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Acknowledgement of Country

ANROWS acknowledges the traditional owners of the land across Australia on which we work and live. We pay our respects to Aboriginal and Torres Strait Islander elders past, present and future; and we value Aboriginal and Torres Strait Islander history, culture and knowledge.

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What does it take? Developing informed and effective tertiary responses to violence and abuse of women and girls with disabilities in Australia: State of knowledge paper.

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This work is part of the ANROWS Landscapes series. ANROWS Landscapes (State of knowledge papers) are medium length papers that scope current knowledge on an issue related to violence against women and their children. Papers will draw on empirical research, including research produced under ANROWS’s research program, and/or practice knowledge.

This report addresses work covered in ANROWS research project 3.4 “What does it take? Developing informed and effective tertiary responses to violence and abuse of women and girls with disabilities in Australia”. Please consult the ANROWS website for more information on this project. In addition to this paper, an ANROWS Horizons and ANROWS Compass will be available at a later stage as part of this project.

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Introduction

The aim of this paper is to establish the state of knowledge about tertiary responses to violence and abuse for women and girls with disabilities. Reviewing existing literature to better understand the current state of knowledge will assist in addressing the broader aims of our research, titled *What does it take to develop informed and effective tertiary responses for women and girls with disabilities who have experienced violence and abuse?*

A number of decisions have been made in designing this study that will guide both this review and the research that follows: it is focused on women and young women with disabilities, and on tertiary responses to violence and abuse. Within these focus areas key definitional, theoretical and practice components are defined. Firstly, while the focus is on women and girls with disabilities it is important to note that boys and young men with disabilities also experience higher rates of violence and abuse than do their peers without disabilities (Stalker & McArthur, 2012). Secondly, while the focus is on tertiary responses to violence and abuse, there is full recognition that tertiary responses are a part of the public health model of prevention of violence that also includes primary and secondary prevention³. In this review we define tertiary responses as ensuring safety and support for women after violence has occurred. In addition to responding to the immediate safety and support needs of women who have been affected by violence, tertiary responses also aim to minimise the impact of violence and prevent ongoing negative and repeat events associated with it (Flood, 2011; Martin et al., 2009; World Health Organization, 2002). Effectiveness of tertiary responses is not well defined in the literature with very little literature quantifying or qualifying effectiveness; this is a limitation of this paper and the available literature. Finally, while the study is focusing on an Australian context, this review will by necessity look further afield.

³ Primary prevention aims to prevent violence from occurring in the first place through attitude and behaviour change; *secondary responses* provide early intervention (WHO, 2002).

This state of knowledge report addresses two key questions:

- What does the Australian and international literature say about tertiary responses to violence and abuse for women and young women with disabilities?
- What does the evidence say about effectiveness about tertiary responses for women and young women with disabilities?

This report starts by describing the search strategy used to identify literature for review, and is followed by background information about the scope, nature and incidence of violence and abuse experienced by women in general and against women and young women with disabilities in particular. Dominant ideas about disability have shifted over time, key theoretical models that inform an understanding of disability are reviewed. The review then moves on to address the state of knowledge concerning the two research questions identified above, and to discuss what and how the current state of evidence contributes to the development of tertiary responses for women and girls with disabilities.

Search strategy

Literature searches were conducted using electronic databases; PubMed, CINAHL (EBSCO), Scopus (Elsevier), Health & Society (Informit) and ProQuest as well as Google and Google Scholar.

The search was open to any timeframe; the temporal boundaries of this review acknowledged the need to have a broad timeframe to ensure the review was comprehensive (Schlosser, 2007), and inclusive of early as well as current literature on tertiary response models.

There were no geographic restrictions on the origin of the paper, although only papers and reports that were written in English were included.

Hand searches were also conducted on the following key journals; *The Lancet*, *Journal of Interpersonal Violence*, *Journal of Sexuality and Disability*, *Journal of Sociology and Social Policy*, *Journal of Violence against Women*, *Journal of Intellectual and Developmental Disability*, *Journal of Child Abuse Review*, *Journal of Trauma Violence and Abuse*, *Journal of Disability and Society*, *Journal of Advances in Nursing Science*, *Journal of Social Work in Disability and Rehabilitation and*, *Journal of Health Care for Women International*.

The search string contained the following three concepts:

- “disability”,
- “women” AND/OR “young women” and
- “abuse AND/OR “violence”.

Synonyms of these three key conceptual terms were used interchangeably throughout the search strategy, such as “impairment” OR “disabled” OR “handicapped” OR “mentally impaired”; “sexual assault” OR “domestic violence” OR “tertiary responses” OR “tertiary prevention”; “effective models” OR “approaches”. Grey literature, that is, reports, papers and web pages that are not published in peer reviewed journals, were also searched. Citations were downloaded to an Endnote X6 file, which resulted in a total of 685 papers, 460 of which remained after duplicates were removed. Once each title and abstract were extensively reviewed, there remained 162 articles that were deemed to have appropriate material relating to the research questions. The final

number of references used in this review represent the key references drawn from these 162 articles after closer reading and writing of this paper.

The literature

Research about violence and abuse against women and women with disabilities has been undertaken by researchers from universities and from the disability, and more recently women with disabilities, advocacy sector; some contributions have been partnered research between universities and the community sector. Inclusive and participatory research methodologies that include and prioritise participation of women with disabilities in the research rather than as subjects of the research are increasingly used. One aim of these approaches is to ensure the “nothing about us without us” dictum of the disability advocacy movement is respected in research and that the voices, experiences and expertise of women with disabilities are central and valued. What underpins all research though, is the politics of research; who decides what data is needed, how it should be collected and why and how it gets used as evidence, are all political choices made from a position of power. What counts as evidence is also political, and what counts as credible evidence is not subjected to scrutiny by those who are the subject of, or are impacted on by the research on a regular basis (Eyben et al., 2013).

In the academy (and in governments) the highest order evidence comes from published, peer reviewed randomized control trials (RCTs), followed by other methods of peer reviewed research reported in high quality journals. Community based research is often considered to be lesser research, particularly if it is not peer reviewed and is published in community reports. Yet this grey literature often comes from the grassroots and represents first-person experiences that may not be represented in more traditional academic literature. When it comes to the state of knowledge concerning violence against women and young women with disabilities the politics of evidence comes into play. In this report we draw on both academic and grey literature from reliable sources equally as we explore the state of knowledge concerning tertiary response services.

Background

Violence against women (VAW), or gender-based violence (GBV) takes many forms and is known by a range of different terms. It has been suggested that the phenomenon should be called men's violence against women because it is overwhelmingly violence perpetrated by men against women (Pease, 2008). Domestic violence (DV), intimate partner violence (IPV) and family violence (FV) are all terms used to describe the violence experienced in the main by women and perpetrated by men they know.⁴ This violence or abuse may be physical, sexual, emotional, social or economic (WHO, 2013). Violence against women also occurs at the hands of strangers in the form of sexual assault or rape and sexual harassment (UN Women, 2006). Another form of violence against women that has only recently been recognised is stalking. Stalking can be intimate partner or stranger perpetrated violence (Women's Information and Resource Centre, 2009). All forms of violence and abuse against women are known to have social and systemic bases that can have both immediate and long lasting effects on the health, wellbeing and social and economic participation of women in society (UN Women, 2006).

Violence against women and young women with disabilities includes all of these forms of violence, as well as institutional violence, forced or coerced contraception and sterilisation, forced or coerced psychiatric interventions, withholding of, or forced, medication and medical exploitation, violations of privacy, deprivation of liberty, and denial of provision of essential care, (Women with Disabilities Australia 2010, 2013; Chenoweth 1996; Dowse, Soldatic, Didi, Frohmader, & van Toorn, 2013). In addition to high rates of physical, sexual, psychological, and economic violence and abuse, the impact of this violence in the lives of women and young women is significant and far-reaching. As highlighted by Frohmader, Dowse & Didi (2015, p. 6), a lack of structural response to this harm in women's lives results in "unnecessary institutionalisation, denial of control over their bodies, lack of financial control, denial of social contact,

employment and community participation, and denial of the right to decision-making". Central to the question of violence and abuse of women and girls with disabilities, as with women and girls without disabilities, is the question of gender. The lack of a gendered approach to disability and the impact this has on a range of issues for women and girls with disabilities, including violence and abuse, is discussed later.

Gender

Although colloquially the terms "sex" and "gender" are used interchangeably they do have different meanings. Sex refers to the biological characteristics that define maleness and femaleness. Although gender is usually assigned at birth to align with secondary sex characteristics, rather than a biological given like sex, gender is socially constructed and depends on prevailing attitudes and norms in different cultures at different times. Gender is related to the "roles, behaviours, activities and attitudes" considered appropriate for women and men, girls and boys (WHO, 2014). Despite stereotypes that suggest that humans fit into one of two categories, sex and gender are in practice far more complex. Connell (2012) argues that it is not "a level of reality underlying action" rather it is brought into being by the way we "conduct ourselves as gendered subjects and through which we are understood as masculine or feminine" (Connell, 2012, p.1676).

Gender theorist Judith Butler argues that this occurs through the "forced reiteration of norms" that sustains gender identity (Butler in McNay, 1999, p. 177). This is sometimes called performativity. While most people are born either male or female, they learn what behaviours and norms are considered appropriate. Learning about acceptable gender behaviour occurs in multiple sites, from the family to schools, peer groups, religion, sports, the media and workplaces (Connell, 2003). Rather than being an essential part of who we are gender operates at different levels of the social structure. At one level it is about personal identity, intimate relationships and how individuals experience their masculinity and femininity; at another level it operates within the institutions which structure relationships and individual

⁴ Although the vast majority of gender-based violence is perpetrated by men, a small percentage may also be perpetrated by women. This can occur in both heterosexual and homosexual relationships.

practices (Connell, 2006). Gender identities are defined in culture, language, symbols of gender difference, prevailing beliefs and attitudes (Connell, 2006). Despite the dominance of gender as a binary system, gender identity does not always align with sex – some people who are born into typically male or female bodies feel more masculine or feminine than other people with that body type, or they may feel as if they have been born into the wrong body.

According to Connell (2006) gender is best understood as an embodied social structure. The term “gender order” has been used to describe the assumptions which take as natural a gender-based hierarchy (typically, that men are superior to women); this system is inextricably linked with power. Gender is deeply embedded in the legal, religious and cultural norms that are taken as normal in everyday life. Gender relations are multi-dimensional, interwoven relationships of power, economic arrangements, emotional relationships, systems of communication and meaning. Gender inequalities are embedded in relationships which can be detected at every level of human experience – from individual emotion and inter-personal relationships to economic organisation, culture and the state (Connell 2003).

As noted by Dyson (2014), gender-based violence is rooted in the deeply held gender norms described by Connell (above). Research demonstrates a strong association between sexist peer norms, low status of women and violence against women (Flood, 2011; United Nations Division for the Advancement of Women, 2008; Victorian Health Promotion Foundation, 2010). Violence supportive attitudes and behaviour can be found almost anywhere, and recognised as a lack of support for gender equality; and contribute to belief in the inferior status of women in relation to men. The goal of prevention is to make these attitudes and behaviours visible and change them through the promotion of equal and respectful relationships (Dyson, 2014). Gender equality between women and men is recognised as a principle in international law, and articulated in many United Nations documents from the 1948 Universal Declaration of Human Rights onwards. They are also enshrined in Australian law.

Gender-based violence

Gender-based violence is a problem of global proportions. Internationally, 30 per cent of women have experienced physical and or sexual intimate partner violence and seven per cent have been sexually assaulted by someone other than a partner (García-Moreno et al., 2013). In Australia the issue has been identified as a public health problem which is prevalent, serious and preventable (Victorian Health Promotion Foundation, 2004) and considerable work has been undertaken in recent decades to respond to and prevent intimate partner violence and sexual assault. Australian data demonstrates that, “nearly one in three women over the age of 15 years have been subjected to physical violence and one in five report having experienced sexual violence at some time in their lives” (Australian Bureau of Statistics, 2012).

The current national emphasis in policy and practice on the prevention and response to women experiencing domestic and family violence, while of critical importance, is based predominantly in conceptual understandings of partner-oriented violence, which overlook the experience of many women with disability, particularly those who live in or rely on disability services (Frohman et al., 2015).

Violence and abuse against women and young women with disabilities

Women and young women with disabilities experience all forms of violence and abuse as other women experience. However, as the next section of the report demonstrates, women with disabilities experience violence and abuse, including sexual assault, at significantly higher rates than women who do not have disabilities (Plummer & Findley, 2012).

Compounding this experience, women and young women with disability face specific forms of violence and abuse related to their impairment (Harpur & Douglas, 2014). This may include:

- controlling access to medication, mobility and communication supports,
- threats to withdraw care or institutionalise,
- abuse of Powers of Attorney,
- controlling menstruation,
- forced sterilisation, and
- terminating pregnancies (Healey, Howe, Humphreys, Jennings, & Julian, 2008).

As well as these forms of violence, women and young women with disabilities also experience institutional violence. Violence and abuse is defined as institutional if the nature of the relationship between the person being abused and the abuser is determined, at least in part, by the service system (Sobsey, 1994). This abuse and violence continues without sanction because a series of related factors are in play: poor quality environments are developed and maintained, with oppressive routines, neglect of the needs, preferences and aspirations of people living in the service, with practices which are outside of community norms, individual and group cruelty, and negligence (Sobsey, 1994; Robinson, 2013).

A number of current inquiries have recognised that violence perpetrated against women and young women with disabilities in such settings and environments is a widespread and urgent problem, including the Australian Government Senate inquiry into violence and abuse against people with disability in institutional and residential settings; the Royal Commissions into Institutional Responses to Childhood Sexual Assault, and into Family violence in Victoria; and the Victorian Ombudsman Inquiry into Abuse in Disability Services.

Prevalence and incidence of violence, abuse and neglect: Women and girls with disabilities

Although research concerning the prevalence and incidence of violence and abuse against women with disabilities is limited, the weight of evidence consistently points to women with disabilities being vulnerable to higher rates of both physical and sexual abuse from both those closest to them and strangers, when compared with other women (Plummer & Findley, 2012). Furthermore, the actual incidence of violence against women and young women with disabilities is believed to be higher than the data demonstrates due to under reporting and inadequate data collection processes (Dowse, 2013; Hughes, Lund, Gabrielli, Powers, & Curry, 2011; Jones, Bellis, Wood, Hughes, Eckley, et al., 2012; Lund, 2011; Mikton, Maguire, & Shakespeare, 2014).

International studies repeatedly report increased rates of violence experienced by women with disabilities. In the USA, for example:

- Secondary analysis of a behavioural risk factor survey of 23,154 women from seven states, of which 6309 were women with disabilities found that 33 percent of women with disabilities had experienced IPV compared with 21 percent of those without disabilities (Barrett, O'Day, Roche, & Carlson, 2009).
- A retrospective longitudinal study of findings from a national survey of violence against women (n=6273) found that women with severe disabilities were four times more likely to be sexually assaulted than women without disabilities (Casteel, Martin, Smith, Gurka, & Kupper, 2008).
- Mitr, Manning & Lu (2012) investigated the incidence of abuse of women with disabilities during, before and after pregnancy (n=2876). It was found that there was a disproportionate prevalence of abuse in this group during pregnancy. The prevalence of women with disabilities in this study was 4.9 percent (n=138). Prevalence of physical abuse of women with disabilities was 13.8 percent compared to 2.8 percent for women without disabilities.
- McFarlane, Hughes & Nosek, et al., (2001) report on a multiethnic study involving 511 women with

physical disabilities. They found a 9.8 percent prevalence of abuse (50 of 511) of women with disabilities in the past 12 months. This study also found that abuse occurred at the hands not only of intimate partners, but also at those of carers and health professionals.

- A survey of 200 women with physical, and physical and cognitive disabilities was undertaken by Powers et al. (2002) finding they experienced abuse by any perpetrator at approximately twice the rate of women without disabilities.

These findings from the USA are supported by Canadian research. A study that investigated the risk of IPV for women with disabilities reported that they were 40 percent more likely to have experienced violence in the five years preceding the study than non-disabled women, and that the violence was likely to be severe (Brownridge, 2006).

Increased levels of risk are similar for adult and young women with disabilities. Recent studies with school aged young women in the USA report that those with disabilities are at heightened risk of sexual abuse (Alriksson-Schmidt, Armour, & Thibadeau, 2010; Haydon, McRee, & Halpern, 2011). A national Swiss school-based survey of 6749 adolescents of whom 360 self-identified as having a physical disability was analysed to look at prevalence of sexual victimisation of young people with physical disabilities. This study reported that adolescent young women with physical disability were 29 percent more likely to experience contact forms of sexual violence (including penetration, touching, kissing), and 44 percent more likely to experience non-contact forms of sexual violence (including exhibitionism, verbal harassment, exposure to sexual acts or cyber sexual violence) than young women who did not have physical disabilities (Mueller-Johnson, Eisner, & Obsuth, 2014). In a study with children and young people with disabilities in New Zealand, 32 percent of young women aged between 11 - 17 years disclosed experiences of sexual abuse at the hands of step-fathers, mothers' boyfriends and older brothers (Briggs & Hawkins, 2005).

In Australia the situation is similar to the US. The work of disability advocacy and activist groups such as Women with Disabilities Victoria (WDV) and Women with Disabilities Australia (WWDA) demonstrates findings similar to those drawn from the international literature (Dowse, et al., 2013; Healey, Howe, Humphreys, Jennings & Julian, 2008; and Healey, 2014). Whilst the Australian research indicates high rates of violence and abuse and reflects the gendered nature of violence and abuse experienced by women with disabilities, it remains anecdotal, and the cited literature for the most part remains in the domain of grey literature³. The 2012 Australian Bureau of Statistics, Personal Safety Survey (PSS) collected information to determine if respondents had a disability and reported findings based on identified disability. While this is useful there are clear gaps in the data, for example it required that people be able to participate in the interview in private, thereby excluding people who needed support to participate, for example women with communication difficulties and those who reside in residential services (WWDA, 2015 p. 7). Despite these gaps, the PSS reports that of all women over 18 years with a long term disability or health condition, six percent (N=169600) had experienced violence (ABS, 2012). Women's disability advocacy organisations are calling for a review of the way Australian population based violence and abuse statistics (such as the ABS Personal Safety Survey) are developed to ensure they more accurately and comprehensively address disability (WWDA, 2013; Frohmader, Dowse & Didi, 2015).

What is known is that violence against women and young women with disabilities often goes unreported, and when it is reported is often either dismissed, ignored or covered up (Chenoweth, 1996; Frohmader et al., 2015; Webster & Woodlock, 2013).

³ Grey literature publications are in general non-peer reviewed publications which may include reports, conference proceedings, technical specifications and standards, bibliographies, technical and commercial documentation, and official documents not published commercially.

Understanding disability

The ways in which disability is understood has implications for responses to women and girls with disabilities at risk of, or experiencing, violence (Frohmader, Dowse & Didi, 2015, p. 5).

Approximately 19 percent of people in Australia (almost one in five) report having a disability (Australian Bureau of Statistics, 2011). Of these, almost six percent are classified as having a severe or profound level of disability and over 17 percent are women and young women with disabilities. Definitions of disability differ across Australia and internationally; however, increasingly “bio-psycho-social” definitions are used based on the World Health Organization’s (WHO) *International Classification of Disability and Health framework* (ICF). Drawing on the ICF as the basis for understanding disability, The World Health Report on Disabilities highlights that, “Disability is complex, dynamic, multi-dimensional and contested” (WHO, 2011). The ICF asserts that the experience of disability should be mainstreamed and that it should be recognised as a universal human experience, “...a decrement in health and thereby experience some disability” (WHO, 2002, p. 3). This multi-dimensional, “mainstreamed” definition of disability is informed by critical theorising about disability and from the grassroots advocacy of “disabled people’s organisations” over the past three decades. While a thorough review of the evolution of understandings of disability is beyond the scope of this paper, the following sections briefly discuss and outline the emergence of an understanding of disability that acknowledges the complexity, dynamism, multi-dimensional and contested nature of disability.

Historical overviews of how disability has been understood often include a pairing of the concept with deviance, superstition, social disdain, segregation and ridicule in early history through to early twentieth century (Braddock & Parish, 2001). The history of disability, authors argue, has always been understood in part by the way society has responded to people labelled “different”, “deviant”, “impaired”, “handicapped” or “disabled”. In Western societies there have been a range of responses from total segregation, alienation and disregard to eugenics and the medicalised response to disability in the nineteenth and twentieth centuries, and the emergence of a socio-political response in the later twentieth century. This “evolutionary” understanding of disability is well documented in the literature and needs no further analysis here, though questions of how these understandings of disability have taken account of and responded to gender are relevant, as are questions of how understandings of disability have and continue to relate to and impact on understandings of and responses to disability, violence and abuse.

The medical model of disability views disability as a feature of the person, focusing on the aetiology of their impairment. Medically based responses to disability include biological and psychological tests and interventions that aim to change something about the person; to address and minimise where possible what is “impaired”; limbs, cognition, and senses. There has been and continues to be debates in the literature about the shortcomings of this model, most significantly because it disregards the human experience of living with a disability and the socio-relational factors that impact on the way people live and experience disability (Swain & French, 2000). Critics, especially those from the critical disability studies tradition have argued that this model is ideologically and socially incongruent with the lived experiences of people with a disability (Crow, 1996; Grue, 2011; Hague, Thiara, & Mullender, 2011; Oliver, 1996). Meekoosha & Dowse (2007) summarise the “shift” or “turn” towards a social understanding of disability as moving from considering body, intellect or behaviour to examining the social, political and cultural factors that

impact on experiences of disability (cited in Frohmader, Dowse & Didi, 2015, p. 5). Gender is one socio-political factor of disability that was not accounted for by the medical model.

The beginnings of the social model were articulated in a publication of the Union of Physically Impaired against Segregation (UPIAS), *Fundamental Principles of Disability* which questioned the medical, individual explanation of disability and its applicability to lived experiences, in particular experiences of oppression experienced by people with physical disabilities (UPIAS, 1976). Disability theorists further developed an understanding of disability as socially constructed (Oliver, Barnes & Shakespeare, 1999); a result of a society that limits access and oppresses and excludes people with disabilities by refusing to address the physical and attitudinal barriers which marginalise them (see, for example, Oliver (1990) and Barnes (2000)). The social model proposes that barriers to participation for people with disabilities can be overcome through social change. While it is argued that this perspective has done much to progress the rights of people with a disability and inclusion, it is clear from the debates in the disability literature and from the perspective of disabled people and disabled people's organisations "we are not there yet" and that further theorising is needed to be able to account for the lived experience/s of disability (see Shakespeare, 2014, p. 5, who supports an approach to understanding disability prominent in Nordic countries; a relational or interactional model).

Consequently from the mid to late twentieth century, disability is understood from multiple perspectives. Internationally there are remnants of the medical model in policies, laws and practices and while the social model is strongly held, for example in critical disability studies and feminist disability studies, it has been critiqued as not adequately accounting for all experiences of disability. This includes a view that it does not address the barriers experienced by people with an intellectual disability (Chappell, Goodley, & Lawthorn, 2001) and that it lacks a gender analysis, failing to take account of the gendered nature of violence against women with disabilities (Hague et al., 2011; Mays, 2006). Carol Thomas notes, "Whether

we consider the gains made by disabled people or the distance yet to be travelled toward full social inclusion... then we find that disabled women are in a relatively more disadvantaged position than disabled men" (2006, p. 178). This disadvantage is evident in education, employment, healthcare, housing and personal safety as outlined earlier in this paper. Despite the social and systemic focus of the social model, this literature highlights its inadequacy, as with the medical model, for considering and including a gendered perspective.

Critiques of the medical and social models thus represent part of a wider debate into which a new development emerged that proposed that physical and social elements are always intertwined (Ussher, 1997). The relational or interactional model (see Shakespeare, 2014) discussed below, departs from the dichotomous medical and social models which, Shakespeare suggests was polarising in the disability movement (2014, p.18).

The interactional model, a relational "bio-psycho-social model" underpins the WHO classification of disability (ICF) and the United Nations Convention on the Rights of Persons with Disabilities (UN, 2008). It does not reject impairment as an underlying factor of disability or see the experience of disability as purely socially constructed, rather it acknowledges the experience of disability as a holistic one where the "impairment effect" is acknowledged along with "social" and "systemic factors" which together encompass the disability experience. Mays (2006) argues that the interactional model works to bring about both individual and systemic changes that result in greater agency for people with disabilities. It has also been claimed that the interactional model of disability can be aligned with other systemic models including the public health model of violence and abuse prevention (Mikton & Shakespeare, 2014). Further it is argued that this alignment between public health and disability advocacy could strengthen efforts in both fields to prevent disability violence and abuse (Mikton, Maguire, & Shakespeare, 2014). This model, unlike the medical or social models has been reported as having the capacity to put forward a gendered perspective and to relate more with public health frameworks of violence and abuse.

Social inclusion

Despite the social and political gains of the disability movement based on the social model, people, and in particular women, with disabilities still experience significant social exclusion, as evidenced by the literature and incidence and prevalence data of violence and abuse reported earlier.

Left Behind (Llewellyn, Emerson, & Honey, 2013), a study that monitored the social inclusion of young Australians with disabilities, found, "...Relative to their non-disabled peers, young disabled Australians are significantly less likely to do well on participation indicators" (Llewellyn, Emerson, & Honey, 2013, p. 2). Overall they were five times more likely to suffer multiple and entrenched disadvantage, including being less likely to have completed schooling to Year 12, being less likely to be employed, be engaged in full time work or education, and more likely to experience homelessness, feel unsafe in the community and be victims of crime. This marginalisation of people with disabilities is also reflected in other countries and is particularly prevalent in the lives of people with intellectual disabilities (Hall, 2005; Officer & Shakespeare, 2013). Their experiences of social inclusion are inextricably "entangled" with experiences of social exclusion due to societal responses to them as "other" and not "equal to" through attitudes and behaviours that marginalise and in some instances victimise them (Hall, 2005). It is these experiences of social exclusion outlined in this section that need to also be considered in prevention of violence and abuse of women and girls with disabilities.

A human rights approach to inclusion

Social inclusion principles and equality are entrenched in domestic and international laws and policies, led by the 2008 *United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD) to which Australia is a signatory. While the UNCRPD has done much to raise awareness about the equality of people with disabilities, French (2007) argued that for the Convention to meet its aims of inclusion, it needed to be interpreted as incorporating "substantive equality". This refers to both making adaptations that will enable the vast majority to participate (universal design) and providing targeted adaptations and accommodations to meet the needs of groups who, despite these "universal" changes, can still experience exclusion. Substantive equality sits well with the interactional model of disability that takes into consideration what barriers are left behind once universal accommodations and adaptations are made; in short what is still difficult for "me" in this situation with "my" particular needs and experience of disability.

In considering why social exclusion is prevalent in the lives of people with disabilities despite inclusionary policy, Hall and Kearns (2001, p. 242) assert, communities need to be able to respond affirmatively to people with a disability. This requires a close look at all interactional "spaces"; relationships including social, care and intimate; activities of daily living including education, employment, recreation and leisure, and carefully considering what adaptations and accommodations can be made to address barriers. In conjunction with this the question needs to be asked, 'What else is needed to support the individual?'; this could include specialist interventions, assistive technologies specifically adapted to the person, and/or enhanced or differently provided services and models of support. This approach is what French (2007) was referring to as reflecting substantive equality. It is relevant to the question of "What it takes to develop effective tertiary responses to violence and abuse for women and girls with disabilities?"; suggesting it might take universal and targeted responses, and these may need to be developed from a more nuanced understanding of disability (the relational/interactional model) that includes a gendered perspective (Ortoleva & Lewis, 2012).

Women with Disabilities Australia (WWDA) and Women with Disabilities Victoria (WDV) take up the mantle of advocating for a gendered approach to disability policy, and a gendered analysis of lived experiences of people with disabilities. Voices against violence (Healey, 2013), a research project undertaken by WDV, the Victorian Office of the Public Advocate and Domestic Violence Resource Centre Victoria, makes a strong case for recognition of, and affirmative responses to, the particular kinds of oppression women with disabilities experience. This includes in the domestic sphere, in access to support services, in the wider community, and as a result of a range of legal and social structures that exclude them. International and Australian research literature (Brownridge, 2006; Chenoweth, 1996; Cockram, 2003; Healey et al., 2008; Woodlock et al., 2014) has informed and supports this advocacy message. Despite this, and the relatedness between a gendered and human rights approach (Frohman, et al., 2015), gender continues to be under-addressed in disability policy. In Australia, while the *National Disability Insurance Scheme Act* (2013) acknowledges people's right to dignity, and to live free from abuse, neglect and exploitation, it falls short of acknowledging the gendered nature of these and fails to identify any specific focus on women and young women with disabilities (Frohman et al., 2015). Others have termed the experience of women and disability as double jeopardy to highlight their multiple forms of exclusion in education, employment and health and their increased experiences of violence and abuse in comparison with women who do not live with a disability (Dreidger, 1991).

Intersectionality

Violence against women and young women with disabilities (as with all violence against women) is not a simple matter of gender. As discussed above in the section on gender and gender-based violence, gender inequality is at the root of gender-based violence. However, violence against women is not limited to any particular group or class in society, and gender intersects with other forms of difference to compound discrimination, which in turn affects the experience of violence and abuse for individuals. Particular groups of women may be more vulnerable to, or experience multiple forms of violence and abuse. This includes but is not limited to marginalisation on the basis of race, religion, caste and class, as well as women who are refugees, undocumented workers, in detention, affected by armed conflict and women with disabilities (UN Women, 2012). This phenomenon is theorised as "intersectionality".

According to McCall (2005, p. 1771) intersectionality refers to "the relationship between multiple dimensions and modalities of social relations and subject positions". That is, the complexity of lived experience is very much dependent on factors such as gender, race, class, culture, dis/ability, sexual and gender identity, among others. These factors also differ across time and according to geographical location and are thus not the same for everyone. Because of the complexity of the social condition, research that addresses and seeks to understand these complexities is essential. This does not eliminate the need for population based research but adds a layer of responsibility for the researcher to seek to understand complexity and ensure that all research is planned and implemented in such a way as to capture data that reflects diversity and is inclusive.

Intersectionality is particularly relevant for understanding the complexity of the experience of gender-based violence for women with disabilities, because of their experience of multiple and intersecting forms of discrimination based not only on gender and disability, but also on diversity (Ortoleva & Lewis, 2012).

In an Australian context understanding violence against women and girls with disabilities from an intersectional

perspective requires knowledge about experiences of gender and disability and other factors of diversity. Public health data confirms that in Australia rurality, being indigenous, and living in a remote area are all contributing factors to poorer health outcomes, including increased experience of disability (ABS & AIHW, 2008; AIHW, 2015). The Australian Personal Safety Survey (ABS, 2012) offers some analysis of these factors and experiences of violence and abuse, identifying for example that age, state or territory of residence and disability status are factors that impact on experiences of violence and abuse. An intersectional analysis that looks across these factors is not yet publically available.

North American research has found other intersections to have an impact on experiences of violence and abuse of women with disabilities. Nosek, Hughes, Taylor & Taylor (2006, p.846) compiled and analysed data from 415 minority women with primarily physical disabilities and their experiences of physical, sexual and disability-related abuse, concluding that young, socially isolated, more educated and less mobile women were more likely to experience violence. The finding about level of education and its correlation to experiencing violence is described as “counter-intuitive” by the researchers. They suggest that their methodology of face to face interviews may have skewed this outcome, surmising that more educated women with disabilities may be more able to articulate and report their experiences of violence. This study is important in terms of its capacity to relate intersectional factors to experiences of violence in a way that has not been done elsewhere.

There is a dearth of Australian research from a disability and intersectional perspective, with only one key study including data and analysis on women’s cultural background (Cockram, 2003). This study surveyed family violence, domestic violence, and community and government services in Western Australia that had contact with women with disabilities who had experienced family and domestic violence. Across the 107 agencies that responded to the survey, 709 women with disabilities were identified as service users; of these 20 percent were from a non-English speaking background and 28 percent from an Indigenous background. An intersectional analysis is

not undertaken in this study so little else that speaks to the intersectionality of their experiences is explored or reported, nor is the statistical representation further analysed in relation to the Western Australian demographic context.

Research that can work with the available data to disaggregate findings about experiences of disability in Aboriginal communities, rural women with disabilities and women from Culturally and Linguistically Diverse (CALD) backgrounds along with data about income, education and other social indicators of inclusion, and experiences of violence and abuse is needed. WWDA calls for this approach in their latest paper (Frohman, et al., 2015) that sets out an agenda for preventing and responding to violence and abuse against Australian women with disabilities.

Responding to violence against women and young women with disabilities

Despite the high rates of violence and abuse reported in the literature, research about effective prevention and response is lacking (Lund, 2011). The World Health Organization advocates an approach to violence against women that is based on a public health model of disease prevention that has been successfully employed in other socially based public health prevention programs, such as smoking cessation and seatbelt use in cars. The public health model has been adopted by the Commonwealth of Australia and underpins responses to the prevention of violence against women in Australia. Put simply, in this three level model, *primary prevention* aims to prevent violence from occurring in the first place through attitude and behaviour change; *secondary responses* provide early intervention, for example, with perpetrators and *tertiary responses* ensure safety and support for women after violence has occurred. In addition to responding to the immediate safety and support needs of women who have been affected by violence, tertiary responses also aim to minimise the impact of violence and prevent ongoing negative consequences and repeat events (Dyson & Flood, 2007; Flood, 2011; Martin et al., 2009; World Health Organization, 2002). Needless to say each of these approaches are more complex than this explanation, however, because the focus of this review is on tertiary responses, here we go into no further details about primary or secondary prevention.

The public health model of prevention is central to the Council of Australian Governments' *National Plan to Reduce Violence against Women and their Children 2010-2022* (COAG, 2011). A significant body of primary prevention evidence based knowledge and practice has been developed as a result of this plan (Council of Australian Governments, 2012), however, there is less evidence available concerning the most effective and appropriate immediate tertiary responses needed for women who have experienced violence, for both the general population and minority groups, including women with disabilities (Healey, 2013).

To be effective, immediate tertiary prevention requires a rapid, coordinated response which should ideally encompass the range of services needed by victims once violence has occurred. In the immediate term this includes policing, medical care for physical injuries, safety planning, advocacy, legal services and refuge services. In the medium to longer-term services such as trauma counselling, support groups, employment assistance, transitional housing, children's services and specialist support and advocacy services are also part of the tertiary response.

Services for women who need immediate support are always under pressure, however, limited access to these services for women and young women with disabilities can further compound the issue. In the disability sector there is a lack of awareness about, and response to, the needs of women and girls with disabilities who have experienced violence (Mikton, Maguire & Shakespeare, 2014). In the response sector there are problems for women with disabilities in terms of access to appropriate, accessible sexual assault and domestic violence services (Dowse et al., 2013; Healey, 2013; Healey et al., 2008; Woodlock, et al., 2014). It has been argued that despite the public health approach to understanding disability and a rights based approach to promoting equality to prevent violence against women, to date there has been little attention paid to the intersection of the two fields of disability and violence (Mikton et al., 2014).

Tertiary responses to violence for women and girls with disabilities

International and domestic anti-discrimination legislation requires all community services and facilities to be “accessible”, with standards and guidelines guiding what this means in given situations. People with disabilities should not experience discrimination or “exclusion” because of issues of physical (broadly understood to also include sensory and communication), economic or social access. Australia’s disability discrimination legislation provides the legal framework for equality for people with disabilities and for addressing discrimination. As with other disability discrimination legislation it also has provisions for providers to argue that they cannot meet their legislative responsibilities because of “unjustifiable hardship” (*Disability Discrimination Act, 1992*). While the expectation is one of “universal access”, the reality is that access is limited or non-existent as a result of a process of weighing up the costs and barriers of providing access.

Domestic violence, sexual assault and other violence and abuse services are subject to the same accessibility requirements as other community services, yet the literature suggests that universal access has not been achieved in this sector. This is despite the fact that access is an important cornerstone for how women and young women with disabilities experience tertiary responses to violence and abuse.

Determining the nature of access for different people with different experiences of disability is complex and multidimensional, reflecting what we know about disability; it is experienced in different ways by different people and is impacted by intersectional factors as outlined earlier. Despite this there is an ideal of “universal access” which has been developed particularly in relation to the built environment. Guidelines have been established in building standards in particular for physical access and in some countries disability or other anti-discrimination legislation establishes the legal framework for determining what “access” means. As noted above, these standards

apply across society and all community and private organisations should comply. In the USA, research has been undertaken on compliance of domestic violence and sexual assault services finding great variability in actual physical accessibility (Chang, et al., 2003; Frantz, Carey, & Bryen, 2006). Frantz et al., in their review of 55 rape crisis agencies representing 81 services in Pennsylvania, reported that while 87 percent of services surveyed reported that they were able to provide services to all clients with disabilities who requested them, all of them sometimes only provided partial services. Similarly, a study in the UK reported that 76 percent of domestic violence services surveyed did not comply with the *UK Disability Discrimination Act* (Hague et al., 2011). Hague et al. reported that disability access had been narrowly defined as wheelchair access in some services.

As discussed above tertiary response services are always under pressure from the sheer numbers of women requiring services and from limited (and diminishing) funding. Some studies interviewed service managers as part of their research who reported that (a lack of) funding and the need to prioritise budget expenditure to support physical access were key barriers to developing fully accessible services (Chang et al., 2003; Frantz et al., 2006; Healey et al, 2013; McClain, 2011).

Access and inclusion

In Australia the disability advocacy sector and domestic violence sector collaborated to develop a resource for tertiary response services to facilitate access for women with disabilities (People With Disabilities Australia & Domestic Violence NSW, 2015). This resource calls for existing services to go beyond what is required by the *Disability Discrimination Act 1992* (Cth) to make their services as accessible as possible and for specialist accommodation, programs and supports targeted at women with disabilities to be developed. It has a significant focus on organisational change and readiness, highlighting the need for organisation wide training underpinned by inclusive policies, and further argues that services must look broadly at what physical access

means. Practical guidance on addressing physical access, information access, attitudinal access and procedural access is incorporated in the resource. Similarly, WWDA in their work on prevention of violence and abuse of women and girls with a disability call for a broader human rights approach to recognising and responding to violence and abuse. This approach they argue acknowledges the need to address social barriers that impact on the incidence, prevalence and severity of abuse and on approaches to preventing and responding to violence and abuse for women and girls with disabilities in Australia.

Healey (2013) confirms the need for a broad definition of access and inclusion and for policy and standards to explicitly address access. The term programmatic access has been used in research and policy to cover all components of a service that relate to working with the women; this includes approaches used from intake through to counselling and outreach and includes service policies and staff training (Frantz et al., 2006). Similarly, Frohmader et al. (2015) refer to programmatic access as incorporating both procedural and attitudinal components. Frantz et al. tested programmatic access in their research and reported that it was lower than physical access with only 57 percent of services reporting they asked at intake if people required any accommodations or adaptations to the way services were provided.

Chang et al. (2003) found that while the vast majority of services reported that they provided services for women with disabilities many had difficulty providing “full service” where this referred to all aspects of the service that other women could use. Notably only partial access to outreach and counselling was reported. The UK study by Hague et al., (2011) found only 38 percent of organisations were able to provide “a service” with physical access being used as the measure of access. These services were limited to transport and accommodation.

Staff training to address skills and attitudes to access and inclusion and organisational policy were reported in the literature as key factors in addressing programmatic access, yet not all services provided such training. Of interest is the view though that staff lack of knowledge and understanding about the needs of women with disabilities led to feelings of trepidation, anxiety and

concern when faced with providing services to women with disabilities (Hague et al., 2011). Frantz et al., (2006) found that of 55 rape crisis, domestic violence and sexual assault agencies, over a third of services reported having training for staff and volunteers, while only nine percent had training for board members. Despite the call for staff training, no studies were found that assessed the outcomes of training, or policy on practice, and Healey (2013) found services lacked a focus on inclusion policies for women and young women with disabilities.

Recognising and responding to the breadth of needs and experiences of women and girls with disabilities who experience violence and abuse can present challenges for service providers. Research in the USA has investigated the disability experience of women and girls who have accessed tertiary response services and found that women with an intellectual disability and women with mental illness were the highest represented groups (Chang et al., 2003; Frantz et al., 2006). Both Chang and Frantz found that women with significant communication disabilities including women with hearing impairments, women who used augmentative communication and women with other communication needs associated with speech and learning represented a small number of overall clients. For these women barriers included lack of access to specialist skills, or staff lack of knowledge about how to engage with women whose communication challenged existing approaches. Cost was cited as a barrier to accessing specialist communication supports and services for these women (Chang et al., 2003).

In Australia, Healey (2013) found a lack of policies and standards concerning data collection about disability by family violence services. They argue that this lack of data collection keeps disability invisible in services and thus negates the need for services to address physical and programmatic access for women and young women with disabilities.

Collaborations and partnerships

Cross sector collaborations between the disability and domestic violence sectors is highlighted in much of the literature as an important factor for more effective outcomes for women and girls with disabilities (Chang

et al., 2003; Healey et al., 2008; McClain, 2011). Despite this knowledge, cross sector collaboration is reported to be low. A survey of UK disability and domestic violence services found that only six percent of disability services surveyed attended locally provided multi-agency domestic violence training (Hague et al., 2011). Similarly, a study in the USA which studied inter-agency collaboration in the provision of domestic violence services to women and young women with disabilities found that despite agencies believing they collaborated well, women with disabilities reported frustration and anger at what they saw as a total lack of collaboration (McClain, 2011).

Collaboration requires that both disability and the violence and abuse response sectors recognise violence and abuse of women and girls with disabilities as significant and as “their core business” In Canada a survey of 579 disability centres found that very few provided staff training about domestic violence services or advocated for improved access to these services (Swedlund & Nosek, 2000). McClain’s study of inter-agency collaboration found that while agencies had strategies in place including cross-training, cross-referral systems, policies and funded activities to bring the sectors together, where inter-agency collaboration existed it was difficult to sustain (McClain, 2011).

In the USA collaborative efforts to improve services for women with disabilities has helped to change the ways in which services interact both with women with disabilities and with each other (Smith & Harrell, 2011). Factors such as “the environment in which the collaboration exists, its purpose, the characteristics of the [organisations] and people involved, the process and structure of the collaborators’ work, the quality and frequency of their communication, and the resources available” were identified as key factors for effectiveness (Smith & Harrell, 2011, pp. 9-11). Similarly in Australia, the *Stop the Violence* Project developed a resource compendium that recommended adopting a human-rights approach which consists of the following principles: empowerment through participation, removing barriers, working in partnership, building capacity, building and using the evidence base, preventing violence before it occurs and promoting leadership and advocacy. These are supported by a number of approaches such as providing appropriate accessibility, ensuring transferable and open communication, creating inclusivity and equality for all stakeholders and guaranteeing that clear accountabilities are agreed upon before program development and implementation (Dowse et al., 2013).

Sexual Assault services in Victoria have had a focus on

service provision to victims/survivors with disabilities for almost two decades (Frawley, 1997; 2000), with cross-sector collaboration including staff training in both sectors being a key component addressed. One service, South Eastern Centre Against Sexual Assault (SECASA) with support from Victorian community legal services, the Office of the Public Advocate, Victorian Police and WDV developed the *Making Rights Reality* program to enhance counselling and advocacy, including legal advocacy for victims/survivors with a cognitive impairment and/or communication difficulties. This program addressed cross-sector collaboration in a number of ways; through disability training for sexual assault service staff, SECASA engaging with the disability sector to develop “Easy English” resources about sexual assault, and involvement of the sexual assault service project worker on advisory groups for women with disability advocacy and research projects. While the effectiveness of this component was not measured, the evaluation data indicated that 40 percent of referrals to the program came from disability organisations and the police (Frawley, 2014, p. 12). Importantly, the number of people with disabilities using SECASA increased over the two year period of the pilot project; by 2014, four percent of clients of SECASA were people identified as having a cognitive impairment (Frawley, 2014, p. 12).

Effectiveness of tertiary responses for women and girls with disabilities

Effectiveness can be defined as the degree to which something is successful in producing a desired result. To provide effective tertiary responses for women and young women who have experienced violence, first clarity is needed about what results are desired. In the previous section we described how research has demonstrated that despite many services wanting to be accessible, very few actually are, and we discussed a range of research findings concerning access. A search of literature reveals that very little is known about how effective tertiary responses are for women and young women with disabilities. A systematic review of effective interventions to prevent and respond to violence against persons with disabilities reported that there is a dearth of literature that has systematically reviewed the effectiveness of interventions, and that most evaluations are not rigorously executed (Mikton et al., 2014). According to Mikton et al., this makes it difficult for policy-makers and practitioners to make informed decisions about which model and approach would be the most effective.

Examples of programs that have been evaluated reveal some of the problems, for example, the evaluation of the *Safer and Stronger Program* (Powers et al., 2009) focused on users of the service rather than the program itself. The findings thus focused on who used the program and why, rather than whether the program was an effective response for women who had experienced violence and abuse. Despite this there are learnings from this study about effectiveness and the needs of women with disabilities who have experienced violence from this evaluation, which found that:

- women with disabilities were more likely to first reach out to someone they know and trust, such as a friend or a family member rather than a domestic violence service (Powers et al., 2009, p. 1064); and
- participants who faced multiple levels of abuse such as physical, sexual and emotional abuse were more likely to have sought education and knowledge about abuse, compared to those with little or no experiences of abuse (Powers et al., 2009, p. 1065).

One of the key themes was that women who had experienced high levels of abuse across a number of different areas dealt with safety promoting behaviours very differently to those who had experienced little or no abuse (Powers et al., 2009, p. 1065). What became apparent, just as experiences of violence and abuse are different for each person, so too are the personal responses and needs for each person. Some women require more integrated levels of support and service provision, and others require more preventative levels of support (Powers et al., 2009).

Another evaluation of a program called *A Safety Awareness Program for Women with Disabilities* (ASAP) was evaluated, and overall the program was reported to be effective on a number of qualitative measures (Hughes et al., 2011). For example:

- as a safety awareness program it was effective in educating women with disabilities at risk of abuse, as well as those that have already experienced abuse;
- it was effective at engaging women who had previously experienced abuse and violence; those who had experienced the most abuse were more likely to have greater gains in safety self-efficacy after completing ASAP;
- participation in ASAP greatly improved the protective factors for women with disabilities, and the generalisability of protective factors to other locales;
- participants responded positively to the classes and found the learning materials to be engaging and effective at helping them learn safety promoting behaviours; and
- the program is regarded as being easily accessible, relevant and feasible to participants.

Upon completion of the program, participants gained significant increases in self-efficacy and safety skills, as well as safety promoting behaviour and an increase in social support after completing the program, as women became quite cohesive during the training (Robinson-Whelen et al. 2014). However, this program appears to be an education program rather than an immediate support

service to provide women with safety after being abused. There are, however, some lessons that can be learned from such a program in the development of guidelines for tertiary response services to provide appropriate services for women and young women with disabilities.

Effectiveness of tertiary responses for women with disabilities compared to women without disabilities was the focus of one study (Grossman & Lundy, 2008). The results of this study revealed a number of factors that are important considerations for effective tertiary responses for women and young women who are survivors of sexual abuse. Their study confirmed what was also found by Powers et al. (2009), that women with disabilities are very likely to reach out to family and friends and added that they were more likely to do this and use telephone counselling than non-disabled women. They also found women with disabilities require more hours of tertiary services, and are less likely to be involved in group counselling. Further, women with disabilities were also likely to have more service contacts and be referred by healthcare professionals than self-referred. This study also found that the vast majority of people with disabilities who used the tertiary response services were more likely to enter the service-system as an adult rather than a child – this is understood as a major problem in the way abused children with disability are not linked to the system when they are young. Grossman & Lundy assert that empowerment information is crucial to all levels of response to violence and abuse: this includes education about who perpetrators are, in what settings they exist, how it might occur, and how to report it when it happens (Grossman & Lundy, 2008).

Another key factor in effectiveness is inter-agency collaboration and the importance of a broader authorising environment (such as support from national and state governments) for prevention and intervention. This can be accomplished by improving responses to services for women with disabilities in abusive/violent situations, such as enhancing crisis response services that are specifically designed for women with disabilities, and their children if required (Healey, 2013). One of the most important aspects of success is the willingness and expertise of staff. This is a crucial aspect of the success or failure of programs, as noted by various other commentators in their evaluations of tertiary response services (Grossman & Lundy, 2008; Hague et al., 2011; Lund, 2011).

A study of service collaboration in the USA (McClain, 2011, pp. 14-24) recommends the following to assure effective inter-agency collaboration:

- Employing an outside facilitator who can broker communication and agreement between service providers and women with disabilities. This can be achieved by laying down the foundations of what the collaboration is trying to achieve, sharing philosophies, building common definitions of abuse, domestic violence, disability and accessibility, and clarifying expectations;
- Training on the intersections of gender, violence and disability, both between organisations and within communities;
- Development of policies, procedures and budgets that specifically include the provision of services to women with disabilities who are victims/survivors of domestic violence/sexual assault;
- Creating welcoming environments for victims/survivors with disabilities.

The review of the literature looking at effectiveness of tertiary responses found very little research that has focused on how effectiveness is understood or measured. The literature reviewed in this section points to some broad approaches, principles of practice and patterns of service use by women and girls with disabilities that might reflect effectiveness rather than measuring effectiveness as outcomes. This suggests there is a gap in the research about what characterises and determines effectiveness of tertiary responses from the perspective of women and girls with disabilities and tertiary response services.

Principles of “good” practice in tertiary responses for women and girls with disabilities

This review of literature sought to identify tertiary response models and approaches for women and girls with disabilities, to gain an understanding of how they have been implemented, and the effectiveness of their outcomes. While insights have been gained from this review about factors that need to be considered in developing these responses, there are very few actual models of tertiary responses presented in the literature. As a result, the review has been more able to identify principles of “good” practice rather than whole models. The following section presents these principles synthesised from the reviewed literature in the previous sections of this paper.

Identification of and data collection about tertiary response service use by women and girls with disabilities

The reported incidence of violence and abuse of women and young women with disabilities is lower than the actual incidence and this is a result of a number of complex factors that have to do with reporting and data collection. Education about violence and abuse is not a tertiary response and there is no research that clearly indicates a link between more knowledge about violence and abuse and more reporting. There is a need reported in the literature for more education for women with disabilities to understand what kinds of behaviour constitute gender based violence and how to report and escape situations where they are subjected to violence so they can access a tertiary response service. High quality data collection processes based on an understanding of disability, intersectionality and accessibility need to be developed so the services used by women and girls with disabilities can shape responses. These data must in turn be analysed and used in the development of policies that take account of the needs and experiences of women and girls with disabilities as well as informing systemic and individual advocacy processes.

Effective services provide staffing adequate to the needs of the users of the service

A study in the UK found that most disability services were severely understaffed and unable to provide services or support for women experiencing domestic violence. Further, only a few of these organisations employed staff that had completed multi-agency domestic violence training, with most staff members promoting the view that domestic violence was not their business (Hague et al., 2011). Disability services provide housing, personal support and assistance and specialist support approaches to people with disabilities. If they are to respond to the needs of women and girls with disabilities they need to be safe places where women and girls with disabilities feel they are getting a response to the violence and abuse they have experienced from skilled and informed staff (Lund, 2011).

Services are physically accessible, address programmatic access and are underpinned by cross sector collaboration

Three key factors stand out as important for accessible, effective tertiary response services. These are physical and programmatic accessibility, cross sector collaboration and evidence based practices. In this review no single model stands out as adequately addressing these three aspects of an effective service. Healey et al. (2013) developed a framework to assess the inclusiveness of domestic violence standards that is based on current understandings about “best practice” in this area. These include that:

- the voices of women with disabilities should be used to inform policy and practice;
- services should collect disability data;
- to be eligible for funding, services should provide evidence that they meet physical access standards (that are inclusive of all disabilities) as well as programmatic access through use of accessible information and approaches;
- services must provide evidence based and rigorously reviewed therapeutic and educational practice;
- services must engage in cross sector collaborations;
- services should be based on a human rights, gendered and intersectional framework; and
- these principles must underpin the service, its programs, the approaches used and workforce development.

The *Stop the Violence Project* in Australia (WWDA, 2013) proposed a number of principles for effective services:

- adopting a human-rights approach;
- promoting empowerment through participation;
- removing barriers;
- working in partnership;
- building capacity;
- building and using the evidence base;
- preventing violence before it occurs and promoting leadership and advocacy;
- providing appropriate accessibility;
- ensuring transferable and open communication;
- creating inclusivity and equality for all stakeholders; and
- guaranteeing that clear accountabilities are agreed upon before program development and implementation.

While research is lacking on implementation and evaluation of services that reflect these standards, a number of the studies found these or similar principles do underpin practice. Research is needed that looks for, names and then evaluates these principles in practice.

Conclusion

This state of knowledge paper on tertiary responses to violence and abuse for women and girls with disabilities highlights the need for further research concerning the identification of tertiary responses and research about the effectiveness of these tertiary responses. While a number of approaches to address physical and programmatic access are reported in the literature, there were no definitive models identified; rather the literature pointed to a number of key principles that should underpin tertiary responses. The effectiveness of existing tertiary responses that seek to meet the needs of women and girls with disabilities is inadequately reported in the literature.

Based on the current state of knowledge it appears unlikely that any single organisation has all the services and expertise that the diversity of women with disabilities require during or after experiences of violence and abuse. A key finding of this review is that effective, accessible services for women and girls with disabilities must be built on multi-agency collaborations. Research in the USA suggests that collaboration must be based on having a clear purpose understood by all parties, and be developed within an environment conducive to the active and productive engagement of all parties. Other factors include the quality and frequency of communication, and the existence of supportive resources (Smith & Harrell, 2011). Added to this, tertiary response services must engage women with disabilities as partners in the planning and strategic stages of service development, as they are the experts in their own lives and can contribute a different perspective on appropriate services and support needs for women with disabilities (Healey, 2013). Other factors for effective collaborations include that they should be well managed and require substantial efforts from affiliated agencies/stakeholders that are not driven by financial gain or funding obligations but by a genuine desire to challenge existing barriers and make firm cultural/community change. Well-functioning collaborations must address access issues relating to multiple forms of disability and gender, and the intersection of these with other forms of diversity such as race, class and socio-economic status (Dowse, 2013).

A central tenet of effective tertiary response services for women and young women with disabilities concerns power, and the need for service users to exercise agency in all aspects of the service experience. Further, the limited research which works directly with women and young women with disability to identify their strategies, hopes and aspirations for responding to violence and abuse, and for promoting personal safety (Frawley et al., 2012; Robinson 2013, 2014; Powers, et al., 2004), can be used to promote effective practice in tertiary services, ensuring that the perspectives of women with lived experience increasingly inform service responses.

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