

*What people with disabilities would
like direct care service providers
to know about . . .*

Communication



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Summary

This little book is designed to remind those directly involved with people with disabilities of skills they already have and to help them acquire some new communications skills.

We hope that providers and the people they serve will have better days as a result of providers reading and working through the exercises in this book.

Readers will learn how to help people with disabilities personally, instead of clinically, and how people with disabilities can help control their own lives.

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Members of the executive committee of People First of Georgia and the Athens Chapter of People First of Georgia reviewed this curriculum. Their ideas and suggestions are included in the text.

Why this training is important

This short module on communication can be used by direct-care service providers to learn new communication skills and sharpen the skills they already have to more effectively communicate with people with disabilities.

It is important for people with disabilities to know that those who work with them understand how to communicate with them. Communication is a two-way exchange. In the past, communication with people with disabilities too often flowed only one way – from care giver or provider to the person with the disability. Common courtesy and good sense tell us that all people should be given the chance to communicate comfortably, and that true communication should always flow both ways.

Some people with disabilities communicate in words. Others use sign language, sounds, symbols, communication devices, or message boards. Everyone uses facial expressions and body language. It is especially important for service providers to take the time to learn the communication methods of people who do not use words, or who have severe cognitive or physical impairments that interfere with speech and make it difficult for them to communicate

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verbally. It is also important for providers to listen carefully and use their observational skills to understand people who use words, but who also communicate with behaviors.

The following are suggestions for good communication from people with disabilities who have been supported by direct care workers. These ideas may help service providers to communicate more effectively and respectfully with people with disabilities.

Be a good listener and observer.

Listen to and observe the person who is trying to communicate with you. Become familiar with their method of communication. This type of learning and observation requires spending enough time with the person to become familiar with the wide range of communication methods the person uses to express ideas, emotions, thoughts, and preferences. A good listener gives the other person time to communicate and does not interrupt or cut them off when they take more time than others to convey their thoughts, moods or preferences. A good listener does not finish other people's sentences for them or speak for them without permission.

Practice Exercise: Find a practice partner whom you do not know well. Spend a few minutes talking together about a current event and practice observing each other closely. Then answer the following questions:

- What gestures or other non-verbal communication did your partner use?

- Did you notice any particular facial expressions or use of the eyes or eyebrows?
- What about voice inflection and other vocal expressions?
- What about the speed of the conversation? Did your partner speak quickly or slowly?
- Talk with your partner about what you observed of their personal communication style.

Speaking with adults as adults.

People with disabilities who are adults prefer to be spoken to as adults. Sometimes providers address people with disabilities as though they are children, using a patronizing pattern of speech or tone of voice. These behaviors are demeaning to the person with a disability. Addressing a person with a disability in an appropriate tone of voice, using common courtesy, and treating the person as an adult shows respect. However, people with disabilities often experience just the opposite. They may be addressed without the proper title even though a provider would never address a friend or acquaintance of a similar age without saying Miss, Ms., Mr., or Mrs. unless that person had asked to be addressed by their first name.

Addressing a person with a disability in an appropriate tone of voice, using common courtesy, and treating the person as an adult shows respect.

Support staff may adopt the habit of telling people to do things by making demands or giving commands, rather than asking in a courteous way. It is

equally offensive to talk about a person in their presence as if they are not there and cannot hear what is being said about them. Self-advocates interviewed for this publication described how they feel invisible and disrespected when this happens to them. Support staff may need to share information about an individual with a disability with one another, but this should be done in private – never in front of the individual or around others who need not know the information being shared. People with disabilities deserve the same everyday courtesy we practice with people without disabilities.

Using Person-First Language

Current best practices are changing from supporting people with disabilities in sheltered workshops, day treatment centers, and day habilitation programs to integrating support into less isolated settings such as supported employment and natural environments in the community. With these changes, it is important for staff to update their vocabulary by using person-first language when speaking to and describing individuals with disabilities. Following are examples of how person-first language should be used.

Always emphasize the person, not the disability, by putting the person-noun first.

- There is a big difference between having a disability and being defined by a disability. Most people would be offended by someone who described them to a friend or co-worker only in terms of their race or sex. People with disabilities are equally offended when they are described as one of

“the disabled” or “handicapped,” rather than as unique individuals with talents and gifts of their own. Always emphasize the person, rather than the disability, by putting the person-noun first. Instead of saying the “disabled” or “a handicapped person,” try saying “people with disabilities” or “a person with [a specific disability].”

- Describing a person’s disability as a “handicap” is also inappropriate. Handicaps are social or environmental obstacles imposed by society on people with disabilities. A building without a wheelchair ramp is one example of a handicap that might restrict the lives of some individuals with disabilities. Remember that disability does not equal inability. People are never “handicapped” by their disability.

- Avoid using unnecessary negative vocabulary. Don’t use words that suggest struggle, pain, or suffering when it is not part of the circumstances being described. Never refer to a person who uses a wheelchair as “wheelchair bound” or “confined to a wheelchair.” Instead, try describing someone as a “wheelchair user.” People with disabilities are offended when they are described as “cripples” or “victims” of their disability. Avoiding this language is another way of remembering that people with disabilities are unique individuals with the potential for a full and active life.

- Avoid using words such as “normal” and “abnormal.” Referring to people without disabilities as “normal” implies that individuals with disabilities are “abnormal.” These terms are insufficient to

Handicaps are social or environmental obstacles imposed by society on people with disabilities.

describe any person's physical appearance, personality, habits, or interests.

- Finally, be careful not to overdo it! Try not to be overly "nice" by using phrases like "physically challenged" or "differently abled." These terms don't hide the disability and are merely confusing. Terms such as "special" are also inadequate to describe a person with a disability. We are all special people.

Person-first language involves speaking to and describing individuals with disabilities with sensitivity and respect. Although there are no absolute rules for what language is sensitive and what language is not, the previous examples should furnish some guidelines for thinking about the person first, rather than the disability.

Speak with plain words and be sure your meaning is clear to the other person by asking for feedback.

Acronyms (letter abbreviations such as ISP, etc.) and jargon (inside words like "meds," etc.) should

People with disabilities are capable of understanding many things when they are described in words they know.

not be used unless the person to whom you are speaking is familiar with the terms. People with disabilities, including those with significant cognitive impairments, are capable of understand-

ing many things when they are described in words they know and if the ideas are presented clearly.

Always check to be sure the person has understood

what you are trying to communicate by listening and watching the person as they give you feedback. It may take some advance planning and practice to learn how to communicate a complex idea or situation to someone else in this way.

Practice Exercise: Take turns with your partner, one taking the role of a person with a disability and the other the role of a service provider.

First partner: Practice explaining clearly and in plain words what an individual service plan is and what might be included in such a plan. Ask your partner what he would like to have included in a plan for him. Then invite him to attend the planning meeting at a time and place that is convenient for him. Ask if he would like his family to attend. Listen carefully to your partner in his role as a person with a disability to be sure that he understood. Ask for feedback to make certain your partner understood you.

Second Partner: Practice explaining clearly and in plain words that your partner needs to see a doctor for a yearly physical examination. Talk about what the nurses and the doctor will do in the examination. Explain about any procedures such as lab tests, drawing blood, taking blood pressure, or other intrusive examination procedures. Listen carefully to your partner to see what his concerns are. Then think of ways to explain what these procedures are and why they are important without unnecessarily upsetting your partner. Give the person choices in as many ways as you can. If necessary, use pictures or demonstrate actions to make your meaning clear. Be sure to

Most of us talk too fast and don't give people a chance to talk when they are ready.

ask for feedback and check to make sure your partner fully understood you.

Slow down and allow time for the person to think and respond.

Slowing down your speech and pausing to give another person time to understand what you have said and to respond is one way to improve communication with almost everyone. Most of us talk too fast

People with disabilities are capable of giving important feedback and asking valuable questions when they are given time to think and respond.

and sometimes don't give people a chance to talk when they are ready. We often forget to listen because we are too busy giving directions or are in a hurry to

finish a task. Assuming that someone does not have something to say if they do not respond quickly is disrespectful. Many people with disabilities feel rushed when talking and working with care providers. We often appear to be busy or annoyed when we have to wait for a response. People with disabilities are capable of giving important feedback and asking valuable questions when they are given time to think and respond.

Practice Exercise: Describe your job to your partner and share something about your strengths and weaknesses in your work. Slow down and present your ideas clearly. Give your partner time to ask questions. Respond by asking your partner questions to make sure he has understood. Each partner should take a turn being the listener.

People who are non-verbal appreciate being given the opportunity to communicate their thoughts, ideas, and preferences.

Giving someone the gift of your time to understand them can create important bonds of respect and trust. People with disabilities who are non-verbal are sometimes offended or feel ignored and less valued when providers assume they don't have thoughts, ideas, and preferences. When providers assume they know what a person wants to say without checking with the person first, people with disabilities are often frustrated.

People like to be given choices in communication, such as the opportunity to use sign language, gestures, or a communication book or device. Similarly, they like to have their facial expressions and body language attended to carefully. When someone likes something a lot, or when something is uncomfortable or painful, it is easy to understand that emotion, even if the person doesn't use words. It takes more time and careful observation to learn the more subtle ways in which people communicate.

Think about the way an infant communicates completely without words. New parents quickly learn to understand their baby's cries, sounds, facial expressions, and body language. This happens because the parents are motivated to learn what their baby is trying to communicate non-verbally so they can provide the right support and form a bond.

This same observational skill can be applied to communicating with people who are non-verbal or who have severe physical and cognitive impairments

Looking and listening with your heart as well as with your eyes and ears can help you understand what people want and need.

that make it more difficult to understand their desires and needs. Looking and listening with your heart as well as with your eyes and ears can help you understand what people without words want and need in order for you to support them effectively.

Practice Exercise: As a group, share ideas about ways to better understand non-verbal communications.

For better understanding, spend time with the person outside of meetings and talk with them about the different aspects of their lives.

When a caregiver's knowledge of a person revolves around the disability, their knowledge of the person is incomplete. Remember that people with

Remember that people with disabilities are people first; ask them about their preferences and interests.

disabilities are people first. Ask them about their preferences, interests, work, vacations, hobbies, friends, family, and pets. People with disabilities are more like people without disabilities than

they are different. They like to talk about many of the same things you like to talk about – television programs, movies, favorite things, where they'd like to live, and their dreams for the future.

Practice Exercise: With a partner, take turns being the listener and the talker. Talk with your partner about things that will help you to know them better as a person.

Ask for information, one item at a time, such as “Where do you want to work?” and then, “Who would you like to work with?” rather than, “Where do you want to work and who do you want to work with?”

Ask questions in a straightforward manner, such as, “Do you agree with this?” rather than, “You agree with this, don’t you?”

Practice Exercise: With the listener taking the role of a person with a cognitive impairment, the talker should ask straightforward questions to find out about where the person would like to live in the community; whether they would like to live alone or with a roommate; and if they have any preferences for whom that roommate would be.

Remember to ask for information one item at a time. Each partner should take a turn as talker.

Come to work with a positive attitude and leave behind negative experiences, personality conflicts, and personal baggage. People often bring their emotional and mental baggage with them to work. This causes them to be preoccupied or grumpy, and sometimes to take it out on people with whom they work. *Having a negative attitude can interfere with communication in many different ways.* Care providers may become impatient, cut people off, or provoke inappropriate behaviors when they have a negative attitude. A care provider may also misunderstand

Approaching people with a positive attitude encourages them to communicate.

someone's words or behaviors when they have a negative attitude. Approaching people with a positive attitude encourages them to communicate.

Practice Exercise: As a group, brainstorm strategies to minimize the effects of negative personal experiences, emotions, and ideas on your work. Ask individuals to share personal experiences of communication when either their attitude or that of another person affected the exchange.

Give people with disabilities the benefit of the doubt when they have a negative attitude.

People with disabilities feel insulted and belittled when staff assume that their negative attitude or their behaviors resulted from not taking medications or from their being deliberately noncompliant. They are especially offended when important discussions or decisions are postponed until later — “after you’ve taken your medicine” or “when you feel better.” People with disabilities have the right to their negative emotions and the right to voice their negative feelings.

Practice Exercise: Ask the group if they have ever had the experience of being patronized and how they felt about the experience? Ask, what can you learn from someone who has a negative attitude?

People with disabilities have the right to their negative emotions.

Use your words, eyes, ears, and experience to figure out what a person is trying to communicate when they have difficult behavior.

Exercise: Ask the group to answer the following questions:

- What are some things that cause problem behaviors?
- Why are problem behaviors more likely among people with disabilities?
- How do you figure out what a person is trying to communicate by their behavior?
- What are some strategies you have developed to deal with problem behaviors?

Show appropriate concern and follow procedures when people with disabilities report abuse and neglect.

It is usually not your job to figure out whether the person is telling the truth. Your job is to protect the person from further harm and provide appropriate support to them so they can be heard by people who investigate their reports. People with disabilities are about twice as likely as people without disabilities to experience abuse.

Exercise: Encourage the group to explore ways in which they could support someone with communications challenges who reports abuse or neglect.

Summary

Communication is a person's way of connecting with the world. Many people with disabilities have expressed to me their experience of loneliness and isolation. Improving your understanding of their ideas, thoughts and feelings and supporting them to improve their understanding of others' ideas, thoughts and feelings can have a positive effect, not only upon your working relationship with them, but also upon their quality of life.



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