

Sexual Health and Sexual Education for Women with Disabilities: Challenges & Opportunities

McMaster Research Shop Report



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EXECUTIVE SUMMARY

Women with disabilities (both physical and intellectual) have a higher risk of experiencing sexual violence as a result of systemic oppression (the barriers we create as a society and the environment that limits access to services, information, opportunities, experiences etc.). In this report, we will explore current research about sexual violence experienced by people with disabilities, discuss the gaps in sexual education for this community, and evaluate future needs for more effective and informative education and violence prevention.

*What's the current research around **sexual violence** against individuals with disabilities?*

People with disabilities are at a higher risk of experiencing sexual violence, especially women, than those without disabilities (Oram, 2016; Basile, 2016). Systemic barriers (e.g. lack of access to education) put these individuals in vulnerable situations and increase the risk for sexual violence and disability specific violence (e.g. the abuser may withhold providing support for personal hygiene activities or eating). Additionally, while some people with disabilities rely on personal assistance services, service providers are often identified among the top perpetrators of sexual violence (Powers, 2002). This report discusses a combination of systemic barriers (e.g. oppression due to race, disability type and severity) from an intersectional lens (considering the different structural and societal oppression that different women face including oppression against race, age, disability type, and disability severity (Crenshaw, 1991)) and the implications that it may have to lead to further risk of violence.

*What's the current research around **sexual education** for individuals with disabilities?*

There is a lack of effective and informative sexual health education in Canada (and North America overall) for individuals with disabilities—which may increase their risk of experiencing violence. Individuals with disabilities are often viewed as de-sexualized or childlike (Esmail, Darry, Walter & Knupp, 2010; Couldrick, 2008), a harmful stereotype, which discourages sexual education. Importantly, the current approach to sexual education does not address many of the systemic barriers, putting women at higher risk. Structural barriers are only used as a starting point rather than a complete solution.

In Canada, there are guidelines for health care professionals, educators, policy makers, organizations and government bodies to provide sexual health education to the general population (Public Health Agency of Canada, 2008). While the guidelines recognize that individuals with disabilities should be provided information about sexuality that is specific to their disability, there are limited resources available to do so. Researchers suggest that parents and healthcare professionals in Canada lack the confidence and necessary resources to provide sexual health education to individuals with disabilities (East & Orchard, 2014).

What can we do to better support this community?

There is clear evidence there are limited accessible resources on sexual health education to prevent sexual violence in Canada (Couldrick, 2008; Kedde, van de Wiel, Schultz, Vanwesenbeeck and Bende, 2012). This report draws attention to the need for more adequate sexual health education for women with disabilities, to help prevent sexual violence, and emphasizes the need to address this issue through an

intersectional and social theory of disability approach. The report calls for increasing the quantity and quality of sexual health education resources for individuals with disabilities and dismantling systemic barriers to sexual health for this population. Adopting a multi-pronged approach that incorporates: i) inclusive sexual health education targeted at a range of audiences, ii) inclusive sexual violence resources and policies, and iii) encourages participatory research (includes the voices of people with disabilities in both the design and implementation of research and evaluation) is critical for moving forward.

Legislation, policy, and programming need to improve around the safety of individuals with disabilities. To make changes, the first step is being in the know!

Introduction

Understanding Violence Against Women & Disabilities as Socially Constructed

According to the General Social Survey on Canadian Safety report (2014), conducted by the Canadian Broadcasting Corporation (CBC), 45% of all violent incidents involving females are committed against women with disabilities. Using a sociological perspective to understand violence against women, and specifically women with disabilities, is crucial because it highlights the role society plays in creating and maintaining systemic oppression. The social theory of disability describes disability as a result of structures and institutions created by society that limit the abilities of individuals, rather than disability being a result of a person's difference (Shakespeare, 2006). For example, "women with disabilities are more likely to be of low socioeconomic status" (SES) (Brownridge, 2006; American Psychological Association, 2018). Low socioeconomic status can stem from educational institutions being unable to provide accessible and equitable education to women with disabilities, which then acts as a barrier to employment reducing potential income (Brownridge, 2006). Moreover, "low SES has generally been associated with violence against women" (Barnett et al., 2005; Brownridge, 2006). Lacking financial stability increases the risk of being placed in vulnerable situations and relying on others, making violence more likely.

This report has been prepared by student Research Associates from the McMaster Research Shop at the request of the Hamilton Centre for Civic Inclusion. The report is intended to explore the following:

- Current research about sexual violence experienced by people with disabilities
- Gaps in sexual education for this community
- Future needs for more effective and informative education and violence prevention

Methodology

This report draws on academic and grey literature to explore the issue of access (or lack of access) to sexual health education for people with disabilities and the implications of this for sexual violence. The report includes a broad selection of materials that collectively demonstrate experiences of sexual violence and sexual health education among people with disabilities. However, we specifically focused on women with disabilities although some literature included men as well. Since women are the focus of the report, it is important to note that the terms 'people with disabilities' and 'women with disabilities' are used inter-changeably throughout the report.

To gather the peer-reviewed academic literature, the following research databases were used: Google Scholar, McMaster Library Catalogue, and JSTOR. The specific keywords used for searching were 'sexual violence, disability, sexual health education, women and risk.' We limited our search to academic literature within the last 10 – 20 years given the small amount of research in this area.

The team also searched grey literature (e.g., reports and policies) and program websites federally, provincially and worldwide using Google Search. The members searched individually for literature that focused on various sexual health education programs and sexual violence studies that has been conducted thus far. We used a combination of 'old' (published over 6 years ago) and 'new' (published less than 6 years ago) grey literature for this report.

From this literature, we identified three broad themes which are relevant to the understanding of sexual health among individuals with disabilities. The themes are discussed below and consist of: systemic oppression, dependency on caregivers, and lack of support and resources.

Limitations

This report, along with most research on sexual violence against women with disabilities, has limitations. It is critical to recognize that many intersecting minorities are underrepresented within the literature including (but not limited to) those with severe disabilities, women of colour, those who are homeless, or those who identify as LGBTQ+. Those who also identify with additional minority groups experience different or compounding systemic oppression (e.g. a woman who identifies as having a disability and as a woman of colour experiences additional barriers to education along with compounding societal oppression—increasing their risk of violence). Thus, there is a gap in the literature as the experiences of people with disabilities facing sexual violence must be understood from an intersectional lens. Additionally, the authors recognize that this report is, at best, a summary of the literature, and in no way is meant to speak on behalf of the lived experiences of these women. In order to make the necessary changes to support women with disabilities, it is critical to give these women the necessary power and autonomy to make choices for themselves.

The team also faced challenges finding up-to-date literature and information that focused exclusively on the Canadian context. As a result, the team extended their literature search to other countries (e.g., England, Australia and United States).

Background

Sexual Violence

Sexual violence is embedded within our society and some populations are at higher risk of exposure to sexual violence. Ethnic minorities, children, women with disabilities, women in poverty, young women, and women who experienced violence as a child have a higher risk of experiencing sexual violence (Oram, 2016; Basile, 2016). The sexual assault prevalence rates are higher for individuals with disabilities—especially women with disabilities (Cotter, 2014). This is due to a variety of common, yet misinformed, beliefs about people with disabilities and sexuality such as: i) no one would take advantage of a disabled person, ii) any form sexual contact is enjoyed by people with an intellectual disability as they are more easily stimulated than other people, and iii) people with an intellectual disability have impaired sexuality (Carmody, 2009, p. 231). There is also an assumption that the individuals have “less sexual education and knowledge, less understanding of sexual abuse, poorer self-protection skills and higher levels of belief that someone other than themselves should decide whether they should have sex” (Eastgate, 2011, p.22). Nevertheless, people with disabilities are often not given adequate preparation to protect themselves as they tend to have trouble obtaining treatment services that are accessible and appropriate to their needs. In addition, there is a lack of attention paid to individuals with intellectual disabilities experiencing sexual violence and how to prevent these outcomes (Sobsey & Doe, 1991). Thus, there is a need for accessible sexual health education resources to help prevent sexual violence encounters (Oram, 2016; Basile, 2016).

Sexual Health Education

Access to Sexual Health Education

Part of the reason that individuals with disabilities are at greater risk of sexual violence is because they often lack access to adequate and inclusive sexual health knowledge, and therefore, may be less prepared to protect themselves in risky sexual situations. For instance, individuals with intellectual disabilities tend to have less sexual health knowledge (Eastgate et al., 2011; Jahoda & Pownall, 2014) and understanding of sexual abuse than the general population, and they also lack adequate self-protection skills (Murphy & O'Callaghan, 2004; Eastgate et al., 2011). These individuals are at a much greater risk of sexual abuse than the general population (Cotter, 2014). Yet, it has been shown that people with intellectual disabilities can navigate appropriate relationships if they have been given access to sexual health resources (Murphy & O'Callaghan, 2004). For individuals with physical disabilities, there is a need for improved access to sexual education regarding the emotional and mechanical adjustments to sex with a disability (Coultrick, 2008; Kedde, van de Wiel, Schultz, Vanwesenbeeck and Bende, 2012). Although many individuals with physical disabilities desire professional help for these concerns, most do not access—or do not have positive experiences accessing—healthcare professionals for these issues (Kedde et al., 2012). Their sexual issues specifically include practical problems (e.g. how to adapt their former methods of intimacy to their current level of ability), the inability to enjoy their sexuality (e.g. this could result from an altered body image or incongruence with how the expression of intimacy and sexuality is portrayed in society), or concerns about finding a sexual partner (Kedde et al., 2012).

Limited sexual health education programs and support available for these populations may, in part, be the result of harmful societal stereotypes that persist regarding individuals with disabilities. These negative stereotypes include de-sexualized and child-like views of individuals with disabilities among the general public, caregivers, and health professionals (Esmail, Darry, Walter & Knupp, 2010; Coultrick, 2008). However, people with disabilities have sexual desires and needs just like everyone else (Rushbrooke, Murray & Townsend, 2014; Coultrick, Sadlo, & Cross, 2010). Negative stereotypes surrounding the sexuality among people with disabilities leads to the tendency to marginalize their sexual needs and suppress their expression of their sexuality (Esmail et al., 2010). This lack of recognition by others may lead to secrecy (Rushbrooke, 2014) and a subsequent lack of support in these relationships. The assumption that individuals with disabilities are not sexually active can also lead to a failure to recognize signs of sexual abuse in this population (Eastgate et al., 2011).

Caregivers may also limit the sexual expression of their dependents by restricting or overseeing their intimate relationships. Although this is usually done out of concern for the individual, it can demean the individual by limiting their control, privacy and time alone with their partner (Rushbrooke et al., 2014). Research indicates that caregivers need greater access to education on how to provide appropriate sexual health support to their disabled dependents (Swango-Wilson, 2008).

Health professionals are also not adequately educated on how to provide sexual health education to individuals with disabilities (Haboubi & Lincoln, 2003; Higgins et al., 2012). Researchers indicate that health professionals are poorly prepared to provide sexual health education and often do not initiate discussion about sexual issues with their disabled patients (Haboubi & Lincoln, 2003; Higgins et al., 2012), primarily due to a lack of training, time, and embarrassment (Haboubi & Lincoln, 2003). The provision of training programmes to health professionals has been shown to increase their levels of knowledge, skill and comfort levels regarding navigating sexual health with their patients with disabilities (Higgins et al., 2012). Furthermore, the sexual health of individuals with disabilities needs to be prioritized by health care

professionals. Sexual functioning is a major concern for many newly disabled individuals, but it may not be considered when completing housing adaptations or during the provision of immediate support following an accident (Couldrick, 2008).

Finally, it is important to consider that although greater attention needs to be paid to the sexual needs of all individuals with disabilities, certain sub-populations, such as Lesbian, Gay, Bixsexual, Transgender, Queer, and others (LGBTQ+) individuals with disabilities are particularly marginalized (Esmail et al., 2010; Abbott & Howarth, 2007). Care should be taken to provide resources that are tailored to address the sexual health needs of specific populations.

Sexual Health Education in Canada

In Canada, the Public Health Agency provides a set of publicly available guidelines for health professionals, educators, policy makers, organizations and government bodies to use to provide comprehensive sexual health education to the general population (Public Health Agency of Canada, 2008). The guidelines recognize that individuals with disabilities, among other groups, often lack access to sexual health education. The guidelines also indicate that individuals with disabilities should be provided basic sexual health education as well as information about sexuality that is specific to their disability. The Government of Canada also provides specific information on sexual health education for youth with physical disabilities (Government of Canada, 2014). Finally, one of the most detailed resources available is an educational website (www.tasccalberta.com) which publishes information about hygiene, dating, safe sex, and puberty specifically for youth with disabilities in Canada (Talking About Sexuality in Canadian Communities, 2016).

Though there are some sexual health resources available for youth with disabilities in Canada, there appears to be a lack of resources for adults with physical and intellectual disabilities. Furthermore, there does not appear to be resources available for individuals with disabilities who are non-heterosexual or who identify as non-binary.

Research on the quality of the resources (Esmail, Krupa, MacNeill, and MacKenzie, 2010) indicates that individuals with disabilities perceive that the available resources do not provide adequate information and are not specific enough with regards to maintaining sexual health for individuals with different types of disabilities. Individuals in this study also felt that a variety of delivery methods should be used, taking into consideration the limitations of the specific disability (e.g. tactile models for those with visual impairments). Further research should seek to evaluate the quality, utility, and comprehensiveness of the more recently developed resources mentioned above.

Discussion

Intersectionality

Women who identify with more than one marginalized group are at an even higher risk of experiencing violence since the social barriers restricting women with disabilities extend beyond just disability. Intersectionality—considering the different, overlapping structural and societal oppressions that women face such as oppression against race, age, disability type, and disability severity (Crenshaw, 1991)—acts in conjunction with disability to increase the risk of violence (Shaw, 2012).

With respect to race, there is a lack of literature examining rates of sexual violence perpetrated against women of colour with disabilities (Ballan et al., 2014). Despite this gap in the literature, studies that examine race as a potential risk factor find that women of colour with a disability are at higher risk of experiencing sexual violence than white women with a disability (Martin et al., 2006). Such a difference can be explained through disability compounded by race, further marginalizing women of colour and putting them at greater risk for violence.

Along with race, age is also a risk factor for sexual violence for women with disabilities. Despite the higher prevalence of disability in older women, younger women with disabilities are at greater risk of experiencing physical and sexual violence (Martin et al., 2006). Partners are more commonly abusive to younger women with disabilities compared to older women with disabilities (Brownridge, 2006).

In Canada, it is important to highlight existing literature focusing on Indigenous women. Indigenous people face consistent oppression by way of westernized societies, structures, and institutions (Heart, Chase, Elkins & Altschul, 2011). Along with discrimination against women and against individuals with disabilities, the compounding oppression results in “the prevalence of disability [being] higher among Aboriginal than non-Aboriginal Canadians” and Indigenous women have a higher risk of violence than non-Indigenous Canadians (Brownridge, 2006; Melcombe, 2003).

Similar to women of colour, individuals with moderate to severe disabilities are underrepresented within the literature. Individuals with disabilities are more often institutionalized and are excluded as potential participants in research. Despite the lack of data, the existing literature does suggest that women with moderate to severe disabilities (both physical and mental) are at higher risk of experiencing violence (Casteel, Martin, Smith, Gurka & Kupper, 2008). Even more, women with cognitive impairments are at greater risk of experiencing violence than those with physical disabilities (Martin et al., 2006) since women with intellectual disabilities or cognitive impairments face increased barriers to understanding and addressing sexual violence. It has been reported that individuals with intellectual disabilities typically have lower sexual knowledge and negative attitudes with respect to sexuality (Rushbrooke, Murray & Townsend, 2014). This lack of education is a societal issue that results in a lack of resources available to educate women with intellectual disabilities about sexual violence in ways that support their learning. Further, research suggests that women with intellectual disabilities experience more difficulties when trying to report violence and convey their experiences to authorities (Keilty & Connelly, 2012). After experiencing violence, the obstacles that women face in reporting the violence deter them from seeking support and ensuring offenders receive retribution—further perpetuating instances of violence.

In trying to understand violence against women with disabilities, as well as understanding how to reduce risk, it is critical to attend to intersectionality. Since sources of oppression do not occur in a vacuum attending to the multitude of barriers that increase the risk of violence must be addressed in order to help break the cycle and reduce risk. Thus, the consistent barriers that increase the risk of violence must be considered and addressed in order to help break the cycle and reduce risk.

Caregiver Dependency

Reliance on support services, namely, personal assistance services (PAS) is common among disabled women. Access to quality PAS services is integral to personal independence and living in the community. In fact, over 4.5 million women in the United States use PAS, which are broadly defined as “one or more persons assisting another person with tasks which the individual would typically do if they did not have a

disability” (Litvak, Zukas, & Heumann, 1987). Therefore, when PAS abuse occurs, women’s rights to autonomy and safety also become compromised. Sexual abuse and assault by PAS has been well documented in disability literature. In an early Canadian survey of 245 women (with disabilities), over 40% experienced sexual abuse and 12% were victims of rape; service providers were among the top perpetrators of sexual violence (Riddington, 1989). In another survey of 200 women recruited from independent living centres and disability service agencies, inappropriate sexual touching occurred in 11% of participants (Powers, 2002).

In addition to sexual violence, abuses propagated by PAS include stealing money or personal items, forging checks or credit cards, threatening physical harm, being drunk or high on the job, insulting or putting down, yelling or screaming, making decisions without asking, handling roughly, snooping in belongings, denying choice, and ignoring requests (Powers, 2002). The fine line between professional and personal boundaries are often confused in the PAS relationship, leading to abuses by the employer or informal provider. It is not surprising that PAS providers inappropriately mistaken their sense of familiarity with their client as intimacy. Therefore, activities that involve close proximity by the PAS provider, such as bathing and dressing, set the stage for abuse (Saxton, Curry, Powers, Maley, Eckels, K., & Gross, 2001).

In addition, women with disabilities are not only placed at greater risk of experiencing sexual abuse, but also experience abuse for longer durations than women without disabilities (Young, Nosek, Howland, Chanpong, & Rintala, 1997). This phenomenon points to challenges faced by women living with disabilities, including both physical limitations and societal factors that serve as barriers to respond to and/or report abuse. It has been suggested that women with disabilities are met with perceptions of powerlessness and a lack of credibility when reporting abuse (Nosek, 1995). In addition, some abuse victims attribute the difficulty of retaining PAS providers as a reason not to report an incident, as has been expressed “better the devil you know than the devil you don’t” (Saxton et al., 2001). Therefore, it is important to distinguish this behaviour from tolerating sexual abuse, as women with disabilities have learned to live in a world that devalues and discriminates against them. Other documented barriers to handling women’s abuse include lack of access to abuse resources, difficulty recognizing abuse, feeling shame or embarrassment, lack of emergency back-up services, fear of institutionalization or loss of their children if abuse is reported, and lack of crisis services (Saxton et al., 2001).

Community resources to assist women with disabilities are lacking. One study that surveyed 67 domestic violence programs in North Carolina reported that 99% provide service to at least one women with a physical or mental disability – yet many of these programs do not offer services that address the unique needs of this population (Saxton et. al., 2001). Suggestions for improving PAS have been put forth by study participants who were surveyed about their experience using PAS (Saxton et al., 2001). A common theme among focus group participants was the need for rigorous and sophisticated methods for screening and recruitment of PAS workers, involving thorough criminal background checks with the police, written contracts, in-service training, and regular meetings with a supervisor to discuss concerns or questions. Raising the wage of PAS workers and providing benefits has also been proposed as a way to improve the quality of and supply for PAS providers. Aside from improving the quality of PAS provisions, having access to emergency and back-up services, using humour to maintain a positive relationship with their PAS worker, and participating in support groups are some alternative strategies that have been put forth for preventing abuse (Saxton et al., 2001).

Recommendations

There are two primary sets of recommendations that can be made based on the findings of this report. These include:

1. Increasing the quantity and quality of sexual health education resources for individuals with disabilities.
2. Dismantling systemic barriers to sexual health for this population.

1. Increasing the quantity and quality of sexual health education resources

The findings of this report indicate that there is a significant need for more sexual health education resources for, and regarding, individuals with disabilities; these resources should be specific to age, gender identity, sexual orientation, and disability type. The provision of specific sexual health education for individuals with disabilities serves two purposes: i) it recognizes the sexual needs of individuals with disabilities as legitimate and allows them to enjoy healthy sexual relationships, and ii) it provides them with the knowledge and support to avoid sexual abuse, of which they are at high risk of experiencing.

In addition, there is also a clear need for information for caregivers and health professionals on how to best support an individual with a disability who wishes to enjoy healthy sexual relationships. Evidence indicates that both parents and health care professionals in Canada feel ill-equipped to provide sexual health education to individuals with disabilities (East & Orchard, 2014). The development of a comprehensive Canadian resource base would be highly beneficial to improving the sexual rights of this population.

In accordance with this, educators should be provided with the resources to deliver sexual health education to individuals of all ability types. This reduces the risk that individuals with disabilities will not receive an appropriate sexual health education in their school years or will feel that they cannot enjoy healthy sexual relationships because they are unlike their peers.

2. Dismantling systemic barriers to sexual health

As discussed, dependency on a caregiver can sometimes increase the risk of abuse (Riddington, 1989; Powers, 2002). Rigorous screening of PAS workers and more effective mechanisms for reporting abuse are required.

One of the systemic barriers to sexual health for this population is the tendency to de-sexualize these individuals or consider them 'child-like' (Esmail et al. 2010; Couldrick, 2008). These harmful stereotypes should be targeted in the public domain and the media by providing alternative discourses that emphasize that individuals with disabilities have sexual needs just like everyone else.

A longer-term approach to reducing sexual violence among this population is to target some of the underlying factors that lead to this violence, including barriers to employment, access to education, and financial instability. Community supports in the form of legal advice, mental health services, and support groups for individuals who have experienced abuse will also be beneficial.

Table 1, below, represents a proposed 3-pronged model for meeting the diverse needs of women with disabilities in terms of sexual health education and sexual violence. The model identifies the need for appropriate sexual health education for individuals with disabilities, for caregivers, and for health

professionals. At the same time, inclusive sexual violence resources (policies, and practices) are needed to address and support the experiences of women with disabilities. Those that are currently available in the local area have been included here. Lastly, participatory research is an essential aspect of the model. In order to create an inclusive and supportive system for people with disabilities, it is essential to engage the voices of individuals with disabilities in the design and development of research as well in the monitoring and evaluation of education, practices, and policies.

Table 1: Proposed Model that Reflects Diverse Needs of Women with Disabilities

Sexual Health Education	Sexual Violence Resources	Participatory Research
For individuals with disabilities	Sexual Assault Centre Hamilton Area http://sacha.ca/	Voices of individuals with disabilities
For caregivers/PAS	Sexual Violence Response Protocol https://svrp.mcmaster.ca/	Inclusion of individuals with severe disabilities
For health professionals		Specific groups such as LGBTQ+, minorities
The public		

Conclusion

Although this report has delivered a somewhat bleak picture of the barriers to sexual health that individuals with disabilities face, there are numerous opportunities for improvement, as outlined above. As members of the disability community, we believe that you are well-positioned to provide some of these supports and hope that this report was helpful in the continuation of your efforts.

Some key takeaway points of the report are:

- Women with disabilities have a higher risk of experience sexual violence
- There is limited access to sexual health education for this population
- There should be an intersectional lens taken into consideration when exploring the sexual violence and sexual health education resources for people with disabilities
- Dismantling the systemic barriers to be more informative and provide better preventative action

Thank you for reading.

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