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Caring for People with Disabilities: Prevention of Victimization

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Abstract. *This article reviews the literature that surrounds the victimization of people with disabilities. Several theoretical models are discussed in an attempt to explain the basis for the abuse. Issues affecting the work of life care planners are highlighted and specific recommendations are made to minimize the potential for abuse of individuals who are severely disabled.*

Introduction

In January of 2002, a story about Freddie Watkins appeared in the Seattle Post-Intelligencer Reporter (Foster, 2002). Freddie is a 38 year old individual with tetraplegia who was found in the basement of his home covered in his own excrement. He had severe bedsores that had penetrated his skin to the bone. His caretakers were reportedly his wife and his stepdaughter.

In May of 2001, television station Channel Five of East Boston, Massachusetts reported that Timothy Kubara was accused of assaulting 34 year old Mary Elizabeth Morrow (Caregiver Charged, 2001). Mary is autistic and lives in a group home for people with severe disabilities. Her family believes that the physical assaults had been occurring for some time. Because of her disability, she was unable to defend herself or tell anyone about the attacks. Kubara worked as a staff member of the group home.

Unfortunately, the incidence of physical violence against people with disabilities is probably much more prevalent than we would like to believe. To date, the problem of victimization of individuals with disabilities has received little attention (Sigmon & Edmonds, 2002). However, in preparing a report on victimization and disability, Sigmon and Edmonds (2002) concluded that people with disabilities are at a much greater risk of physical, sexual, or emotional abuse than the general population. Additional studies suggest that there is strong evidence that these crimes against people with disabilities are greatly underreported (Petersilia, 1997; Sanders, Creaton, Bird, & Weber, 1997).

In another review of the literature, The Roeher Institute reported that more than half of the abusers fall into one of three groups: family members, paid caregivers, or other people with disabilities in the service setting (Ticoll, 1994). The Roeher Institute also reported that the abuse takes place in the following areas: social groupings such as family or other social relationship, residential settings (homes), service settings and public places. Sobsey (1988) reports that about 25% of abusers are caregivers.

Victims of catastrophic injury are vulnerable to victimization due to the severity of their injury and their diminished or inability to defend themselves and/or report crimes. It is imperative that life care planners accept this reality, include appropriate precautions and

interventions in their plan, and prepare for ongoing case management of this very serious potential outcome of the catastrophic event.

Definition of Abuse

It is important to first define what is meant by abuse in intimate relationships. Rodenburg and Fantuzzo (1993), in developing an effective measurement tool for abuse in marriages, identified four different forms of abuse: physical, sexual, psychological, and verbal. While this typology of abuse might be sufficient in describing abuse of persons who are able-bodied, it does not fully capture the spectrum of abuse for individuals with severe disabilities. In addition to the types of abuse listed above, persons with a disability are also susceptible to forms of abuse that are unique to their disability (Saxon, Curry, Powers, Maley, Eckels, & Gross, 2001). People with disabilities may experience abuse that includes the withholding of medicine or medical care, the refusal to physically transfer from bed to chair, the denial of information, visitors, or privacy, interference with mail or other forms of communication, humiliation, "juvenalization," forcing to sell property and other forms of financial abuse.

The Department of Community Service, Province of Nova Scotia, Canada (2002, sheet 8) defines abuse and violence against people with disabilities in the following manner:

1. Physical abuse: infliction of pain and injury such as hitting, shaking, inappropriate handling, administering inappropriate medication or poisonous substances, suffocation, confinement, forced feeding and the use of restraints (tying the person to a chair or bed).
2. Sexual abuse: includes involuntary, forced sexual contact such as kissing, fondling, and intercourse. Forcing an individual to have an abortion or submit to sterilization are also considered to be forms of abuse.
3. Psychological/emotional abuse: behavior intended to control, instill fear or diminish a person's sense of self worth. This includes persistent verbal aggression, forcing the victim to do degrading things, forced confinement, social isolation, intimidation, humiliation, degradation, threats to harm the victim or others, threats to destroy pets or property, and deliberately doing things to frighten the victims such as playing with weapons. Removal of decision-making power, refusal/removal of aids necessary for mobility (wheelchair or crutches), preventing the person from communicating by restraining his/her hands, and threats to withdraw services or send the person to an institution are other examples.
4. Financial abuse: the involuntary control of a victim's financial resources, including withholding money for basic necessities such as food, clothing, medication, and transportation. As well, economic abuse can include preventing a victim from getting to work or denying access to employment altogether. Denial of the right to control one's financial affairs is abuse.
5. Neglect: failure to provide the necessities of life such as proper food, fluids, suitable clothing, safe and sanitary place of shelter, proper medical attention and personal hygiene, general care and supervision, (e.g. leaving the victim in unsafe conditions).

Theories of Abuse

Many theories have been developed in an attempt to identify causal factors of intimate abuse. Wallace (2002) grouped the predominate theories into three broad classifications: the psychiatric

model, the social-psychological model, and the sociocultural model of family violence.

In the first group of theories, the psychiatric model, domestic violence is seen as being caused by the individual mental characteristics and personality traits of the perpetrator. This model, then, explains abuse as a pathology of some sort that afflicts the abuser, such as a mental disorder or chemical dependency.

The second group of theories, the social-psychological model, focuses on external factors that could facilitate abuse by impacting the family unit. Family dynamics, stress, living arrangements, family history, and the social learning experiences of family members are examples of causal factors of violence within this group of theories.

The sociocultural theories of abuse maintain that the roles assigned to people in society play a role in the victimization of intimates. They also suggest that societal attitudes support the victimization of certain segments of society. The sociocultural model includes observations that people in society with the least power are at the highest risk of being a victim of family violence, and is sometimes referred to as the power and control model of family violence. This model usually focuses on the gender positive nature of domestic violence; women are battered much more often than are men (Bachman & Saltzman, 1995). Not coincidentally, women have much less power in contemporary society than men, and thus, are much more likely to be targets. Likewise, people with disabilities generally are seen as having less power in society (Williams, 2001) and therefore are more likely to be victims of abuse.

These three theoretical groupings, while different in many respects, all suggest that people with disabilities, in general, and those suffering from catastrophic injuries, in particular, should be considered at very high risk for abuse and maltreatment.

Abuse of people with disabilities

For many people with disabilities, abuse is part of their life. Persons with disabilities may experience violence perpetuated on them by a wide variety of persons in their lives including caregivers, family members, and intimate partners (Curry, Hassouneh-Phillips, & Johnston-Silverberg, 2001; Saxton, et al., 2001; Schaller & Lagergren-Fieberg, 1998; & Sobsey, 1995). Due to the unique vulnerability of this population, individuals are at-risk for experiencing multiple forms of victimization (Schaller & Lagergren-Fieberg, 1998).

Persons with disabilities often find themselves in systems and circumstances that significantly limit their personal freedoms, power, and choices. These limits, in combination with caregiver authority and control, place persons with severe disabilities in a uniquely vulnerable position. Gilson, Cramer, & DePoy (2001) detail the specifics of this vulnerability by identifying that persons with disabilities may be victimized by greater numbers of perpetrators (including various healthcare professionals) than other persons in the general population due to both turnover of professional helpers and exposure to multiple systems.

Thierry (1998) suggests that women with disabilities are among the most disadvantaged groups in our society, experiencing limited protection and advocacy from our healthcare systems, and often being afforded only limited access to health education, preventive medicine and healthcare interventions. This lack of systemic support places women with disabilities at a distinct disadvantage in protecting themselves against abuse. It is not surprising, therefore, that recent studies have documented the seriousness of the problem of violence against women with disabilities. For instance, Young, Nosek, Howland, Chanpong, and Rintala (1997) report that women with physically disabilities are at the same risk for physical and sexual abuse as able-bodied women but that these women experienced abuse for longer periods of time and

had fewer resources available to them for removing themselves from abusive environments. Additionally, they report that these women are at increased risk for abuse from non-family members with whom they may have close relationships with such as attendants and caregivers.

Gilson, Cramer, and DePoy (2001) found that women with disabilities experience higher rates of emotional, physical and sexual violence and that these women experience this violence for longer periods of time than women in the general population. This finding was confirmed by Young, Nosek, Howland, Chanpong, and Rintala, (1997) who found that 62% of women with disabilities indicated that they had experienced some type of abuse at some point in their lives. They further state that about half of this group had experienced physical or sexual abuse. A comprehensive review of the literature on disability and violence conducted by Schaller and Lagergren-Fieberg (1998) found that reported rates of abuse and violence toward women with disabilities varied from 33% to 83% of the population describing at least one abusive episode during their lives.

Petersilia reports that persons with developmental disabilities seem to be at very high risk for sexual abuse (2000). She explains that this increased vulnerability has several facets. People with cognitive disabilities may lack the vocabulary to report abuse, and their reports may not be believed anyway. They may have limited access to, or restrictions in the use of, resources such as telephones and transportation. They may fear loss of social contact if they report, or they may simply be unable to resist abuse.

Petersilia asserts that, as a group, people with cognitive disabilities live lives that place them in environments where abuse is likely to happen. She states that criminologists realize that when one distinct group of citizens are targeted for crime more frequently than other citizens, that group typically meets three conditions: "1) the group members are exposed more frequently to motivated offenders (proximity), 2) group members are more attractive as targets in that they afford better yield to the offender (easier sex), and 3) group members are more accessible and less defended against victimization" (pp.10-11). Of course, people with developmental disabilities meet all three of these conditions, as do many persons who have experienced catastrophic injuries.

In the larger general population, women are much more likely to be assaulted than are men (Bachman & Saltzman, 1995,), and men are at much lower risk. However, there is very little data to suggest whether men with disabilities are at a significantly lower risk for abuse than are women with disabilities. Because of similar vulnerability risks and dependency issues, men with disabilities may also be a very high risk for abuse. Unfortunately, most of the literature about abuse and disabilities has focused on women.

Implications for Life Care Planners

Life care planners should understand that their clients may be at high risk of being victimized. First, caregivers may be at high risk of developing mental health problems, including alcohol abuse, but rarely seek help for their problems (Polen & Green, 2001). Second, the intensive demands of caregiving place an incredible amount of stress on families and caregivers, and many people with catastrophic injuries may have to depend on families that never functioned well before the accident, much less after the accident. Third, people with disabilities, in general, and those with catastrophic injuries, specifically, could be seen as being much more vulnerable than are people without disabilities.

General strategies for reducing abuse for people with disabilities

Nosek, Howland, and Young (1997) point out that rehabilitation counselors and others who work with people with disabilities often feel that it is not their responsibility to screen for abuse or to intervene in client's personal lives, and they do not fully understand the degree to which abuse hinders goal attainment. They further suggest that rehabilitation professionals are not adequately trained to identify and communicate with clients about abuse and that they do not understand community resources available to victims of domestic violence.

The medical field, particularly physicians and nurses, have responded to the need for improvement in domestic violence interventions by developing a number of screening and assessment tools (Little, 2000; Sherin, Sinacore, Xo, Zitter, & Shakil, 1998; Wasson, Jette, Anderson, Johnson, Nelson, & Kilo, 2000). Unfortunately, these screening protocols rely heavily on communicative exchange between client and professional.

It has been empirically demonstrated that domestic violence training in the medical professions can improve both the behaviors and the attitudes of those who work with battered women (Maiuro, Vitaliano, Sugg, Thompson, Rivara, & Thompson, 2000). Simply training workers to routinely ask basic questions about abuse during interviews has been shown to increase the number of findings of abuse in patients (Thompson, Rivara, Thompson, Barlow, Sugg, Maiuro, & Rubanowice, 2000), and these findings might be applicable for those who work with people with disabilities.

Despite these efforts at improving the medical field's response to abuse, several barriers exist in the medical field to discourage screening. Providers may be at a loss as to what to do if disclosure of abuse occurs, and they may worry that they will offend patients if they ask about abuse. Additionally, providers cite time limitations in working with patients as well as a lack of knowledge about abuse issues (Waalen, Goodwin, Spitz, Petersen, & Saltzman, 2000). The most important consideration in screening for abuse should be safety for the victim. Gielen, O'Campo, Campbell, Schollenberger, Woods, Jones, Dienemann, Kub, & Wynne (2000) report that women, in general, and battered women, in particular, have a great deal of fear regarding screening for domestic violence by health care workers. This fear, of course, is rooted in the belief that disclosure of abuse might be revealed to the abuser, resulting in higher risk for the victim. Great care should be taken not place a suspected victim at higher risk.

Strategies for Risk Management

Sobsey (1994) maintains that the most effective way to reduce abuse risks for people with disabilities is to include them as full citizens in society. Sobsey found that, in general, home environments seem safer than other settings for persons with disabilities. However, where specialized service environments, such as group homes or institutions, are required, steps may be taken to reduce risk. Specifically, Sobsey (pp. 252-266) suggests that a risk management approach should include the following elements:

1. Design and Organization: Service delivery systems should be designed from the ground up to prevent or reduce abuse of consumers. An agency culture that does not support or allow abuse should be carefully cultivated. Human services should be an integral part of the larger community to minimize the risks associated with isolated service environments.
2. Policies and Procedures: All agencies and service delivery systems should have clear policies regarding maltreatment of consumers. Staff should completely understand

these policies and be expected to follow them. Behavior management should be accomplished through the use of non-aversive interventions rather than punitive approaches, such as punishment, restraint, or chemical intervention.

3. Recruitment and Screening: Potential staff should be carefully screened. Conviction and arrest records should always be checked, references should be contacted, applicants should be interviewed thoroughly, and a large pool of candidates to choose from is desirable.
4. Orientation and In-Service Training for Staff: This element may be the most important in eliminating abuse in the service delivery setting. Staff should be taught about abuse during orientation and in subsequent trainings in direct and explicit terms. A focus on the presence of positive attitudes towards client's rights may be more effective than a focus on negative examples of abuse and violations of those rights. They should know how to respond to abuse when they encounter it, and they should be encouraged to identify and confront their own personal feelings regarding their potential for abuse. Stress and frustration is a common response for caregivers and staff should understand the risks for abusive behavior in such work. Workers should be trained in identifying sexual abuse, and they should be prepared for the continuum of sexual behaviors found in a group setting. The environment of the facility should cultivate in staff an overall positive attitude towards people with disabilities.
5. Counseling and Support Programs: Access to counseling or a support group provides employees with opportunities to address issues that might cause them to be at higher risk of becoming abusive.
6. Supervision and Leadership: Supervisors and management should spend time in the facilities they are responsible for, interacting with staff and consumers, and they should model appropriate behavior by remaining respectful and non-abusive in their interactions with others. Leaders must remember that the care of the consumer is their primary responsibility, and they must be willing to discipline staff that mistreat consumers. Through effective communication, supervisors can gather information and assess situations in order to minimize the potential for abuse.

Recommendations for Life Care Planners

It is imperative that the life care planner be aware of the potential for abuse at the hands of both paid and unpaid caregivers. It is also appropriate that the life care planner recommends the hiring of a case manager who is aware of the risks of physical and emotional abuse and knows the signs of abuse.

Sobsey (1994, pp. 27-33) compiled a list of things to watch for in assessing for abuse, which include the following signs:

1. Physical signs of abuse include abrasions, bites, bruises, burns and scalds, coma, dental injuries, dislocations, ear injuries, eye injuries, fractures, lacerations, ligature marks, and welts.
2. Behavioral signs of abuse may include aggression, atypical attachment, disclosure, fearfulness, learning disabilities, noncompliance, regression, sleep disturbances, and withdrawal.
3. Circumstantial signs of abuse may include aggressive behavior of caregivers, alcohol or drug use, devaluing attitudes, isolation of social unit, other forms of abuse, other violence in setting, previous history of abuse.

The case manager should monitor for physical, behavioral, and circumstantial signs of abuse and initiate discussions about abuse as a regular part of their follow-up practice when making contact with the client and members of the client's family. The case manager should schedule annual medical reviews and specify that the client should be examined for signs of abuse. It should never be assumed that such an evaluation would take place; it must be clearly stated. A copy of the medical report should be directed to the case manager's attention. The physician should be knowledgeable about the prevalence of abuse towards people with disabilities, and sensitive to the risk. It is incumbent upon the case manager to educate the physician about disabilities and abuse if necessary.

Obviously, the life care plan must include funds to cover the annual medical exam. It is the authors' opinions that the prevalence and incidence of abuse of those populations typically served by life care planners dictate that plans be proactive in addressing abuse, and that sufficient funds be included in the plan to pay for appropriate attendant services. Services procured from an agency rather than individuals from the community are more likely to provide adequate oversight of staff and some level of liability for the actions of their employees, hopefully, reducing the chance of abuse. Unfortunately, hoping may not be sufficient in insuring that the client is served in an appropriate, beneficial, and abuse free manner.

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