



Office of Developmental Primary Care

Improving outcomes for people with developmental disabilities

Abuse Against People with Mental and/or Developmental Disabilities: Physical, Sexual and Verbal Abuse in Institutional or Community Settings

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Nothing About Us Without Us!

I consulted a number of disabled friends about what I should talk about today. They all started talking about experiences with professionals and therapeutic services. Communication barriers between professionals and people with psychiatric and developmental disabilities can lead to mistreatment. A basic principle of disability rights is nothing about us, without us. People with disabilities need to be at the table when anything that impacts us is being discussed. People with disabilities need to be part of the solution, to lead policy discussions, and to be full partners in care.

Let me give you some examples:

- A non-verbal patient was walking up to people and punching them in the chest. This was his presentation of heart pain. Instead of getting a work up for heart disease, he got medicated for aggressive behavior.
- A non-verbal patient couldn't be discharged from the hospital because he wasn't eating. The reason he wasn't eating is that he needs someone to cut up his food. But nobody took a history of his functional needs, so a feeding tube was placed instead.
- A woman with an intellectual disability who uses a wheelchair nearly died of cervical cancer because her doctor didn't ask about sex. Her doctor assumed she didn't need a pap smear.
- A child is being sexually abused. Her communication device has vocabulary to request food and games—but no vocabulary to protest, set boundaries or communicate that she is being mistreated.

- Police use a taser on a Deaf man, because he didn't respond to a verbal command.
- A man with a psychiatric disability is excluded from a meeting where his doctors and family discuss placing him in a residential program.
- A person with a disability develops pneumonia. He feels pressured to choose comfort care instead of treatment because his doctors feel he has suffered enough and antibiotics won't cure his disability.
- A woman is brought to the psychiatric emergency room where she is separated from her supporter. She gets scared and agitated because she can't communicate, and is treated with physical and chemical restraint.
- A person with a speech impairment and movement disorder goes to the emergency room repeatedly for a serious wound infection. But, he never gets examined because the emergency room staff assume he is drunk.

There are simple things we can do to prevent these kinds of tragedies. Here are my ten tips:

First, speak directly to patients. All people communicate. All behavior is communication. It's our job to figure out how people communicate best and to support that. Observe carefully. Listen. Give time, a peaceful environment, and tools.

Second, presume competence. Assume there is a good reason why people do what they do and that and they have a right to be included in decisions that impact them. That means giving access information and education as well as support for people to make their own decisions.

Third, give people the tools to communicate about mistreatment. No matter how profound their disability, all people need a way to communicate when they are being mistreated. Sometimes this skill takes time, training and creativity to teach. Start early. Repeat often. Developing the tools and skills to communicate about mistreatment, boundaries and choices should begin on the first day of early intervention.

Fourth, teach people to set boundaries and protest. It isn't our job to make people calm and compliant in the context of unacceptable circumstances. It is to help people maximize their potential and to participate fully. Compliance training is a set up for abuse. Compliance based behavioral treatments are often cited by self-advocates as traumatic experiences.

Fifth, train families and professionals. People with disabilities aren't the only ones who need training. We need to teach others how to listen and respond. Communication is a two-way street. How we listen is as important as how our communication partners express themselves. Put people with disabilities in charge of developing the curriculum.

Sixth, take all complaints about mistreatment seriously. Investigate them, and protect people from the accused during that process. Even if it is clear that no abuse happened, following protocol teaches that complaints of abuse lead to appropriate action.

Seventh, give people opportunities to try and fail. That is how we learn. This should be done when the stakes are low, so that people have experience with natural consequences when the stakes are higher.

Eighth, get a history of baseline function. In people with communication challenges, illness presents as a change in behavior or function. If we don't know a person's baseline, we won't recognize that there has been a change.

Ninth, respect personal boundaries. Offer assistance, but wait for a response and instructions before acting. Treat assistive devices such as wheelchairs and communication devices as personal space.

Tenth, give people access to their chosen advocates and supporters. Many people need support to communicate and to make decisions. Too often, we separate people from their support when they need it the most such as when they are in crisis or transition. This leads to errors, violations of autonomy, and misunderstanding. It is dangerous.

On this last point, I want to highlight the leadership of the Autistic Self Advocacy Network. They have drafted model, state legislation to allow people with disabilities to designate a supporter to assist with communication and decision-making. Like a Power of Attorney for health care, this legislation would enable an advocate to access confidential information in order to provide support and advocacy. However, unlike a Power of Attorney or Conservatorship, it doesn't transfer decision-making to another person. It is voluntary and less bureaucratic than other solutions. It protects clinicians who respect the patient/supporter relationship and decisions. This is part of what we need to improve communication between people with disabilities and professionals, and to make self-determination work. I hope California will enact this legislation.

AN ACT RELATING TO THE RECOGNITION OF A SUPPORTED HEALTH CARE DECISION-MAKING AGREEMENT FOR ADULTS WITH DISABILITIES <http://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-Supported-Decisionmaking-Model-Legislature.pdf>; <http://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-Q-and-A-on-model-legislature.pdf>

There are many resources on the Office of Developmental Primary Care's website to help professionals, families and self-advocates work together more effectively. <http://odpc.ucsf.edu>. Safety and communication go hand-in-hand.