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**Issues Paper**

**The Sexual and Reproductive Rights of Women and Girls with Disabilities**

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## 1. Introduction

Sexual and reproductive rights are fundamental human rights. They embrace human rights that are already recognised in international, regional and national legal frameworks, standards and agreements.<sup>1</sup> They include the right to autonomy and self-determination – the right of everyone to make free and informed decisions and have full control over their body, sexuality, health, relationships, and if, when and with whom to partner, marry and have children - without any form of discrimination, stigma, coercion or violence. This includes the right of everyone to enjoy and express their sexuality, be free from interference in making personal decisions about sexuality and reproductive matters, and to access sexual and reproductive health information, education, services and support. It also includes the right to be free from torture and from cruel, inhumane or degrading treatment or punishment; and to be free from violence, abuse, exploitation and neglect.<sup>2</sup>

However, women and girls with disabilities throughout the world have failed to be afforded, or benefit from, these provisions in international, regional and national legal frameworks, standards and agreements. Instead, systemic prejudice and discrimination against them continues to result in multiple and extreme violations of their sexual and reproductive rights, through practices such as forced and/or coerced sterilisation, forced contraception and/or limited or no contraceptive choices, a focus on menstrual and sexual suppression, poorly managed pregnancy and birth, forced or coerced abortion, termination of parental rights, denial of/or forced marriage, and other forms of torture and violence, including gender-based violence. They also experience systemic exclusion from sexual and reproductive health care services. These practices and violations are framed within traditional social attitudes and entrenched disability-based and gender-based stereotypes that continue to characterise disability as a personal tragedy, a burden and/or a matter for medical management and rehabilitation.<sup>3</sup>

This Briefing Paper examines the sexual and reproductive rights of women and girls with disabilities in the context of the future development agenda Beyond 2014 and Post 2015. It deliberately focuses on women and girls with disabilities in recognition that they are generally more likely to experience infringements of their sexual and reproductive rights given the physiology of human reproduction and the gendered social, legal and economic context in which sexuality, fertility, pregnancy and parenthood occur.<sup>4</sup> This Paper examines some of the key sexual and reproductive rights violations experienced by women and girls with disabilities around the world. It includes a discussion of intersectionality and multiple identity, recognising that this reality is important to any examination of the sexual and reproductive rights of women and girls with disabilities. It provides an analysis of the cycle of accountability in relation to the sexual and reproductive rights of women and girls with disabilities, looking at the dimensions of responsibility, answerability and enforceability. It poses some key priority considerations for ensuring the future development agenda Beyond 2014 and Post 2015 is inclusive of, and responsive to, women and girls with disabilities all over world. Importantly, as opposed to *'needs'*, this paper speaks to the sexual and reproductive *rights* of women and girls with disabilities – rights that for far too long have been violated, denied, ignored and trivialised by those in positions to make a difference.

## 2. Disability – A Brief Global Snapshot

Approximately 15% of the world's population (one billion persons) lives with some form of disability. The vast majority (80%) of people with disabilities live in developing countries<sup>5</sup> with two-thirds in the Asia-Pacific region.<sup>6</sup> These figures are rapidly increasing, as a result of population growth, ageing, violence, war, conflicts, environmental degradation, poor workforce conditions, sexual and gender-based violence, harmful traditional practices, and improvements in measurement techniques. Between 2.5 and 3.5 million of the world's 35 million displaced persons also live with disabilities,<sup>7</sup> with numbers likely to be much higher, given the injuries caused by civil conflicts, wars, or natural disasters that displaced people are fleeing.

There are significant differences in the prevalence of disability between men and women in both developing and more developed countries: the male disability prevalence rate is 12% while the female disability prevalence rate is 19.2%.<sup>8</sup> However, a detailed global picture on how gender and disability intersect is not yet possible as data collection and research has been extremely limited and often clouded by factors that are quantification challenges, such as the feminisation of poverty, cultural concepts of gender roles and sexual and reproductive rights, violence, abuse and other types of exploitation, such as child labor.<sup>9</sup>

Disability is not restricted to any one social or economic group, culture or age group.<sup>10</sup> Disability is both a cause and a consequence of poverty, with people with disabilities, particularly women and children with disabilities, over-represented amongst the world's poor.<sup>11</sup> It is now accepted that development measures to eradicate poverty will not be achieved without the inclusion of people with disabilities.<sup>12</sup>

## 3. The Convention on the Rights of Persons with Disabilities (CRPD)

The *Convention on the Rights of Persons with Disabilities* (CRPD), which entered into force on 3 May 2008, establishes, for the first time in a binding human rights convention, that human rights and fundamental freedoms apply to all persons with disabilities. Its fundamental purpose is to ensure that all human rights and fundamental freedoms are promoted, protected and fulfilled and that the inherent dignity of persons with disabilities are promoted and respected.<sup>13</sup> The CRPD also reflects the “*Nothing about us without us*” principle of full inclusion and participation of persons with disabilities. The CRPD states that “disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.” Thus, the CRPD adopts a broad categorisation of people with disabilities, moving away from the traditional medical and welfare orientation and embracing a social model of disability within which civil, political, economic, social and cultural rights are enumerated and elaborated.

Among other things, the CRPD mandates States Parties to: protect persons with disabilities from violence, exploitation and abuse (including the gender-based aspects of such violations) (CRPD Art. 16); ensure that persons with disabilities enjoy legal capacity on an equal basis with others (CRPD Art. 12); enjoy access to justice (CRPD Art. 13); are not subjected to arbitrary or unlawful interference with their privacy (CRPD Art. 22) and family (CRPD Art. 23), including in all matters relating to marriage, family, parenthood and relationships; guarantee persons with disabilities, including children (CRPD Art. 7), the right to retain their fertility; take measures to ensure women and girls enjoy the full and equal enjoyment of their human rights (CRPD Art. 6); prevent people with disabilities from being subjected to torture, or cruel, inhuman or degrading treatment or punishment (CRPD Art. 15); prohibit involuntary treatment and involuntary confinement (CRPD Arts. 12, 17 and 25); implement disability inclusive development practices (CRPD Art. 32), and, ensure the right of people with disabilities to the highest attainable standard of health without discrimination, including in the area of sexual and reproductive health and population-based public health programs (CRPD Art. 25).

The CRPD recognises gender as one of the most important categories of social organisation, emphasising the need to incorporate a gender perspective in all efforts to promote the full enjoyment of human rights and fundamental freedoms by people with disabilities. It recognises that women and girls with disabilities are subject to multiple discriminations, and that States Parties to the Convention have an obligation to take measures to ensure women and girls with disabilities experience the full and equal enjoyment of all human rights and fundamental freedoms (CRPD Art. 6).<sup>14</sup> Yet despite this, people with disabilities are often treated as asexual and genderless human beings. This view is borne out in disability and development policies and

programs world over, which consistently fail to apply a gender and/or disability lens. Most proceed as though there are a common set of issues - and that men and women experience disability in the same way. However women with disabilities and men with disabilities have different life experiences due to biological, psychological, economic, social, political and cultural attributes associated with being female and male. Patterns of disadvantage are often associated with the differences in the social position of women and men. These gendered differences are reflected in the life experiences of women with disabilities and men with disabilities, particularly in relation to sexual and reproductive rights and gender-based violence.

Gender equality has long been recognised both as a human right and a core development goal. Discrimination against women and girls impairs progress in all other areas of development,<sup>15</sup> and remains the single most widespread driver of inequalities in today's world.<sup>16</sup> The UN System Task Team on the Post 2015 UN Development Agenda,<sup>17</sup> and the High-Level Task Force for the ICPD<sup>18</sup> make it very clear that sexual and reproductive rights and health, the empowerment of women and girls (including women and girls with disabilities) and the protection and promotion of their rights, lie at the heart of sustainable development and should therefore be centre-pieces of the new Post-2015 global agenda.

#### **4. The Sexual and Reproductive Rights of Women and Girls with Disabilities**

No group has ever been as severely restricted, or negatively treated, in respect of their reproductive rights, as women with disabilities.<sup>19</sup> The CRPD Committee<sup>20</sup> has clearly identified that discrimination against women and girls with disabilities in areas of sexual and reproductive rights, including gender-based violence, is in clear violation of multiple provisions of the CRPD. The CRPD Committee has explicitly articulated the urgent need for States Parties to address these multiple violations.<sup>21</sup> Whilst it is outside the scope of this Briefing Paper to address in detail the extensive, pervasive and unresolved raft of sexual and reproductive rights violations of women and girls with disabilities around the world, the following examples are provided to highlight just some of the key issues and to serve as a human rights-based way to assess other violations.

**Forced and/or Coerced Sterilisation:** Women and girls with disabilities are at particular risk of forced and coerced sterilisations performed under the auspices of legitimate medical care or the consent of others in their name.<sup>22</sup> Forced sterilisation<sup>23</sup> of women and girls with disabilities is a practice that remains rife throughout the world, and represents grave violations of multiple human rights.<sup>24</sup> It is an act of violence,<sup>25</sup> a form of social control, and a clear and documented violation of the right to be free from torture.<sup>26</sup> Perpetrators<sup>27</sup> are seldom held accountable and women and girls with disabilities who have experienced this violent abuse of their rights are rarely, if ever, able to obtain justice.<sup>28</sup>

The monitoring bodies of the core international human rights treaties<sup>29</sup> have all found that forced/involuntary and coerced sterilisation clearly breaches multiple provisions of the respective treaties.<sup>30</sup> International medical bodies, such as the *International Federation of Gynecology & Obstetrics (FIGO)*,<sup>31</sup> have now developed new protocols and calls for action to put an end to the practice of forced sterilisation, shoring up informed consent protocols and clearly delineating the ethical obligations of health practitioners to ensure that women, and they alone, are giving their voluntary and informed consent to undergo a surgical sterilisation. Importantly, in early 2013, the UN Special Rapporteur on Torture [and other cruel, inhuman or degrading treatment or punishment], in addressing reproductive rights violations under the torture framework,<sup>32</sup> clarified that forced sterilisation of people with disabilities, regardless of whether the practice is legitimised under national laws or justified by theories of incapacity and therapeutic necessity, violates the absolute prohibition of torture and cruel, inhuman and degrading treatment.

However, it is also recognised that adult women with disabilities have the same rights as their non-disabled counterparts to *choose* sterilisation as a means of contraception. In this context, safeguards to prevent forced sterilisation should not infringe the rights of women with disabilities to choose sterilisation voluntarily and be provided with all necessary supports to ensure that they can make and communicate such a choice based on their free and informed consent.<sup>33</sup>

**Forced Contraception:** Women with disabilities, like all women, have a right to safe and effective contraception. Yet widespread discriminatory attitudes which portray women with disabilities as either asexual or hyper-sexual, often see them denied this most basic right. These pervasive negative attitudes, values and stereotypes about the reproductive capacity of women with disabilities make getting accurate

information about contraceptive options very difficult. Although the contraceptive needs of women with disabilities are essentially no different from those of the general population,<sup>34</sup> the pattern of contraceptive use amongst women with disabilities and non-disabled women, differs widely. Women with disabilities (particularly those with intellectual disabilities) are more likely to be sterilised, more likely to be prescribed long-acting, injectable contraceptives and less likely to be prescribed oral contraceptives. In addition, women with disabilities are much less likely to be involved in choice and decision-making around the type of contraception they use.<sup>35</sup>

Forced contraception, recognised as a form of torture,<sup>36</sup> is commonly used on women and girls with disabilities to suppress menstruation or sexual expression for various purposes, including eugenics-based practices of population control, menstrual management and personal care, and pregnancy prevention (including pregnancy that results from sexual abuse).<sup>37</sup> For example, the disproportionate use of Depo-Provera and other long acting contraceptives on women with disabilities (including those who are not sexually active, or who are yet to begin menstruation), has been recognised for some time in a number of different countries.<sup>38</sup> It is very much a contemporary and widespread problem, and illustrates that the legacy of past eugenic ideologies and practices has far from disappeared.

**Gender Based Violence:** Multiple and intersecting forms of discrimination contribute to and exacerbate violence against women and girls with disabilities.<sup>39</sup> Although women with disabilities experience many of the same forms of violence all women experience, when gender and disability intersect, violence has unique causes, takes on unique forms and results in unique consequences. Further, women and girls with disabilities who are also members of other identity groups can be subject to particularised forms of violence and discrimination. Despite the evolution of normative frameworks concerning both the human rights of women and of persons with disabilities, the impact of the combined effects of both gender and disability have not gained sufficient attention and violence remains at shockingly high rates when these multiple identities collide.

Violence against women with disabilities occurs in various spheres including the home, the community, perpetrated and/or condoned by the State and private institutions and in the transnational sphere. The forms of violence to which women with disabilities are subjected are varied: physical, psychological, sexual and/or financial violence, neglect, social isolation, entrapment, degradation, trafficking, detention, denial of health care and forced sterilisation and psychiatric treatment, among others. Women with disabilities are twice as likely to experience domestic violence as non-disabled women, and are likely to experience abuse over a longer period of time and to suffer more severe injuries as a result of the violence. The perpetrator of the violence may also be their caregiver, someone that the individual is reliant on for personal care, mobility or other types of support. Yet for many women with disabilities, identification and recognition that violence in their lives is a problem or a crime remains a significant issue. They may have difficulties in recognising, defining and describing the violence; have limited awareness of strategies to prevent and manage it; and lack the confidence to seek help and support. Frequently they do not report the violence, they often lack access to legal protection; law enforcement officials and the legal community are ill-equipped to address the violence; their testimony is often not viewed as credible by the courts; and they are not privy to the same information available to non-disabled women. The lack of appropriate, available, accessible and affordable services, programs and support is a factor that increases and contributes to violence against women and girls with disabilities.<sup>40</sup> Sexual and gender-based violence also contributes to the incidence of disability among women.

International and regional human rights bodies have recognised that women and girls with disabilities throughout the world experience, and are more vulnerable to, all forms of violence, exploitation, abuse and neglect, and have called on States to urgently address this global problem that remains largely ignored by governments and other actors.<sup>41</sup> Violence against women and girls with disabilities has devastating social, economic and inter-generational consequences and jeopardises their sexual and reproductive health and rights.<sup>42</sup>

**Denial of Maternity, Parenting & Parental Rights:** Parenting remains an attitudinal minefield for women with disabilities and an area in which they experience widespread violations of their human rights. Women with disabilities the world over are discouraged or denied the opportunity, to bear and raise children.<sup>43</sup> 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.<sup>44</sup> Alternatively, women with intellectual disabilities in particular may be regarded as overly sexual, creating a fear of profligacy and the reproduction

of disabled babies, often a justification for their sterilisation.<sup>45</sup> These perceptions, although very different, result in women with disabilities being denied the right to reproductive autonomy and self-determination. Recent data demonstrates that a parent with a disability (usually a mother) is up to ten times more likely than other parents to have a child removed from their care, with the child removed by authorities on the basis of the parents disability, rather than any evidence of child neglect.<sup>46</sup> Women with disabilities are also coerced to have hysterectomies after they have given birth to one or more children, who have usually been taken from their care; or as a condition of having access to their child who has been taken from their care.<sup>47</sup> Fears of women with disabilities as parents persist although evidence demonstrates that parents with disabilities are no more likely to maltreat children or to raise so-called “defective” children than non-disabled parents.<sup>48</sup> Statutes in many countries on termination of parental rights, child custody and divorce include disability-related grounds for termination of parental rights or loss of custody and may emphasise and focus on disability status rather than actual parenting skill or behaviour, implicitly equating parental disability with parental unfitness.<sup>49</sup> Because of such legal definitions and societal prejudices, mothers with disabilities may be subjected to greater scrutiny by social service agencies than non-disabled women. Fear of being incorrectly perceived as an unfit mother by a court on the basis of disability, and the breakdown of their relationship with children, has frequently discouraged mothers with disabilities from separating from an abusive partner.

**Denial of Legal Capacity & Decision-Making:** The determination of capacity is inextricably linked to the exercise of the right to autonomy and self-determination. To make a finding of incapacity results in the restriction of one of the most fundamental rights enshrined in law, the right to autonomy.<sup>50</sup> Yet millions of women with disabilities worldwide are stripped of their legal capacity, due to stigma and discrimination, through judicial declaration of incompetency or merely by a doctor’s decision that the woman “lacks capacity” to make a decision. ‘Incapacity’ is very often used as a valid justification for violations of the sexual and reproductive rights of women and girls with disabilities. However, the CRPD clearly mandates States Parties to recognise that persons with disabilities enjoy legal capacity on an equal basis with others and should be supported to exercise their legal capacity (CRPD Art. 12). This means that an individual’s right to decision-making cannot be substituted by decision-making of a third party, but that each individual without exception has the right to receive the supports they need to make their own choices and to direct their own lives, whether in relation to medical treatment, family, parenthood and relationships, or living arrangements.<sup>51</sup> The CRPD also requires respect for the evolving capacities of children (CRPD Art 3 and 7) and the provision of support for children with disabilities to express their views, and for these views to be given appropriate weight in the context of their age and maturity.

The UN Special Rapporteur [on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health], has recently clarified that States which use the law as a tool to regulate the conduct and decision-making of individuals in the context of their sexual and reproductive rights, represents ‘*serious violations of the right to health of affected persons and are ineffective as public health interventions*’.<sup>52</sup>

The right to participate in all decision-making processes that affect sexual and reproductive health and development is a basic right of all women, including women and girls with disabilities. Yet, more often than not, many women and girls with disabilities are excluded from participating in decisions that affect their lives on a daily basis, including as active partners in their own sexual and reproductive health care. They are further excluded and ignored in sexual and reproductive health policy, service and program development, including information and education resources.<sup>53</sup>

**Lack of Access to Sexual and Reproductive Health Services & Programs:** The discrimination experienced by women with disabilities is played out in their access to and use of sexual and reproductive health services and programs. For many, the services and programs they require to realise their sexual and reproductive rights are simply not *available* to them. Even where services and programs are available, many women with disabilities remain excluded due to economic, social, psychological and cultural barriers that impede or preclude their access. For example, support for choices and services in menstrual management, contraception, abortion, sexual health management, pregnancy, birth, parenting, assisted reproduction, and menopause remain inappropriate, absent or inaccessible. Breast and cervical cancer screening services are often not available or accessible to women with disabilities, yet a disproportionate number of deaths from breast and cervical cancer occur among women with disabilities.<sup>54</sup> Services and programs for women with disabilities experiencing, or at risk of violence is a further area where women with disabilities experience

exclusion and often when a woman with a disability is seen by health care workers, they fail to perform screenings for possible domestic violence based on stereotypical attitudes. Even where sexual and reproductive health services and programs are available, women with disabilities are inadequately served, due to a wide range of factors, such as: inaccessible venues; lack of transport; lack of appropriate equipment; non-inclusive and/or inflexible service policies and programs; lack of skilled workers; and pervasive stereotypes and assumptions that women with disabilities are asexual.<sup>55</sup>

Health practitioners and workers have long been seen as complicit in denying women with disabilities their sexual and reproductive rights, and in perpetuating myths and negative stereotypes about women with disabilities.<sup>56</sup> The lack of education and training of health providers has been identified as a major barrier to women with disabilities accessing sexual and reproductive health services. This lack of education and training is borne out in a myriad of ways. For example, many practitioners lack knowledge of disability, hold inaccurate perceptions about women with disabilities, and have a tendency to view women with disabilities solely through the lens of their impairments. Insufficient time to address the full range of needs is a common barrier during encounters with practitioners, as is the general lack of sensitivity, responsiveness, courtesy and support shown to women with disabilities. Health practitioners can have a tendency to treat women with disabilities as objects of treatment rather than rights-holders, and do not always seek their free and informed consent when it comes to interventions.<sup>57</sup>

**Lack of Access to Information and Education on Sexual and Reproductive Rights:** For many women and girls with disabilities, knowledge of sexual and reproductive rights and health has been shown to be poor and access to information and education limited. Women with disabilities express desires for intimate relationships but report limited opportunities and difficulty negotiating relationships.<sup>58</sup> For women with intellectual disabilities in particular, attitudes toward sexual expression remain restrictive and laws addressing sexual exploitation may be interpreted by others as prohibition of relationships.<sup>59</sup> Paternalistic and stereotypical attitudes towards women and girls with disabilities, often result in others deciding on a disabled woman or girls behalf what is in their 'best interests'. The best interest approach has, however, only served to perpetuate discriminatory attitudes against women and girls with disabilities, and facilitates violations of their sexual and reproductive rights. In reality, the 'best interest' approach has been shown to have very little to do with the young disabled girl or woman, and more to do with the 'best interests' of others, particularly health workers, families and caregivers.<sup>60</sup> It is clear that negative attitudes, values and stereotypes about the reproductive capacity of women with disabilities influences decisions taken about their sexual and reproductive rights. When these negative attitudes are combined with authority and power, they are a potent combination.<sup>61</sup>

There is a dearth of accessible and relevant information and education for women and girls with disabilities on sexual and reproductive rights. This lack of information and education remains an urgent and unaddressed issue worldwide. Accessibility in this context, includes the right to seek, receive and impart information and ideas concerning sexual and reproductive rights in an accessible format. This includes both content that reflects the experiences of women with disabilities and format of information available, such as Braille, audio, plain and simple language, the use of telephone access relay services, sign interpreters, and accessibility compliant websites. A further dimension of access includes being able to understand and meaningfully participate in the services and programs available, including information and education resources.

**Lack of Access to Justice:** The right of access to justice is among the most important civil and political rights as it determines the extent to which individuals can secure and enforce their other substantive human rights.<sup>62</sup> In various ways the justice system itself (and therefore the state) perpetrates and/or condones the discrimination and violence women and girls with disabilities experience through various barriers. Women and girls with disabilities, particularly those with intellectual, cognitive, and/or psychosocial disabilities are often denied effective access to justice because they do not receive assistance to report violations of their rights or to participate in legal processes; they are often not believed or are viewed as unreliable or not credible witnesses; and violations of their rights are often accepted and condoned as 'behaviour management' practices, such as forced administration of medication.

For example, despite high levels of physical and sexual violence against women with disabilities, particularly in institutional settings, few cases are ever reported or prosecuted and when they are, they are inadequately investigated, remain unsolved or result in minimal sentences.<sup>63</sup> This is in part due to the stereotypical

perceptions of women with disabilities that operate at almost all levels of the criminal justice system, including police and courts, i.e.: that women with disabilities are sexually promiscuous, provocative, unlikely to tell the truth, asexual, childlike, or unable to be a reliable witness.<sup>64</sup>

## **5. Intersectionality & Multiple Identity: Sexual and Reproductive Rights of Women and Girls with Disabilities**

A human rights based response to the denials of sexual and reproductive rights of women and girls with disabilities requires holistic measures that address both inter-gender and intra-gender inequality and discrimination, requiring human rights to be treated as universal, interdependent and indivisible; and situating discrimination on a continuum that spans interpersonal and structural factors. Thus, any analysis must account for both individual and structural discrimination, including structural and institutional inequalities; and analysing social and/or economic hierarchies among women, and between women and men, i.e. both intra- and inter-gender differences.

Although women with disabilities experience many of the same forms of discrimination all women experience, when gender and disability intersect, discrimination takes on unique forms, has unique causes, and results in unique consequences. Further, women with disabilities who are also people of colour or members of minority or indigenous peoples, or who are lesbian, trans-gender or intersex or who live in poverty, or who are older, or who are incarcerated in institutions or prisons, can be subject to particularised forms of violence and discrimination. These intersections must be explored in greater depth to ensure that the complexities of denials of sexual and reproductive rights of women and girls with disabilities are properly understood and addressed. Social sanctions on identity status or life experiences can further increase the risk of group or individual exclusion and denial of sexual and reproductive rights for women with disabilities.<sup>65</sup> The recognition of this reality variously referred to as “intersectionality,” “multidimensionality,” and “multiple forms of discrimination,” is important to any examination of the sexual and reproductive rights of women and girls with disabilities. Additional disaggregated data is needed on how all of these other identity categories impact or compound discrimination against women with disabilities. Women with disabilities who also belong to (or are perceived as belonging to) disfavoured or minority groups may face compounded violence and discrimination based on several factors simultaneously rather than one or two. To illustrate some of the barriers, impacts for a few identity groups are explored, but greater analysis is needed.

**Women with disabilities from Indigenous or Rural Communities:** Although no global data exists regarding indigenous persons with disabilities, available statistics (not sex-disaggregated) show that indigenous peoples are disproportionately likely to experience disability in comparison to the general population.<sup>66</sup> Indigenous persons with disabilities often experience multiple forms of discrimination and face barriers to the full enjoyment of their rights, based on their indigenous status and their disability; the discrimination is compounded when gender is part of the mix. Barriers from conflicting or overly complex traditional and contemporary service systems result in a jurisdictional quagmire<sup>67</sup> and they may lack information about access to health services and response.<sup>68</sup> The myriad<sup>69</sup> of issues that confront women with disabilities are significantly more pronounced in rural areas due to inaccessible environments and lack of services, information and awareness, education, income, and contact resulting in extreme isolation and invisibility.<sup>70</sup>

**Women with disabilities in Conflict or Post-Conflict Situations:** Women with disabilities in conflict or post-conflict regions may be at additional risk of violence as members of a targeted race/ethnic, religious, or linguistic group and may have great difficulty in accessing services in the conflict environment.<sup>71</sup> Refugee camps impose additional burdens. Justice and post-conflict reconciliation activities generally do not include women with disabilities, nor are such programs made accessible or inclusive.<sup>72</sup> The situation of women with disabilities in refugee camps is dire because of many factors, including dislocation and inaccessible facilities and programs. The inaccessible layout and infrastructure of refugee camps has been identified as seriously problematic for women with disabilities. Because camps and facilities are generally inaccessible, most women with disabilities are forced to remain in their shelters and their voices go unheard in decision-making.<sup>73</sup>

**Lesbians or members of other sexual minorities:** Women with disabilities who are lesbians or members of other sexual minorities face double discrimination in terms of sexual and reproductive rights.



They may experience a societal-imposed ‘cultural contradiction,’ as lesbian is viewed as a sexual identity while women with disabilities are often stereotyped as asexual.<sup>74</sup> Lesbians and other sexual minorities who identify as female who have disabilities confront social barriers and isolation from both sexual minority status and disability. They face a complex matrix of able-ism and discrimination on the basis of sexual orientation and both heterosexuality and ableism function as a social matrix, with exclusionary practices that operate in similar ways.<sup>75</sup> Lesbians with psycho-social disabilities often have been excluded or overlooked in research and treatment, despite expressed need or use of mental health care and other psycho-social services.

**Older Women:** Since, in general, women live longer than men, the numbers of women with disabilities will increase. As women with disabilities age, certain daily routines may become more complicated. Older women face multiple, or multidimensional, forms of discrimination, with gender, disability, and age compounded by other forms of discrimination, which can result in a wide range of human rights violations, including for example, physical violence, psychological, verbal and financial abuse, exploitation and neglect.<sup>76</sup> Sexual and reproductive health policies and programs in age-related contexts may not be available or accessible to older women with disabilities and may not make effective interventions addressing age and gender-related issues.<sup>77</sup>

**Women in institutions or in detention:** When combined with pervasive discrimination against women with disabilities, poor living conditions and systemic violence already present in many prisons raises the risks of incarceration for women with disabilities to new and unacceptable heights. They may be actively targeted based on their disabilities or simply have their disability-related rights and needs neglected.<sup>78</sup> Those with psychosocial disabilities face similar threats of inadequate care and mistreatment, in addition to the risks of self-harm and the deterioration of their mental well-being due to the nature of incarceration.<sup>79</sup> Incarceration of persons with disabilities without necessary services or accommodations, has been deemed illegal, degrading treatment as well as a potential violation of the International Covenant on Civil and Political Rights (ICCPR).<sup>80</sup> In several countries female prisoners with disabilities, are housed in security levels not justified by their risk assessment undertaken on admission.<sup>81</sup> This is further compounded by the lack of facilities able to house women with “impairments,” meaning that “because of these access and support issues, it would appear that female prisoners with certain physical, mental health or intellectual disabilities are much less likely to be located in one of the low security facilities compared to women without a disability.”<sup>82</sup>

## 6. The Cycle of Accountability in Relation to the Sexual and Reproductive Rights of Women and Girls with disabilities

Accountability is a cornerstone of the human rights framework. Human rights accountability is often understood to have three main constituent elements: responsibility, answerability and enforceability. The normative framework of human rights, and the processes through which it is applied, can give effect to these different dimensions of accountability.

**Responsibility** requires that those in positions of authority - primarily governments but also the private sector, inter-governmental and regional bodies - have clearly defined duties and performance standards, against which their actions can be judged. The human rights framework helps to define the substantive responsibilities of public officials and other actors, by setting out specific obligations which should inform their conduct. **Answerability** requires public officials and institutions to provide reasoned justifications for their actions and decisions to those they affect. Human rights standards elucidate the freedoms and entitlements that public officials must guarantee in order to be answerable to citizens and others whom their decisions affect. **Enforceability** requires public institutions to put mechanisms in place that monitor the degree to which public officials and institutions comply with established standards, impose sanctions on officials who do not comply, and ensure that appropriate corrective and remedial action is taken when required.<sup>83</sup> Human rights principles and mechanisms help to enforce accountability and give effect to claims for redress. Principles of due diligence and the right to an effective remedy are an essential pillar of accountability.<sup>84</sup>

Embedded in the human rights accountability framework, is the clear cross-cutting duty of States to *eliminate discrimination and ensure substantive equality* in the enjoyment of rights. This means that in addition to refraining from adopting discriminatory laws, policies, programmes and expenditures, States

should take specific, deliberate and targeted measures (including gendered measures) to ensure rights are enjoyed equally, in practice and in law. The rights to non-discrimination and equality are non-derogable rights, that is, rights that may not be violated under any circumstances, even in cases of emergency.

### **6.1. Human rights accountability in the context of sexual and reproductive rights of women and girls with disabilities**

Sexual and reproductive rights and freedoms remain a distant goal for many women and girls with disabilities all over the world. Instead, systemic prejudice and multiple forms of discrimination against them by a wide range of actors, continue to result in pervasive denial of their right to bodily autonomy and integrity – to make decisions about their own bodies, experience their sexuality, have sexual relationships, found and maintain families, gain an education and live a full and meaningful life.

Throughout the world, there have been, and remain, significant systemic failures in legislation, regulatory frameworks, policy, administrative procedures, availability and accessibility of services, education, information and support to prevent and address the grave violations of disabled women and girls' sexual and reproductive rights. Underlying these systemic failures is an entrenched culture throughout all levels of society that devalues, stereotypes and discriminates against women and girls with disabilities, and invariably perpetuates and legitimises not only the multiple forms of discrimination perpetrated against them, but also the failure of governments and other actors to recognise and take action on these violations.<sup>85</sup>

In considering *accountability* in relation to the sexual and reproductive rights of women and girls with disabilities, it is not possible to truly move forward without an understanding of the depth and seriousness of current violations of their sexual and reproductive rights. Discriminatory or absent laws and policies the world over see women and girls with disabilities being tortured and violated while complicit governments and other actors remain uninterested, apathetic and indifferent to these violations and their devastating and life-long effects. For many women and girls with disabilities who, on a daily basis, are being tortured and experiencing other egregious violations of their sexual and reproductive rights, aspirational goals and statements in the Beyond ICPD14 and Post 15 Development Agenda, have little meaning whilst barbaric practices and gross violations of their rights are allowed to continue. Human rights accountability in the context of sexual and reproductive rights of women and girls with disabilities therefore has an immediacy that warrants urgent action which can no longer be ignored or minimised.

**Responsibility:** Human rights law obliges the State and other duty bearers not to infringe on or compromise the fundamental freedoms and rights of people, and to take action to realise them.<sup>86</sup> The international human rights normative framework, including the international human rights treaties and their optional protocols, and the general comments and recommendations adopted by the bodies monitoring their implementation, provide the framework to delineate the respective obligations and responsibilities of governments and other duty-bearers, (including measurable standards of conduct and operational principles) in relation to the sexual and reproductive rights of women and girls with disabilities.

The right to be free from torture is one of the few absolute and non-derogable human rights, a matter of *jus cogens*,<sup>87</sup> a peremptory norm of customary international law, and as such is binding on all States, irrespective of whether they have ratified specific treaties.<sup>88</sup> A State cannot justify its non-compliance with the absolute prohibition of torture, under any circumstances. International human rights law not only prohibits torture (as well as any inhuman and degrading treatment) but also prohibits (a) the failure to adopt the national measures necessary for implementing the prohibition and (b) the maintenance in force or passage of laws which are contrary to the prohibition. The UN Special Rapporteur on Torture has made it clear that the failure of the State to exercise due diligence to intervene to prevent torture and provide remedies to victims of torture '*facilitates and enables non-state actors to commit acts impermissible under [the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment] with impunity,*' and its indifference or inaction provides a form of encouragement and/or de facto permission.<sup>89</sup>

In this context, States must act immediately to '*adopt effective measures to prevent public authorities and other persons acting in an official capacity from directly committing, instigating, inciting, encouraging, acquiescing in or otherwise participating or being complicit in acts of torture.*'<sup>90</sup> This means that governments must prevent those reproductive rights violations of women and girls with disabilities which

constitute torture (such as forced sterilisation, forced contraception, forced abortion) from taking place; investigate promptly, impartially and effectively all cases; remove any time limits for filing complaints; prosecute and punish the perpetrators, and, provide adequate redress to all victims.<sup>91</sup>

**Answerability:** Human rights standards elucidate the freedoms and entitlements that the State and other duty bearers must guarantee in order to be answerable to women and girls with disabilities whom their decisions affect. The following principles are essential in this context: non-discrimination and equality, participation, and access to information. These cross-cutting norms are expected to guide the State and other duty bearers in their implementation of human rights.

The *participation* of women with disabilities in all areas of public life remains woefully inadequate.<sup>92</sup> States and other duty bearers must ensure the active, free, informed and meaningful participation of women and girls with disabilities at all stages of the design, implementation, monitoring and evaluation of decisions and policies affecting them, including those relating to sexual and reproductive rights. This requires capacity-building and human rights education for women and girls with disabilities, and the establishment of specific mechanisms and institutional arrangements, at various levels of decision-making, to overcome the obstacles that women and girls with disabilities face in terms of effective participation. Women and girls with disabilities, their representative organisations and networks, must be empowered with sufficient resources, training and opportunities to effectively participate in shaping and monitoring the policies that affect them, at the national, regional and international levels. Organisations and groups of women with disabilities play a critical role in raising awareness of, and working to address the violations, denials and infringements of their sexual and reproductive rights. The empowerment of women with disabilities is achieved principally through women with disabilities coming together to share their experiences, gaining strength from one another and providing positive role models. There is currently no international civil society organisation of and for women and girls with disabilities. Financial and political support is therefore urgently needed for the establishment and maintenance of such groups of women with disabilities at international, national, regional and local levels.

Fulfilling the right to *information* is a key prerequisite for the active, free, informed, relevant and meaningful participation of women and girls with disabilities. Yet many women and girls with disabilities are denied the right to seek, receive and impart information about decisions affecting their lives, including information related to their sexual and reproductive rights. They are far less likely than their non-disabled counterparts to receive general information or information that is gender and disability-specific on sexual and reproductive rights. They are denied access to information as to how their sexual and reproductive rights and freedoms can be enforced and violations remedied. Women with disabilities have limited, if any, input into the development of accessible and appropriate sexual and reproductive health policies, services and programs, including information and education resources.<sup>93</sup>

Information must therefore be available to women and girls with disabilities in a timely, comprehensive, accessible and understandable way so that it can be used to enable women with disabilities to realise their sexual and reproductive rights, and to hold duty bearers accountable if those rights are violated. All information must be provided in language, both spoken and written, that is understood, and in accessible formats such as sign language, Braille, large print, audio, plain and/or non-technical language, and captioned video. All web based information and sites must also be accessibility compliant.

**Enforceability:** As rights-holders, women and girls with disabilities must be in a position to exercise and *enforce* their sexual and reproductive rights, seeking and receiving effective remedy and redress through impartial, transparent, and prompt processes, including but not limited to independent judiciaries, with the power to sanction States and other duty bearers for wrongs committed. Enforcement is critical to setting out clear incentives for those exercising authority to respond to women and girls with disabilities (whose sexual and reproductive rights have been violated by their actions), in a fair, open, timely and efficient manner. Without clear, universal responsibilities as laid out in international human rights treaties, States and other duty bearers cannot be judged fairly and objectively for their conduct.<sup>94</sup>

*Access to justice and equal recognition before the law* are essential to the preservation and advancement of the sexual and reproductive rights of women and girls with disabilities. Historically and to this day, many legal systems restrict the legal capacity of women with disabilities solely because of their disability. Women with disabilities experience significant barriers to access to justice, including for example: inaccessibility of

courthouses, inaccessible procedures, stereotypes about women with disabilities which operate to exclude or discount their testimony; problems accessing legal representation and protection; assumptions that women with disabilities lack credibility, lack of accessible information and processes, and much more.

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

## 7. The Rights of Women and Girls With Disabilities in the Future Development Agenda Beyond 2014 and Post 2015

The achievement of the Millennium Development Goals (MDG's)<sup>95</sup> has been uneven across and within regions and countries. Moreover, progress has slowed in some areas, and a few of the goals remain out of reach. It is the poorest and those most marginalised and discriminated against on the basis of, gender, disability, age and ethnicity who have seen the least progress.<sup>96</sup> Hunger and under-nutrition, particularly amongst children, remain the most critical of global challenges. Despite the fact that some progress has been made towards greater gender equality, women remain profoundly disadvantaged in many fields, especially in terms of access to sexual and reproductive health care, decision-making, productive employment opportunities in the formal sector, and productive resources. One of the biggest obstacles to progress on the achievement of all the MDG's, is the scourge of violence against women and girls, including conflict-related sexual violence.<sup>97</sup> In addition to inequalities between men and women, inequalities that exist among women, including on the basis of disability, have also served as obstacles to the realisation of the MDG's.<sup>98</sup>

In December 2012, the UN General Assembly reiterated that the full, effective and accelerated implementation of the Beijing Declaration and Platform for Action<sup>99</sup> and the outcome of the twenty-third special session of the General Assembly<sup>100</sup> are essential to achieving internationally agreed development goals. In this regard, the Assembly called for the goal of gender equality and the empowerment of women to feature prominently in the discussions of the post-2015 development framework, bearing in mind the importance of mainstreaming a gender perspective.<sup>101</sup>

In order to address the widespread and deeply rooted inequalities experienced by women and girls with disabilities, including the pervasive human rights violations they experience, disability and gender must be mainstreamed as a cross-cutting issue throughout the whole post-2015 framework. The future development agenda Beyond 2014 and Post 2015, must therefore incorporate the following elements.

The new development agenda must be grounded in the **universal human rights framework**. Any new framework of goals, targets and indicators must fully reflect the fundamental human rights principles of universality, indivisibility, equality, non-discrimination, participation, transparency and accountability. It must also reinforce the duty of states to guarantee at least minimum essential floors of rights enjoyment, to use the maximum of their available resources to realise rights progressively for all, and to engage in international cooperation for this purpose. Recognising that the respect, protection and fulfilment of all human rights should be both the purpose and the ultimate litmus test of success for the Beyond 2014 and Post 2015 development agenda.<sup>102</sup>

The new development agenda must prioritise and contain a transformative, standalone goal on **eliminating and addressing all forms of violence**. It is undisputed that violence, in all its forms, is the most pervasive human rights abuse in the world today, happens in all countries, is the biggest impediment to development and has been the over-arching major obstacle to progress on the achievement of all the MDG's.<sup>103</sup> No other goals and targets in the future development agenda framework can possibly be achieved without prioritising the elimination of all forms of violence. Whilst it is recognised that violence, in all its forms, disproportionately affects women and girls, is one of the most telling signs of gender-based inequalities in society, and remains the most egregious violation of women and girls' human rights, there is a risk that linking violence only to gender equality goals, may in fact, minimise the imperative for the elimination of violence throughout and across the Post 2015 development agenda.

The new development agenda must prioritise and contain a standalone goal on **equality and non-discrimination**. Given the undisputed fact that it is those most marginalised and discriminated against (on

the basis of, gender, disability, age and ethnicity) who have seen little benefit from the MDG's to date, the whole post-2015 development agenda must make equality and non-discrimination a priority. Clearly, for persons with disabilities, particularly women and girls with disabilities, this includes the need to ensure that disability and gender specific targets and indicators are embedded throughout the new development agenda. The new framework must reflect the range of measures states are already obliged to take to ensure the equal enjoyment of human rights by people with disabilities, women, indigenous people and others facing systemic discrimination.

The new development agenda must prioritise and contain a standalone goal on **gender equality** with gender-sensitive indicators mainstreamed across and throughout the new development framework. Women the world over have failed to benefit from the MDG's, in fact, they have been heavily impacted by the global crises that have arisen or intensified since the establishment of the MDGs, including the global financial and economic crisis, climate change, the food and fuel crises, and the increasing rates of violence perpetrated against them. A standalone goal on gender equality must be transformative and address the structural determinants of gender inequality in the economic, social, political, and environmental realms. Without a dedicated focus on gender equality in the new development framework, the risk is that gender-based differences in power and resources that block the realisation of women's rights are rendered invisible: the structural causes of discrimination and harm on the grounds of gender are left unchanged.<sup>104</sup>

Effective civil society **inclusion and participation** is not only a human rights imperative, but will be critical to the success of the Beyond 2014 and Post 2015 development agenda. As this paper has already highlighted, the participation of women with disabilities in all areas of public life has been and remains woefully inadequate. Women and girls with disabilities must be meaningfully involved in all decision-making processes of the new development agenda and frameworks. Critically, the role of civil society organisations of women and girls with disabilities, is vital in this process. They must be empowered with sufficient resources (including financial), capacity building, training and opportunities to enable them to effectively participate in development agenda and frameworks.

The new development agenda must ensure that **accountability and good governance** is built into all facets of the Beyond 2014 and Post 2015 development agenda. Any new global review mechanism for post-2015 development commitments should explicitly refer to international human rights treaty standards, and should ensure rigorous independent review, effective civil society participation and high-level political accountability. In turn, international human rights mechanisms, should be strengthened, and should take more consistent and explicit account of monitoring and reporting processes for new global development goals. The data generated by the review mechanisms for post-2015 global development goals should feed systematically into international human rights review and reporting processes.<sup>105</sup>

## **For More Information on the Sexual and Reproductive Rights of Women and Girls with Disabilities**

The websites of Women With Disabilities Australia (WWDA) and Women Enabled, both contain extensive resource materials on women and girls with disabilities, including on Sexual and Reproductive rights.

### **Women With Disabilities Australia (WWDA)**

Women With Disabilities Australia (WWDA) is the peak non-government organisation (NGO) for women with all types of disabilities in Australia. Although primarily a national organisation, WWDA is increasingly working at the international level to advance the human rights of women and girls with disabilities. WWDA is run by women with disabilities, for women with disabilities. WWDA's work is grounded in a rights based framework which links gender and disability issues to a full range of civil, political, economic, social and cultural rights. Promoting the reproductive rights of women and girls with disabilities, along with promoting their rights to freedom from violence and exploitation, and to freedom from torture or cruel, inhuman or degrading treatment are key policy priorities of WWDA.

Web: [www.wwda.org.au](http://www.wwda.org.au)

Facebook: <http://www.facebook.com/WWDA.Australia>

### **Women Enabled**

Women Enabled educates and advocates for the human rights of all women and girls, with a special focus on women and girls with disabilities, in collaboration with organisations of women and girls with disabilities worldwide. Women Enabled, Inc. focuses on human rights programming and training in developing, transition, and post-conflict countries, as well as consulting for governments, non-governmental organisations and international organisations to ensure the inclusion of women and girls with disabilities in international policy and development program design and implementation.

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Facebook: <http://www.facebook.com/WomenEnabled.org>

## **About the Authors**

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**Stephanie Ortoleva** is a highly recognised international human rights lawyer, policy and development consultant, author and researcher on issues of women's rights, disability rights and the rights of women and girls with disabilities. She is the Founder and President of Women enabled, Inc. She has numerous scholarly publications regarding women's rights, disability rights, sexual and reproductive rights, access to justice, violence against women, conflict and post-conflict situations, electoral and political reform, and rule of law, and her papers can be accessed from the Women Enabled, Inc. website. As a woman with a disability herself she brings the development, academic and legal perspectives to her work as well as her personal experience as a woman with a disability. Previously Stephanie served as an attorney and human rights officer at the U.S. Department of State, where she served on U.S. Government Delegations at international multilateral venues regarding disability rights and women's rights and she received several honors for her work. Stephanie received her J.D. from Hofstra University School of Law with outstanding academic honors.

## Endnotes

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- <sup>2</sup> Ibid.
- <sup>3</sup> Frohmader, C. (2013) 'Dehumanised: The Forced Sterilisation of Women and Girls with Disabilities in Australia'. Women with Disabilities Australia (WWDA), Rosny Park, Australia. At: [http://www.wwda.org.au/WWDA\\_Sub\\_SenateInquiry\\_Sterilisation\\_March2013.pdf](http://www.wwda.org.au/WWDA_Sub_SenateInquiry_Sterilisation_March2013.pdf) Ortoleva, S. & Lewis, H. (2012) 'Forgotten Sisters- A Report on Violence Against Women with Disabilities: An Overview of its Nature, Scope, Causes and Consequences'; Northeastern University School of Law Research Paper No. 104-2012. At: <http://ssrn.com/abstract=2133332>
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- <sup>14</sup> The CRPD Committee's commitment to increasing the focus on women and girls with disabilities was recently highlighted during their 9th session *Half Day of General Discussion on Women and Girls with Disabilities* where sexual and reproductive rights, violence against women and girls with disabilities, and the intersectionality of gender and discrimination, were prioritised as key themes for action. See: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGD17April2013.aspx>
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- <sup>18</sup> The High-Level Task Force for the ICPD is an independent body established to provide a bold, progressive voice for advancing sexual and reproductive health and rights, gender equality and the empowerment of women and young people, particularly for marginalised groups, in the Post-2015 Development Agenda. See: <http://www.icpdtaskforce.org>
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- <sup>23</sup> 'Forced/involuntary sterilisation' refers to the performance of a procedure which results in sterilisation in the absence of the free and informed consent of the individual who undergoes the procedure, including instances in which sterilisation has been authorised by a third party, without that individual's consent. This is considered to have occurred if the procedure is carried out in circumstances other than where there is a serious threat to life. Coerced sterilisation occurs when financial or other incentives, misinformation, misrepresentation, undue influences, pressure, and/or intimidation tactics are used to compel an individual to undergo the procedure. Coercion includes conditions of duress such as fatigue or stress. Undue influences include situations in which the person concerned perceives there may be an unpleasant consequence associated with refusal of consent. Any sterilisation of a child, unless performed as a life-saving measure, is considered a forced sterilisation.

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- <sup>26</sup> Méndez, Juan. E. (2013) UN.Doc A/HRC/22/53, Op Cit., See also: Nowak, M. (2008) *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*; UN General Assembly, UN Doc. A/HRC/7/3; Committee on the Rights of the Child (2011) *General Comment No. 13: Article 19: The right of the child to freedom from all forms of violence*; UN Doc. CRC/C/GC/13.
- <sup>27</sup> A State's obligation to prevent torture applies not only to public officials, such as law enforcement agents, but also to doctors, health-care professionals and social workers, including those working in private hospitals, other institutions and detention centres. As underlined by the Committee against Torture, the prohibition of torture must be enforced in all types of institutions and States must exercise due diligence to prevent, investigate, prosecute and punish violations by non-State officials or private actors. See: Méndez, Juan. E. (2013) UN.Doc A/HRC/22/53, Op Cit.
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- <sup>42</sup> High-Level Task Force for the ICPD (2013) OpCit.
- <sup>43</sup> Women With Disabilities Australia: *'Parenting Issues for Women with Disabilities in Australia' - A Policy Paper* (May 2009). Available at: [www.wwda.org.au/motherhd2006.htm](http://www.wwda.org.au/motherhd2006.htm)
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- <sup>45</sup> Women With Disabilities Australia (WWDA) (2007b) *'Forgotten Sisters - A global review of violence against women with disabilities'*. WWDA Resource Manual on Violence Against Women With Disabilities. Published by WWDA, Tasmania, Australia.
- <sup>46</sup> This happens in two main ways: a) the child is removed by child protection authorities and placed in foster or kinship care; and b) a Court, under the *Family Law Act*, may order that a child be raised by the other parent who does not have a disability or by members of the child's extended family. See: Victorian Office of the Public Advocate (OPA) (2012) *OPA Position Statement: The removal of children from their parent with a disability*. <http://www.publicadvocate.vic.gov.au/research/302/>
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