



Women  
With  
Disabilities  
Australia  
(WWDA)

# WWDA Policy Paper:

## ‘The Role of Advocacy in Advancing the Human Rights of Women with Disabilities in Australia’

April 2008



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# Abbreviations

<b>WWDA</b>	Women With Disabilities Australia
<b>CEDAW</b>	Convention on the Elimination of All forms of Discrimination Against Women
<b>CRPD</b>	Convention on the Rights of Persons with Disabilities
<b>FaHCSIA</b>	Commonwealth Department of Families, Housing, Community Services & Indigenous Affairs
<b>NDAP</b>	National Disability Advocacy Program
<b>ICESCR</b>	International Covenant on Economic, Social and Cultural Rights
<b>CRC</b>	Convention on the Rights of the Child
<b>ICCPR</b>	International Covenant on Civil and Political Rights
<b>SCAG</b>	Standing Committee of Attorneys-General

# 1. About Women With Disabilities Australia (WWDA)

Women With Disabilities Australia (WWDA) is the peak organisation for women with all types of disabilities in Australia. WWDA is run by women with disabilities, for women with disabilities. It is the only organisation of its kind in Australia and one of only a very small number internationally. WWDA is inclusive and does not discriminate against any disability. WWDA is unique, in that it operates as a national disability organisation; a national women's organisation; and a national human rights organisation. The aim of Women With Disabilities Australia (WWDA) is to be a national voice for the needs and rights of women with disabilities and a national force to improve the lives and life chances of women with disabilities.

WWDA addresses disability within a social model, which identifies the barriers and restrictions facing women with disabilities as the focus for reform. More information about WWDA can be found at the organisation's extensive website at: [www.wwda.org.au](http://www.wwda.org.au)

## 2. Introduction

Like many concepts, 'advocacy' is contested and has many different definitions. In Australia, the issue of exactly what 'disability advocacy' is - who should do it, how it should be done, and how it should be evaluated – remains problematic for both those who fund it and those who profess to practice it.

WWDA has previously argued that the way disability advocacy is funded and conceptualized in the Australian policy context, is paternalistic and outdated and has not kept pace with the international shift in perspective from an approach motivated by charity towards the disabled, to one based on rights.

This paper seeks to articulate WWDA's approach to disability advocacy in advancing and promoting the human rights of women with disabilities. It describes critical elements of WWDA's disability advocacy and stresses that developing a sense of personal worth and autonomy for women with disabilities is as equally important a function of advocacy as achieving social inclusion and change.

The paper also looks at how human rights instruments such as the Convention on the Elimination of All forms of Discrimination Against Women (CEDAW) and the Convention on the Rights of Persons with Disabilities (CRPD) can and should be used to inform and guide disability advocacy work. WWDA argues that in translating these powerful human rights instruments into concrete change in the lives of women and girls with disabilities, Governments must establish and support mechanisms and structures which enable women with disabilities to 'do it for themselves', and to act politically as agents in their own right.

The final section of the paper identifies a number of key human rights issues for women and girls with disabilities in Australia and links the issue with the relevant core international human rights treaty. Each issue area is briefly discussed, and the key advocacy outcomes are detailed.

### **3. The Position of Women With Disabilities Australia (WWDA)**

- 3.1.** WWDA ascribes to a model of disability advocacy that enshrines the values, principles and practices of self-advocacy.
- 3.2.** For WWDA, critical elements of disability advocacy include: women with disabilities speaking and/or acting in their own interests; the presence of a collectivity and a basis in self-determination; and a discourse of human rights.
- 3.3.** WWDA's approach to advocacy recognizes that developing a sense of personal worth and autonomy for women with disabilities is as equally important a function of advocacy as achieving social inclusion and change.
- 3.4.** WWDA's systemic advocacy work seeks to reflect and implement a number of international human rights instruments, in particular the Convention on the Elimination of All forms of Discrimination Against Women (CEDAW) and the Convention on the Rights of Persons with Disabilities (CRPD).
- 3.5.** In focusing on the role of advocacy in promoting the human rights of women with disabilities, WWDA's systemic advocacy priorities include:
  - Social inclusion
  - Violence against women with disabilities
  - Sterilisation
  - Removal of babies/children from mothers with intellectual disabilities
  - Parenting & Motherhood
  - Housing Options
  - Access to women's health screening services
  - Research & Data Collection
- 3.6.** In employing a human rights approach and framework to models of disability advocacy for women with disabilities, WWDA recommends that Australian government/s establish mechanisms and structures which enable women with disabilities to 'do it for themselves', and to act politically as agents in their own right. This includes the need to support and strengthen organizations, networks and groups run and controlled by women with disabilities in the pursuit of their collective interests, as defined by them.

## 4. Conceptualising Disability Advocacy

In the Australian context, the term 'disability advocacy' has been deployed by funding bodies within the field as a policy and administrative category (Dowse 2007, FaCSIA 2006). Despite this, conflict occurs within the field as to its definition and boundaries - the issue of exactly what disability advocacy is, who should do it and how it should be evaluated remain problematic for both those who fund it and those who profess to practice it (Dowse 2007, FaCS 1999, FaCSIA 2006, 2007). As Dowse (2007) states: '*Questions about its nature include whether it is a therapeutic intervention, a support service, a community development activity or a political endeavour*'. In Australia, a range of disability advocacy 'models' are funded by the Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) through its National Disability Advocacy Program (NDAP). According to FaHCSIA, the NDAP '*assists people with disability to overcome barriers (i.e. physical access, discriminatory attitudes, abuse, neglect etc.) that impact on their daily life to facilitate their full participation in the community*' (FaHCSIA 2008). Several models are funded (Individual, Family, Citizen, Parent, Self, Systemic) with most of the funding directed to the individual advocacy model through an array of individual advocacy services across the country. The NDAP defines individual advocacy as '*speaking, acting or writing with minimal conflict of interest on behalf of the interests of a person or group, in order to promote, protect and defend the welfare of and justice for either the person or group*' (FaCSIA 2007). It defines systemic advocacy as '*a focus on introducing, influencing or producing broad and/or long term change in the community to ensure the rights of people with disability are attained and upheld*' (FaCSIA 2007).

WWDA has previously argued that the way the Australian Government conceptualizes (and funds) disability advocacy is outdated, paternalistic and inconsistent with a human rights approach (WWDA 2007). The traditionally dominant individual advocacy model and approach is essentially about professionals and others invested with the legitimacy and power to speak and act on behalf of people with disabilities in pursuit of what is deemed 'in their best interest'. In this context, governments remain conditioned by service and charitable models of the past, viewing improvement of the social and material conditions of people with disabilities as a matter to be solved by service systems and the frameworks of professional expertise. As a result, recognition and legitimacy continue to be withheld from people with disabilities (Clear 2000; Dowse 2007).

Dowse (2007) in her major work on self-advocacy and people with intellectual disabilities, unpacked this issue further:

*beliefs about advocacy by and for people with intellectual disability are contested and contradictory. When a person who has an intellectual disability is able to put forward their views, this would be considered speaking on their own behalf or self-advocacy. In such instances their need is not for advocacy on their behalf but for support in sharing their views with others. If on the other hand, the person is actually unable to effectively express their wishes, then advocacy is clearly not about helping them put forward their views, but about something entirely different; that is, either about the advocate assuming what the person might want, or more likely what the advocate thinks is best for the person. In this instance, advocacy is actually about putting forward the views of the advocate cloaked in the voice of the protégé. This kind of paradox and lack of clarity signals the complexity of definitional issues and*

*highlights the assumptions on which thinking about advocacy for people with intellectual disability is based.*

WWDA has argued that disability advocacy should be about providing the mechanisms and structures which enable people with disabilities to 'speak' and/or act for themselves, and to do so in whatever way best suits them (WWDA 2007). WWDA asserts that if conceptualized this way, Self Advocacy would be the dominant model/approach of disability advocacy in Australia. WWDA recognises that the term 'self-advocacy' in relation to disability, is largely understood in the context of people with intellectual disabilities (eg: in Australia) and/or people with learning disabilities (as in the UK). However, WWDA believes that the **values, principles and practices** of self-advocacy have applicability for all people with disabilities, and are consistent with, and enshrine, a human rights framework and approach.

Self-Advocacy, is essentially about people 'speaking' for themselves. Self-advocacy can be a practice which individuals can use to contest oppressive practices and structures within the social world. It can also represent the interests of people with disabilities in a collective manner (Dowse 2007, Dowse & Meekosha 2007). It can enable the formation of personal and collective identities, creating a sense of solidarity, purpose and shared strength. Through the practice of Self-Advocacy, people with disabilities can make a stand for legitimacy and argue for recognition of their self defined interests (Dowse 2007). Importantly, self-advocacy practice can include visibly challenging the meanings others give to disability and questioning the legitimacy of others to interpret 'best interest' (Dowse 2007).

Women with disabilities have made it clear that one of the best ways to challenge oppressive practices, cultures and structures is to join with other women with disabilities - to share experiences, to gain strength from one another and to work together on issues that affect them – describing, researching and recording their issues and experiences, developing programs to address these issues, and working to influence legislative, policy, and service development. This coming together promotes the development of personal identities, where women with disabilities are able to recognise the need for personal autonomy, and importantly, develop a sense of personal worth. At the broader level, it enables the formation of a collective identity, where women with disabilities are able to speak out about their experiences and take action to collectively improve their lives (WWDA 1997, 2000; Duncan & Berman-Bieler 1998).

Systemic advocacy is a vital mechanism for this collective identity to contest oppressive practices and structures within the social world (Dowse & Meekosha 2007). For Women With Disabilities Australia (WWDA), systemic advocacy is '*a process of enabling and supporting women with disabilities to promote, protect, maintain and ensure their human rights and fundamental freedoms*' (WWDA 2007). Systemic advocacy work can employ a range of strategies, which can include: policy and program development; legislation, policy and program review and critique; research; needs identification; consultation; development of resources; community education and awareness; lobbying and legal reform; representation; building alliances and coalitions; information dissemination.

As an organization **of, by and for**, women with disabilities, WWDA ascribes to a model of disability advocacy that enshrines the values, principles and practices of self-advocacy. As a national organisation constituted and run by women with disabilities, WWDA could be described as a self-advocacy organisation which undertakes

systemic advocacy work. That is, it is an organization that enables and represents the collective interests of women with disabilities (self-advocacy) and works at a national and international level to promote, protect, maintain and ensure their human rights and fundamental freedoms (systemic advocacy).

For WWDA, critical elements of disability advocacy include: women with disabilities speaking and/or acting in their own interests; the presence of a collectivity and a basis in self-determination; and a discourse of human rights. WWDA's advocacy approach recognizes that a disabled woman's experience of marginalization and discrimination is likely to be common to others and that action taken to address such oppression can and should be transmuted into action on behalf of others who share similar experiences (Dowse 2007).

**WWDA's approach to advocacy also recognizes that developing a sense of personal worth and autonomy for women with disabilities is as equally important a function of advocacy as achieving social inclusion and change.**

## 5. A Human Rights Approach to Advocacy for Women With Disabilities

There are a number of international human rights instruments that delineate the clear and specific responsibilities of governments to promote the human rights of women, including women with disabilities. Examples include: the Convention on the Elimination of All forms of Discrimination Against Women (CEDAW) and the Convention on the Rights of Persons with Disabilities (CRPD). The need for the universal application to women of the rights and principles with regard to equality, security, liberty, integrity and dignity of all human beings, are enshrined in a number of other international human rights instruments [1].

CEDAW is arguably, the most important human rights treaty for women, yet it does not mention women with disabilities. Recognising this omission, the monitoring body of the Convention passed a general recommendation to ensure that States Parties understand that this instrument also covers the human rights of disabled women. General Recommendation 18 (1991) requests States Parties to provide information on disabled women in their periodic reports and on measures taken to deal with their particular situation [2]. Despite this, signatories to CEDAW have shown scant regard for women with disabilities in their CEDAW Implementation Progress Reports (Quinn & Degener 2002).

The Optional Protocol to CEDAW was adopted in 1999 and contains two procedures: a communications procedure allowing individuals, or groups of individuals, to submit claims of violations of rights to the CEDAW Committee; and an inquiry procedure, enabling the Committee to initiate inquiries into situations of grave or systemic violations of women's rights. Individuals may make communications only if the nation concerned is a party to the protocol. The Howard Liberal Government refused to sign the Optional Protocol to CEDAW, meaning that women with disabilities in Australia were locked out of using an enforcement mechanism to investigate violations of their human rights. The recently elected Australian Labor Party has on the other hand, committed to *'provide Australian women with a new avenue to seek redress of their fundamental human rights where domestic avenues have been exhausted, by signing and pursuing ratification, through domestic treaty-making processes, of the Optional Protocol to the UN Convention on the Elimination of All Forms of Discrimination Against Women'* (ALP National Platform 2007).

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol opened for signature on 30 March 2007. The Convention aims to ensure that persons with disabilities enjoy human rights on an equal basis with others. The CRPD contains a specific Article on Women With Disabilities (Article 6), which recognises that women with disabilities are subject to multiple discrimination, and that States parties will need to undertake a range of measures in guaranteeing the human rights of disabled women. Having signed the CRPD (but not its Optional Protocol), Australia has signaled its intention to *'continue the treaty-making process'* (UN 1999) and is currently undertaking the process of ratification. It is not clear at this stage whether Australia intends to sign and ratify the CRPD Optional Protocol.

The Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), and the Convention on the Rights of Persons with Disabilities (CRPD) both go a long way in affirming the rights and dignity of women with disabilities and are potentially powerful tools in addressing violations of their human

rights. Although they both provide a legal framework for disabled women's rights, they do not automatically confer rights on disabled women. They do, however, afford the opportunity to serve as a potent framework to inform and guide domestic legislation, policy, programs and services that impact on women with disabilities – and importantly, they can create the space for disabled women's agency.

In employing a human rights approach and framework to models of disability advocacy for women with disabilities, WWDA argues that as a priority, governments should establish mechanisms and structures which enable women with disabilities to 'do it for themselves', and to act politically as agents in their own right. This includes the need to support and strengthen organizations, networks and groups run and controlled by women with disabilities (UN 2007) in the pursuit of their collective interests, as defined by them.

The idea of supporting organisations run and controlled by people with disabilities is hardly new. The United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993) clearly articulated the need for States to '*encourage and support economically the formation and strengthening of organisations of persons with disabilities*' [3]. Similarly, Article 29 (Participation in political and public life) of the Convention on the Rights of Persons with Disabilities (CRPD) articulates the importance of forming and supporting organisations run and controlled by people with disabilities.

As a national organisation constituted and run by women with disabilities, and working to promote, protect, maintain and ensure their human rights and fundamental freedoms, WWDA is a critical actor in ensuring the translation of human rights instruments into concrete change in the lives of women and girls with disabilities.

In this context, WWDA's systemic advocacy work reflects the fundamental human rights values of

- dignity (the inestimable value and inherent self-worth of women with disabilities);
- autonomy (the presumption of capacity for self-directed action and behaviour);
- equality (all people are inherently equal in terms of self-worth, regardless of their differences);
- solidarity (social support for freedom and equality)

and deliberately focuses on efforts to realise explicit rights for women with disabilities, including:

- equality before the law without discrimination
- right to life, liberty and security of the person
- freedom from torture, exploitation, violence and abuse
- right to health, work, education, and an adequate standard of living
- right to participate in political, public and cultural life
- right to respect physical and mental integrity
- right to live in the community
- respect for home and the family

## **6. Key human rights issues for women with disabilities in Australia**

There are 4 million people in Australia with a disability, making up 20% of the total population. Just over fifty per cent (50.5%) of people with disabilities in Australia are women. The issues which affect women with disabilities are manifold and include issues related to citizenship, education, employment, housing, violence, health, poverty, telecommunications, motherhood, sexuality, and reproductive rights. Negative stereotypes from both a gender and disability perspective compound the exclusion of women with disabilities from support services, social and economic opportunities and participation in community life (Meekosha 2000; Frohmader 2002). Just some of the key human rights issues facing women with disabilities in Australia are detailed in the following section, along with WWDA's recommended systemic advocacy priorities for each issue area.

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## Social Inclusion

**Core International Human Rights Treaties:** [CRPD: 1 - 31] [CEDAW: 3, Gen Rec 18]  
[ICESCR 6, 7, 11, 13, 15] [ICCPR 25, 26]

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*'To be socially included, all Australians need to be able to play a full role in Australian life, in economic, social, psychological and political terms. To be socially included, all Australians must be given the opportunity to: secure a job; access services; connect with others in life through family, friends, work, personal interests and local community; deal with personal crisis such as ill health, bereavement or the loss of a job; and have their voice heard' (Gillard & Wong, 2007).*

Women with disabilities are, from the government record, one of the most excluded, neglected and isolated groups in society. They suffer manifold discrimination - female, poor and disabled - compounded further by intersections of race and culture. Women with disabilities remain largely invisible and voiceless, ignored by national policies and laws, even though they face multiple forms of discrimination, structural poverty and social exclusion (UNFPA 2005). Their issues and needs are often overlooked within services and programs. They remain marginal to social movements designed to advance the position of women, and the position of people with disabilities. Despite the fact that the Universal Declaration of Human Rights affirms that *'all human beings are born free and equal in dignity and rights'*, there is no doubt that there are widespread and serious violations of the human rights of women with disabilities, as well as failures to promote and fulfil their rights (Byrnes 2003).

### **Systemic Advocacy Priorities – Social Inclusion**

WWDA endeavours to foster the social inclusion of women with disabilities by undertaking systemic advocacy work which promotes:

1. Ratification and Implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) & the CRPD Optional Protocol;
2. Ratification of the Optional Protocol to the Convention on the Elimination of All Forms of Discrimination Against Women (OPCEDAW);
3. Employment of focused, gender-specific measures to ensure that disabled women experience maximum participation in the labour market on the basis of equality;
4. Employment of focused, gender-specific measures to ensure girls and women with disabilities equal access to education and training;
5. Data collection – in all areas, disaggregated by gender & disability, and routinely collected, analysed and published;
6. Research – encompassing qualitative and quantitative methodologies; inclusive of women with disabilities; and findings integrated into relevant national policy;
7. Establishment, support and strengthening of organisations, networks and groups run and controlled by women with disabilities;
8. Provision of information on women with disabilities in CEDAW Periodic Reports and CEDAW NGO Shadow Reports;
9. Establishment of a Parliamentary Committee on human rights and disability.

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## Violence against women with disabilities

Core International Human Rights Treaties: [CRPD 6, 15, 16, 28] [CEDAW 3, 5]

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Despite increasing recognition of, and attention to, gender based violence as the *'most widespread human rights abuse in the world'* (Krug et al 2002), violence against women and girls with disabilities continues to thrive in a culture of silence, denial and apathy. Although the actual prevalence of violence against women with disabilities is unknown, the research that has been conducted indicates that violence against women with disabilities is a problem of epidemic proportions, and that compared to non-disabled women, women with disabilities:

- experience violence at higher rates and more frequently;
- are at a significantly higher risk of violence;
- have considerably fewer pathways to safety;
- tend to be subjected to violence for significantly longer periods of time;
- experience violence that is more diverse in nature; and,
- experience violence at the hands of a greater number of perpetrators.

Yet, despite these facts, legislation, policy and services for women with disabilities experiencing, or at risk of experiencing violence, are limited at best and non-existent at worst (Barile 2002, Curry et al 2001, Nosek 2003, Nosek et al 2001, Powers et al 2002, Hassouneh-Phillips & Curry 2002, Frantz et al 2006, Gilson et al 2001, Zavirsek 2002, NCGV 2004, Cohen et al 2005).

### Systemic Advocacy Priorities – Violence

WWDA endeavours to end and prevent violence against women with disabilities by undertaking systemic advocacy work which promotes:

1. Domestic/family violence law reform – to ensure comprehensive and inclusive legislation and definitions;
2. Data collection – including the National Personal Safety Survey (Australian Bureau of Statistics) to incorporate data collection on violence against women with disabilities;
3. Research – encompassing qualitative and quantitative methodologies; inclusive of women with disabilities; and integration of findings into relevant national policy;
4. Information, Education & Training – including the development of accessible resource materials; development and implementation of learning programs for workers in the disability; family violence; and justice sectors;
5. Development of inclusive and accessible services and programs;
6. Policy Development - including the development of a National Action Plan/Strategy on violence against women with disabilities;
7. Ratification and Implementation of relevant International Conventions and Agreements – including CRPD and the Optional Protocols to CEDAW & CRPD.
8. Conducting of a Royal Commission into the abuse of people living in institutions, both historically and currently.

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## Sterilisation of women and girls with disabilities

**Core International Human Rights Treaties:** [CRPD 5, 6, 7, 12, 15, 16, 17, 23, 25] [ICESCR 10]  
[CEDAW 2, 3, 12, 16, Gen Rec 18] [CRC 2, 6, 12, 19, 23, 24, 37]  
[ICCPR 7, 23, 24, 26]

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WWDA has worked for a number of years on a sustained systemic advocacy campaign asserting WWDA's position that Australian Governments are obliged to develop universal legislation which prohibits sterilisation of children (regardless of disability) except in those circumstances where there is a serious threat to health or life, and refrain from enacting legislation that raises concerns of compatibility with the objects and purposes of a number of international human rights treaties to which Australia is a signatory.

Australia is a party to the International Covenant on Economic, Social and Cultural Rights (ICESC). The Committee on Economic, Social and Cultural Rights in its 1994 General Comment No.5 on 'Persons with Disabilities' referred to the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted by the General Assembly on 20 December 1993, stating that *'persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood.'* The Committee emphasized that *'[b]oth the sterilization of, and the performance of an abortion on, a woman with disabilities without her prior consent are serious violations of article 10 (2) [of the International Covenant on Economic, Social and Cultural Rights].'*

In August 2003, the Standing Committee of Attorneys-General (SCAG) (the national ministerial council made up of the Australian Attorney-General and the States and Territories Attorneys-General), agreed that a nationally consistent approach to the authorisation procedures required for the lawful sterilisation of minors is appropriate. In November 2006, the SCAG released for consultation with selected stakeholders, its draft *Children with Intellectual Disabilities (Regulation of Sterilisation) Bill 2006*. The draft model provisions set out the criteria and procedures that jurisdictions could adopt in authorising the sterilisation of children who have an intellectual disability to the extent that the child is incapable of giving informed consent to the sterilisation procedure.

In its 2006 General Comment No. 9 on the Rights of Children with Disabilities, the UN Committee on the Rights of the Child expressed its deep concern about *'the prevailing practice of forced sterilisation of children with disabilities, particularly girls with disabilities.'* The Committee emphasized that forced sterilization *'seriously violates the right of the child to her or his physical integrity and results in adverse life-long physical and mental health effects.'* The Committee urged States parties to *'prohibit by law the sterilisation of children on grounds of disability.'* In considering Australia's report under Article 44 of the CRC (Fortieth Session), the Committee on the Rights of the Child encouraged Australia to: *'prohibit the sterilisation of children, with or without disabilities...'* (46 (e) CRC/C/15/Add.268, Oct 2005).

In April 2007, after having *'noted the views expressed by stakeholders during the SCAG Working Group's consultation on the draft Bill'*, the Standing Committee of Attorneys-General (SCAG) signaled its intention to continue developing the draft *Children with Intellectual Disabilities (Regulation of Sterilisation) Bill 2006*. In light

of the change of Government in late 2007, WWDA has sought clarification from the Federal Attorney General as to the status of the *Children with Intellectual Disabilities (Regulation of Sterilisation) Bill 2006*.

### **Systemic Advocacy Priorities – Sterilisation**

WWDA endeavours to address issues relating to sterilisation and reproductive health of women and girls with disabilities by undertaking systemic advocacy work which promotes:

1. Reconciliation - to redress the human rights violations against women and girls with disabilities who have been sterilised without their consent;
2. Law Reform – to prohibit the sterilisation of children (regardless of disability) except in those circumstances where there is a serious threat to health or life;
3. Data collection and research – national research (encompassing qualitative and quantitative methodologies) which includes an investigation into the practice of menstrual suppression of girls and women with disabilities;
4. Education, awareness and information dissemination;
5. Implementation of the recommendations from the report *'Moving Forward' - Sterilisation and Reproductive Health of Women and Girls with Disabilities (WWDA 2001)*;
6. Ratification and Implementation of relevant International Conventions and Agreements – including CRPD and the Optional Protocols to CEDAW & CRPD.

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## Removal of babies/children from mothers with intellectual disabilities

**Core International Human Rights Treaties:** [CRPD 5, 6, 13, 23, 25] [CEDAW 16] [ICCPR 23, 23, 24]  
[CRC 2, 7, 9, 18, 25]

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Australian research has shown that parents with intellectual disabilities are disproportionately represented in child protection services and care proceedings (McConnell et al 2000; Swain et al 2002, Booth et al 2005, Young & Hawkins 2006). The research also shows a substantial over-representation of mothers with intellectual disabilities involved in care proceedings. International research shows high rates (40–60 per cent) of child removal from the family home when a parent has an intellectual disability (Booth & Booth 1996). Researchers have concluded without a suitable environment, adequate legal representation and support to comprehend the court process, the parent's voices are not heard resulting in discrimination based on their disabling conditions. The Court's reliance on expert opinion further disadvantages these parents as they are assessed according to diagnosis rather than by their parenting performance. Finally, the absence of suitable support services results in more invasive actions than would otherwise be the case if services were available to assist parents in the community (McConnell et al 2000, Kroese et al 2002, Aunos & Feldman 2002, Woodhouse et al 2001, Newman et al 2005).

It has been shown that being a parent and having an intellectual disability does not inevitably result in child neglect or child abuse – there is no clear relationship between parental competence and intelligence (Booth & Booth, 1993; Sheerin 1998, Willems et al 2007). Intellectual disability does not cause parental inadequacy (Feldman 1994; Tymchuk, 1990). Yet despite this, WWDA continues to receive anecdotal reports from members that their babies have been removed from their care on the grounds the mother has an intellectual disability. In a number of cases, it appears that the decision to remove the baby has been made prior to the birth of the child.

### **Systemic Advocacy Priorities – Removal of babies/children from mothers with intellectual disabilities**

WWDA endeavours to address the issue of removal of babies/children from mothers with intellectual disabilities by undertaking systemic advocacy work which promotes:

1. Law Reform – to prohibit the removal of babies/children solely on the grounds of disability in one or both parent/s;
2. The undertaking of an urgent National Public Inquiry into the removal of babies/children from mothers with intellectual disabilities – to be conducted by the Human Rights & Equal Opportunity Commission (HREOC);
3. Data collection and research – national research (encompassing qualitative and quantitative methodologies);
4. Education, awareness and information dissemination;
5. Development of inclusive and accessible service models to support parents with intellectual disabilities.
6. Ratification and Implementation of relevant International Conventions and Agreements – including CRPD and the Optional Protocols to CEDAW & CRPD.

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## Parenting & Motherhood

**Core International Human Rights Treaties:** [CRPD 5, 6, 8, 19, 23] [CEDAW 16, Gen. Rec 18] [ICCPR 23]

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Many mothers with disabilities who have been interviewed both in Australia and overseas have reported that society doubts that they can perform the job of mothering adequately (Elvish et al 2006; Aunos & Feldman 2002; Blackford et al 2000, Thomas 1997; Blackford 1993, 1999, O'Toole 2002; McKeever, 2003). Historically society has always disapproved of disabled women bearing children marginalizing them by using negative attitudes and by using a barrage of skepticism and prejudicial assumptions relating to an inadequacy when providing care and well-being for their children (Kroese et al 2002; Feldman et al 2002, Prilleltensky 2004). Therefore it is not surprising that parenting by women with disabilities is often seen as a negative experience instead of a positive event and despite the growing number of women in our society who have a disability this attitude still seems to exist.

Over the past two years, WWDA has witnessed a significant increase in contact to the organisation from disabled women who are desperate to find any sort of information/support/service to assist them in their role as mothers and/or potential mothers. It has become evident that this is a major, unaddressed area in Australia for women with disabilities, and covers a wide range of issues – everything from locating adaptable equipment, information on pregnancy & birth, through to accessing assisted reproductive technologies.

### **Systemic Advocacy Priorities – Parenting & Motherhood**

WWDA will endeavour to address the issue of parenting/motherhood and women with disabilities by undertaking systemic advocacy work which promotes:

1. Data collection and research – a three year, national research project (encompassing qualitative and quantitative methodologies) be implemented to develop a clearer understanding of the issues as well as develop strategies to address this unmet need;
2. Establishment of a National Resource Centre for Parents with Disabilities, focusing on pregnancy & birthing, adoption, custody, adaptive baby care equipment, as well as general parenting issues;
3. Development of inclusive and accessible service models to support parents with disabilities;
4. Education, awareness and information dissemination;
5. Ratification and Implementation of relevant International Conventions and Agreements – including CRPD and the Optional Protocols to CEDAW & CRPD.

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## Housing Options

**Core International Human Rights Treaties:** [CRPD 6, 9, 19, 28] [CEDAW 13, 14, Gen. Rec 18] [ICESCR 11]

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It is clear that women with disabilities in Australia are unable to realise their right to 'adequate housing' - security of tenure, availability of services, affordability, habitability, accessibility, location and cultural adequacy. Housing situations are precarious for many women with disabilities. In fact, women with disabilities who are not able to maintain stable housing independently and who need supportive services and accommodations to meet their needs - are considered to be of the highest risk for homelessness. Access to decent accommodation is at crisis point for many women with disabilities in Australia. Secure and appropriate accommodation is critical to a disabled woman, yet there is a shortage of appropriate housing stock for women with disabilities in state based housing, in the private rental market and in real estate. Women with disabilities in Australia face overwhelming obstacles to the realisation of their basic right to 'adequate housing'. Some of these obstacles include: Lack of Income and Vulnerability to Poverty; Discrimination; Lack of Low Cost Housing; Safety/Location; Lack of access to crisis services, such as women's refuges; Additional costs of living with a disability; Deinstitutionalisation; Lack of data.

### **Systemic Advocacy Priorities – Housing**

WWDA will endeavour to address the issue of housing options and women with disabilities by undertaking systemic advocacy work which promotes:

1. Data collection – including the inclusion of a specific disability indicator in the SAAP National Data Collection Agency (NDCA) data collection forms;
2. Research –encompassing qualitative and quantitative methodologies on issues including: options for women with disabilities' choices in housing; affordability; identifying where women with disabilities live; accessibility of public housing stocks; models of co-operative housing;
3. The conducting of a national audit of SAAP funded services to assess accessibility for women with disabilities;
4. Implementation of the Access to Premises Standard;
5. Ratification and Implementation of relevant International Conventions and Agreements – including CRPD and the Optional Protocols to CEDAW & CRPD.

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## Access to Women's Health Screening Services

Core International Human Rights Treaties: [CRPD 6, 9, 19, 21, 25] [CEDAW 12, Gen. Rec 18]

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Studies have shown women with disabilities are less likely than women without disabilities to participate in breast and cervical cancer screening (Davies & Duff 2001; Kroll et al 2006; Wei et al 2006; U.S. Department of Health and Human Services 2004; Verger et al 2005; Cheng et al 2001, Piotrowski & Snell 2007). All women have barriers to screening, which include time constraints, costs, childcare, language and literacy differences, lack of knowledge and cultural differences. Women with disabilities face these and many additional barriers, including:

- inadequate access to facilities and equipment
- difficulty positioning for examinations
- lack of provider knowledge and insensitivity to needs
- lack of accessible transportation
- lack of knowledge about provider accessibility
- negative and discriminatory attitudes towards disability

Breast cancer is the most common cancer for females in Australia, and is the leading cause of death from cancer in females. The risk of developing and dying from breast cancer increases with age and this risk is highest for women aged over 70 years. Women with disabilities are as likely, statistically, to develop cervical cancer as women without disabilities (Temby 1996). There is no data collected in Australia on uptake rates of breast and/or cervical screening for women with disabilities, despite the fact that women with disabilities are one of the most under-screened groups of women in Australia (Temby 1997, Frohmader 1998).

In February 2006, the United Nations Committee on the Elimination of All forms of Discrimination Against Women (CEDAW), in assessing the Australian Government's CEDAW Implementation Report '*Women in Australia*', expressed its concern at the lack of attention given by the Australian Government to disabled women, including in relation to their access to health services: '*...The Committee [also] recommends that the State party develop the necessary infrastructure to ensure that disabled women have access to all health services.*' (CEDAW/C/AUL/CO/5, 2006)

### **Systemic Advocacy Priorities – Access to Women's Health Screening Services**

WWDA will endeavour to address the issue of access to women's health screening services and women with disabilities by undertaking systemic advocacy work which promotes:

1. Data collection – including inclusion of disability indicators in national breast screen and cervical cancer data collection programs;
2. Research – encompassing qualitative and quantitative methodologies; incorporating issues such as screening rates and the prevalence of barriers to screening to women with disabilities;
3. Information, Education & Training – including the development of accessible resource materials;

## **Systemic Advocacy Priorities – Access to Women’s Health Screening Services (cont’d)**

4. Development of inclusive and accessible services and programs;
5. Policy Development - including the development of a National Action Plan/Strategy on Promoting Women With Disabilities’ Access to Women’s Health Screening Services;
6. Development of alternative protocols and techniques for clinical care;
7. Investigation of mechanisms to ensure compliance with RACGP Standards for General Practices (3rd Edition) Criterion 5.1.3 (Indicator 4): ‘provision of adjustable height examination beds’;
8. Ratification and Implementation of relevant International Conventions and Agreements – including CRPD and the Optional Protocols to CEDAW & CRPD.

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## Research and Data Collection

**Core International Human Rights Treaties:** [CRPD 4, 6, 31 ] [CEDAW Gen. Rec 18, ]

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Over the last decade, WWDA has found that one of the greatest difficulties in determining the needs and wishes of women with disabilities is the acute lack of available gender and disability specific data in Australia – at all levels of Government and for any issue.

Comprehensive research and data collection encompasses both quantitative and qualitative methodologies and in the Australian context, includes national, state/territory, regional, local and service levels. Of paramount importance, is the need for all aspects of research to include women with disabilities. This entails the funding and empowerment of groups and organisations of women with disabilities, to undertake their own research in order to include their own experiences of issues, and their recommended strategies to address these issues (Calderbank 2000, DAA 1997).

In February 2006, the United Nations Committee on the Elimination of All forms of Discrimination Against Women (CEDAW), in assessing the Australian Government's Report 'Women in Australia' (the combined Fourth and Fifth Reports on Implementing CEDAW), expressed its concern at the lack of attention given by the Australian Government to women with disabilities. The Committee states:

*'.....The Committee regrets the absence of sufficient information and data on women with disabilities. The Committee requests the State part to include adequate statistical data and analysis, disaggregated by sex, ethnicity and disability, in its next report so as to provide a full picture of the implementation of all the provisions of the Convention. It also recommends that the State Party regularly conduct impact assessments of its legislative reforms, policies and programmes to ensure that measures taken lead to the desired goals and that it inform the Committee about the results of these assessments in its next report.'*

(CEDAW/C/AUL/CO/5, 2006)

### **Systemic Advocacy Priorities – Research & Data Collection**

WWDA will endeavour to address the issues of research and data collection and women with disabilities by undertaking systemic advocacy work which promotes:

1. Data collection – in all areas, disaggregated by gender & disability, and routinely collected, analysed and published;
2. Research – encompassing qualitative and quantitative methodologies; inclusive of women with disabilities; and findings integrated into relevant national policy;
3. Establishment, support and strengthening of organisations, networks and groups run and controlled by women with disabilities;
4. Provision of information on women with disabilities in CEDAW Periodic Reports and CEDAW NGO Shadow Reports;
6. Ratification and Implementation of relevant International Conventions and Agreements – including CRPD and the Optional Protocols to CEDAW & CRPD.

## Endnotes

- [1] See for example: the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT), and the Declaration on the Elimination of Violence Against Women (1993).
- [2] General Recommendation No. 18 (tenth session, 1991) of the on the Convention on the Elimination of All forms of Discrimination Against Women (CEDAW) recommends:
- '.....that States parties provide information on disabled women in their periodic reports, and on measures taken to deal with their particular situation, including special measures to ensure that they have equal access to education and employment, health services and social security, and to ensure that they can participate in all areas of social and cultural life.'*
- [3] Rule 18 of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993) identifies the various roles of such organisations, and includes:
- Representation of people with disabilities;
  - Participation in the development of disability policy;
  - Identification of needs and priorities;
  - Participation in the planning, implementation and evaluation of services and measures concerning the lives of persons with disabilities;
  - Public awareness to advocate change;
  - Skill development, mutual support, information sharing

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