

What works to prevent violence against women with disabilities Ingrid Van Der Heijden

Key messages:

- WWD are at increased risk for GBV due to the intersection of gender bias and disability stigma and discrimination.
- In order to develop appropriate responses and interventions to prevent violence and protect women with disabilities, we need to know the risk factors and context respond to them accordingly.
- Some violence and abuse prevention interventions for women with disabilities (WWD) have been developed.
- None of these prevention interventions demonstrate a decreased incidence of violence, and many lack rigorous planning, implementation and evaluation.
- There is only 1 published systematic review of the prevalence of violence against adults with disabilities but does not include gender-based violence against women
- Much more research and innovation is needed to develop effective approaches to recognise and prevent violence against WWD, especially in low and middle income settings.

Introduction

We present key findings on the evidence from research studies on violence against women with disabilities and evidence from interventions to prevent violence. Responses to prevent and address gender based violence against women in this high risk group need to take into account the intersection of gender and disability and how this increases the vulnerability of women with disabilities to violence. Women with disabilities experience the same forms of violence that other women experience, but there are also unique causes, forms and consequences of violence against women with disabilities that call for tailoring of prevention responses.

Some interventions to prevent violence against women have been shown to be effective (WHO 2012), but there is insufficient evidence that interventions for women with disabilities have any effect. Indeed most literature on prevention of violence against women does not discuss women with disabilities as a special group with particular prevention needs. This review includes some evidence from interventions to prevent sexual assault for women with intellectual disabilities (Lund 2011; Barger et al 2009). However, it largely relies on wider literature on the risks, nature and consequences of violence against women with disabilities and asks what can be done to fill the intervention gaps to prevent it. We searched of for

published reviews and papers, and examined websites such as the Washington Coalition of Sexual Assault Programmes, WHO and other disability organisations to find interventions that seek to specifically reduce or prevent violence against women with disabilities, and those that target key risk factors for violence perpetration and experiences. The evidence presented is limited to that which is published and accessible on the internet and is drawn from a desk review of development reports, other reviews, commentaries of interventions and published research studies.

The prevalence of violence against women with disabilities

The most recent global estimates for IPV reveal that 30% of women aged 15 and over have experienced physical and/or sexual IPV in their lifetime (WHO 2013; DeVries, Mak, Garcia-Moreno, Petzold et al 2013) and for non-partner sexual abuse show that 7.2% women experience this, with adverse health effects (WHO 2013). A systematic review and metaanalysis of the global prevalence and risk of violence against adults with disabilities published in the Lancet two years ago found that overall adults with disabilities are 1.5 times more likely to be victims of violence than those without a disability; while adults with mental health conditions are at nearly four times the risk of experiencing violence (Hughes, Bellis, Jones, Wood, Bates et al 2012)¹. This is the only published systematic review that presents the prevalence and risk of violence for adults with disabilities, although it does not look at violence against women with disabilities (WWD) separately. However, the small number of studies and wide variation in sample and study characteristics included in the review mean a great deal of uncertainty exists around the pooled risk estimates. The quality of the studies included in the review are deemed moderate, revealing that "[quality] evidence for the prevalence and risk of violence against individuals with disabilities is scarce, and hampered by methodological weaknesses and poor measurement of disability and violence" (Hughes et al 2012, 1628).

Research on prevalence of GBV against women with disabilities is rare, with a few studies using population based samples. In the United States of America and Canada, women with disabilities are found at least twice as likely as their non-disabled counter-parts to be victims of rape, sexual abuse and IPV (Chenoweth, 1996; Nosek, Howland & Hughes 2001; Hassouneh Phillips & Curry, 2002; Brownridge 2006; Smith 2008). Young et al (1997) found that both physically disabled and non-disabled women had an equally high lifetime prevalence (62%) of emotional, physical and sexual abuse. However, the prevalence of violence toward women with disabilities is also largely underestimated, because studies use large population based surveys undertaken for other reasons, not specifically on violence; thus in the surveys "experiences of violence are only a side issue and are generally not explored in detail using the specific methods developed to uncover the extent and contexts of violence in an appropriate, sensitive and ethically responsible way" (Schröttle & Glammeier 2013, p235)

Research suggests that the most common perpetrators of violence against WWD are their spouses or male partners (Brownridge 2006; Brownridge 2009, Milberger 2003; Martin et al 2006; McFarlane et al 2001; Young et al 1997). Barret et al. (2009) reveal that WWD are

¹ Another recent systematic review also found that children with disabilities are almost four times more likely to experience violence than non-disabled children (Jones 2012).

significantly more likely to have experienced IPV as compared to those without disabilities (33.2% and 21.2% respectively). In Germany, Schröttle & Glammeier's (2013) prevalence rates obtained in a representative general population sample revealed that women with disabilities experienced violence by a current and/or former intimate partner at about two to five times higher than the general female population. Using a representative sample of 7,027 Canadian women currently in a relationship from the General Social Survey (GSS), Brownridge (2006) found that, compared to women without disabilities, Canadian women with disabilities had 40% greater chance of experiencing intimate partner violence in the five years prior to the study, and this elevated risk was statistically significant. Brownridge found women with disabilities were twice as likely to report being kicked, bit, or hit with a fist, and 3 times more likely to report being forced into sexual activities by their partner by being threatened, held down, or hurt in some way.

Risk factors for violence against women with disabilities

Women with disabilities' experiences and risks of violence are compounded by physical, sensory or intellectual impairments, marginalisation from society and inaccessible environments. The term 'disability' refers to the marginalisation of people from society due to social and cultural attitudes (stigma) and physical and environmental barriers. The risks women with disabilities face stem from the devaluing of disabled women by society as well as its patriarchal nature. This creates a double burden of discrimination. Many of the risk factors for violence against women in the general population are more prevalent among women with disabilities. For example, due to their disability, they are less educated and less likely to be employed, more likely to be poor and are more socially isolated than women without disabilities (Brownridge 2006; Nosek, Hughes, Swedlund, Taylor & Swank 2003).

Their physical, economic and social dependence is a key risk factor associated with gender based violence. WWD are exposed to multiple potential perpetrators on which they are dependent, including intimate partners, family members, health care providers and personal assistance workers (Plummer & Findley 2012). Disabled women often find themselves trapped in abusive or neglectful relationships because they are financially and physically dependent on their partners, families or care givers who are perpetrators of violence and abuse (Brownridge 2006).

More importantly, their reliance on others increases their risk of forms of emotional and physical abuse which are **disability-based forms of violence**, such as being prevented from using a wheelchair or other assistive device, being over or under-medicated, being neglected or refused help, or the misuse of their welfare grants by family members adds further exploitation and vulnerability (Curry, Renker, Hughes et al 2009).

The social and cultural myths around disability equally work to increase a women's likelihood of victimisation. The sexuality of women with disabilities is often denied or ignored and there is pervasive stereotyping of disabled women as asexual because of the stigma associated with their disability (Nosek et al. 1997). Myths around their asexuality mean that they are considered virgins and therefore more likely to experience virgin cleansing or virgin rape (Groce & Trasi 2004). The body of a disabled woman is perceived as unable to reproduce, preventing disabled women from fulfilling normative gender roles of

reproduction and motherhood and resulting in increased difficulties to access reproductive health care services — including limited contraceptive options, health care providers' insensitivity and lack of knowledge about disabilities, and limited information tailored to their health needs (Becker 1997), and on the most perverse side, forced sterilization or forced abortion (Ortoleva & Lewis 2012). Women with disabilities are also less likely to receive sex education or information on reproductive health (Naidu, Haffejee, Vetten & Hargreaves 2005), and are assumed to not be eligible for marriage and are more likely to be divorced and less likely to marry than men with disabilities or women without disabilities (Gerschick 2000). Because of myths around the asexuality and ineligibility for marriage, it is rarely assumed that women with disabilities have intimate partners, so **IPV often goes undetected** (Barnett et al 2005, p353).

Women's mental health as a risk factor and consequence of violence. Survey research conducted in Cambodia on the impact of disability and partner violence on women's mental health reveals that there was a strong relationship between disability and symptoms of severe psychological distress, and that the presence of partner violence further accentuates this relationship (Astbury 2012). The psychological or mental health of women with disabilities increases their chances of being victims of violence. Social and cultural discrimination and use of stereotypes may be internalized by women, translating into self-devaluation, poor self-esteem and body image (Hassouneh-Phillips & McNeff 2005), and feelings of blame related to the abuse (Plummer & Findley 2012). They fear rejection and being alone, forcing them to stay in an abusive relationship. Once in a relationship, Oktay and Tompkins (2004) found that disabled women were more likely to tolerate abuse from their partners rather than leave and be single. Therefore studies suggest that disabled women experience abuse for longer periods of time compared to those without disabilities (Nosek et al 2001; Young et al. 1997).

Overall, GBV is a major health issue, with both mental and physical health outcomes for women, and physical and psychological health effects can linger long after the abuse has stopped. Pain and injuries range in intensity and chronic stress, anxiety and depression, sleep disorders and substance abuse can manifest or increase as a result of the abuse and add further impairments to already disabled women (Nosek et al. 1997). Astbury (2012) recognises the important gap in the evidence base on how GBV affects the psychological well-being of WWD, and these consequences need to be further elaborated in more studies.

Type of disability increases risk. The variety of impairments associated with a disability is wide and can make a significant difference in the risks and forms of abuse women face. Hughes, Bellis, Jones et al. (2012) report the association between intellectual impairment and risk of violence to be significantly higher than with women with other disabilities. Impairments that reduce emotional and physical defenses, communication barriers that hamper the reporting of violence, societal stigma and discrimination, and institutionalization contribute to disabled women's increased vulnerability to violence (Nosek, Howland & Hughes 2001; Saxton, Curry, Powers et al 2001). It is commonly assumed that women with developmental disabilities and cognitive impairments are most at risk for stigma and therefore more likely to be victims of abuse, violence and neglect (Powers, Renker, Robinson-Whelen et al. 2009). Risk factors are found with greater prevalence among women with intellectual disabilities; they are less likely to receive *any* sexual education,

often socialized to be compliant, more likely to live in poverty and are more reliant on caregivers (Barger et al 2009). They are more likely to be institutionalized and are unlikely to disclose violence as for them communication is difficult or they are unlikely to be believed (Powers, Renker, Robinson-Whelen et al 2009). Institutionalization is notoriously associated with mistreatment and abuse, and disabled women, in greater numbers than disabled men, have been incarcerated in prisons, hospitals, nursing homes, psychiatric and other institutions (Meekosha 1998, p177-178). Also, the bodily signs of disability may put physically disabled woman at risk of stigma and therefore violence or abuse (Young et al 1997; Nosek et al. 1996). Furthermore, blindness may hamper women from identifying perpetrators, or their immobility put them at increased risk of non-escape from violent acts (Plummer and Findley 2012).

WWD are less likely to disclose violence or seek help. This is due to women being unaware they are being abused or recognizing ill treatment – thinking it is normal; a cognitive inability to comprehend what is happening; dependence on partner and/or fear of losing partner or children; fear of institutionalization, lack of screening for violence, not being aware of her rights and laws to protect her, and lack of access to information on prevention or protection. If they do seek help, they are met with physical, resource and attitudinal barriers. Some of the reasons why women with disabilities may not get the help they need include:

- Lack of physical access to justice system and courts, communication barriers and not seen an credible witnesses
- They are met with insensitive behaviour by service providers (Swedlund & Nosek, 2000).
- Social workers may not understand the issues facing women with disabilities, and disability sector workers may not be educated about the high risk of violence.
- The various agencies that help people with disabilities aren't networked well, creating service gaps. For example, a woman might be referred back and forth between two agencies, such as sexual assault services and disability services, without receiving help from either because she falls outside the guidelines of both agencies.

What Works to prevent violence against disabled women?

Summary of Evidence available: Our search revealed nine interventions to prevent abuse or violence against women with disabilities. Unfortunately, many of the interventions did not include any tested outcomes nor had documented evaluation results of the program or curriculum. Those that did have assessments had evaluations that were not rigorously designed.

Description: The interventions focus on awareness and skills building, and are for groups of women with developmental/intellectual disabilities, and some include their carers and service providers. They aim to increase awareness of abuse, and educate on how to avoid dangerous situations, resit 'lures' by potential perpetrators, and provide safety promoting information. Empowerment and self-determination are also components of some of the interventions.

| Examples of interventions: | Evidence: |
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| Examples of interventions. | Lividence. |
| Personal SPACE (2000) (USA) stands for safety, planning, awareness, choice, and empowerment and lesson plans cover definitions of sexuality healthy relationships, sexual harassment, sexual assault, domestic violence, acquaintance assault, and safety planning components | No RCT, pre and post program evaluation surveys Outcomes: attitudes, knowledge, and skills related to sexual assault prevention – did not measure actual sexual assault incidence after the program. Results: change in attitudes and knowledge, not behaviour |
| Sexuality Education for Adults With Developmental Disabilities (Planned Parenthood, USA) is a cognitively accessible curriculum that deals with sexuality education and common challenges and how to overcome them | No evaluation Outcomes: No specific outcomes measured. Results: No evidence |
| F.L.A.S.H (Family Life And Sexual Health) Special Education Curriculum (2010) contains 28 lessons for special needs classrooms and topics include self-esteem, gender identity, assertiveness, relationships, understanding the body, consent, and reproduction. | No evaluation Outcomes: No specific outcomes measured. Results: No evidence |
| Taking Care of Me (Australia) is a violence prevention program for women with mild intellectual disabilities focused on assertiveness and safety planning for women with intellectual disabilities. | No evaluation, participant satisfaction survey Outcomes: No specific outcomes measured. Results: No evidence. |
| Living Safer Lives (Australia) focuses on decision making skills related to sexuality and relationship issues and to increase individual empowerment. | No evaluation, participant satisfaction survey Outcomes: No specific outcomes measured. Results: No evidence. |
| Safer and stronger program (SSP) (USA) is an computer based program for women who listen to video narratives of abuse and survival experiences and are asked a series of questions related to their awareness of interpersonal violence, the different types of interpersonal violence they experience, including disability-related violence, and their use of safety promoting behaviours. Topics relate to seeking abuse-related safety information, identifying dangerous people, finding help, trusting your instincts, communicating safely, using emergency self-defence techniques, using relationship support, avoiding tricks and lures by potential perpetrators, taking legal action, and managing personal assistance relationships | Acceptability evaluation with randomised design. Outcomes: None Results: None. Field test / RCT of internet-based adaptation for men in process |
| Increasing Independent Decision-Making Skills of Women With Mental Retardation in Simulated Interpersonal Situations of Abuse examines individuals' decision making skills by presenting them with audio stories that posed interpersonal psychological, physical, and sexual abuse situations. An Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment (ESCAPE) is a cognitive based decision making skills intervention expanding on the Increasing Independent Decision-Making Skills of Women with Mental Retardation in Simulated Interpersonal Situations of Abuse, including an abuse-prevention curriculum for disability service providers A Safety Awareness Program for Women with Disabilities | RCT, no follow up Outcomes: Knowledge, decision making, empowerment Results: Intervention group increased on measures of knowledge, decision-making, and empowerment but not a measure of stress management. (Khemka, Hickson & Reynolds 2005) Evaluation: Baseline and post- intervention |
| (ASAP for Women)— a peer-led psychoeducational group—addressed topics such as self-care, communication, healthy | questionnaires administered to a sample of women (N=7) who completed a safety |

relationships, the nature and dynamic of interpersonal violence and consisted of 8, 150-minute sessions. Disability Services ASAP staff provides education and training for professionals (i.e., disability service providers, domestic and sexual violence agency staff, criminal justice personnel) to help increase awareness about and prevent sexual and domestic violence and abuse against people with disabilities. The program staff also offer technical assistance and / or consultation to individuals and organizations seeking information and guidance to reduce the risks of abuse against people who have disabilities or to increase accessibility of victim service agencies or programs to survivors of abuse who have disabilities.

awareness program.

Outcomes: Safety self-efficacy, safety skills, social support/isolation, and safety promoting behaviors

Results: Significant increases from baseline to post-intervention were found in self-efficacy and safety skills. Although not statistically significant, improvements were also found in safety promoting behaviour (Hughes, Robinson-Whelen, Pepper et al 2010).

Effectiveness: No rigorous evaluations of these interventions exist to date. All evaluations had small sample sizes and minimal desired behavioural outcomes were demonstrated at follow up. The review found one controlled trial (with no follow up) of an intervention specifically to address the unique needs and experiences of women with disabilities.

Impact on violence occurrence: To date there is *no evidence* that these interventions have an impact on the prevalence or incidence or perpetration of violence against women with disabilities specifically.

Impact on risk factors: There is some evidence that interventions can lead to an increase in self efficacy and decision-making, knowledge and empowerment.

Lessons learned

- It is important to include women with a range of disability types, not just intellectual or developmental disabilities
- There is a need different types of interventions, including awareness campaigns, changing social norms, mental health interventions, childhood and school-based interventions for early prevention etc.
- Rigorous evaluations are needed to provide best practice evidence

Conclusions

Few violence and abuse prevention efforts geared towards women with disabilities exist, and none of these prevention interventions demonstrate that they decrease incidence of violence, or help to mitigate risk factors. They lack rigorous planning, implementation and evaluation. There is a need for substantial work in this area. Issues to consider and pointers for future intervention development include the following:

- ❖ Interventions need to be informed by evidence and theory of what increases risk of violence against WWD
- ❖ Interventions need to include caretakers on prevention of violence against WWD as protectors and potential perpetrators
- Social services and agencies need to be more aware of disability-based forms of violence, such as being prevented from using a wheelchair or other assistive device,

- being over or under-medicated, being neglected or refused help, or the misuse of their welfare grants by family members
- ❖ Interventions need to be developed to empower WWD to strengthen resilience through economic empowerment to decrease dependency and social empowerment to become more knowledgeable partners in their own health care focus on sex education and reproductive health. These need to be evaluated.
- Social norm change interventions are needed to address perpetuation of social and cultural myths that encourage disability stigma and gender stereotypes, and denial of sexuality of WWD which leads to silence around their IPV
- Safety planning discourse and strategies for women with disabilities need to take into account their impairments and the accessibility of their environments

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