



## Quarterly E-Newsletter

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### **Communication Issues for Women with Cognitive and Other Disabilities that Affect Verbal Communication<sup>1</sup>**

In 1990, the Americans with Disabilities Act (ADA) was passed to address discrimination faced by people with disabilities. Like other pieces of civil rights legislation, choice, equal opportunity, empowerment and equal access are at the heart of the ADA. Yet for many women with disabilities (or women who have children with disabilities), barriers to accessing domestic violence services and programs remain, especially barriers involving effective communication.

Providing effective advocacy support to a victim/survivor of domestic violence requires trust. Miscommunication or lack of communication altogether can pose significant barriers to an effective and trustworthy advocacy relationship. This article describes some of the communication barriers an advocate might encounter when working with clients with cognitive disabilities or other disabilities that affect verbal communication.

Use of the term **cognitive disability** means that to some degree a person has difficulty learning in all areas of her life. The diagnosis is generally determined as a lower measure of intelligence when compared to others of the same chronological age. Some of the primary difficulties for people with cognitive disabilities might be best understood as the problem of not noticing and remembering which details are the most relevant, and challenges in communicating with others unfamiliar with them.

Part of ensuring equal access for women victims with disabilities is ensuring effective communication. Fortunately, you probably already have good listening skills and an understanding that abuse has many faces. There are some basic concepts to keep in mind regarding effective communication. Assure the woman that she did nothing wrong and that you are glad that she came for help. This affirmation may need to be repeated more than once or communicated using terms that are more understandable for the woman. Because of past experience many people with developmental disabilities expect to “get in trouble” for things they do or say because it was labeled “inappropriate” or felt troublesome for the family member or support person to hear.

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<sup>1</sup> Excerpted from Wisconsin's Violence Against Women with Disabilities Project's publication, Accessibility Guide for Domestic Violence and Sexual Assault Service Providers (April 2004).

*Often, a woman knows she has a disability, so do not be afraid to ask her politely about what types of accommodations are needed and what she needs to communicate effectively.*

This question acknowledges that many women with disabilities know what is most helpful for them in order to get their needs met.

Be clear about who you are and why you are asking her questions. Explain your role: “I’m a advocate who helps people after bad things have happened to them.” Then, develop a rapport with the woman. Spend some time talking with her about non-abuse related topics. This rapport building gives you a feel for how she talks and also helps you understand any speech impediments, body language, or substitution for concepts the woman uses, such as saying “911” to mean “police.”

It is common for people with developmental disabilities to possess better receptive language than verbal language. A woman with cerebral palsy, for instance, may look or sound in a way that makes you think she has a cognitive disability, when she may not. On the other hand, many women, especially those with mild disabilities, know they have a disability and want others to think they understand everything. They may possess very good verbal and social skills, but still not completely understand the entire content of what you are saying or what the implications of it are.

***Practice Tip:***

- There is no “correct” way to speak with women who have cognitive disabilities and you certainly don’t have to be an “expert” to do it. If you follow a couple of basic ideas, you need not worry about making any serious mistakes. After all, they are women seeking your assistance, and as with every woman you assist, you figure out how best to ensure effective communication exists when conversing with each other.*
- Above all, be respectful to the person. Like other women with whom you work, a woman with a disability has been traumatized. She may have a lifetime of family and caregivers who have not believed her when she reported things that are uncomfortable for them to hear.*
- Allow yourself enough time. Communicating with a woman who has a cognitive disability may take roughly twice as long as with a woman who does not. If you are patient and thoughtful, you will usually understand what the woman is trying to say and be able to speak to her in a way that she understands.*

Sometimes a woman with a cognitive disability may come to you with a family member or staff person who helps her with daily living skills. The person might have an opinion about the woman’s situation, ability level, or even veracity. That information may color your response to the victim. Ward off too much “pre-information” about the woman, just as you would honor the

confidentiality of any other victim. If the woman who is seeking help is present and agrees to have someone with “background knowledge” fill you in, then an exception to find out how the victim communicates may be warranted.

## **Some Common Myths and Stereotypes that Impact Communication**

Understand that no matter how well-intentioned you are, you will bring your own biases and misconceptions about people with developmental disabilities and abuse to your work.

**Myth:** Sexual abuse of people with developmental disabilities doesn’t happen because they are undesirable or perceived to be vulnerable.

**Reality:** *Among adults who have developmental disabilities, as many as 83% of females and 32% of males are victims of sexual assault.<sup>2</sup>*

**Myth:** People with developmental disabilities can’t understand what’s happening to them, feel no pain, are too disabled to know or care or even if they did, it wouldn’t make any difference to them.

**Reality:** *People who have been sexually or physically assaulted often will relay in poignant detail the fear and pain they felt. Even people who do not communicate through speech frequently show physical and behavioral signs of trauma after an assault.*

Often people with developmental disabilities are expected to be compliant with what family or caregivers ask of them. They are not encouraged to say “no,” or follow their own instincts or desires in many situations. In fact, their “gut feeling” may have been discounted or overridden so many times that they may no longer be able to use this to detect danger. This contributes greatly to the ability of perpetrators to successfully sexually or physically abuse people with developmental disabilities. In many police interviews, the interviewer will ask the victim/survivor why they complied with whatever act the perpetrator requested. Invariably, the person says, “Because he told me to.” No threat, no secret, no weapon.

“Where, what, who” concepts are often the easiest for people with cognitive disabilities to understand. “How” is more difficult. “When” is the most difficult. Many people with developmental disabilities cannot tell time or sequence events. It is a myth that because of the developmental disability, a person cannot tell the truth or is one to fabricate stories. Sometimes an inability to understand time sequences or use of verbal language may make it seem like the person isn’t being truthful. Help the woman figure out time sequences by associating things.

### ***For example:***

- ♦ ***“What was on the television when that happened?”***
- ♦ ***“Was that before or after your birthday?”***

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<sup>2</sup> Johnson, I., Sigler, R. “Forced Sexual Intercourse Among Intimates,” *Journal of Interpersonal Violence*. 15(1) (2000).

- *“Is that the day you visited your parents?”*
- *“Was it dark outside?”*
- *“Were there leaves on the trees?”*

To verify that you are communicating adequately or effectively, you may be tempted to ask the woman, “Do you understand?” The answer will invariably be “yes.” You feel satisfied that you have conversed effectively and have even verified this with the woman. In fact, you have only succeeded in relaying to the woman that you *want* her to understand! Try a different way, e.g., “Can you tell me in your own words what we have just talked about?”

***Practice Tip:***

*Be aware of your own body language, tone of voice, and facial expression. Even people who are not skilled with language will often pick up on your mood or affect. Because many people are taught to be compliant, they may also want to please you or say what they think is the “right” answer. If you ask a question and are giving signs of what you want or think you will hear, you will probably get that response.*

**Case Example: Concrete Thinking Processes**

**Keep it simple! One of the most difficult things to do when speaking to a person with a developmental disability is to make language uncomplicated. This does not mean talking baby talk or shouting at the person. It means using simple words and analyzing if they may have another meaning. It may be tempting for you to use the jargon of your profession, explain legal concepts in technical terms, or talk on and on to “make things clearer.”**

**In an interview with a woman who had been sexually assaulted, the detective said “Let’s go back to the time he came in the room.” Each time he said this, the woman panicked and said, “I don’t want to go back!” What do you think would have worked better? Another woman who has autism is a very concrete thinker (e.g., what you say is exactly how she interprets it). The attorney asked her, “After the assault, did you drive away in his car?” (She had previously testified that the man drove her back to the bus stop after the assault.) She said, “No.” Why do you think she said this?**

Many people with developmental disabilities do not read or do not fully understand what they read. Giving a woman written materials without helping her understand them might be of little use to her. She probably will not volunteer that she cannot read.

***Practice Tips:***

*Some other strategies to ensure effective and accessible communication include the following:*

- *Talk directly to the woman at eye level.*

- *Speak at a normal volume.*
- *Ask one thing at a time and wait for the answer.*
- *Give the woman time to process the information. Be patient.*
- *Don't complete the woman's sentences or guess what she is about to say.*
- *Be repetitious. Ask question in a different way. Give examples.*
- *If you are having difficulty understanding what the woman is saying, ask her to repeat herself, e.g., "Could you help me by slowing down?"*
- *Keep the counseling or other type of session to the limit of the woman's attention span.*
- *The woman will show you if she is uncomfortable talking to you about the situation. Most people with developmental disabilities have had their privacy invaded many times. Honor her need to talk or her need for silence.*

It is always best if you can communicate directly with the woman who has a developmental disability. However, if you feel the woman is not comfortable talking to you alone (be sure you show her that *you* are comfortable talking to her!), has speech that is difficult for you to understand, or needs assistance in other ways to communicate with you, you may need a helper. Find out if the victim is connected to a disability or other social service agency or has a friend, advocate, or other person whom she trusts. If she identifies someone, you will have to verify that this trusted other is not the abuser. If the victim then agrees to involve a trusted other, use this person to assist you in the interview or provide you with information. The helper will only be valuable if she/he understands the way the woman communicates. Just because she/he works with the woman doesn't mean she/he is the best at communicating with her.

Define the role of the person who is helping in the presence of the woman and be sure that is acceptable to her, e.g., "We would like you to help us if I have any problems understanding Jane or she does not understand me. Jane and I have discussed this and she agrees to this. If I ask you or you see we are stuck, please tell me what she has said or tell her what I have said. Right now we are not interested in your opinion or any other information about it." Always talk directly to the woman, not to the person who is assisting, e.g., avoid saying, "Ask Jane how she is feeling." Be sure the person is not speaking for the woman or exhibiting power and control over the situation.

As with some of the other victims with whom you work, a woman with a developmental disability may get stuck on one thought. You might notice signs of distress or inattention or she may repeat the same thing over and over again. This can happen when something that has been said either reminds her of something else or she does not understand what you are saying. Speaking further will likely be futile until you have ascertained what the block is. The most effective way to do this is just by asking her what she is thinking.

### **Case Example: Checking In**

**While being prepped by the Assistant District Attorney to testify at a preliminary hearing, a woman began rocking back and forth with a distressed look on her face. The Assistant District Attorney talked louder and used bigger words in an effort to convey information. When someone finally asked what she was thinking about, the**

**woman said, “I don’t want to be in trouble.” The courthouse had reminded her of the terrible time in her life when she had lost the custody of her children, and she thought something bad was going to happen again.**

There can be some difficult issues in sorting through abuse with women with developmental disabilities. Sometimes you may think that a woman is lying or changing her story. While there are occasional false reports from women with developmental disabilities, just as there are from the other women with whom you work, this perception also can be due to other factors. Frequently people with developmental disabilities are not provided sexuality education and lack names for intimate body parts and functions. The woman may get confused about the details of a situation. This confusion may be the result of a jumbled memory, having difficulty with certain language skills, anxiety about the situation, or an inability or lack of knowledge about how to tell time accurately. A woman may be able to tell you the details of abuse, but not be able to tell you that the abuse happened 20 years ago rather than last week and involved her now deceased father. You will have to use some good detective skills to sort through this by asking her questions about place, time, people, etc. For example, “Where were you living when that happened?”

Fabrication, if it does exist, could be due to psychological issues or an understanding from past experience that this is what it takes for someone to listen to her. As with women without disabilities, some women with cognitive disabilities have reported real abuse in the past which has not been believed.

### **Communication with Women who do not Communicate Verbally**

There are some additional communication barriers that arise when working with women who do not communicate verbally. Although these situations might cause you to feel inadequate in your skills to assist women who communicate non-verbally, there are strategies you could employ to help understand the circumstances she is experiencing.

#### ***Practice Tips:***

#### ***Tips for communicating with women who have a cognitive disability and are non-verbal or are hard of hearing or Deaf:***

- ***Everyone communicates in some way, even through behavior. This behavior may be the key to learning about the abuse.***
- ***The victim may use sign language, an interpreter, a communication board, a computerized device (e.g., a Dynavox), pictures, props, maps, drawing, writing, pointing, nodding, hand/feet movements, eye-blinking, hand-squeezing, or head nodding to communicate.***
- ***You may need to ask “yes” and “no” questions to build your understanding of what she is communicating to you. Try asking questions that have one answer, instead of asking about several different issues at once. This method reduces confusion and ensures effective communication.***
- ***Observe the victim’s reactions to caregivers, family members, and others to see what she may be feeling. Watch her body language.***

## **Communication Issues for Women with Psychiatric Disabilities**

Women labeled or diagnosed as having a psychiatric disability carry with them an enormous social stigma; they frequently are misperceived as violent, manipulative, and delusional. This stigma may have permeated your agency and its work with women with psychiatric disabilities. It is necessary to acknowledge this stigma because it likely affects your interactions and communications with women who have psychiatric diagnoses. Since domestic violence and sexual assault agencies must ensure effective communication with a person with a disability who seeks your services, keep in mind that this requirement also applies to women with psychiatric disabilities.

As with any woman who has experienced domestic violence, sexual assault or stalking, a victim/survivor feels an overwhelming sense of emotional distress. For many women with psychiatric disabilities, this increased stress exacerbates symptoms they experience due to their psychiatric disability. As a result, meaningful, respectful and effective communication might be hindered.

Building rapport and trust with the woman is an important first step. Because many women with psychiatric disabilities have been labeled negatively and stigmatized, it might take longer to build the trust needed to communicate effectively, and ultimately provide the services and support the woman needs and wants. Learn from her what environment would be most conducive to have a conversation. For example, some women might feel threatened if you meet in a small room with the door closed. Other women might have trouble focusing on the conversation if there is too much distraction around them, such as phones ringing, people talking outside of the door, etc.

Because many women with psychiatric disabilities have been placed on medications, there might be communication issues that result from medication side effects. For example, a woman might need water to drink because her medication causes extreme dry mouth, resulting in difficulty talking. Another side effect with some medications is difficulty concentrating or processing information. These issues are not only the result of medication side effects, but also could be a symptom of a woman's psychiatric disability.

If concentration difficulties arise, ask the woman whether or not it might be helpful to take short breaks, or find out from her specifically what would be most helpful. Sometimes concentration difficulties lead you to feel that the person is "going off on tangents." Respectfully explore with her how the issues she raises might relate to her needs for services. You might predetermine that these issues are irrelevant until you learn from her how they, in fact, are pertinent. If after listening thoroughly you feel that the conversation has strayed from addressing sexual assault, domestic violence and the services you have to offer, bring the person back to the issue you both started to address. It might be helpful to say, "I appreciate you sharing that with me. To make sure that I answer any questions or provide any assistance related to why you are here today, I would like us to focus on ...."

*Practice Tips:*

*If a woman you are working with seems to have difficulty processing information, you have a responsibility to clarify what you are communicating.*

- *Ask her what would be helpful or not helpful to the conversation, such as meeting in the morning or later in the afternoon or writing down appointments or options you are discussing.*
- *Encourage her to state back to you her understanding of the information you are conveying to her. This strategy helps ensure that you are on the “same page.”*
- *If her situation is complex, break it down into smaller, more manageable parts. Inquire which part she would like to address first.*
- *Find out if it’s helpful to write things down or audiotape information for her to review and consider at a later time.*
- *Above all, inquire if she feels safe, has a place to live and food to eat. If she needs assistance in any of these areas, work with her to secure what is necessary to survive safely.*

As with all women, there is no “correct way” to ensure effective communication with a woman who has a psychiatric disability. Yet, remember that **she has come to you for assistance for violence related issues, not mental health ones**. As a result, take your cues from her and learn what might be most helpful to promote her healing and safety.

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