

Recognizing and Interrupting Abuse of Adults with Disabilities

Sadly, people with disabilities get abused, sometimes at the hands of people who help or care for them. Care providers and personal assistants, including family members and service providers (paid or unpaid) can be abusive. When abuse occurs, a disabled person's personal health, safety and emotional well-being may be at risk, along with their ability to engage in daily life activities.

Who uses help or Personal Assistance Service (PAS)?

10 million disabled and elderly people in the United States use personal assistance services (PAS). PAS is one or more people helping a disabled person with tasks that they would do for themselves if they did not have a disability.

Who provides personal assistance service (PAS) to people with disabilities?

79% receive PAS services from unpaid, informal providers.

11% receive a combination of paid, formal services and informal services.

10% receive exclusively formal, paid services.

(Rutgers University Bureau of Economic Research, 1999).

What is Abuse?

Abuse or mistreatment of a disabled person is any behavior that is unwanted, hurtful, inappropriate, neglectful, frightening, insulting, or demeaning. It includes physical, sexual, verbal, emotional or financial mistreatment by anyone in a "helping" role.

Types of Abuse

Does a family member, attendant, or helper:

- Get into personal stuff without permission?
- Yell, scream, threaten or say insulting things? Make negative comments about the person's disability?
- Steal money, checks, credit cards, medication, or other personal belongings?
- Show up for work drunk or high?
- Neglect or ignore needs or withhold medication?
- Pressure a person to eat fast or go to bed early so he or she can leave?
- Prevent a person from controlling his or her wheelchair, phone or other equipment?
- Control where someone goes, what they do, who they can see?
- Gossip, threaten, blackmail or manipulate?

- Listen to and believe someone who shares that they are uncomfortable or unhappy with their care.
- Do background checks on employees.
- Have a plan for backup care in the event of caregiver burnout or illness.
- Make sure the disabled person does not feel forced to keep a caregiver who is abusive.
- Know that many people with disabilities are fully capable of managing their own personal assistance including hiring, training, supervising, and firing their own providers. Offer support through challenging times in the PAS relationships. Be someone they want to talk to about disability and PAS.
- Allow the disabled person a "reasonable right to risk" independent living. Overprotection can be abusive too.

For Service Providers and Family Members:

- Give clear instructions to providers about what you need.
- Expect to listen and to be listened to and respected by providers.
- Speak up if you are unhappy with your care.
- Learn about community resources.
- Talk to other people with disabilities who use assistance.
- Do criminal background checks on people you hire.
- Have locks that can be easily changed.
- Secure finances and banking systems to protect against theft.
- Don't put up with abuse – get help!

For people with disabilities:

Tips to Reduce Abuse

- Disabled people are sometimes disrespected and discriminated against in our society.
- Disabled people may not be believed or may have difficulty telling someone they are being abused because of their disability.
- Services and resources may not meet their needs.
- Lack of choice of providers so that someone who is not qualified is used.
- Low wages for PAS workers mean fewer qualified people working and staying in the field.
- Blaming the person or their disability for things that go wrong or are difficult.
- Power struggles with a provider.

Both societal and interpersonal factors:

What Contributes to Abuse?

- Hit, kick, slap, or hurt the person in any way, including rough handling?
- Pressure or touch someone sexually in unwanted ways?
- Keep a person from being as healthy or independent as he or she could be?

- Unnecessary institutionalization is illegal under the Americans with Disabilities Act. Disabled people who can manage their own care with reasonable support are legally entitled to Independent Living.

How to Help Someone Being Abused

If you suspect a person is being mistreated:

- Approach the person alone in a relaxed setting (a confidential, safe space).
- Stay calm, don't panic.
- Raise the issue by expressing your concern for their safety and well-being.
- Respect their right to autonomy and self-direction, and affirm their competence and ability to live independently and with self-direction.
- Offer to support this individual in handling the situation in his or her own way. Your primary resources include good listening, information about abuse prevention, and referral to community resources.
- Offer to brainstorm resources, including different PAS support until the abusive situation is remedied.
- Pressuring someone to act quickly, or a patronizing attitude, may undermine trust in you. You need to be patient to allow the individual to learn to take control of his or her own situation for the long range and develop new avenues of support. You may be challenged to modify your own standards of care, in consideration of his or her right to autonomy.

If you are concerned for someone's immediate physical safety or survival:

- If the individual appears unwilling or unable to take action on their own, or if the individual has a significant cognitive disability or dementia, you may need to contact the police or adult protective services without the individual's consent.

If you are a mandated reporter, you are required by law to report an abusive situation. Certain professionals are required by law because of their job or role to report suspected or existing abuse.

- Be aware that immediate removal of a PAS provider with no alternative plan may threaten a disabled person's survival.
- Check out your own thinking with skilled resource people who have knowledge of resources for the disabled community.

