

CONSUMERS
WITH
COMMUNICATION CHALLENGES

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BACKGROUND

The 1993 amendments to the Lanterman Developmental Disabilities Services Act (SB 1383) require a *person-centered* approach to planning services for individuals with developmental disabilities. Person-centered planning is an approach to determining, planning for, and working toward the *preferred future* of a person with developmental disabilities and his or her family. A *preferred future* is what the person and family want to do in the future based on their strengths, capabilities, preferences, lifestyle and cultural background.

Along with person-centered planning changes, the type of living options available to people with developmental disabilities was expanded to include a variety of community living arrangements. Supported Living is one of these options. Both person-centered planning and supported living are based on the principle that “everybody is ready”. This means people don’t need to “earn” becoming ready or “train” before they can make decisions about their life or live in their own home.

The key to the person-centered planning approach and supported living arrangements is the consumer’s ability to **express choices** they want to make about their life. In general consumers with communication challenges have their own unique ways of expressing themselves. Often the ways in which they communicate are not recognized as such and may be interpreted as barriers when attempting to identify their choices about where to live, how to spend each day and hopes and dreams for their future. When people get together to help a person with communication challenges make plans about their life, they should be familiar with the unique way this person expresses their choice. The following information is on what can be done to successfully support consumers with “communication challenges”.

WHAT CAN BE DONE?

We can be more successful in supporting consumers with communication challenges when we listen and share information. The essential key is to realize that consumers with serious challenges *are* communicating their life preferences. Our ability to understand the methods that a consumer uses to communicate may be limited by how well we know the person, or how well others know the person.

For consumers who have communication challenges the task of understanding how they communicate is never done. Our understanding of the individual and their ways of communicating will improve and change as we embrace the values of person-centered planning and provide the consumer with increased interaction with the world at large. This will allow the consumer new ways of expressing their wishes, as only life experience has a way of providing.

The following information will attempt to bridge the gap between philosophy and best practices and assist you and the consumer in developing a person-centered plan. This guide includes information on identifying specific modes of communication that a consumer may use and who may speak for and about the person if you are unable to understand the consumers' preferences, needs, and desires.

EVERYBODY COMMUNICATES IN THEIR OWN WAY

We begin with the assumption that consumers with communication challenges do communicate. People communicate in many different ways. The most common forms of communications are verbal (speaking with words, sounds, yelling), body language, (gestures, facial expressions, and other body movements), and by using a common system of symbols (writing, pictures, signs, and behavior). People communicate about what is familiar to them. Knowledge about what and how to communicate comes from personal experiences in daily interaction with the world of people, objects, and events.

Many people who are leveled as non-communicative exhibit some or all of these forms of communication. In order to communicate, information, thought, or feelings must be expressed (expressive communication) in a form that is satisfactorily received or understood (receptive communication). People with communication challenges may express themselves in a form that is *not satisfactorily received and understood*. In fact, their communication may be perceived as inappropriate behaviors. Traditionally, these behaviors may be the only way the person can express him or herself but are looked upon as something to extinguish or modify.

When working with any consumers on their person-centered plan it is important to help them prepare for the planning meeting. For those with communication challenges, preparation is even more critical for you will have the added task of learning how they communicate.

Sometimes the people with the thickest files are the people we know the least. A person with communication challenges may be known for his or her problems or needs, as a receiver of services and programs, but not as a human being.

Getting to know someone evolves over time. It is a creative discovery process. It does not occur in a series of meetings, but in spending time with the person and their families and friends. It occurs when we create safe places for them to speak.

There are no hidden secrets to getting to know a person with communication challenges. It's no different from getting to know anyone. Knowing any person requires commitment, work, and flexibility. To enhance our ability to support someone with a communication challenge we need to go beyond the traditional sources of information and wrestle with the ambiguous issues of lifestyle choices, core values, and individual complexities.

Here are **FIVE STEPS** you can use to get to know a person with communication challenges. There are no shortcuts, by developing your **knowledge of the person**, you'll be better able to support them.

GETTING TO KNOW THE PERSON

STEP 1. ASK QUESTIONS:

“To address a person in order to gain information”

Merriam-Webster's Collegiate Dictionary

Asking questions that are **open ended** encourages the person to express their feelings. Open-ended questions usually begin with the words...**What...?** Or **Could...?** or **Would...?** Be careful with **Why...?** questions because they could cut off communication by making the person feel defensive.

You may not get a great deal of information at first, especially at the feeling level. It will take time for the consumer or the person speaking for them to feel comfortable with you and feel that you are taking a serious interest in helping them. Find a **comfortable place** and **take your time** don't make it an interview session. Show the respect and dignity that you would offer to a friend. **Empower the speaker** to give you the permission to find out what they, the consumer, needs, wants, and desires, or maybe, what they want to avoid. Remember that challenging behaviors could be the expression of this consumer's unmet needs. Finding answers to the following questions may help you focus your information gathering process:

What have the person's life experiences been?

- What have been the important events and circumstances?
- Where has the person lived, worked, gone to school?
- What have been the best times in the person's life?

What are the person's dreams for the future?

- To what future does the person look forward?
- How do others describe a desirable future for the person?
- What does the person not want in their future? Why?

What experience does the person have making choices?

- What choices does the person make in their daily routine (e.g., what to wear, what and when to eat, when to go to bed, etc.)?
- What choices does the person make in routine scheduling (e.g., choice of leisure activities, choice of companions, etc.)?

“A PARACHUTE IS LIKE A MIND IT ONLY WORKS WHEN IT IS OPEN.”

Unknown author

STEP 2. LISTEN...

“to hear something with thoughtful attention”

Merriam-Webster's Collegiate Dictionary

Listening means to understand and discover what the person feels is important and unacceptable in their life. When listening to the consumer, or significant others in their life, you will need to involve all of your senses and emotions and become an active listener. Sit close to the person, not over them. People come to life when they make contact with someone who works actively and faithfully to understand what they are trying to communicate. A good listener needs to be tuned into the unspoken messages or behaviors.

Examples of underlying unspoken messages are:

- I'm lonely.
- I feel good about myself.
- I can make decisions about my life.
- I have friends and family who care about me.

Listen for the person's successes and make note of the person's strengths, interests, special gifts, dislikes, desires and future goals. *Remember, it's important to ask for the person's permission before speaking with others about them.*

TO EMPOWER THE COMSUMER, ASSURE THEM SELF-DETERMINATION AND CONTROL OVER THEIR ENVIRONMENT.

STEP 3. SPEND TIME TOGETHER...

The best way to understand how a person can communicate is to spend time with them and, if possible, with significant persons in that individual's life. People who have communication challenges may communicate in unique ways. One option for identifying a consumer's method(s) of communicating is spending time with the person in various environments. Not just a few hours a day, but many hours over a typical week and in a variety of places. Again, this does not mean simply observing in a clinical manner, but interacting and learning about the

person. Spending time together means finding out where the person feels comfortable. It might be in a local park or simply in a quiet room. This time together will offer opportunities for the consumer to express her or his preferences. Observe and note how the consumer communicates and identify mobility and environmental adaptations/modifications that will be of help to the person in their home.

When you are spending this time with the consumer you may observe problematic behaviors. Keep in mind that this behavior may be functional for the consumer who has limited skills for communication. Decreasing the problem behavior should not be the focus, but understanding what they are trying to communicate and then responding to the behavior, as communication can be a beginning to developing knowledge about the person.

STEP 4. ASK SIGNIFICANT OTHERS ABOUT THE PERSON...

Many questions may be difficult or impossible to determine directly from the consumer who has communication challenges. Others who have significant interactions with the consumer can be a wealth of information. If possible, talk with the people who are committed to the person and who have been actively involved in the person's life over a long period. These people may be parents, family members, or paid staff. Ask them who else knows and cares about the consumer. Involve all the people you can in the person-centered planning process. Once these significant others have been identified, ask questions to determine the consumer's communication abilities. Often those who spend significant amounts of time with the consumer are not aware of the precise mechanisms used as communication by the consumer and you will need to probe for greater detail (often they will state "I just know"). When probing, attempt to define specific receptive and expressive skills. Key in on their reports of the consumer's special interests, successful experiences, fears, frustrating experiences, ritualistic behaviors and medical needs. This information should allow you to decide to what extent and in what ways the consumer expresses their preferred future and is able to participate in their person-centered planning. Some questions you may want to ask are:

- What is the consumer's primary method of communication?

Verbal?

Signing?

Behavior?

Body Language?

(Most people use a combination of the above both expressively and receptively to communicate their thoughts, feelings and information.)

Facilitated Communication?

- Alternative communication systems?
(Picture Books, Sound Boards)
- How easy are they to understand?
Can most people understand them?
Are they understood only by those who know them well?
- Other than yourself who else understands how they communicate?
(*These people are potential resources!*)
- What activities encourage or discourage communication with the consumer?
- Are there any behaviors the consumer uses to express their needs?
- Who knows and cares about the consumer and can speak for them?
(Other family members, friends, volunteers, staff etc.)

STEP 5. CREATE OPPORTUNITIES FOR NEW EXPERIENCES

Many consumers with communication challenges have been offered few choices in their lives. When in the community they are usually with a companion who may be a teacher, friend, or paid support worker. The companion most likely picked the destination without asking the consumer where they wanted to go or what they wanted to do when they arrived. This points out the problem with just being exposed to activities, as the consumer was not involved in making choices, and therefore did not have the opportunity to develop new skills.

All people need “every day” life experience to develop skills in making choices and to feel part of their community. These experiences build self-esteem, confidence and enhance personal growth. The lack of experience in making choices and being a part of the community life can cause stress, fears or apprehensions. Consumers who have spent considerable time living in the community display confidence and have more fun making choices about planning their lifestyle.

A person from the consumer’s circle of support could help the consumer develop a plan for new community experiences. Initially the focus for community experiences could be helping the consumer become familiar with possible neighborhoods in which they would like to live. *Remember choice needs to be encouraged at every opportunity. With experience comes proficiency.*

Conclusion

Person-centered planning and supported living have changed the way services are planned for and offered to consumers. These changes affect all consumers regardless of their disability. This guide focused on *getting to know the person* by improving our ability to understand a consumer with communication challenges and how they communicate. Getting to know the person is a very important first step when working with any consumer to develop her or his life plan, it is even more important for consumers with serious communication challenges.

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