

**VIOLENCE AND ABUSE AGAINST PEOPLE WITH DISABILITIES:
EXPERIENCES, BARRIERS AND PREVENTION STRATEGIES**

**Laurie E. Powers, Ph.D.
Mary Oswald, Ph.D.**

**Center on Self-Determination
Oregon Institute on Disability and Development
Oregon Health & Science University**

For more information, please contact Laurie Powers or Mary Oswald, OHSU Center on Self-Determination, 3608 S.E. Powell Blvd., Portland, Oregon. Mary Oswald can be reached at (503) 232-9154, ext. 126; oschwald@ohsu.edu Laurie Powers can be reached at (503) 232-9154, ext. 104; powersl@ohsu.edu

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He and I got into the verbal altercation ... so he thought he would put me in my place by throwing me up on the back of the chair, then letting me hang there. I'm on a ventilator ... I had already been off for an hour and a half, and I was getting rather winded. ... So he just left me hanging there, kept screaming at me, and I had to apologize to him ... hardly able to breath ... He really scared the hell out of me.

Man with a disability

Violence and abuse are serious problems for persons with disabilities, who are at greater risk than non-disabled persons (Brown, Stein, & Turk, 1995; Hassouneh-Phillips & Curry, 2002; Hughes, Swedlund, Petersen, & Nosek, 2001; Powers, Curry, Oschwald, Maley, Saxton, Eckels, 2002; Sobsey & Doe, 1991; Turk & Brown; 1993; Young, Nosek, Howland, & Chanpong, 1997). The social context of disability, including factors such as inaccessibility, reliance on support services, poverty and isolation, has a powerful impact on individuals' increased risk for violence. Historically, individuals with disabilities have not been considered reliable reporters of abuse nor have they been given the chance to be self-directed in many domains of their life. Traditional approaches to "protecting" people with disabilities have inadvertently kept them from accessing the tools and resources needed for protecting themselves.

What Do We Know?

Violence against women with disabilities has received far greater attention than has violence against men with disabilities. For example, The Disabled Women's Network of Canada (Riddington, 1989) surveyed 245 women; 40% experienced abuse, 12% had been raped. Spouses / ex-spouses were the most common perpetrators,

followed by strangers, parents, service providers, and dating partners. Less than half of the women reported the abuse because of their fear and dependency on the abuser. A national survey by Nosek, Howland, Rintala, Young, & Chanpong (2001) revealed similar levels of overall abuse among women with and without disabilities; 62% of both groups reported some type of lifetime abuse. Half of both groups had experienced physical or sexual abuse. However, women with disabilities reported significantly longer durations of physical and sexual abuse when compared to women without disabilities. Finally, Powers, et al., (2002) surveyed 200 women with physical and physical and cognitive disabilities: 67% of the women reported having experienced physical abuse and 53% of the women reported having experienced sexual abuse. These rates of physical and sexual abuse are approximately twice those typically found for nondisabled women (National Research Council, 1996). This information shows that abuse and violence are a problem for many women with disabilities.

I've talked to different women and met different women, women don't see emotional or verbal abuse as being abuse the way they see physical abuse. Oh, does that mean I'm abused then? He calls me a bitch every night? And now I'm starting to think I am one? Yeah, that's abuse. And you don't have to take it.

Woman with disability

Although much of the information available suggests that men with disabilities are less likely to be abused than women with disabilities (e.g., Allington, 1992; Turk & Brown, 1993; Sobsey & Doe, 1991), most research has relied on adult protective services (APS) abuse reporting information, which may under represent men who are reluctant reporters. If we look at APS reporting data for individuals who experience cognitive disabilities, where mandatory reporting is common, men and women seem to

experience similar levels of abuse. For example, in one study of physical abuse, the male to female victim ratio was found to be 56% to 44% (Marchetti & McCartney, 1990). Likewise, interviews conducted with 78 men with physical and physical and cognitive disabilities suggested that men experience similar forms of abuse as women and that most men regard abuse as unrecognized and unavoidable (Saxton, Powers, McNeff, & Curry, 2004). Preliminary findings from a survey of 275 men with physical and cognitive disabilities indicated that about 65% of the men had been physically abused while 24% of the men experienced sexual abuse in their lifetimes (Powers, McNeff, Curry, Saxton, & Elliott, 2004). Although there is much left to understand about mens' experience of violence and abuse, it appears to be a lot higher than might be assumed.

Types of Abuse

Individuals with disabilities experience forms of violence and abuse similar to those without disabilities, such as physical injury, sexual assault, emotional trauma, and financial abuse. However, persons with disabilities also face unique forms of abuse, such as disabling equipment, manipulating medications, or refusal to provide essential personal assistance. Men and women with disabilities have identified seven major categories of abusive behavior:

- Physical abuse
- Sexual abuse
- Verbal or emotional abuse
- Neglect or withholding support
- Financial abuse
- Manipulation of medications

- Destroying or disabling equipment

Mistreatment comes in many forms and may have more severe consequences for people with disabilities. Situations such as being dependent on one person for all of one's support, not having access to a telephone or a way to independently get out of the house, or being isolated from other people can increase the risk for people with disabilities who are dealing with abuse. Just as with violence against people who do not have disabilities, all of these forms of abuse involve the perpetrator exercising power and control over the victim.

Abuse by Personal Assistance Providers

Abuse by personal assistance service (PAS) providers (paid or unpaid / friends, family or formal providers) is a unique problem for many people with disabilities. We are beginning to develop an understanding of PAS abuse. For example, Nosek et al., (2001) found that 15% of women with disabilities reported sexual or physical abuse by service providers, compared to 4% of women without disabilities. Ulicny, White, Bradford and Mathews (1990) surveyed 91 users of 15 randomly selected independent living center attendant services programs. Forty percent reported financial abuse while 10% reported physical abuse.

The problem of PAS abuse has been highlighted by our research with women and men who have physical and cognitive disabilities (Saxton, Curry, Powers, Maley, Eckels & Gross, 2001; Powers et al., 2002; Powers, et al., 2004). PAS abuse reported by women included 49% having their provider arrive late or leave early, 41% having been insulted or put down, 36% having their money stolen, 14% having equipment immobilized or broken, 14% having their medication withheld, stolen or overdosed, 14%

having been physically abused, and 6% having been forced into unwanted sexual activity. PAS abuse reported by men included 44% having been insulted or put down, 34% having their provider arrive late or leave early, 14.9% having their medication stolen, 12% having checks or credit card payments forged, 10% having equipment immobilized or broken, 9% having been hit, kicked, slapped or otherwise hurt, and 8% having been forced into unwanted sexual activity.

The context of the personal assistance relationship, between the disabled person as the employer and the "employee" provider (paid or unpaid / family member, friend, or formal provider), is a complex form of employment and support. The PAS relationship often has an inherent imbalance of power and authority, and an increased chance for harm may exist if the abuse is kept hidden and the person is afraid to disclose abuse that may threaten the relationship or lead to retribution. This imbalance of power and control can be understood in the following quotes:

"You finally say, 'Okay this is it. I'm going to do whatever I can to change this marriage.' And by the way, can you bring my scooter to me so I can leave you?"

"I've had one particular attendant. She would just not listen to what I was telling her to do. And she'd want to do my routine in her own way.... I'd tell her and she'd just go ahead and do it her way. It just got to the point where we just got into it, getting into a big huge verbal argument. I used a Hoyer lift, and I thought she was going to leave me up in my Hoyer lift and completely walk out on me. Fortunately, she did not do that. She finished up, she did put me back to my chair, and then I said to her, "Leave, I never want to see you again."

The Price Paid by Individuals and Society

All victims of violence and our society pay a high price. Problems associated with exposure to violence for anyone include injury, death, depression, anxiety,

alcohol/drug use, eating disorders, sleep-disorders, stress-related symptoms, gastrointestinal problems, migraines, suicide ideation/attempts, and post-traumatic stress disorder (American Psychological Association, 1996). Persons with disabilities may face further problems that include health deterioration and inability to accomplish self-care activities required to maintain their jobs and to live independently. For example, 29% of the women with physical disabilities and cognitive disabilities in the Powers, et al study (2002) reported that PAS abuse prevented them from being employed; 64.4% said that PAS abuse prevented them from taking care of their health; and 60.9% indicated that PAS abuse prevented them from living independently. Men with disabilities reported that PAS abuse is less of a barrier to their involvement in these life areas (16% kept from employment, 23% kept from caring for their health, 16% kept from independent living) (Powers, et al., 2004). However, it is clear that abuse impedes a substantial number of men and women from living as self-sufficiently and healthy as possible.

If they're feeling angry for some reason...at you or whatever, they might set you down in your chair a little harder than normal. Or...position you in a little rougher way. And you sit there, thinking "Now, did he mean to do that?" It's really hard to distinguish. It makes you question yourself a lot.

Woman with disability

Barriers to Addressing Abuse

Individuals with disabilities and many professionals with and without disabilities increasingly recognize abuse as a major problem that creates barriers to independent living, safety, and personal well being. Women and men with disabilities have identified a variety of barriers that limit their capacities to prevent and stop abuse. These barriers

exist at the personal level and within victim and disability service systems.

Personal Barriers

Because if you ask them, a lot of them won't say anything because they're afraid. But see, if you go in there and ask them 'have you eaten today?'.... and the expression on their face will tell you if they've eaten today.

Woman with disability

Men and women with disabilities have described common and unique personal barriers to managing abuse. While most individuals are concerned that they won't be believed if they report abuse, men with disabilities and people with cognitive disabilities express particular concern. Likewise, while abuse disclosure is difficult for everyone, women report greater difficulty in naming the abuse, whereas men communicate that although they recognize abuse when it happens, they have a tendency to stay silent because it can feel emasculating to disclose. Another complex issue for men and women with disabilities is addressing abuse when the perpetrator is a family member or a friend who also provides personal assistance. Although many individuals have reported that their risk for abuse is lower when their provider is a family member or a friend, dealing with abuse when it arises in these relationships can be very difficult. Taken as a whole, the personal barriers that are the biggest impediments to addressing abuse include:

- Most people don't believe that men can be abused.
- Embarrassment and shame about disclosing abuse.
- Fear of backlash from the perpetrator.
- No trusted person to talk with about abuse.

- Complexity of managing abuse by PAS providers that are family members or friends.
- Fear of not being believed or considered a credible reporter of abuse.
- Fear of involving police or adult protective services who may take control and disregard the individual's knowledge of the situation, factors that must be considered and the individual's preferences for addressing the problem.

Victims' Services

As part of the community, I think we need to make our shelters for women more accessible and more inviting. Offer a lot more training to people who run the shelters, what the needs are for somebody with a disability. If somebody went into a shelter, I know that a lot of their needs, even if the people were very helpful, could not be met by somebody at the shelter because they haven't gotten the training to know how to do that. Know how to do a feeding tube, how to work with a catheter...all the kinds of things that women with disabilities sometimes need. When I was on staff with the shelter, we would not have been able to assist somebody like you or even myself now.

Social service providers and health care personnel may not fully understand the unique situations that place individuals with disabilities at increased risk for abuse and mistreatment or may not be aware of the system barriers that make addressing abuse particularly complex. As we begin to understand the nature of the individual's personal situation, and the complex and often confusing social context in which the person navigates in order to find quality services, accessibility means more than simply building a ramp to the doorway or placing handrails in the bathroom. Men and women with disabilities have identified several specific barriers in victims' services that impede their access to truly accessible, effective and high quality abuse prevention and management. Key barriers include:

- Lack of knowledge of individuals with disabilities about victim's services available in

the community (crisis lines, domestic violence shelters, sexual assault programs; support groups).

- Most victims' services are not set up for men.
- Lack of accessible shelters or temporary housing (physical, sensory, cognitive and communication accessibility).
- Lack of adequately trained help in shelters or lack of specialized equipment.
- Lack of routine abuse and violence screening for people with disabilities.
- The police and community programs do not understand the unique issues affecting people with disabilities.

Disability Services

Abuse of people with disabilities is a systemic process... with little or nothing to do with the individuals involved... it's the way we treat people with disabilities and care providers ... neither are valued in our culture.

Man with Disability

Men and women with disabilities consistently highlight barriers to violence prevention and management that are inherent in the way disability services are designed and implemented. Major problems relate to a lack of respect, acknowledgement and control that many individuals report in their interactions with disability service agencies, including:

- Disability agencies don't listen or take individual's concerns seriously.
- Agencies don't assist individuals to screen for abuse or proactively offer help with abuse.
- Reporting abuse may lead to agency intrusion in many areas of an individual's life

and disregard for the individual's privacy.

- Reporting abuse may lead to losing independence, like going into a group home or nursing home.
- Reporting abuse may lead to losing custody of children because the person with disability is not considered capable of keeping children safe.

Personal Assistance Services

My husband is my primary care giver and he needs a break, and so I phone up and say I need help. And the follow-through takes weeks and weeks and weeks. Meanwhile, we're just bouncing off the walls. We need help soon. Like next week. We can't wait three months for the whole process to happen. So getting, once again, being able to access some other kind of help would really make a difference.

Woman with disability

Like when you have a bowel movement in your pants or in the bed... to ask someone to help you get cleaned up if they are only going to get six, seven bucks an hour.

Man with disability

Lack of availability of PAS providers and poor working conditions are consistently emphasized by women and men with disabilities as being critical impediments to dealing with abuse. In many cases, these barriers are considered the most fundamental problems that need to be addressed if conditions are going to be present that make it possible for individuals to prevent and manage abuse. Major PAS-related barriers include:

- Low wages and benefits for PAS providers.
- Shortage of qualified, dependable PAS providers.
- Emergency PAS providers are not available to come into the home if the abusive

perpetrator is removed.

- Burnout among PAS providers.
- Lack of knowledge about recruiting, training and managing PAS providers.
- Lack of control over choosing, paying, managing or firing PAS providers.

Strategies to Prevent and Stop Violence and Abuse

Studies like this are very helpful, [but] in the wrong hands they could potentially make it look like, 'We need to jump in there and protect these poor little crippled people'.... We have to be careful that this isn't misinterpreted by some well-meaning legislator... and used against us... you know, try to limit and tell us who we can and who we can't have work for us.

Man with disability

Our knowledge about the experience of violence and abuse by people with disabilities, gained from research, adult protective services sources and directly from individuals with disabilities, suggests that there are key strategies for promoting abuse prevention and management. A few key points deserve highlighting. First, as related in the above quote, our historical tendency in addressing abuse has been to manage the victim by limiting his or her control over life and support options. However, knowledge emerging from both violence research and investigations of outcomes associated with person-directed services documents that individuals are generally best able to maintain their safety when they control their services and supports (Benjamin, Matthias, Franke, Mills, Hasenfeld, Matras, Park, Stoddard, & Kraus, 1998; Foster, Brown, Carlson, Phillips, & Schore, 2001; Foster, Brown, Phillips, Schore, & Carlson, 2003; Powers, et al., 2002; Powers, et al., 2004; Saxton, et al., 2001).

The second point that must be emphasized is the critical importance of assisting people with disabilities to build and exercise their capacities to prevent, identify, and

manage violence and abuse. Most of our current resources in this area are directed toward training agency providers and protective services professionals to recognize abuse and to intervene to protect victims. Professional development should not be ignored. However, we must shift from protection-focused approaches that aim most of the resources toward building professional's knowledge and intervention capacities to empowerment-focused approaches that direct substantial resources toward (a) providing individuals with disabilities with information and tools that they need to prevent and stop abuse, (b) linking them to support from peers, advocates and professionals that they can trust to assist them; and (c) proactively communicating that persons with disabilities have a right to be safe, that experiencing violence or abuse is neither their fault nor a sign of incompetence, and that they can manage abuse in their lives by trusting themselves and using their tools and supports.

A third point is the importance of enhancing the capacities of community-based, victims' services agencies and police departments to serve individuals with disabilities. Most shelters, sexual assault and crisis programs struggle with accessibility and serving persons with disabilities. As increasing numbers of individuals with disabilities live independently or with support in their communities, it is essential that victims' service agencies and the police become accessible and responsive to the needs of persons with disabilities. It is also critical that disability service organizations learn from the expertise of victims' services programs that have a history of approaching the problem of violence from an empowerment and social justice perspective.

The final overarching point is how essential it is that we design systems of support that make it possible for individuals to access and use resources that will keep

them safe. The clearest area of need is PAS payment and benefit rules that, in many cases, prevent individuals from having the capacity to attract and keep qualified providers. The current reality is that many PAS providers that individuals with disabilities are able to hire bring with them histories of poverty, personal victimization or victimization of others, and life instability that provide fertile ground for power and control imbalance and abuse to occur. As a result, many individuals don't want to take a chance in hiring providers because, "The devil that you know is better than the devil that you don't know." This situation, along with lack of access to timely PAS emergency and respite services, places strain on individuals and their family members and friends who are trying to manage the person's needs without other support options. If they are to have a chance to prevent and stop violence in their lives, individuals with disabilities who use PAS must be able to offer competitive wages and benefits so they can have viable options for support providers.

Specific Strategies for Addressing Violence and Abuse

Given these overarching points, there is growing evidence and agreement about specific strategies for assisting individuals with disabilities to prevent and stop violence.

- Encourage individuals to have multiple personal assistance service providers.
- Make back-up emergency personal assistance providers available to all individuals with disabilities who use PAS (paid / unpaid, family member / friend / formal provider).
- Allow individuals to choose who provides their personal assistance services.
- Make it possible for individuals to pay their personal assistance providers at a competitive wage and to offer benefits.

- Encourage and assist individuals to screen for abuse.
- Conduct cross-training activities and encourage the establishment of protocols and agreements that assist victims' service organizations and the police to increase their accessibility, that increase the capacities of community disability organizations to assist individuals with abuse and violence, and that build linkages among violence, criminal justice and disability organizations and agencies.
- Involving centers for independent living, self-advocacy organizations, psychiatric consumer / survivor drop-in centers and other peer-based groups in violence education, screening and support activities.
- Provide every individual with disability with information about violence and sexual assault advocates and support groups, and help them to connect to these groups, as they desire.
- Provide assurances that a person will not be placed in a group home or institution or have their children or pets taken away if abuse is disclosed.
- Provide a 24-hour crisis line for individuals to talk with an advocate experienced in disability and victim services, and to get assistance with safety planning.
- Establish emergency transportation services that individuals can call upon.
- Establish emergency child and pet care services that individuals can call upon.
- Establish emergency interpreter services that individuals, police and community organizations can call upon.
- Give all PAS users information and training about safely managing personal assistants and dealing with abuse, including:
 - Interviewing and selecting PAS providers;

- Making the assistants responsibilities clear in a job description;
 - Doing regular performance evaluations;
 - Communication strategies and maintaining relationship boundaries; and
 - Dealing with abuse by family and friends.
- Provide training for all PAS providers in ways to identify and deal with abuse.
 - Make it possible for individuals with disabilities to access information about the prior employment of and complaints against personal assistants.
 - Provide individuals with disabilities with an abuse tool kit that includes items such as information about what behavior is okay and not okay and validation that it is the person's right to be safe; self-administered abuse screening tools; a wallet card with emergency phone numbers; and tips for safety planning.
 - Encourage individuals to have their checks direct deposited into an account in their name.
 - Provide individuals with disabilities with assistance to communicate with the police and the district attorney's office, to get restraining orders, to deal with perpetrators who violate restraining orders and to prepare for testifying at the grand jury or trial.
 - Make it possible for individuals to easily change their representative payee.
 - Ensure that all individuals with disabilities have an accessible phone or alert button that they can use independently anywhere in the home.

This is an extensive list and establishing these practices and policies will take a long-term, concerted commitment on the part of state and local disability, violence and criminal justice organizations. The secret is out: People with disabilities are experiencing abuse and violence and there are not effective approaches currently in

place to adequately assist them to manage the problem. Many of the solutions to the problem are known: Fundamentally, we must provide individuals with the tools, supports and resources that empower them to control their lives and respond to the abuse they face. We must move forward in enabling persons with disabilities to claim their right to safety.

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