the UN and European Governments to take a leadership role in advancing the sexual and reproductive rights of women and girls with disabilities globally, through for eg: writing Issues Papers on Sexual and Reproductive Rights for the ICPD Beyond 14 Review, and the Post 15 Development Agenda;
- been sought out to provide expertise and technical advice to international human rights Conferences and forums;
- been invited to showcase our work on the international stage at various Conferences, forums, seminars and more, including for eg: the CRPD Committee’s Half Day General Discussion on Women and Girls with Disabilities (2013); the CRPD Conference of States Parties (COSP)(2013), and the International Women Deliver Conference (2013);
- used mainstream fora at the United Nations, in our endeavours to have issues such as forced sterilisation of women and girls with disabilities, and violence against women with disabilities, taken up as major women’s rights issues, rather than have them conceptualised solely as ‘disability’ issues;
- organised and co-sponsored High Level Panels on Women and Girls with Disabilities at the UN through forums such as the 56th and 57th sessions of the Commission on the Status of Women (CSW);
- been invited as an Australian Expert to be part of the Australian delegation to Jakarta, Indonesia (as part of the Australian Indonesia Partnership for Justice Program), to co-facilitate training workshops on the CRPD with Indonesian Government officials and women with disabilities, and to conduct specific training on violence against women with disabilities.

Our work at this level has resulted in many tangible outcomes. For example, treaty monitoring bodies are now explicitly referring to forced sterilisation and violence against women with disabilities in their treaty monitoring reports and recommendations to States Parties. The CRPD Committee has acknowledged WWDA’s work as assisting in their reviews of other States Parties to the CRPD. CSO’s the world over, including disabled persons organisations, are utilising WWDA’s work as a model for their own work, and raising their own profiles at the UN. WWDA’s campaign on forced sterilisation at the UN and the broader international level, along with our long standing national advocacy on the issue, resulted in the Senate Inquiry into Involuntary Sterilisation of People with Disabilities in Australia. This represented a stark shift from four years ago, when the Australian Government formally advised WWDA that the issue of forced sterilisation was not on the Government’s agenda and there would be no reform in the area.29

3. **Formed Strategic Alliances and Partnerships**

Strategic alliances and partnerships are critical to WWDA’s work to keep the Australian Government accountable to the international human rights treaties it has ratified, including the CRPD. Co-operation and collaboration are not only important strategies in their own right, but are incredibly practical strategies for an organisation like WWDA with only one paid employee. WWDA has, for example:

- built a close and productive working relationship with Australian Human Rights Commission;

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formed a productive working relationship with international networks and campaigns, such as the Global Campaign to End Torture in Health Care; the Beyond15 initiative;
is a member of the International Working Group on Forced Sterilisation; the International CSO Reference Group for the ICPD Beyond14 Human Rights Conference; and the International Network of Women and Girls with Disabilities (INWWD);
co-authored and published international journal articles, book chapters, and reports on specific issues facing women with disabilities;
built alliances with other international networks, such as the and the World Health Organisation (WHO); the International Disability Alliance (IDA); and the Centre for Reproductive Rights (CRR);
built effective alliances with academic and research institutions, both within and outside Australia;
worked collaboratively with Australian NGOs & Disabled Peoples Organisations (DPOs) – People with Disability Australia (PWDA).

4. Maximising opportunities to have our voice heard
WWDA has continually sought out opportunities to speak out about the many violations of our human rights, particularly our sexual and reproductive rights, and our right to be free from violence, exploitation, abuse and neglect. We are always somewhat limited by our lack of capacity, however, the activism and goodwill of our members has enabled us to maximise many opportunities. We speak about our issues 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 appear at parliamentary and senate inquiries, and we write hundreds of submissions. 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 Implementation Panel.

5. 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. We have spent more than 15 years methodically building up extensive email distribution lists, and have used these to regularly disseminate information about our work, and to seek support for our causes. We have embraced the Facebook phenomenon and used it to maximise dissemination of information, to simulate debate, and to consult with our constituency. 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.

6. Continually building on our work
Systemic advocacy can be a slow and arduous process. 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 15 years, we have built up our resources, publications, information and research on the human rights of women and girls 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. Making these resources available and accessible to the broadest possible audience, and encouraging other groups and organisations of women with disabilities to utilise WWDA’s work, is important for our mutual understandings and learnings, and helps to promote accountability of States and other duty bearers.

31 Ibid.
32 Ibid.
7. Monitoring developments

Through our extensive networks, alliances and collaborative relationships, we are able to keep abreast of developments occurring in the human rights field, the disability field, and the women’s field. Monitoring the outcomes of other countries UN reporting processes, particularly where gender and disability 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 violations of human rights of women and girls with disabilities, as well as good practice models and strategies for addressing these violations. Importantly, it places our work firmly in a globalised context.\textsuperscript{33}