



‘Parenting Issues for Women with Disabilities in Australia’

A Policy Paper by Women With Disabilities Australia (WWDA)

May 2009



Winner, National Human Rights Award 2001
Winner, National Violence Prevention Award 1999
Winner, Tasmanian Women's Safety Award 2008
Certificate of Merit, Australian Crime & Violence Prevention Awards 2008
Nominee, French Republic's Human Rights Prize 2003
Nominee, UN Millennium Peace Prize for Women 2000

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Cover photo: Alison Lapper Pregnant, Sculpture by Marc Quinn, Trafalgar Square, London (2005-2007).
This page: Alison Lapper 'Pink Hands' www.alisonlapper.com

Alison Lapper, British artist, was born in 1965 without arms and shortened legs, the result of a medical condition called phocomelia. The first 19 years of her life were spent in residential institutions for people with impairments and the story of those years and her subsequent success as an artist and public figure can be found in her autobiography, My Life in My Hands.

Sources: <http://publicheart.wordpress.com/2008/11/01/alison-lapper-pregnant>
www.alisonlapper.com

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1. Introduction

The *Universal Declaration of Human Rights* (UDHR) recognises the ‘family’ as the ‘natural and fundamental group unit of society’ (Article 16). The right to ‘found a family’ and to ‘reproductive freedom’ is clearly articulated in a number of international human rights instruments to which Australia is a signatory. However, for many women with disabilities in Australia, such fundamental human ‘rights’ are not realisable. Instead, women with disabilities have traditionally been discouraged or denied the opportunity, to bear and raise children (Prilleltensky 2003). 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 (Collins 1999, Farber 2000, Prilleltensky 2003, McKeever et al 2003, Smeltzer 2007, McKay-Moffat 2007, Radcliffe 2008).

The denial of the right to reproductive freedom takes many forms for women with disabilities – coerced abortions, pressure to undergo tubal ligations and hysterectomies, unlawful sterilisation, systematic denial of appropriate reproductive health care and sexual health screening, limited contraceptive choices, a focus on menstrual control, poorly managed pregnancy and birth, and the denial of rights to be a parent based solely on the fact of disability (Dowse & Frohmader 2001, Kallianes & Rubinfeld 1997, Prilleltensky 2003, Gill 1996).

For women with disabilities, the right to reproductive freedom includes the right to sex education, to informed consent regarding birth control, to terminate a pregnancy, to choose to be a parent, and to access reproductive information, resources, medical care, services, and support (Collins 1999). A central tenet to the concept of reproductive freedom is the right of individual choice – the right of women to make informed choices about their bodies without bias and coercion. However, for women with disabilities these choices are often influenced and restricted by their social realities which can include: poverty, lack of education, lack of information and research, lack of services and supports, discrimination, and lack of public awareness and understanding regarding disability issues (Collins 1999).

This paper seeks to examine one area where women with disabilities experience restrictions in realising their rights to full reproductive freedom – their right to parent. The paper will canvass issues relating to parenting for women with disabilities in Australia, and stems from the identified concerns of the members of Women With Disabilities Australia (WWDA)¹, along with the dearth of Australian research in the area. At the same time WWDA recognises the right of women with disabilities to choose not to become parents, and that this decision should be able to be reached by each individual

¹ 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 and operates as a national disability organisation; a national women’s organisation; and a national human rights organisation. WWDA represents more than 2 million disabled women in Australia; is inclusive and does not discriminate against any disability. The aim of 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. More information about WWDA can be found at the organisation’s extensive website at: www.wwda.org.au

woman in a way untrammelled by extraneous societal pressures and prejudices. The paper will include key recommendations to the Australian Government, in particular to the Australian Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), which is the Australian Government's principal source of advice on social policy.

Key Recommendations

In light of the paucity of Australian research, resources and support for women with disabilities who are parents, or seeking to become parents, coupled with the restrictions they face in realising their rights to full reproductive freedoms, WWDA recommends that the Australian Government:

1. Fund a three year, national research project (encompassing qualitative and quantitative methodologies) on the parenting experiences of women with disabilities in order to develop a clearer understanding of the issues as well as allowing women with disabilities to speak their history and give voice to a human rights issue that to date, has been largely ignored in relevant legislation, policy, and services.
2. Collect appropriate statistical and research data on the number of parents with disabilities in Australia, disaggregated by gender and other relevant variables, in order to guide and inform policy, direct funding, and inform service development.
3. Establish, and recurrently fund a National Resource Centre for Parents with Disabilities, focusing on pregnancy & birthing, adoption, custody, assisted reproduction, adaptive baby-care equipment, as well as general parenting issues.
4. Urgently address the over-representation of parents with intellectual disabilities in care and protection proceedings. This should include as a priority, a National Public Inquiry into the removal and/or threat of removal of babies and children from parents with intellectual disabilities; parents with mental health illnesses and parents with psychiatric disabilities.
5. Act immediately to investigate and address the barriers to reproductive autonomy and procreative choice for women with disabilities. This should include as a priority:
 - addressing discrimination in legislation and protocols dealing with access to, and eligibility for, assisted reproduction technologies (ART's);
 - the development of universal legislation which prohibits sterilisation of children with disabilities except in those circumstances where there is a serious threat to health or life. In the case of adults, sterilisation must be prohibited in the absence of the informed consent of the individual concerned, except in those circumstances where there is a serious threat to health or life.
6. Focus on separating disability policy and disability support from family carer policy and support in order to increase the autonomy of women with disabilities and challenge the stereotype of women with disabilities as burdens of care.

In addition to these actions specific to enabling and improving the experience of parenting for women with disabilities, a raft of other actions must be initiated and/or continued in order to address the inequities and barriers which currently deprive women with disabilities of full and equal participation in Australian society. WWDA recommends that the Australian Government:

7. Ensure that information on women with disabilities is provided in the Periodic Reports of relevant human rights treaties, as a matter of course. This must include information on the situation of women with disabilities under each right, including their current de-facto and de jure situation, measures taken to enhance their status, progress made and difficulties and obstacles encountered.
8. Establish mechanisms and structures which enable women with disabilities to have their voices heard, and to act politically as agents in their own right. This includes the need to support and strengthen organisations, networks and groups run and controlled by women with disabilities in the pursuit of their collective interests, as defined by them.
9. Support and fund national research into the recognised markers of social exclusion for women with disabilities, including: socioeconomic disadvantage, social isolation, multiple forms of discrimination, poor access to services, poor housing, inadequate health care, and denial of opportunities to contribute to and participate actively in society.

2. Gender & Disability

There are now more than 2 million women with disabilities in Australia, making up 20.1% of the population of Australian women. As a group, women with disabilities in Australia experience many of the now recognised markers of social exclusion² - socioeconomic disadvantage, social isolation, multiple forms of discrimination, poor access to services, poor housing, inadequate health care, and denial of opportunities to contribute to and participate actively in society.

Although there has been limited research in Australia on the issues facing women with disabilities, we know that women with disabilities experience multiple discriminations as a result of the intersection of gender and disability, giving them little chance of recognising fully their human rights and fundamental freedoms. Compared to non-disabled women, women with disabilities:

- are less likely to be in paid work;
- are in the lowest income earning bracket;
- spend a greater proportion of their income on medical care and health related expenses;
- are less likely to receive appropriate health services;
- are substantially over represented in public housing and more likely to be institutionalised;
- are often forced to live in situations in which they experience, or are at risk of experiencing, violence, abuse and neglect;
- are more likely to be unlawfully sterilised;
- are more likely to face medical interventions to control their fertility;
- are more likely to be assaulted, raped and abused;
- are at particular risk of severe forms of intimate partner violence;
- are more likely to experience marriage breakdown and divorce;
- are less likely to have children;
- are more likely to be single parents.

(Sources: Barrett et al 2009; Barranti & Yuen 2008, Meekosha 2004, Beleza 2003, Malacredia 2009)

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) – including their right to parent.

² Social exclusion is a process that deprives individuals and families, groups and neighbourhoods of the resources required for participation in the social, economic and political activity of society as a whole. This process is primarily a consequence of poverty and low income, but other factors such as discrimination, low educational attainment and depleted living environments also underpin it. Through this process people are cut off for a significant period in their lives from institutions and services, social networks and developmental opportunities that the great majority of a society enjoys (Vinson 2009)

3. Parenting, Gender & Disability- The Context

Much of the internationally published literature on parenting and disability remains embedded in a medical model of disability, which is individualistic, attributing disability to the body's inability to function in a 'normal' way (Radcliffe 2008). The vast majority of this literature focuses only on practical 'help' to relieve the physical 'problems' posed by the parent's disability (SCIE 2005). This conventional, individualistic view revolves around issues of individual impairment, individual coping and risk, and according to Thomas & Curtis (1997) often leads to questions such as: 'can a disabled woman 'cope' with pregnancy or childcare? Will her impairment allow her to meet the needs of a baby or young child? If there is a danger that the woman's medical condition is hereditary, then how can the disabled woman best be prevented from conceiving? What kinds of aids and adaptations are available to assist such women?' Thomas & Curtis (1997) argue that, although well intentioned, this view reinforces notions that impairment may mean that disabled women need a great deal of additional and *professionally determined* help through pregnancy and early motherhood.

In contrast, viewing parenting and disability through a disability rights or socio-political lens, asserts that disability is the restriction of activity which is caused not so much by impairment, but by social barriers which prevent people with disabilities from experiencing full social inclusion (Oliver 1996). From this perspective, rather than looking at issues relating to individual coping and risk in relation to parenting and disabled women, the questions become: what are the attitudinal, institutional and environmental barriers women with disabilities face when they think about having a child, become pregnant, come into contact with maternity and related services, and when they become parents? (Thomas & Curtis 1997).

Whilst the voices and experiences of women with disabilities are almost non-existent in the literature on reproduction and parenting, work in the area of disabled women's parenting experiences is starting to emerge, much of it being undertaken by women with disabilities themselves (Morris 1992, Crow 2003, Thomas 1997, Prilleltensky 2003, Neville-Jan 2004). Overall, most research focusing on parenting and maternity experiences of women with disabilities comes from North America and the United Kingdom, with limited work available concerning the issue in developing countries and across cultures.

Unfortunately, in Australia, there is virtually no published literature or known studies on the maternity and parenting experiences of women with disabilities³. The majority of research around parenting and disability in Australia has been conducted by Professor Gwynnyth Llewellyn and Associate Professor David McConnell of the Australian Family and Disability Studies Research

³ Westbrook & Chinnery (1995) undertook a small study into the effect of physical disability on women's childbearing and early childrearing experiences. 25 women with physical disabilities participated in the survey study, which found that community attitudes rather than their physical limitations caused the major problems for mothers with disabilities.

Collaboration (AFDSRC)⁴, and has focused almost exclusively on parents with intellectual disabilities. Their research studies have focused on issues such as the over-representation of parents with intellectual disability in care and protection proceedings; the threat of child removal; parenting capacity; parent training programs; support networks; and the contextual factors that influence the success or otherwise of intervention programs (see for example: Llewellyn & McConnell 2002, 2005, Llewellyn, McConnell, & Ferronato 2003, Mayes, Llewellyn, & McConnell 2006, 2008, Wade, Llewellyn, & Matthews 2008, Llewellyn, Mayes, & McConnell 2008).

⁴ The Australian Family and Disability Studies Research Collaboration is part of the Faculty of Health Sciences, University of Sydney. The AFDSRC Team is made up of a number of professionals from a range of disciplines - occupational therapy, psychology, social work. See: www.afdsrc.org

4. Parenting, Gender & Disability- The Issues

Women with disabilities who are parents, or seeking to become parents, face economic, social and environmental barriers to their parenting role in both the public and private spheres. Barriers such as poverty, un/underemployment, inaccessible housing and public environments, social isolation, multiple forms of discrimination, poor access to services, heightened vulnerability to violence and abuse, policies that fail to serve families adequately, along with the widely held belief that women with disabilities are 'naturally' unsuited to motherhood/parenthood, all comprise a disablist culture for women with disabilities who are parents, or seeking to become parents (Malacredia 2009).

It is outside the scope of this paper to detail the myriad of issues impacting on women with disabilities who are parents, or seeking to become parents. The following section therefore canvasses a number of the key issues which have been raised by the members of Women With Disabilities Australia (WWDA).

"No one ever told me point-blank I couldn't have children. Nobody had to say it in words. From childhood on, I heard the message in a subtext of denials and omissions." Radcliffe 2003

"When I'm out with my girls, people don't expect that I'm their mother." Armstead 2003

"If we do have a child we get asked if it is ours, "Who is the parent?" "Where is the parent?" or "Why are you holding it?" O'Toole & Doe 2002

"...the association is easily made between being seen as different and being seen as problematic. And so, from a disabled parent's point of view, doing one's best to appear normal may seem like the safest route to a family life free from unwelcome intervention" CSCI 2009

4.1. Discriminatory attitudes and prejudicial assumptions

Parenting remains an attitudinal minefield of bias for women with disabilities and an area in which they are likely to encounter significant prejudice and discrimination. Although there has been virtually no research in Australia on parenting and women with disabilities, researchers overseas have found that parents with disabilities - particularly women with disabilities - experience prejudice about their rights and abilities to parent (Toms Barker & Maralani 1997, Kirshbaum 2000, Aunos & Feldman 2002, McKeever et al 2003, Mazur 2006, Rogers 2006, Gutman 2007, Smeltzer 2007). Anecdotal evidence from women with disabilities in Australia indicates similar experiences.

Women with disabilities have traditionally been discouraged from, or denied the opportunity to bear and raise children. They have been seen as child-like, asexual or over-sexed, dependent, incompetent, passive, and genderless (Prilleltensky 2003, Waxman 1999, Collins 1999, McKeever et al 2003, Smeltzer 2007, McKay-Moffat 2007, Radcliffe 2008) and therefore considered inadequate for the *'nurturant, reproductive roles considered appropriate for women'* (in Collins 1999).

Women with disabilities considering having and/or raising a child are often subjected to the sceptical beliefs of family members, health practitioners, and even complete strangers, regarding their ability to care

for a child (Smeltzer 2007). They can therefore feel that they have to work harder than non-disabled parents in order to be accepted as competent. In fact, several researchers have found that many women with disabilities experience such fear of being judged 'inadequate' as a parent (and of the consequences this might bring), that they go to extraordinary lengths to present themselves and their children as managing and competent – often at significant personal cost in terms of comfort, emotional and physical well-being (McKeever et al 2003, Prilleltensky 2003, SCIE 2005, Thomas 1997, Grue & Laerum 2002, Malacredia 2009).

"I was so scared social services would take my child away because of feeding him on the floor...I was really scared because I wasn't doing things the normal way if you like, that they'd take him away."
Radcliffe 2008

"The only emotional problem was my family...There was a lot of animosity..... They were scared and worried about the future." *Blackford 2000*

A study undertaken by Grue & Laerum (2002) found that disabled mothers who had asked for practical help found that this was sometimes used against them as 'proof' that they were inadequate mothers. As a consequence, many women with disabilities feel the need to demonstrate a better than ideal performance of motherhood in order to pass as socially acceptable, and hence do not request or accept assistance because it contradicts social and internalised conceptions of what constitutes 'good parenting'.

4.2. Lack of access to information, services and support

Research from overseas has found that women with disabilities who are parents, or seeking to become parents, report great difficulty in accessing appropriate information, services and support (McKeever et al 2003, Lee & Oh 2005, Preston 2005, Preston 2009, Collins 1999, Blackford 1993, 1999, Rogers 2006, Radcliffe 2008, Malacrida 2007, 2009, McKay-Moffat 2007) in a wide range of areas. There is a dearth of suitable information on preconception, pregnancy, birth, postpartum, and the varying stages of child rearing (eg: infancy; early childhood; adolescence), as well as in areas such as adoption, assisted reproduction, and broader sexuality and reproductive health issues and care. A significant number of anecdotal reports to WWDA suggest that this lack of information, services and support is also a major, unaddressed issue for Australian women with disabilities. Feedback from WWDA members suggest that it often comes down to informal conversations with other disabled parents and/or the luck of the draw with professionals as to whether relevant information is given. Women with disabilities report that disability services are not knowledgeable of pregnancy related issues, and often refer them onto maternity and health-care services. Such services however, have significant shortcomings in dealing with the dual factors of pregnancy and disability (WWDA 2007, Prilleltensky 2003, Gavin et al 2006, RCN 2007). According to Prilleltensky (2003) *'.....while the medical system has a long history of managing illness and disability, it is literally in its infancy when it comes to dealing with the reproductive issues of women with disabilities.*

Consequently, women with disabilities are often “groping in the dark” as they attempt to gain information about pregnancy in the context of disability.’

“I am really upset with the MS Society. They acted like, “YOU had a baby?”.....I asked if there was any literature I could read about, you know, parents with disabilities and any referrals they could give me and he says, “No, we don’t have anything, there is just nothing.” I said, “So you’re just saying I’m on my own?”.”

In Lipson & Rogers 2000

“We would like a carer who is a qualified child carer as well so I don’t get told, ‘Can’t touch your child’.” *CSCI 2009*

“It has taken a lot more research to find these products than I would expect it to take non disabled parents to decide what pram/cot to use. Our choices are much more limited.”

Radcliffe 2008

“Ante-natal classes obviously relied heavily upon visual material although the lady who ran it was very helpful and would describe things to me. All maternity info.....provided was not in an accessible format and this was not offered.”

Radcliffe 2008

For many women with disabilities, parenthood is not a viable option when social and financial supports are not available. Women with disabilities in Australia have reported undergoing termination of much wanted pregnancies solely on the grounds of lack of such supports (WWDA 2007).

Until such time as planners of family-related policy consciously recognise the existence of women with disabilities as parents and/or potential parents, and indeed rightful beneficiaries of family related policy and programs, the needs of these parents and of their children will continue to be overlooked (Blackford 1993).

The lack of financial support, coupled with the higher cost of parenting with a disability has been identified by a number of researchers as a significant barrier to women with disabilities who are parents, or seeking to become parents (McKeever et al 2003, Prilleltensky 2003, SCIE 2005, Collins 1999, Blackford 1993, Lee & Oh 2005, Preston 2009, Preston 2005). Disabled parents incur substantial additional costs as a consequence of being both disabled, and having parental responsibilities. Income support systems (such as disability support pensions and family assistance benefits) do not recognise the extra costs incurred by disabled parents, which are different from – and often greater than – those incurred by disabled people who do not have children, and by non-disabled parents. Such extra costs can include those related to: child care, transport, cleaning, heating, laundry, food, security & safety, going out with children, holidays, assistive technology and communication; and adaptations to or equipment for the home (SCIE 2005, Preston 2005).

A significant barrier for women with disabilities who are in a parenting role and require service support, is the often inflexible boundaries of elements of the service system, such as those services available to assist adults, and those available to assist children. Children’s services tend to focus exclusively on assessing children’s needs and welfare, including child protection issues; whereas adult services tend to focus only on the provision of personal services to disabled adults (SCIE 2005). For example, women with disabilities who are in a parenting role and require

attendant/personal care have reported frustration that policies around attendant carers do not permit the attendant to assist the disabled woman in performing child care duties. A study undertaken by McKeever et al (2003) found that agencies that provided personal and homemaking services clearly viewed women as clients in need of individual assistance and often overlooked or refused to support their mothering roles.

Women with disabilities have called for direct payments (such as those advocated by In Control⁵) to enable them to arrange help to suit their own needs, rather than having to accept support from service providers that they consider to be rigid and inflexible (SCIE 2005).

The lack of appropriate, adapted equipment to help disabled women in their parenting, especially of babies and young children, is a constant theme of the research which has been undertaken overseas (McKeever et al 2003, Kirshbaum 2000, Preston 2009). Anecdotal evidence to WWDA suggests that this is also a significant obstacle for Australian women with disabilities who are parents, or seeking to become parents. The absence of commercially available adapted infant furniture and equipment can have a profound influence on the amount of extra time, planning and labour required by these women (McKeever et al 2003).

Policy makers, service providers and the broader community have limited understandings of accessibility, believing it requires only a ramp or an accessible toilet (Frantz et al 2006, Safe Place 2005, WWDA 1997, 1999). In fact 'accessibility' has much wider meaning, including being able to receive all service and program information in an accessible format. Experience of Australian community support services suggests that access of this kind is very limited both in terms of appropriate content (i.e. that reflects the experiences of disabled women) and format of information available (such as Braille, audio, Easy English and the use of telephone access relay services and sign interpreters (WWDA 2007b).

Another dimension of access includes being able to understand and meaningfully participate in the services and programs available. Again experience suggests that women with disabilities generally have limited input into the development of services and programs, including information and education resources (WWDA 2007b). The lack of appropriate, accessible information on all aspects of childbearing and childrearing, is an area where women with disabilities who are parents, or seeking to become parents experience significant barriers (Radcliffe 2008).

⁵ In Control was established in the UK in 2003 in order to find a better way of organising support services for disabled people and older people. In Control developed the concepts of Self-Directed Support, Individual and Personal Budgets, Support Planning and Resource Allocation Systems and many other new ways of organising services. These ideas are increasingly being adopted by local and central government (www.in-control.org.uk). In Control has recently been established in Australia (www.in-control.org.au).

4.3. Dependence versus Independence

Embedded in both patriarchy and ableism is the apparently clear-cut division between dependence and independence, between those who 'care' and those who are 'cared for' (Prilleltensky 2003). This division has contributed to the depiction of women with disabilities as residing exclusively on the receiving end of care and support. A number of researchers have found that women with disabilities who are parents are stereotyped as people in need of personal assistance, and rarely as parents who provide it (McKeever et al 2003, Radcliffe 2008, Prilleltensky 2003, Williams & Robinson 2001). The dichotomy between the 'carer' and the 'cared for' is reflected in community care legislation, policies and programs which provide services to individuals on the basis that they are either a 'disabled person' or a 'carer' (Williams & Robinson 2001). There is no provision of services which will support a disabled woman in her role as the carer. In relation to women with disabilities who are parents, there exists a contentious debate around the idea that their children will automatically have to assume the role of carer, thus reversing the traditional role of the care giver and the cared for.

"...the problems we face are because there is a perceived contradiction between being a parent and being disabled, as if you can't actually be both." CSCI 2009

"It is both unhelpful and unrealistic to assume that there is an uncomplicated dividing line between dependency and independence." Keith 1992

"Service providers consider other family members of disabled people as carers and therefore prevent disabled people having a decent and independent life." ECNI 2003

A number of studies on children of disabled parents conclude that they are at-risk for 'parentification' – assuming adult roles before they are emotionally or developmentally ready (in Preston 2009). This assumption that children of disabled parents will be parentified is pervasive and continues to persist in research as well as legal and custody proceedings (Preston 2009, Malacredia 2009, Mullin 2006, Olkin 2000, Radcliffe 2008, Gutman 2007). Olkin (2000) suggests that there are four problems with the assumption that children of parents with disabilities are parentified: 1) it is based on prejudice; 2) it is presumptuous; 3) it ignores cultural and socioeconomic differences in the expectations for children's helping behaviours; and 4) it is not supported by recent research. In fact, recent studies have found that: women with disabilities who are parents frequently take on increased responsibilities and risks rather than ask their children for assistance (Morris & Wates 2006, Cohen 1998, Tuleja & DeMoss 1999, Radcliffe 2008, Grue & Laerum 2002, Kirschbaum & Olkin 2002, Mazur 2006); adolescents of disabled parents perform the same number of household tasks as adolescents of non-disabled parents (Olkin et al 2006); some responsibilities are appropriate and perfectly reasonable (McKeever et al 2003, Grue & Laerum 2002, Olsen and Clark 2003); and the availability of resources is an important mitigating factor in the degree and type of assistance required within the family (McKeever et al 2003, Preston 2009, Radcliffe 2008). A study undertaken by McKeever et al (2003) into the conditions and experiences of mothers who used wheelchairs and scooters for full-time mobility, found that it was often the

unsuitability of the home and community care services, rather than the nature of the mother's disability, which necessitated the suspect provision of personal and homemaking care by children.

It continues to be a criticism that a focus on 'young carers' diverts attention from the substantial ways in which the physical and social environments, together with a lack of services, amenities and resources impede women with disabilities who are parents (McKeever et al 2003, Olkin 2000). Olsen & Clarke (2003) also make the point that the label 'young carer' has been created by adults and professionals and does not necessarily reflect the way the children see themselves or their role within the family.

4.4. Service providers lack of knowledge and understanding of disabled women's maternity needs

A number of studies from overseas suggest that the maternity and health care needs of pregnant women with disabilities are not being met (Lipson & Rogers 2000, Prilleltensky 2003, Radcliffe 2008, Blackford et al 2000, Gavin et al 2006, Morris & Wates 2006, Topp 2004, Preston 2009). These studies have identified a range of barriers to maternity care for women with disabilities, including: medical/health care providers' lack of knowledge and experience on how to manage the pregnancy; medical/health care providers' lack of knowledge and experience on how to manage the women's disabilities; lack of coordination among these providers; inaccessibility of maternity and obstetric services and equipment; negative attitudes from medical/health care providers; and lack of referral to appropriate agencies (Gavin et al 2006). Women with disabilities in Australia report similar barriers (WWDA 2007). It is interesting to note that there are virtually no studies or information on the positive experiences of women with disabilities who access maternity/obstetric services, yet anecdotally such experiences do exist.

A major, national US survey of parents with disabilities was undertaken by Through the Looking Glass⁶, in 1997. This yielded data from a national sample of 1,200 parents with diverse disabilities. In relation to pregnancy, maternity and birthing issues, the survey found that 44% of disabled parents reported that pregnancy and birthing for themselves or their partner was an issue affected by their disability; 36% reported that the providers' lack of disability expertise caused problems during prenatal and birthing services; 31% reported that providers' attitudinal problems caused barriers; 24% reported medical complications related to their disability during pregnancy or birth; and, 18% reported problems with accessibility (in Preston 2009).

⁶ Through the Looking Glass (TLG) is a nationally recognised centre that has pioneered research, training, and services for families in which a child, parent or grandparent has a disability. TLG is a disability community based non-profit organisation which was founded in 1982. In 2008 TLG was awarded a three year grant to continue its national work with parents with disabilities and their families as the National Center for Parents with Disabilities and their Families. See: <http://lookingglass.org/index.php>

"I have given birth to four children. The doctors were most disapproving.....And yet, my impairment has never in any way affected the pregnancy, childbirth or looking after the children."

In Reinikainen 2008

"Doctor's didn't have a bed that I could get on to be examined at antenatal checks. No accessible shower in the maternity ward. My daughter was in SCBU for six weeks and the staff were wonderful in helping to make things easier for me to manage."

Radcliffe 2008

"I just really felt that I was being left out of the important decisions, you know..... there was always someone fussing around me and, you know, 'can you cope?' and 'you'll have to put the head further into the crook of your arm' and it was always wanting to prod and poke and 'are they all right?'....."

In Thomas & Curtis 1997

"In the hospital, there were two nurses who kind of took me under their wing. And they were trying to come up with ways for me to do things easier and better. I think they were kind of interested because it was something out of the ordinary for them."

In Lipson & Rogers 2000

Although there is relatively little research around the experiences of pregnancy and childbirth from the perspective of women with disabilities, the writings that do exist tend to give a mixed picture, with some women reporting maternity services going out of their way to make appropriate adjustments while others experienced unequal access to services and negative attitudes from health care professionals (Morris & Wates 2006). It appears that some professionals are more amenable to providing information and support to women with disabilities who are pregnant or seeking to become pregnant, but this is inconsistent across service providers and an understanding of the differing needs of various impairments appears to still be lacking (Radcliffe 2008, Blackford et al 2000, RCN 2007, Carty 1998).

Topp (2004) in her narrative research study on disabled women's experiences of pregnancy in the UK found that how each woman's needs were recognised and addressed by maternity services varied considerably. Some staff went out of their way to ensure that the woman's needs were met but this seemed to happen as a result of a crisis rather than as planned support. She also found that 'a woman's emotional needs in relation to her having an impairment, as well as the physical and emotional needs of becoming a mother, were often neither explored nor recognised during the pregnancy.' Other writers agree that more often than not, medical/health care providers accommodate women with disabilities, on a case-by-case basis as they present themselves, rather than striving to eradicate disabling barriers more generally (Lipson & Rogers 2000, RCN 2007, Radcliffe 2008).

Crow (2003) in writing of her own experience as a pregnant disabled woman, found that the response she received from medical/health care providers was largely one of 'un-ease, even panic'. She identified a conundrum in her experience: "*.....if, as a disabled woman, I was largely invisible in policies and working practices, as soon as I was noticed, I became centre stage. At the time, I wrote in a journal: "I want to be a pregnant woman – not a problem, not a phenomenon"* (Crow 2003).

4.5. Lack of/inequitable access to assisted reproductive technologies

There is no known published research on the issue of access to assisted reproductive technologies (ARTs) (such as in vitro fertilisation (IVF) and assisted insemination) for women with disabilities. Families created with the aid of assisted reproduction techniques often require the assistance of a doctor at a fertility clinic. The fact that individuals or couples who have difficulties conceiving a child on their own and seek the assistance of state-authorised clinics, essentially makes it possible to regulate who will have access to assisted reproduction techniques (Lind 2008, Petersen 2005).

"We should know better than anyone why the government should not be allowed to restrict what one can and cannot do with one's body."

In Kallianes & Rubenfeld 1997

According to Petersen (2005) in Australia certain groups of women have traditionally been denied access to assisted reproductive technologies - typically single heterosexual women, lesbians, poor women, and those whose ability to rear children is questioned, particularly women with certain disabilities or who are older. Anecdotal information from women with disabilities in Australia suggests that they face discrimination and inequitable access to ART's.

The predominance of white, middle class, able bodied women living as heterosexual couples is evident across private IVF clientele. This is, in part, due to the costs to the client associated with the procedure (Petersen 2005). In Australia, Medicare⁷ covers the treatment of IVF for medical infertility, but for women who are deemed not to be 'medically infertile' (such as single women and lesbian couples), then no Medicare rebate is available. This fact alone would prevent many disabled women (particularly single disabled women, or women with disabilities who are in a lesbian relationship) from accessing ART's.

In Australia, the eight State and Territory governments control assisted reproduction services, with some having enacted legislation to control the procedures involved, while others have traditionally adhered to the National Health and Medical Research Council (NHMRC)⁸ *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (2007). These guidelines, revised in 2007, effectively ignore access and eligibility issues by failing to address them. Instead, the guidelines recommend that each assisted reproduction clinic should develop a 'protocol' around access to, and eligibility for, treatment (NHMRC 2007, p. 21). Whilst some individual clinics specify

⁷ Medicare is Australia's universal health care system introduced in 1984 to provide eligible Australian residents with affordable, accessible and high-quality health care. Medicare was established based on the understanding that all Australians should contribute to the cost of health care according to their ability to pay. It is financed through progressive income tax and an income-related Medicare levy. See: www.medicare.gov.au

⁸ The National Health and Medical Research Council (NHMRC) is Australia's peak body for supporting health and medical research; for developing health advice for the Australian community, health professionals and governments; and for providing advice on ethical behaviour in health care and in the conduct of health and medical research. See: www.nhmrc.gov.au

that assisted reproductive treatment procedures are not denied to women on the basis of marital status or sexual orientation, none mention disability. The decision for eligibility for assisted reproductive services therefore rests with the individual clinics/fertility consultants.

According to Petersen (2005) *'many assisted reproductive technology medical professionals feel entitled to exercise power over the reproductive autonomy of their referred potential clients, denying some women freedom of procreative choice by electing to reinforce entrenched ideologies about the family unit and sexuality'*.

In 2007, the Victorian Law Reform Commission (VLRC) released its final report on ART and adoption. The VLRC had been commissioned by the Victorian Government to enquire into and report on the desirability and feasibility of changes to the *Infertility Treatment Act 1995* [Vic] and the *Adoption Act 1984* [Vic] to expand eligibility criteria in respect of all or any forms of assisted reproduction and adoption (VLRC 2007). In relation to access to assisted reproductive technology, the VLRC decided *"not to include impairment or disability as one of the grounds on which discrimination in relation to access to ART should be prohibited. This is because in some cases there is a nexus between disability and risk of harm to a child (for example, some forms of severe mental illness). Such a nexus does not exist in relation to marital status or sexual orientation. This does not mean that people with a disability or impairment should be refused treatment, but that in some cases a different approach is justified. Such an approach should involve making enquiries about any potential risk to the health and wellbeing of a prospective child"* (VLRC p. 60). The resulting amended legislation, renamed the *Assisted Reproductive Treatment Bill 2008*, omits disability from its non-discrimination clause: *'persons seeking to undergo treatment procedures must not be discriminated against on the basis of their sexual orientation, marital status, race or religion'* (Part 1, 5, p.8). This omission should be subject to scrutiny under the terms of the Victorian Government Charter of Human Rights and Responsibilities Act (2006).

4.6. Removal and/or threat of removal of babies/children by authorities

More than six decades of research has demonstrated that intellectual disability *per se* is an unreliable predictor of parenting performance (Kroese et al 2002, Murphy & Feldman 2002, Aunos et al 2003, 2008, Booth & Booth 2003, 2005, Llewellyn et al 2008, Breeden et al 2008, IASSID 2008). Notwithstanding this, parents with intellectual disabilities are more likely than any other group of parents to have their children permanently removed by child welfare authorities to placements at considerable distance from the parents' home (Llewellyn et al 2003, Booth et al 2005, IASSID 2008). In many cases, child removal is ordered without evidence of abuse, neglect and/or parental incapacity, and occurs at the time, or within days of a child's birth (McConnell & Llewellyn 1998). Anecdotal reports to WWDA from mothers with intellectual disabilities and/or their advocates suggest that this remains a current practice in Australia. These anecdotal reports are also supported by feedback to

WWDA from Disability Discrimination Legal Services in Australia, who have identified the issue of removal of babies/children from women with intellectual disabilities as one of the key legal issues facing such women in Australia today (WWDA 2009).

"On November 28, 2000, they took my daughter away. My mistake, as they put it, was not meeting her medical or her developmental needs. The only health and medical issue was one of having lice and sometimes I could not respond as quickly as I should have because I didn't always have the money right at that time. And that's what they didn't understand. Also, because I was poor, her lunches didn't always include the four food groups, but I did my best with the funds that I had. The school reported me to the Child Welfare.....the social worker I was assigned was not very nice to me....she barely talked to me....told me to go to parenting classes but then never helped me find them. I never exactly knew what the concerns were until I got to Court and they told the judge....."

In Malacredia 2007

Negative stereotypes about women with intellectual disabilities clearly still affect and influence the decision-making process in the legal system over-riding any imperative for family preservation (Aunos & Feldman 2002). As well as being over-represented in care proceedings, termination of parenting rights is often based on the misconceptions that the women's intellectual disabilities automatically make them incapable of adequately raising children, and that they lack the potential to learn (Aunos & Feldman 2002, Booth & Booth 2004, Aunos et al 2008). A number of writers in this field highlight the fact that women with intellectual disabilities who are parents, are scrutinised very closely and held to higher standards than those that are applied to non-disabled women who are parents (McConnell et al 2000, Aunos & Feldman 2002, Llewellyn et al 2008). Furthermore, the evidence used to judge potential for parental inadequacy may be based on unfair and invalid assessment procedures (Aunos & Feldman 2002) which are often carried out in unsupportive environments (Burgen 2007).

The removal of babies/children from women with intellectual disabilities is often based on two prejudicial and invalid assumptions. Firstly, a diagnosis or label of parental intellectual disability *per se* is mistakenly taken for *prima facie* evidence of parental incapacity or risk of harm to the child (IASSID 2008). Secondly such incapacity is deemed to be an irremediable deficiency in the parent such that it cannot be overcome or corrected. According to IASSID (2008) in this situation, the state authority 'naturally' holds little hope of improving the child's situation, resulting in the permanent placement of the child away from their family home. Both assumptions are incorrect and invalid (McConnell et al 2006, IASSID 2008).

It is widely acknowledged in the literature that naïve, prejudicial and discriminatory attitudes and practices lead to premature termination of the parenting rights of women with intellectual disabilities. This is contrary to family legislation that almost universally requires that such action should be a last resort and that the state has an obligation to make efforts to keep families together (Aunos & Feldman 2002).

Most of the literature about the removal or threat of removal of babies/children from women with disabilities, deals almost exclusively with women/parents with intellectual disabilities. However, it is WWDA's experience that removal or threat of removal of babies/children is also an issue for women with other disabilities, and in particular for women with mental health issues. Another dimension to this issue is in Family Court decisions where women with mental health issues can be denied contact with the child/ren solely on the basis of their disability (WWDA 2009).

4.7. Lack of Research and Data

Women with disabilities who are parents exist in significant numbers in all countries of the world, yet information about this population is extremely limited. A major obstacle in estimating the number of disabled women who are parents, as well as their demographic characteristics is the lack of data (Kirshbaum 2000, Blackford 1993, Morris & Wates 2006, Preston 2009, Olkin et al 2006). The acute lack of available gender and disability specific data in Australia – at all levels of Government and for any issue - has been consistently highlighted by WWDA for more than a decade, and identified by the United Nations as an area of concern (CEDAW/C/AUL/CO/5, 2006).

The relatively small amount of overseas research and information that does exist in relation to women with disabilities who are parents, largely concerns those who are already in touch with children's social services and/or specialist adult disability services, and tends to focus on their experience as service users (Morris & Wates 2006). It also tends to be driven by a search for 'problems' in families (Kirshbaum 2002), focusing on solutions to relieve the 'difficulties' posed by the woman's disability (SCIE 2005).

There is an absence of research and information which examines the broader social and structural issues which are critically important for women with disabilities who are parents, or seeking to become parents. Such issues include, for example: poverty, housing, un/employment, access to education, heightened vulnerability to violence and abuse, social isolation, inadequate health care, multiple forms of discrimination, poor access to services, and denial of citizenship.

Importantly, there is a dearth of research around the experiences of all aspects of parenting from the perspective of women with disabilities themselves, and virtually no research which focuses on the positive aspects of parenting for women with disabilities. No longitudinal studies have been undertaken.

Data, research and information about women with disabilities who are parents, or seeking to become parents, is necessary to guide and inform policy, direct funding, and inform service development (Morris & Wates 2006, Preston 2009, Olkin et al 2006). It also enables the monitoring of equality of opportunity and progress towards the achievement of economic, social, political and cultural rights for

women with disabilities. The lack of data, research and information about women with disabilities who are parents, or seeking to become parents, results in invisibility and marginalisation in society, which invariably leads to a critical lack of resources for this group (Kirshbaum 2000).

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 in the context of this paper, is the need for all aspects of research about parenting 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, WWDA 2008).

Indeed, 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, WWDA 2008).

5. Parenting, Gender & Disability - The Human Rights Context

The social exclusion and discrimination faced by people with disabilities has increasingly been recognised as a human rights issue. A paradigm shift, from a medical and charity based welfare model of disability, to today's rights based model, acknowledges the movement to link disability issues to a full range of civil, political, economic, social and cultural rights (ILO 2007). The human rights framework recognises people with disabilities as having the same rights as people without disabilities. A rights based approach also recognises that equal treatment, equal opportunity, and non-discrimination provide for inclusive opportunities for women and men with disabilities in mainstream society (WWDA 2008).

The right to found a family is enshrined in the *Universal Declaration on Human Rights (UDHR)* (1948, Article 16) [1], the *International Covenant on Civil and Political Rights (ICCPR)* (1976, Article 23) [2], and the *International Covenant on Economic, Social and Cultural Rights* (1976, Article 10) [3]. The *Convention on the Elimination of Discrimination Against Women (CEDAW)* (1981, Article 16) [4] articulates the right of women 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.

Like their non-disabled counterparts, adults with disabilities have a fundamental right to 'found a family'. A number of international human rights instruments make explicit recognition of this right. The *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (1993, Rule 9) [5] in dealing with the right of people with disabilities to experience parenthood, makes particular reference to the need for States to 'promote measures to change negative attitudes towards parenthood of persons with disabilities, especially of girls and women with disabilities, which still prevail in society.' The *Convention on the Rights of Persons with Disabilities (CRPD)* (2007, Article 23) [6] gives detailed attention to the rights of people with disabilities to found a family. It articulates the requirement of States to eliminate discrimination against people with disabilities in all matters relating to marriage, family, parenthood and relationships, and makes explicit the need for States to render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.

The need for specific attention to be directed to women with disabilities is also spelled out in several international human rights instruments, which recognise the impact of multiple discriminations caused by the intersection of gender and disability.

The *Convention on the Rights of People with Disabilities (CRPD)* (2007, Article 6), in acknowledging the impact of multiple discriminations caused by the intersection of gender and disability, prioritises women with disabilities as a group warranting specific attention and calls on States Parties to take

positive action and measures to ensure that women and girls with disabilities enjoy all human rights and fundamental freedoms (CRPD Article 6) [7]. The need for National Disability Action Plans to direct special attention to women and girls with disabilities is also clearly articulated in the *Bangkok Declaration on National Action Planning and Disability-Inclusive Development* (UN 2005) [8]. Women with disabilities are identified as a priority group within the *Biwako Millennium Framework* (2002) [9] which calls on governments to implement specific measures to promote the full participation of women with disabilities in mainstream development.

General Recommendation 18 of the *Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)* [10] calls on States Parties to take special measures to address the needs of women with disabilities.

Despite the fact that Australia has affirmed its commitment to the rights of its citizens through ratification of these various international human rights conventions and other instruments, there remains a vast disparity between the standards set in these instruments and the situation of women with disabilities with regard to their right to reproductive freedom - including their right to parent.

"If you are a disabled woman, from any culture, with the desire to have or adopt a child, go ahead. It's your right. Don't leave this decision for somebody else to make or for society to judge. Take for yourself the very enjoyable responsibility of exploring all of your human and social roles."

Berman Bieler 1999

6. Conclusion

The right to found a family and to reproductive freedom is clearly articulated in a number of international human rights treaties to which Australia is a signatory. Yet, for many women with disabilities in Australia who are parents or seeking to become parents, these fundamental human rights are not achievable. Instead, as this paper has shown, disabled women experience a range of barriers and restrictions in realising their rights to full reproductive freedoms, particularly their right to found and raise a family. These economic, social and environmental barriers and restrictions are many, varied, and entrenched – yet remain largely ignored in Australian family related research, legislation, policies, and services.

As this paper has highlighted, women with disabilities who are parents or seeking to become parents experience discriminatory attitudes and widely held prejudicial assumptions which question their ability and indeed, their right to experience parenthood. They experience significant difficulty in accessing appropriate parenting information, services and support in a host of areas. They battle against political agendas and social commentaries which cast their children as ‘young carers’ at risk of parentification and themselves as burdens of care. This simplistic debate conveniently diverts attention away from the significant ways in which the economic, social and physical environments, together with a lack of services, amenities and resources devalue women with disabilities who are parents, and simultaneously stigmatises both parent and child.

Women with disabilities bear and/or parent their babies in spite of the fact that they remain invisible and ignored in maternity, obstetric and related health care policies, programs and services. They face overt discrimination and inequitable access to assisted reproductive technologies. They have their babies and children removed by child welfare authorities without evidence of abuse, neglect and/or parental incapacity – indeed, simply because they are women with disabilities. They lose their children in custody disputes on the same grounds. The lack of data, research and information about women with disabilities who are parents, or seeking to become parents, contributes to their invisibility and marginalisation in society.

Australia ratified the *Convention on the Rights of Persons with Disabilities* (CRPD) in July 2008, and it entered into force for Australia on 16 August 2008. Australia's Attorney-General Hon Robert McClelland said that ratifying the CRPD "*clearly demonstrates the Rudd Government's international commitment to ensuring people with disability are treated equally and not as second-class citizens*" (McClelland 2008). It is clear that we have a long way to go before women with disabilities in this country, who are parents or seeking to become parents, can experience the full and equal enjoyment of their basic human right to experience parenthood – in whatever form that might take.

7. Key Recommendations

In light of the paucity of Australian research, resources and support for women with disabilities who are parents, or seeking to become parents, coupled with the restrictions they face in realising their rights to full reproductive freedoms, WWDA recommends that the Australian Government:

1. Fund a three year, national research project (encompassing qualitative and quantitative methodologies) on the parenting experiences of women with disabilities in order to develop a clearer understanding of the issues as well as allowing women with disabilities to speak their history and give voice to a human rights issue that to date, has been largely ignored in relevant legislation, policy, and services.
2. Collect appropriate statistical and research data on the number of parents with disabilities in Australia, disaggregated by gender and other relevant variables, in order to guide and inform policy, direct funding, and inform service development.
3. Establish, and recurrently fund a National Resource Centre for Parents with Disabilities, focusing on pregnancy & birthing, adoption, custody, assisted reproduction, adaptive baby-care equipment, as well as general parenting issues.
4. Urgently address the over-representation of parents with intellectual disabilities in care and protection proceedings. This should include as a priority, a National Public Inquiry into the removal and/or threat of removal of babies and children from parents with intellectual disabilities; parents with mental health illnesses and parents with psychiatric disabilities.
5. Act immediately to investigate and address the barriers to reproductive autonomy and procreative choice for women with disabilities. This should include as a priority:
 - addressing discrimination in legislation and protocols dealing with access to, and eligibility for, assisted reproduction technologies (ART's);
 - the development of universal legislation which prohibits sterilisation of children with disabilities except in those circumstances where there is a serious threat to health or life. In the case of adults, sterilisation must be prohibited in the absence of the informed consent of the individual concerned, except in those circumstances where there is a serious threat to health or life.
6. Focus on separating disability policy and disability support from family carer policy and support in order to increase the autonomy of women with disabilities and challenge the stereotype of women with disabilities as burdens of care.

In addition to these actions specific to enabling and improving the experience of parenting for women with disabilities, a raft of other actions must be initiated and/or continued in order to address the inequities and barriers which currently deprive women with disabilities of full and equal participation in Australian society. WWDA recommends that the Australian Government:

7. Ensure that information on women with disabilities is provided in the Periodic Reports of relevant human rights treaties, as a matter of course. This must include information on the situation of women with disabilities under each right, including their current de-facto and de jure situation, measures taken to enhance their status, progress made and difficulties and obstacles encountered.
8. Establish mechanisms and structures which enable women with disabilities to have their voices heard, and to act politically as agents in their own right. This includes the need to support and strengthen organisations, networks and groups run and controlled by women with disabilities in the pursuit of their collective interests, as defined by them.
9. Support and fund national research into the recognised markers of social exclusion for women with disabilities, including: socioeconomic disadvantage, social isolation, multiple forms of discrimination, poor access to services, poor housing, inadequate health care, and denial of opportunities to contribute to and participate actively in society.

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9. Endnotes

[1] *Universal Declaration on Human Rights (UDHR) (Article 16):*

1. Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.
2. Marriage shall be entered into only with the free and full consent of the intending spouses.
3. The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

[2] *International Covenant on Civil and Political Rights (ICCPR) (Article 23):*

1. The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.
2. The right of men and women of marriageable age to marry and to found a family shall be recognized.
3. No marriage shall be entered into without the free and full consent of the intending spouses.
4. States Parties to the present Covenant shall take appropriate steps to ensure equality of rights and responsibilities of spouses as to marriage, during marriage and at its dissolution. In the case of dissolution, provision shall be made for the necessary protection of any children.

[3] *International Covenant on Economic, Social and Cultural Rights (Article 10)*

1. The widest possible protection and assistance should be accorded to the family, which is the natural and fundamental group unit of society, particularly for its establishment and while it is responsible for the care and education of dependent children. Marriage must be entered into with the free consent of the intending spouses.
2. Special protection should be accorded to mothers during a reasonable period before and after childbirth. During such period working mothers should be accorded paid leave or leave with adequate social security benefits.
3. Special measures of protection and assistance should be taken on behalf of all children and young persons without any discrimination for reasons of parentage or other conditions. Children and young persons should be protected from economic and social exploitation. Their employment in work harmful to their morals or health or dangerous to life or likely to hamper their normal development should be punishable by law. States should also set age limits below which the paid employment of child labour should be prohibited and punishable by law.

[4] *Convention on the Elimination of Discrimination Against Women (Article 16)*

1. States Parties shall take all appropriate measures to eliminate discrimination against women in all matters relating to marriage and family relations and in particular shall ensure, on a basis of equality of men and women:
 - (a) The same right to enter into marriage;
 - (b) The same right freely to choose a spouse and to enter into marriage only with their free and full consent;
 - (c) The same rights and responsibilities during marriage and at its dissolution;
 - (d) The same rights and responsibilities as parents, irrespective of their marital status, in matters relating to their children; in all cases the interests of the children shall be paramount;
 - (e) The same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights;
 - (f) The same rights and responsibilities with regard to guardianship, wardship, trusteeship and adoption of children, or similar institutions where these concepts exist in national legislation; in all cases the interests of the children shall be paramount;
 - (g) The same personal rights as husband and wife, including the right to choose a family name, a profession and an occupation;
 - (h) The same rights for both spouses in respect of the ownership, acquisition, management, administration, enjoyment and disposition of property, whether free of charge or for a valuable consideration.
2. The betrothal and the marriage of a child shall have no legal effect, and all necessary action, including legislation, shall be taken to specify a minimum age for marriage and to make the registration of marriages in an official registry compulsory.

[5] *Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Rule 9)*

States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood.

1. Persons with disabilities should be enabled to live with their families. States should encourage the inclusion in family counselling of appropriate modules regarding disability and its effects on family life. Respite-care and attendant-care services should be made available to families which include a person with disabilities. States should remove all unnecessary obstacles to persons who want to foster or adopt a child or adult with disabilities.
2. Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. Taking into account that persons with disabilities may experience difficulties in getting married and setting up a family, States should encourage the availability of appropriate counselling. Persons with disabilities must have the same access as others to family-planning methods, as well as to information in accessible form on the sexual functioning of their bodies.
3. States should promote measures to change negative attitudes towards marriage, sexuality and parenthood of persons with disabilities, especially of girls and women with disabilities, which still prevail in society. The media should be encouraged to play an important role in removing such negative attitudes.
4. Persons with disabilities and their families need to be fully informed about taking precautions against sexual and other forms of abuse. Persons with disabilities are particularly vulnerable to abuse in the family, community or institutions and need to be educated on how to avoid the occurrence of abuse, recognize when abuse has occurred and report on such acts.

[6] *Convention on the Rights of Persons with Disabilities (Article 23)*

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:
 - (a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;
 - (b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;
 - (c) Persons with disabilities, including children, retain their fertility on an equal basis with others.
2. States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their childrearing responsibilities.
3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.
4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.
5. States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

[7] *Convention on the Rights of Persons with Disabilities (Article 6)*

1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.
2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

[8] *Bangkok Declaration on National Action Planning and Disability-Inclusive Development*

3. National action plans shall direct special attention to women and girls with disabilities, children and young adults with disabilities, persons with multiple disabilities, and persons who experienced disability as a result of natural disasters or conflicts;

[9] *Biwako Millennium Framework*

15. Further efforts need to focus on priority areas where progress was found inadequate and action was lagging during the implementation of the Asian and Pacific Decade of Disabled Persons, 1993-2002. By resolution 58/4, Governments in the region defined the priority policy areas as:

- (a) Self-help organizations of persons with disabilities and related family and parent associations;
- (b) Women with disabilities;
- (c) Early detection, early intervention and education;
- (d) Training and employment, including self-employment;
- (e) Access to built environments and public transport;
- (f) Access to information and communications, including information, communications and assistive technologies;
- (g) Poverty alleviation through capacity-building, social security and sustainable livelihood programmes.

**[10] *Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)*
*(General Recommendation 18)***

The Committee on the Elimination of Discrimination against Women,

- Taking into consideration particularly article 3 of the Convention on the Elimination of All Forms of Discrimination against Women,
- Having considered more than 60 periodic reports of States parties, and having recognized that they provide scarce information on disabled women,
- Concerned about the situation of disabled women, who suffer from a double discrimination linked to their special living conditions,
- Recalling paragraph 296 of the Nairobi Forward-looking Strategies for the Advancement of Women, 9 in which disabled women are considered as a vulnerable group under the heading "areas of special concern",
- Affirming its support for the World Programme of Action concerning Disabled Persons (1982), 10

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.