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REVIEW ARTICLE

Sexual Abuse Prevention for People with Severe Developmental Disabilities

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Abstract The present manuscript reviews research examining sexual abuse of people with developmental disabilities. Although the relevant studies are few in number and their methodology is not especially strong, their findings suggest that prevalence of sexual abuse is higher for people with developmental disabilities than for people with no disabilities and is highest in people with severe disabilities. Strategies for preventing sexual abuse and detecting its occurrence are considered and possibilities for future research are suggested, particularly in the area of training staff and other caregivers.

Keywords Sexual abuse · Sexual assault · Developmental disabilities · Staff training

Although relevant information has always been hard to obtain, researchers have known for more than two decades that people with developmental disabilities face serious risk of being sexually assaulted or abused (Sobsey and Varnhagen 1989). For example, Sobsey and Doe (1991) conducted a review of 162 reports of sexual abuse of people with developmental disabilities and reported nonconsensual vaginal or anal penetration in 62% of their sample. Most of the victims were under 20 years old and female while most of the perpetrators were male. There was usually a relationship between the victim and perpetrator before abuse occurred, with perpetrators described as family members, acquaintances, service providers, personal care staff, psychiatrists, or residential care staff.

Senn (1988) estimated that between 39% and 68% of female children and 16% and 30% of male children with a developmental disability will be sexually abused before 18 years of age. More recently, Tyiska (1998) estimated that 68–83% of women with developmental disabilities will be sexually assaulted in their lifetimes, as contrasted to an estimated 18% of women generally. Senn and Tyiska collected

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results from survey research, interviews, and state-wide rape and abuse prevention programs that maintain databases on characteristics of people reporting abuse. The surveys and interviews reviewed were conducted at institutions, foster-care homes, or work or activity centers. These data are not necessarily representative of the general population of people with developmental disabilities. Therefore, estimates of the prevalence of sexual abuse and assault in members of this population should be viewed as suggestive, not definitive. Nonetheless, it is clear that sexual abuse of people with developmental disabilities is a real problem and that there is obvious need to develop effective strategies to protect such people from sexual abuse. Efforts have been made to do so, but the relevant literature is small, and very little has appeared concerning sexual abuse prevention for people with severe developmental disabilities.

The purpose of this article is to call attention to sexual abuse in people with severe developmental disabilities by summarizing the relevant literature and offering suggestions for future research that should benefit members of this population. For the purposes of this review, the definition of sexual abuse proposed by Brown and Turk (1992) will be used: sexual abuse occurs where sexual acts are performed on, with or sometimes by someone who is unwilling or unable to consent to those acts, or who has been unduly pressured into consenting within an unequal relationship.

Level of Disability and Likelihood of Abuse

Martin et al. (2006) conducted a survey study to investigate whether women with disabilities are at an increased risk of physical and sexual assault compared to women without disabilities. They used data from the North Carolina Behavioral Risk Surveillance System (NC-BRFSS), a project funded by the Centers for Disease Control and Prevention and administered by the State Center for Health Statistics in Raleigh, NC. NC-BRFSS is an ongoing random-digit dial household telephone survey of a representative sample of non-institutionalized adults (18 year of age and older). In this study, 5,326 women responded to the survey questions.

The survey comprised questions about level of disability and experiences of physical and sexual assault within the past year. Regarding disability, the women were asked if they: 1) had any physical, cognitive, or emotional problems that limited their activities, 2) had trouble learning, remembering, or concentrating, 3) used devices such as a cane, walker, or wheelchair, and, 4) considered themselves to have a disability. Any woman who answered "yes" to any of these four questions was considered to have a disability while any woman who answered "no" to all four questions was considered not to have a disability. Any woman who reported having experienced physical or sexual assault within the past year was also asked about her social relationship with the perpetrator. Results showed that women who reported having a disability were not significantly more likely to report an experience of physical assault alone within the past year, but reported four times more experiences of sexual assault. Data on the perpetrator were not given for women with disabilities alone, but for the total group of women 48% of sexual assaults were committed by a person with whom the women was currently in an intimate relationship or had been in the past.

Though informative, this study likely does not provide a complete picture of the prevalence of sexual abuse among people with severe developmental disabilities,

because members of this population might be unable to answer the telephone. People with severe developmental disabilities may also lack the verbal skills necessary to report abuse by responding to queries. Thus, there may be many cases of sexual assault or abuse against people with severe developmental disabilities that cannot be detected by telephone surveys.

Casteel et al. (2008) conducted a retrospective longitudinal study that specifically compared levels of abuse among women with severe and moderate disabilities and women with no disability. These authors examined the association between the level of disability (not necessarily cognitive) and physical and sexual assault in a sample of 6,273 non-institutionalized US women as least 18 years of age. Women were considered to have a severe disability if they answered “yes” when asked whether they have a disability that significantly limits daily activities. Women considered moderately disabled answered “yes” when asked if they have a disability that moderately limits daily activities. Because level of disability was self-reported, it is likely that most severe disabilities were physical or emotional in nature, and would not be considered as cognitive or developmental disabilities. The sample was collected from the 1995–1996 National Violence Against Women survey. Results indicated that women with severe disabilities were four times more likely to be sexually assaulted than women with no reported disabilities. In addition, little difference was found between women with moderate disabilities and those reporting no disabilities. Casteel et al. concluded that their findings suggest that women with disabilities that severely limit activities of daily living are at increased risk of sexual assault. These results are consistent with those reported by Martin et al. (2006).

Perhaps unsurprisingly, children with disabilities are often victims of sexual abuse. As mentioned above, Senn (1988) reported that between 39% and 68% of female children and 16% and 30% of male children will a disability will be sexually abused before they are 18 years old. These high values suggest that children with disabilities are at elevated risk of sexual abuse. Data reported by Hershkowitz et al. (2007) are consistent with this suggestion. Those authors interviewed 40,430 alleged abuse victims in Israel (males and females 3–14 years old), 11% of which were categorized as children with minor disabilities and 1.2% of which were categorized as children with severe disabilities. The children were categorized as having a disability on the basis of psychosocial reports, documented diagnoses made by educational or welfare agencies, or formal or informal educational assessments. Each child was further classified according to level of disability based on an investigator’s assessment of the child’s functioning during an interview. Children who had difficulty participating in the interview because of diminished cognitive, behavioral, or communicative skills were considered to have a minor developmental disability. Children who had extreme difficulty during the interview process were considered to have a severe disability. The remaining children were considered as typically developing. All children were referred for investigation following a complaint of suspected abuse to the police or child protective services. All interviews conducted for this study were a part of such investigations. Results indicated that children with disabilities were more likely than their typically-developing peers to be victims of sexual abuse. Females with severe disabilities were much more likely to be victims of sexual abuse than males with severe disabilities (61.4% and 38.6%, respectively, were abused). Children with disabilities were not more likely to be victims of

physical abuse, but were more likely to experience physical abuse that resulted in bodily injury. These children were also more likely to experience abuse that involved penetration, repeated abuse, use of force, and threats. They also were more likely to fail to disclose abuse or to delay substantially the time of disclosure. Finally, as is the case with adults, children with severe developmental disabilities were at an increased risk of experiencing sexual abuse relative to children with milder disabilities.

Sadly, past research has found that the sexual abuse of people with developmental disabilities is often perpetrated by service providers. More specifically, Sobsey and Doe (1991) found that 48% of perpetrators of sexual abuse against persons with developmental disabilities were service providers. McCormack et al. (2005) conducted a 15-year review of documented cases of sexual abuse of persons with developmental disabilities who received services from a community-based agency. A similar number of males and females were victims (47% and 53%, respectively), but most perpetrators were male (94%). The type of abuse varied, with 65% of cases involving touching and masturbation and 31% involving actual or attempted penetration. The proportion of abuse case perpetrated by staff, especially multiple instances of abuse, increased substantially over the 15 years.

Taken together, studies by Casteel et al. (2008), Martin et al. (2006), and Hershkowitz et al. (2007) provide strong and consistent evidence that people with developmental disabilities are at increased risk of sexual abuse and that people with severe disabilities are at the highest risk of all. They also suggest that sexual abuse by service providers is far from rare. Obviously, abuse-prevention programs that are effective for people with severe disabilities would be of great value, including programs that foster appropriate staff conduct.

Training People with Developmental Disabilities to Avoid Sexual Abuse

Research evaluating strategies for preventing the sexual abuse of people with developmental disabilities is scarce. Most of the studies that have been conducted focus on abuse-prevention training with potential victims. Doughty and Kane (2010) recently reviewed six studies published on this topic since 1997. These studies appear to constitute the entire relevant literature. Four of them used behavioral skills training (Egomo-Helm et al. 2007; Lee and Tang 1998; Lumley et al. 1998; Miltenberger et al. 1999), two used in-situ training (Miltenberger et al. 1999; Lumley et al. 1998), one used an escape intervention (Khemka et al. 2005), and one used a cognitive decision-making curriculum (Khemka and Hickson 2000). Results of all studies were promising, although the long-term effectiveness of the interventions in participants' everyday environments was not evaluated.

Participants in all six studies exhibited developmental disabilities that ranged from mild to moderate and most participants had relatively good communication skills. Doughty and Kane (2010) speculated that, "perhaps none of the reviewed studies included participants with severe or profound intellectual disabilities, or participants with relatively poorer communication skills, because of the verbally mediated assessment and teaching procedures used" (p. 335). Determining the range of people for whom particular abuse-prevention strategies are appropriate, as well as assessing the long-term benefits of exposure to such strategies, certainly merits

attention. Nonetheless, it appears that the kinds of strategies used to date will not be appropriate for some people with severe disabilities. Interventions that focus on providing appropriate training for staff and other caregivers may benefit these individuals, although no published research has evaluated this possibility directly.

Training Staff and Other Caregivers

Although information is again limited, studies suggest that professionals who provide care for people with developmental disabilities are not well informed regarding sexual abuse in this population. For example, Furey and Kehrhahn (2000) set out to determine the knowledge base of people from public and private facilities that served individuals with developmental disabilities in four states. These authors conducted 874 surveys that included managers, supervisors, and executives. Responses to the surveys suggest that service providers lack basic knowledge about sexual abuse, including typical perpetrator characteristics and potential victims.

Staff knowledge and attitudes also were addressed by Bowman et al. (2010), who attempted to increase staff knowledge and change attitudes through a sexual abuse prevention training program that targeted staff, not clients. Their study used an assessment package that consisted of a Sexual Abuse Attitudes and Knowledge Questionnaire, the Global Perceptions Scale, and a variety of demographic information questions. Data were collected prior to and following training, which was arranged through workshops conducted at three residential and day treatment programs for children and adults with developmental disabilities.

Staff scored relatively low on both pretests and posttests on the knowledge part of the questionnaire. Moreover, staff attitudes about individuals with developmental disabilities did not change. The authors concluded that their training procedure was not effective in increasing staff knowledge regarding sexual abuse of people with developmental disabilities or their attitudes regarding this topic. Importantly, they emphasized that staff responses to a questionnaire, regardless of the knowledge or attitudes reflected in those responses, do not necessarily relate meaningfully to the risk that people in the care of those staff will be sexually abused. As they note, observation and measurement of on-site performance is necessary to demonstrate the effectiveness of staff training and future research in this area should include staff-client interactions as a dependent variable. In addition, follow-up probes are necessary to ensure that the effectiveness of the training will persist.

Professionals responsible for caring for people with developmental disabilities have a responsibility under the law to report perceived or disclosed sexual abuse. They may, however, fail to detect such abuse, especially if they are not specifically trained to do so and if the victim is unwilling or unable to reveal its occurrence, as may occur when the person has a severe disability. Burke et al. (1998) identified three categories of signs of sexual abuse (physical signs, behavioral signs, and circumstantial signs) that caregivers should monitor. Training staff and caregivers to identify such signs and to understand the procedural issues surrounding disclosure and investigation of sexual abuse could allow for appropriate medical care and follow-up mental health treatment for the victim. Additionally, training staff and caregivers shows that the organization, on an administrative level, is aware of the

problem and willing to take steps to prevent its occurrence. This could directly reduce likelihood of abuse by dissuading potential abusers. To our knowledge, however, there are no published reports of training procedures that have accomplished these invaluable outcomes.

Suggestions for Future Research

Published reports unanimously confirm that sexual assault and abuse deleteriously affect the lives of many people with developmental disabilities, and that the threat of harm is greatest for people with severe disabilities. Nevertheless, public acknowledgement of this problem does not appear to be widespread and systematic efforts to reduce the sexual abuse of people with severe cognitive and other disabilities are rare. Wacker et al. (2008) recently suggested that developmental disabilities advocacy groups should join forces with sexual assault advocacy groups to call attention to the problem and to initiate steps towards solving it. They suggest that changing the legal system to better protect people with severe cognitive impairments is one significant step, because current statutes and the way they are interpreted "stem from and perpetuate a legacy of systematic oppression including, but not limited to, the sexual exploitation and deprivation of people with cognitive impairment…Current statutes not only fail to diminish but may also enhance the risk of sexual assault to adults with cognitive disabilities" (p. 86).

Other authors have noted that negative stereotypes regarding people with intellectual disabilities and their sexuality appear to increase the likelihood of abuse and to reduce the probability that perpetrators will be accused or, if accused, found guilty in a court of law and justly sentenced (Andrews and Vernon 1993; Sobsey and Doe 1991; Nosek et al. 2001). As Wacker et al. (2008) suggest, strong public advocacy is probably a necessary stimulus for improvement. So, too, is the widespread availability of effective behavior-change interventions for reducing sexual abuse in people with severe disabilities. To date, no such interventions have been reported in the literature. They are badly needed and we encourage researchers to prioritize developing effective sexual abuse prevention strategies tailored for people with severe cognitive and other disabilities.

An obvious starting point is to ascertain whether interventions shown to be useful in teaching people with mild to moderate developmental disabilities to avoid sexual abuse (Egomo-Helm et al. 2007; Khemka and Hickson 2000; Khemka et al. 2005; Lee and Tang 1998; Lumley et al. 1998; Miltenberger et al. 1999) can be adapted for use with people with more severe disabilities. Evaluating staff-training programs that, for example, teach caregivers how to detect and report signs and symptoms of sexual abuse and to minimize the likelihood of abuse by ensuring that caregiver and client behaviors are appropriately monitored is another viable option.

Organizations should also consider incorporating an abuse-prevention model into their management system. Such a model ought to include manager oversight of direct care staff, staff training on signs and symptoms of abuse, and administration training on the steps to take when abuse is reported. Thus, a comprehensive intervention would involve: a) training all possible clients to avoid abuse and to report its occurrence; b) training all staff to identify signs of abuse and precursors to

abusive behavior (in both staff and individuals with disabilities), and c) training responsible personnel to implement the program and arranging rules and consequences to ensure that they do so.

Regardless of the kind of intervention being evaluated, researchers who study sexual abuse face formidable methodological issues, among them devising a strategy for accurately assessing whether observed changes in the behavior of potential victims, staff, or other people in the experimental setting parallel their actions in the naturalistic setting and, even more importantly, whether observed changes translate to actual reductions in sexual abuse. Though formidable, with care such obstacles can be overcome, at least to the extent that obtained results are at least *suggestive* of an intervention's practical value, and suggestive data are far better than no data at all, which is what we have at present.

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