A Review of the Literature on Qualitative Studies of Sexual Abuse and People with Disabilities:

Findings and Methodologies

Introduction & Overview

There is a growing body of literature that identifies disabled individuals as being at increased risk of sexual abuse (Baladerian, 1991; Sobsey, 1994; Casteel et al, 2008; Lan-Ping et al, 2009). Identified acts of abuse tend to be recurrent, and to last for longer periods of time, when the target of the abuse is a person with a disability (Young et al, 1997). Sobsey (1994) emphasised the point that although disability is associated with the risk of abuse, it is important to avoid the assumption that disability is a direct cause of vulnerability. He suggested that the increased vulnerability may be more associated with society's response to disability rather than to disability itself.

Quantitative research in this area has demonstrated that boys appear to suffer more physical abuse and neglect, whereas girls experience higher rates of sexual abuse (Sobsey et al, 1997). Lan-Ping et al (2009) in their analysis of nationwide sexual assault data in Taiwan, found that the number of reported cases of sexual assault of people with disabilities in 2007 was 586 persons, and that people with an intellectual disability were the most likely to be assaulted (304 cases), followed by those with a chronic mental health difficulty (135 cases). Other disabilities, including multiple disabilities, physical disability, and sensory disability, accounted for less than 30 reported cases in the same period. Research has also demonstrated that most sexual abuse cases occur in the victim's home, and most perpetrators of abuse are known to the victim (Furey, 1994; Nannini, 2006). Nannini (2006) in the US also found a high rate of a past history of sexual assault (69%) among their sample of women with disabilities (n = 1,711).

Focusing on the reporting of abuse, it has been recognised that adults with a disability can face particular barriers to disclosure of sexual assault (Murray & Powell, 2008). Murray and Powell (2008) writing in the Australian context, argued that enabling disclosure and providing the most appropriate responses, across public policy, the criminal justice system, and the service sector, require urgent attention. They reported

that there is no consistent or standardised recording of allegations or incidents of sexual abuse of people with a disability across sexual assault victim services, the disability sector, and other relevant agencies. A study of police data on sexual assault for Victoria, Australia indicated that just over a quarter of all victims were identified as having a disability (n = 850). Of this group, 15 per cent had a psychiatric disability or mental health issue and 6 per cent had an intellectual disability (Heenan & Murray, 2007).

Much of the research conducted in this area has focused on data collection through sexual assault treatment centres, rape crisis centres, disability organisations, case reports of sexual abuse from existing records, surveys of staff members from health authorities, and other public organisations. In this regard, Roberto and Teaster (2005) noted that the primary focus of the empirical literature is on the sexual abuse of women with intellectual disabilities and is mostly limited to descriptive information retrieved from case records or small qualitative studies of the experiences of women who have been sexually abused.

Meanwhile, Nosek et al (2001) pointed out that the literature in the disability arena has focused mostly on abuse of children with developmental disabilities. A few studies have looked at the situation of women with disabilities; however, they considered that concepts are not well defined; the samples mix together children and adults, and include the full spectrum of intellectual, sensory, and physical disabilities. It is important to keep these issues in mind in any review of the literature.

According to McCarthy (2003), professionals have in the past been slow to listen to what people with intellectual disabilities have to say about the issue of sexual abuse. However, she believes that this is changing and that the development of both group and individually based sex education programmes, as well as the development of more general self-advocacy networks, have enabled many people with learning difficulties to speak out about the abuse they have experienced (McCarthy, 2003).

Review Procedure

The primary focus of this review is on the available empirical research which has used qualitative methods to explore people with disabilities' experiences of sexual abuse.

Within this context, this review discusses the current knowledge relating to disclosure of sexual abuse and appropriate responses.

While the main emphasis is on findings from empirical research which are relevant to the focus of this review, we have also considered the methodological approaches adopted in these studies. Points regarding the methodologies used are relevant in that they may highlight issues to be addressed in a future study. In addition, while the focus is on qualitative studies, research on sexual abuse and people with disabilities which has used quantitative approaches are referred to where the findings are of relevance.

In identifying studies, the research team initially drew on the body of literature that had been gathered during the completion of the first phase of the project. At that stage search terms related to all forms of abuse and the full range of types of disabilities. The search included databases such as ERIC Omnifile, ProQuest, PsychINFO, PsychArticles, PubMed, Oxford Journals Online, Social Sciences Citation Index, SCOPUS and Swetswise. In preparing this review the team applied a broad definition of disability but focused on sexual abuse particularly. In gathering relevant literature, the research drew on studies specific to sexual abuse, but also more general studies on sex, sexuality and abuse that reported information relevant to the focus of the study. Studies that used qualitative approaches focusing on the experiences of people with disabilities were considered most relevant. However, studies that used more quantitative survey-based methods, and studies that gathered information from professionals working with people with disabilities were also noted in relation to key areas of the review.

Appendix 1 provides a summary of the key studies identified. This review demonstrated that there has been little qualitative research conducted with people with a broad range of disabilities on their experiences of abuse and even less on their experiences of systems of prevention, reporting and redress.

Types and Nature of Sexual Abuse Experienced

Two key issues emerged in the review of relevant studies. These were the range in forms of abuse experienced, and the extent to which people with disabilities who experienced sexual abuse, also reported other types of abuse.

One qualitative study with 31 adult women with physical disabilities conducted by the Centre for Research on Women with Disabilities (Nosek, 1996) examined several themes relating to sexuality and women with physical disabilities, including the issue of abuse. Twenty-five of the women with disabilities interviewed together reported 55 separate experiences of abuse. Of these, 15 were reported as sexual abuse, 17 were physical (nonsexual) abuse, and 23 were emotional abuse. Among the 15 experiences of sexual abuse reported, there was considerable variety in the type of experience, including fondling (3), coerced sexual activity (3), forced oral sex (1), sexual assault (5), and rape (3). These experiences occurred across the lifespan, and the majority were single incidents (Young et al, 1997).

It is important to recognise that the choices made in designing a study, including the way in which abuse is defined, can influence the types of behaviours examined. In a recent study, Hickson et al (2008) defined sexual abuse (in accordance with New York State reporting requirements) as touching and fondling of the sexual or other body parts of a participant for the purpose of gratifying sexual desire, whether directly or through clothing. Abuse, as defined, also included causing a participant to touch anyone else for the purpose of arousing or gratifying that person's sexual desire. In this study, the term sexual abuse encompassed any sexual activity involving participants who are considered to be legally 'non consenting ' and any sexual activity that is perceived by a 'consenting' participant as harassment, coercion, or exploitation.

Olsvik (2006) suggested that sexual abuse can take the form of both physical abuse, such as unwanted sexual touch and rape, and emotional abuse, such as obscene comments and peeping. Eight of the thirteen women in their qualitative study of violence and abuse against Norwegian women had experienced different types of sexual abuse, including 'peeping' (which involved a disabled woman's bed clothes being removed while she was sleeping in a hospital bed); molestation by a medical professional; and the molestation of a young woman over the period of a year while she was staying in a residential school. These studies highlight the variation of experience reported by individuals with disabilities.

Research by Nosek et al (2001a) identified disability-related sexual abuse which can take the form of fondling or forcing sexual activity in return for accepting help. Perpetrators can take advantage of physical weakness and inaccessible environments to force sexual activities. Spousal rape is a particular problem for women with disabilities as they may have a reduced ability to defend themselves. Nosek et al (2001a) found that disability limited escape options and created the need for assistance with essential personal care. This opened up opportunities for sexual abuse, emotional abuse, physical abuse and neglect in ways that most women do not experience. The researchers noted that aspects of abuse related to disability fell into two broad categories. The first category related to variations on common forms of abuse that would not be as likely among individuals without a disability, while the second related to abuse that occurred in a disability-related care or service context. They highlighted that while the nature of the abuse centres on the dynamics of power and control (as with individuals without a disability), the presence of disability (and the associated settings) open new channels for the expression of those dynamics (Nosek et al, 2001a).

Nosek et al argued that disability serves as an additional vulnerability factor, while a disabling social environment also increases vulnerability. This can be the case in that the stigma and social isolation that can accompany disability may reduce an individual's ability to defend themselves by lowering self-esteem and removing the supports available from others which might otherwise serve as protective factors (Nosek et al, 2001a). Similarly, a UK-based study on domestic violence by Hague, Thiara, McGowan and Mullender (2007) emphasised the occurrence of disability related abuse, where women's impairments were frequently used in the abuse. Indeed, in this study, sexual violence appeared to be proportionately more common for disabled than for non-disabled women. Interestingly the authors noted that current definitions of domestic violence were clearly too narrow to encompass the range of experiences of disabled women. All the respondents in the Hague et al study said that being disabled made the abuse worse and also severely limited their capacity to escape or take other preventative measures.

Another issue emerging from the literature review was whether or not a person identifies their experiences as abusive. Williams (1995) argued that extensive

experience of victimisation can lead to the belief that this is part of normal life. Nosek et al (2001a) give the example of a woman with an acquired physical disability (a spinal cord injury) who is fondled by a staff member who is helping her get dressed – she may not define this as forced sexual activity or label it as sexual abuse. They argue that this issue underlines the need to develop interventions to support women with disabilities to recognise abuse, to act to protect themselves in abusive situations, and to remove themselves from potentially abusive relationships and situations.

Given the variation in types of sexual abuse experienced and the factors that may influence the definition of an incident as abusive, a final study of note is Jenkins et al's (2007) focus group study of 70 staff members from independent and statutory services in the UK relating to reporting of abuse. Jenkins et al found that a 'hierarchy of abuse' existed among staff who worked with people with intellectual disabilities whereby staff members seemed to be 'weighing up' or assessing incidents to identify those they perceived as serious abuse before reporting the concerns.

Jenkins et al noted that the point at which action is taken was frequently not in line with relevant adult protection system's definition of abuse which required action. They reported that some staff distinguished physical and sexual abuse (and in some cases financial) from other abuse forms in terms of level of severity and associated level of necessary response. The authors argue that this informal allocation of experiences into a 'hierarchy of abuse' clearly has implications for a consistent response to protection from abuse.

Referring to methodological difficulties in abuse studies in general, Manley (2005) noted that variations in defining demarcation lines between abusive and normative behaviours are evident from one locale to another in the US and from one country to another internationally, a phenomenon described by Chadwick (2002) as 'worker bias'.

Patterns of Disclosure

Regarding the experience of reporting abuse, there was a noticeable lack of qualitative research in this area. The UK study by Hague et al (2007) noted in relation to disclosure of abuse, that women reported that professionals rarely asked about abuse, and that the women were reluctant to disclose if not asked.

Given the lack of qualitative research in this area some key points can be drawn from quantitative research. For example, some relevant points were identified in a large-scale survey by Nannini (2006). This research, conducted in the US and involving 1,711 women with disabilities (44% of whom had a mental health disability) found that reported rates and nature of disclosure were generally similar when women with disabilities and women without disabilities were compared. The majority of survivors contacted rape crisis centres themselves and women on average waited more than four years before reporting the sexual assault. Women with disabilities reported the abuse to police or crisis centres more often. Higher proportions of women without disabilities disclosed to friends and family. Nannini reported that less than one third of women in either group intended to pursue a prosecution and, interestingly, this group contained a significantly greater proportion of women with intellectual disabilities (43%) or visual impairment (48%).

In comparison, only one in four women with mental health disabilities intended to pursue prosecution (27%). This study explored some patterns within the group of individuals with a disability, particularly those comparing women with different difficulties. Only 34% of women with intellectual disabilities contacted the centre themselves, but nearly 77% of this disability group made contact with support services within the first year. Nannini found that the average time between the assault and the report was 0.7 years for women with intellectual disabilities, compared with between 5.2 and 8.6 years for other women with other types of disability (excluding multiple disabilities). Women with intellectual disabilities were also more likely to report the incident to the police. Looking at women with mental health disabilities, this group was least likely to contact others before seeking support services. In addition, nearly three-quarters of women with mental health disabilities reported a previous assault. In comparison, the rate of previous assault among women with hearing impairments was similar to that of women without disabilities (47%).

This study highlighted a number of issues that are relevant to prevention and intervention for people who experience forms of sexual abuse. The presence of a history of previous assault was particularly noted for women with intellectual, mental health, or physical disabilities and there was a greater probability of reporting rape, as

compared with other types of assault, by women with disabilities. For those with disabilities (and similarly to those without disabilities) the majority of assailants were family members or friends and the assault(s) most often occurred at home. It is noteworthy that women with a disability were less likely to confide in friends before seeking support services.

While this is a useful study to consider in relation to patterns of disclosure, there are a number of limitations noted by the author. Reporting of the experiences may have been influenced by recall bias, which may itself have been the result of the passing of time, the level of stress, or difficulties in aspects of cognitive functioning. In addition, the representativeness of the sample must be considered and in particular the lack of participation by women with sensory disabilities was noted. Finally, Nannini noted that data were representative of women who chose to contact a support service, and quoted Estrich (1987), who highlighted that different groups choose to report to the police, support services or interviewers in crime victimization surveys. A key difference noted between these groups was that women reporting to the police typically reported being assaulted by strangers, whereas those contacting rape crisis centres or other support services had generally been assaulted by known assailants. A key conclusion drawn by Nannini was that data collected from disability settings may only provide certain insights into the experience of abuse as the focus in these settings is often on mandatory reporting by service providers and not the woman herself.

Barriers to Disclosure

While there is a lack of qualitative research on the experience of reporting, a number of studies were identified that considered the possible and actual barriers to reporting sexual abuse among people with disabilities. Many factors influence whether people with disabilities disclose incidents of abuse and how others might identify the problem when it is unreported. The factors considered here reflect a key report by the Roeher Institute (1995) and a number of other studies identified in the literature.

Perceived significance of the incident

Earlier it was noted that the issue of reporting abuse may be influenced by the extent to which the target of the behaviour identifies the behaviour as abusive. Even if it is identified as such, the victim may be influenced by the perceived seriousness of the incident. Women who took part in the Hague et al (2007) study described 'not recognising their experiences as abuse' as a particular barrier to reporting. Several research participants in a study by the Roeher Institute (1995) had indicated that they had not told others because they did not consider the incidents serious enough. The authors suggest that gender differences can play a part in the minimisation of the significance of an abusive incident. They suggest that males may be more inclined than females to rationalise such incidents as normal cultural occurrences and to attach less significance to them. Interestingly, a study by Saxton et al (2006) involving focus group discussions with 78 men with physical disabilities or physical and intellectual disabilities demonstrated both reluctance to disclose abuse and ambivalence about reporting. Research participants in this study spoke about the culture that prohibits men from complaining or 'squealing', in case that might highlight their vulnerability.

It has also been suggested that, for some people with disabilities, being socialised in a climate of violence may affect the importance they attach to particular acts (Roeher Institute, 1995). In this regard, Saxton et al (2001) suggested that while marginalised individuals may resist mistreatment, they may inadvertently internalise negative assumptions. In their study, participants reported weighing up the pros and cons of a relationship that had become abusive. A later US-based study by Copel (2006) examined related issues with a group of 25 women with physical disabilities. Copel noted that many women, including those with disabilities, had difficulty recognising and labelling abuse and associated this with lower self-esteem, and feelings such as shame, embarrassment, humiliation and fear. She considered that it was common for women with disabilities to think they deserve mistreatment and abuse because of their disability and that consequently they may believe the abuse is their own fault. Copel (2006) argued that these beliefs will have implications for a disabled woman's willingness to report a sexual crime.

Probability of being believed

In addition to the personal beliefs of individuals with disabilities, the study by the Roeher Institute (1995) also considered the way in which the process of disclosure is affected by whether a person feels he or she will be believed. They described how one

participant with a mental health disability felt that the police were unlikely to believe her if she were to report her husband's physical abuse of her and her children. She associated this with her history of mental health difficulties. The authors noted incidents of abuse where police and courts found individuals with intellectual disabilities were considered to lack credibility because of their disability. Interestingly, the authors of this report also questioned whether the *perception* in the disability community that people with disabilities will not be believed when they disclose, in itself acts as a barrier to disclosure (The Roeher Institute, 1995).

Hague et al's (2007) study of domestic abuse highlighted that women with disabilities also report not trusting agencies to respond effectively to a report of abuse. Participants also feared that reporting their experiences might result in losing their independence and being institutionalised and even losing their children.

The sense of fear on the part of victims was echoed in one qualitative study on the issue of reporting abuse. Keilty and Connelly (2001) undertook a study to look at the barriers that arise at one particular stage in the prosecution of a complaint – making an official statement to the police. Semi-structured face-to-face interviews were conducted with 13 police officers and 27 sexual assault workers in the greater Sydney area. The researchers themselves recognised that study was limited by the non-inclusion of women with intellectual disability (the disability group of interest). The authors cited a lack of resources to provide follow-up support to participants as the key reason for this. As a result, the study inferred barriers from the observations of the police and assault workers rather than the experience of people with disabilities.

Keilty and Connelly's (2001) findings demonstrated that women with intellectual disabilities may face a number of barriers to successfully making a formal statement to police following a sexual assault. One barrier noted was the stigmatising attitudes of police officers, e.g. the belief that women with intellectual disabilities are promiscuous; and that the complainant's story would not be credible. The authors expressed concern that cases of sexual assault were not being thoroughly investigated. The interviews indicated that police assessments of credibility influenced their decision to take a statement and to proceed to prosecution. According to the authors, courts in Sydney distinguish between evidence about credibility and about

the substantive issues of a given case; however, they noted that police appeared to take credibility and the substantive elements into account together when deciding how to proceed.

Issues in Communication

In considering the process of reporting abuse the Roeher Institute (1995) commented on the challenge of communication for individuals with some types of disability. They noted that this may particularly affect people with mobility impairments and may involve difficulties in physically accessing police stations and support services, as well as lack of access to technical devices. They gave the example of a person's access to the telephone being blocked by the abuser. Related to this is the issue of communication skills. Any individual whose disability results in limited communication skills is at risk of not being able to effectively disclose the abuse and of not having their complaint taken seriously (The Roeher Institute, 1995). This problem may also add to an individual's vulnerability and increase the risk of being abused. Lightfoot and Williams (2009) writing in the US pointed to the double communication barriers experienced by immigrants who are deaf or hard or hearing, and who may never have had an opportunity to learn to sign or to learn English.

Identifying Someone to Report To

Aside from the challenge of communicating their experiences, the research literature also notes that there are challenges in knowing to whom to report abuse. Yoshida et al (2009) explored the barriers to leaving abusive settings and seeking service for 16 women with disabilities in Canada. This study found that the process of having to tell someone about the abuse in order to gain assistance was associated with particular fears relating to endangering those who might provide help. Reluctance to disclose abuse to other family members has been associated with a concern that the disclosure could result in having to leave the family home, and lose social, economic, and disability-related supports (Roeher Institute, 1995). In such a situation people with disabilities may feel that they have only two options: remain silent or disclose to others in the community. But there are associated challenges with knowing who else to talk to about abuse.

Not knowing where to turn for help can make it more difficult for an individual with a disability who has been abused (Roeher Institute, 1995). People with disabilities often experience social isolation as a result of their disability, and this may compound access to information and knowledge about services. In addition, as has already been noted, Yoshida et al, (2009) noted that services that deal with complaints of violence and abuse may not be accessible to people with disabilities, e.g. refuges, counselling services. Another barrier may be the cost of services, e.g. private counselling sessions.

Clear Procedures for Making Complaints

In addition to the challenges of reporting abuse, there are also a number of challenges relating to the abilities and knowledge of the people hearing the reports. Keilty and Connelly's (2001) study of the barriers reported by police officers and sexual assault workers raised this issue.

While policies and procedures existed, they reported that the level of awareness and implementation of these policies was low. They found that there was confusion about what constitutes an intellectual disability, particularly where the disability was mild; about how the disability impacts on the 'victim' and how police should adapt their interview techniques so as to ensure that a statement has a forensic value. In addition to this knowledge on the part of those receiving reports, it is essential that people with disabilities know and understand the procedures for reporting an incidence of abuse if those procedures are to be effective.

Perceived Consequences of Reporting to Safety and Well-Being

The issue of consequences as a barrier to reporting appears in the literature on several levels.

Several respondents in the Roeher Institute's research (1995) indicated that threats and fears of reprisal from the perpetrators of abuse inhibited disclosure. Keilty and Connelly (2001) found concerns that the court process would lead to excessive trauma for the complainant. Some participants felt that securing protection for the complainant from further sexual assault was a greater priority than prosecuting the suspect. Assessment of capacity to give evidence was also experienced as a barrier to taking a statement. Police saw the complainant's capacity to give evidence in court as relevant to whether they would take a statement, proceed to prosecution, or refer the complaint to the DPP (Keilty & Connelly, 2001). The authors argued that it is premature to consider whether a person has capacity to give evidence in court at the point of deciding whether or not to take a statement or to charge the accused. A complainant is entitled to give his/her version of the complaint and to have it fully investigated, irrespective of whether the complaint proceeds further.

Dickman and Roux (2005) also highlighted the difficulties in obtaining redress for people with intellectual disabilities. They noted that it is very rare for sexual abuse cases involving a complainant with disabilities to go to court, and for the complainant to appear as a witness. Green (2001) focused on case reports of witnesses with intellectual disabilities in the UK, and highlighted concerns, including the assessment of capacity to give consent and the ability to withstand court procedures as a witness.

Therefore there is evidence of a large number of barriers to reporting abuse for people with disabilities, relating both to their ability to assess behaviours as abuse, their ability to engage with reporting systems and the way in which those systems respond when a report is made.

Prevention and Protection

Another aspect of the literature is the experience of prevention and protection systems as reported by people with disabilities. The study by Hague et al (2007) found that the lack of accessible services, and particularly the inaccessibility of refuge services, was seen as a challenge for a group of women with disabilities who had experienced abuse. However the lack of research in the area limits the extent to which we can consider the experience of people with disabilities in this area. Nevertheless a number of studies in the literature have implications for our understanding of these issues.

In relation to prevention, Lan-Ping et al (2009) considered the key question to be how sex education can be provided most effectively to prevent abuse. Neufeld et al (2002) recommended that health and sex education should include the development of effective communication skills, decision-making skills, assertiveness, and the ability to say 'no'. However, Lan-Ping (2009) noted that basic sex education for people with intellectual disabilities is needed prior to the delivery of a sexual assault prevention

programme. McDermott et al (1999) found that an individualised hygiene education programme for women with intellectual disabilities had beneficial effects on knowledge related to sexuality, which again may form the basis for prevention education.

One study that did look at protection for people with disabilities was Hickson et al's (2008) research in New York. This included 36 women with intellectual disability who had either a documented history of abuse or no history in the previous five years. This study looked at decision-making in response to simulated situations of different forms of abuse, including sexual, physical, and verbal abuse. Findings showed that the women with a history of abuse differed from those without, in the extent to which they employed passive/avoidant strategies in response to vignettes depicting abuse. Although the two groups did not differ in the extent to which they used independent, prevention-focused decision-making or reporting strategies, the women with documented abuse showed a greater tendency to offer passive/avoidant responses to the situations. Hickson et al (2008) suggested that in situations of ongoing or repeated abuse by a known individual, passive/avoidant responses.

Saxton et al (2006) noted from their research with men and women with disabilities about abuse perpetrated by personal assistants, that men's responses to abusive situations were different from women's. They reported that men were more likely to assume that nothing could be done to prevent abuse. In contrast, women with disabilities tended to assume that something ought to be done about the abuse, and reported more positive beliefs that that they were not to blame. The researchers recommended alternative avenues for abuse reporting, in order to enable disabled men to communicate with resources, citing examples such as peer-run hot lines and on-line chat rooms and discussions lists (Saxton et al, 2006).

Methodological Considerations

Given the small number of studies that were directly relevant to the focus of the present literature review, it is useful to learn not only the findings of these studies, but also the methods employed. For example, Hague et al (2007) highlighted some of the issues involved in sampling for a qualitative study. The researchers noted that they attempted to form a purposive and diverse sample of disabled women who had experienced domestic violence, including women with mobility, hearing and visual impairments and other conditions, and from diverse backgrounds, on the basis of ethnicity, sexuality, socio-economic status and age. They noted that the interviewees were approached and treated paying particular attention to safety and to confidentiality, and with sensitivity in addressing specific issues raised by each individual woman's access needs. Accessible locations and interpreters were found, where needed. The interviews focused on experiences of domestic violence and of services. However, like many of the studies considered above, the researchers did not discuss in detail their sampling strategy or how they accessed participants for the study, but referred to distribution of publicity materials and following up contact with various organisations.

One aspect of methodology that is considered in detail is the method of data collection employed, which is most often individual interviews. McCarthy (1998) provides a useful discussion on methodological issues in her qualitative research on the sexual experiences reported by 17 women with intellectual disabilities. McCarthy provides support for semi-structured interviews and argues that highly structured interviews would not allow for the flexibility and follow-up questions that were necessary in these types of studies. However she considered that some structure is needed to facilitate discussion with people who have difficulties with verbal communication.

There has been much discussion in the literature on forensic interviewing of children and adults with intellectual disabilities, which can inform qualitative interviewing strategies in this area. Researchers who have studied forensic interview practices and the best ways of obtaining information from people with intellectual disabilities (e.g. Milne et al, 1999; Gudjonsson & Henry 2003; Kebell et al, 2004) recommend the use of open question types whenever possible, as these are considered to maximise accurate recall. Cederborg at al (2008) note from a review of the literature (e.g. Gordon & Schroeder, 1995; Poole & Lamb, 1998) that interviewers should start with open questions and proceed to more specific questions.

However they stress the importance of bearing in mind that responses to more focused questions may be less accurate (Henry & Gudjonsson 2003; Kebbell et al, 2004), particularly as focused questions may encourage individuals with intellectual disabilities to respond even when they do not know the requested information (Clare & Gudjonsson, 1993; Gudjonsson & Clare, 1995).

Cederborg et al's study (2008) explored how individuals with intellectual disabilities are interviewed by police officers in Sweden and the impact of these procedures on their ability to report accurate information. They carried out a quantitative analysis of the type of questions asked of 11 individuals (adults and children) and the number of words and details they elicited. When interviewing alleged victims of crime, officers used many focused questions regardless of the witnesses' responsiveness or type of disability. Their findings indicated that interviewers did not provide sufficient opportunities for the adults and children to be responsive and did not make enough use of open-ended questions. According to Cederborg et al (2008) the unnecessary use of focused questions may have decreased the accuracy of the information provided to police. Based on their findings they argued there was an urgent need to inform police officers of the rationale for using the types of open questions that maximise accurate recall.

A number of additional recommendations regarding interviewing people with disabilities about abuse are evident in the literature. When interviewing individuals with intellectual disability about multiple incidents of abuse, Lamb et al (2008) advised investigators to focus on one abuse incident at a time, using open-ended, directive, and, when necessary, option posing questions before switching focus to another incident. Interviewers were also encouraged to ask short questions using simple vocabulary and sentence construction, and to slow down the pace of the interview.

Saxton et al's research (2001) used interviewers experienced in clinical interview techniques, and prior to the beginning of the study, rehearsals were conducted to review strategies for building rapport with the respondents. In an example of the range of issues that can present when interviewing people with disabilities about abuse, the researchers on The Roeher Institute study (1995) accessed participants through disability and advocacy organisations who were asked to make initial contact with individuals whom they knew had experienced abuse and who might feel comfortable talking with interviewers. The authors reported that several of the interviews were terminated because the incidents were too painful to recount. However, it was also noted that the interviews in many cases resulted in a wide range of issues being raised, due to the sensitivity of the subject and the associated feelings. As a result,

interviewers reported using a questionnaire guide to ensure that issues, which did not surface during the natural flow of the conversation, were covered. In comparison to Saxton et al's research (2001) the interviewers in the Roeher study noted that sometimes the use of ice-breakers and rapport-building was not required as many interviewees were keen to share their own stories.

Irish studies

The NDA recognises that research on the issue of abuse and disability has been limited in Ireland. The organisation has prepared a number of online publications on this issue, including a booklet outlining best practice when dealing with women with disabilities who have experienced violence or abuse (NDA & Women's Aid, 2002) and a briefing paper on the current research and policy context in this area (NDA, 2009). The NDA (2004) also published the proceedings of a seminar which brought together researchers, service providers and policy makers to discuss the development of a strategic framework to address this issue. These resources include many of the studies relevant to the issue of sexual abuse and disability and also include some unpublished presentations, such as a report of an audit of the services provided by Rape Crisis Network Ireland from a disability perspective

With regard to relevant empirical studies, two Irish studies have looked at intellectual disability and aspects of abuse. McConkey and Ryan (2001) explored staff perspectives on dealing with aspects of sexuality in service settings. Two of the scenarios considered, as part of a survey of staff, related to abuse and involved unwanted sexual advances and inappropriate touch by a stranger. However, the most relevant Irish study involved an analysis of clinical case files of all allegations of sexual abuse, over a 15 year period (McCormack et al, 2005). In this study all allegations of sexual abuse where the victims or perpetrators were service users in a particular intellectual disability service were reviewed. This study found that the abuse was most often reported by the victims of abuse or their families. Almost half of the alleged reports were confirmed and the most common type of abuse was sexual touch, with one third of episodes involving penetration or attempted penetration. The authors noted that a key feature of the reports was the variation in incidence – this was attributed to multiple episodes of abuse. The authors also concluded that the findings

suggest that the incidence of confirmed episodes of sexual abuse of adults with intellectual disabilities may be higher than previously estimated.

Despite the relevance of these two studies to understanding the issue of sexual abuse among people with disabilities, this review has not identified any Irish studies that have gathered information directly from people with disabilities who have been abused.

Conclusion

In concluding on this literature review it is important to begin by recognising the difficulty in sourcing research, particularly qualitative research, on the systems of reporting, redress, prevention and protection experienced by people with disabilities who have been abused. While this clearly points to the need for caution in drawing conclusions based on a small number of very varied studies, more importantly it also highlights the urgent need for research in this area. A clear pattern found in the literature is the dominance of views from North America and to some extent the UK; however as is clear from the appendix to this review, no study of this kind has been conducted in Ireland and that systematic research on this issue is needed.

The literature that was available highlights a number of key issues. To begin, it is clear that people with disabilities experience a range of types of sexual abuse, from fondling to sexual assault and rape. Also there is evidence of broad variation in the age, gender and type of disability profile among people who experience abuse. A key point relates to the issue of sexual activity when a person is considered to be 'non-consenting' or coerced and the implications of this for people with disabilities. There are also some worrying patterns regarding the way in which incidents are defined (or not) as abuse, on the part of people with disabilities, those who care for them, and those charged with investigating complaints or allegations of abuse. Findings relating to the factors that influence the extent to which behaviours are defined as abusive, even among care professionals highlight the possibility that even when people with disabilities identify themselves as having been abused, their reports will not be followed up.

A second issue relates to the disclosure or reporting of abuse. Again, while there is little qualitative research on this topic, it appears that there are disability-specific patterns of reporting, which would need to be considered in examining education and support in this area. In addition to general patterns of disclosure, this review has highlighted some of the significant barriers to disclosure faced by people with disabilities. These include the aforementioned issues of definition, but also extend to concerns regarding credibility, ability to communicate and be communicated with, and the existence of clear and appropriate procedures to support disclosure. While many of these barriers raise challenges for people without disabilities who have experienced sexual abuse, the added impact of disability must also be considered.

The penultimate issue relates to the topic of intervention and protection and it was this area that showed the most significant lack of specific research. While the review did draw on studies relating to sexual education and health, there was a notable paucity of research that examined the experience of prevention and protection among people with disabilities.

The final issue of note in the present review relates to the methodological issues evident in this research. While the review does highlight a number of limitations to the knowledge base, including issues relating to the sampling of participants, the focus on particular disability groups and also female participants, a more important focus is the guidance that is available in the existing literature. There is no doubt that researchers have been successful in developing understanding of the issue of sexual abuse and disability. However they have also highlighted what works in researching this topic. Despite the challenges that must be addressed in researching this area it is evident that, with due care and attention, we can develop our understanding of the experience of people with disabilities of this challenging topic.

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Qualitative Study	Description	Accessing Sample	Sample Size	Level of Homogeneity within the Sample	Types of Abuse Explored
Carlson (1998) US	Exploratory study describing intimate partner violence among adults with DD living in the community	Through services, referral by staff members	11 adults	-10 women and 1 man -developmental disabilities	Physical, emotional and sexual abuse
Nosek (1996) US	Sexual abuse of women with physical disabilities		31 adult women with physical disabilities	Disability type, age of onset of disability, ethnicity, single/married	Sexual abuse, physical abuse, emotional abuse
Gilson et al (2001) US	Explored the experiences of abused women with disabilities	Recruited through Centers for Independent Living	16 disabled and non- disabled people	15 women and 1 man 13 women had physical disabilities; 2 women with multiple disabilities; 2 women with sensory disabilities	Physical, emotional, neglect, control/restraint
Saxton et al (2001) US	Investigated the experiences of women with physical and physical and cognitive disabilities related to abuse by formal and non-formal personal assistance providers	Recruited through independent living centers and disability service organisations	72 women with physical disabilities or physical and cognitive disabilities 49 women participated in focus groups and 23 women in individual interviews	-Women from different ethnic groups included -aged 18 years or older -51 women with physical disabilities -5 women had cognitive and physical disabilities -9 women had ongoing health conditions -2 women had sensory disabilities -2 women declined to reveal their primary disability	Abuse by personal assistance providers
Saxton et al (2006) US	Investigated how men with disabilities define and describe abuses that may arise in provision on personal assistance	Recruited through independent living centers, self- advocacy groups and disability service organisations	78 men with physical disabilities or physical and cognitive disabilities	-aged 18 years or older -different ethnic backgrounds -54 men with physical disabilities -13 with cognitive disabilities -7 with sensory disabilities	Abuse by personal assistance providers including physical, neglect, financial abuse and other forms of abuse
Hassouneh- Phillips and McNeff (2005) US	Examined the link between low sexual and body esteem and intimate partner abuse in women with physical disabilities	Recruitment: flyers, word of mouth, and snowball sampling	72 individual in-depth interviews with disabled and non-disabled women -37 women with physical disabilities; including women with psychiatric conditions	-aged 19-60 -ethnicity	

Appendix 1: Summary of Thirteen Qualitative Studies on Abuse and People with Disabilities

Qualitative Study	Description	Accessing Sample	Sample Size	Level of Homogeneity within the Sample	Types of Abuse Explored
Copel (2006) US	Explored risk of intimate partner violence for women with physical disabilities	Convenience sample recruited from an outpatient clinic and a local rehabilitation center	25 women with physical disabilities	-over the age of 21 years to be included	
Yoshida et al (2009) Canada	Explores women living with disabilities knowledge and experiences of violence and abuse	-promotional material National consultation using internet technology (message boards and chat rooms)	16 women -11 with physical disabilities -2 with sensory disabilities -2 with learning disabilities -1 with mental health problems -of these 3 had multiple disabilities	-18 years of age or older -geographic area -disability -age	Range of experiences considered to be abuse
Lightfoot and Williams (2009) US	Explores the issues faced by people with physical and sensory disabilities in accessing help for domestic violence with a particular focus on people of colour	Participants were service providers serving people with disabilities of colour in the area of domestic violence from across the US	19 people with physical and sensory disabilities	-ethnicity -9 women who were deaf and hard of hearing -10 (9 women) with physical disabilities	-unique domestic violence issues for people of colour
Murphy et al (2007) UK	Aimed to describe the consequences of abuse and changes in behaviour following alleged abuse	Interviewed the carers of people with severe ID who had been allegedly abused	Parents or other carers for 18 adults with severe ID	-abuse must have resulted in the involvement of the criminal justice system	
Cramer et al (2004) US	Range of types of abuse endured by disabled women. Two themes emerged: vulnerable beginnings and complexity of abuse	Recruited through the Center for Independent Living (CIL) and related disability advocacy organisations	20 people with physical disability and 4 non- disabled people	-21 women and 3 men -18 abuse survivors	
Hickson et al (2008) US	Women with intellectual disabilities who had experienced documented history of abuse within the last five years were compared to women with intellectual disabilities without known abuse history.	Recruited from a clinic and three day programme sites of an adult service agency in New York city. Recruitment was conducted by staff members using a participants screening form to refer all women based on certain criteria	36 women with mental retardation 21 had a documented history of abuse within the previous 5 years 15 did not have a documented history of abuse within the previous 5 years	Criteria for inclusion were gender, intellectual functioning (IQ 35-75), chronological age (22 -55 years), and residential placement	Data on incidence of abuse were provided by each participant's case manager using a Risk Indicator Survey (Hickson, Khemka, & Will, 2002). The Risk Indicator Survey asked about history of physical, sexual, or verbal abuse within the preceding 12 months and/or within the previous 1 to 5 years
Olsvik (2006) Norway	3 year research project on violence and abuse against women with	Letters of invitation were sent to the members of the	13 women with physical disabilities participated in	-10 were mobility impaired, 1 was hearing impaired, 1 was	

Qualitative Study	Description	Accessing Sample	Sample Size	Level of Homogeneity within the Sample	Types of Abuse Explored
	physical disabilities. constructs a typology of abuse.	Norwegian Network for Women with Disabilities, and advertisements were published in newsletters of a number of user organisations.	in-depth telephone interviews	visually impaired and 1 had a speech impairment -aged between 33 and 61 years -four were married, four were divorced, four were single, and one was a widow -education -employment	