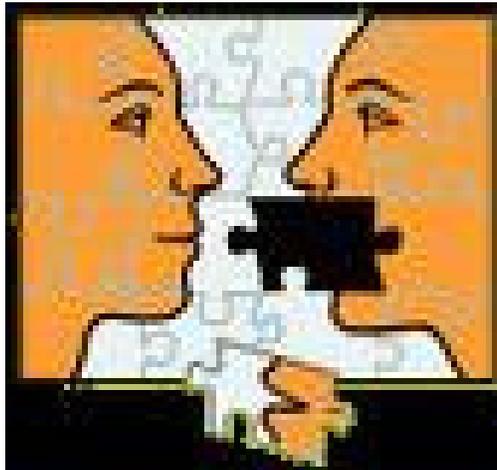




MODULE 4 DSP NOTEBOOK



HUMAN INTERACTION AND COMMUNICATION

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"I enjoy having support. I will always need support with certain things. Some I really can't do. I know I will always need support workers. But I know it is important to always try on my own."

Jackie

Red Light/Green Light

Red Light! Please DON'T...	Green Light! Please DO...
Give us dehumanizing labels in order to "help" us	Get to know us as people
Treat us like we're subhuman because of our "issues"	Treat us like human beings
Focus on the things we do or have done wrong	Focus on what we do or have done right
Talk down to us or patronize us	Talk to us with respect
"Fib" to us about what's going on with our services	Tell us the truth
Ignore our gifts, talents, hopes and dreams	Encourage us to use them
Try to "rehabilitate" us so that we "get better"	Help us to be stronger people
Try to "fix" or "change" our behavior	Learn what's really wrong. Ask us.
Make decisions for us	Give us choices so we can learn
Refer to us as an "alcoholic", etc. in front of people	Introduce us by our own names
Ignore it when someone abuses or neglects us	Protect us and report this right away!
Look down on us because "we made bad choices"	Give us a second (or third) chance
Keep a "professionally distant" attitude	Support us and be one of our allies
Pity us	Think of us as unique and valuable
Think you're better than us because you're a "helper"	Treat us as equals and partners
Pressure us into doing or believing things we don't want to	Let us form our own opinions
Think we're only worth something if we have jobs, etc.	Recognize our "worth from birth"
Assume you know everything about us and our "issues"	Learn and grow along with us
Invade our privacy	Respect our right to privacy
Forget us once we leave "services" or "the system"	Keep in touch. Keep supporting us.
Tell us "we can't" or "that's not realistic", etc.	Believe in us and in our dreams!

Submitted by Amy Walker, Self-Advocate/Illinois Voices Systems Change Activist
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The Importance of Communication

Communication is the process of exchanging information. Information is conveyed as words, tone of voice, facial expression and body language. According to A. Barbour, author of *Louder Than Words: Nonverbal Communication*, words account for 7 percent of the information communicated. Vocal tone accounts for 55 percent and body language accounts for 38 percent.

Remember, everyone communicates! Your success as a DSP will largely depend on the positive relationship you establish with the person(s) you help support as well as the relationships you develop with your peers. Communication is a key component in developing positive and supportive relationships.

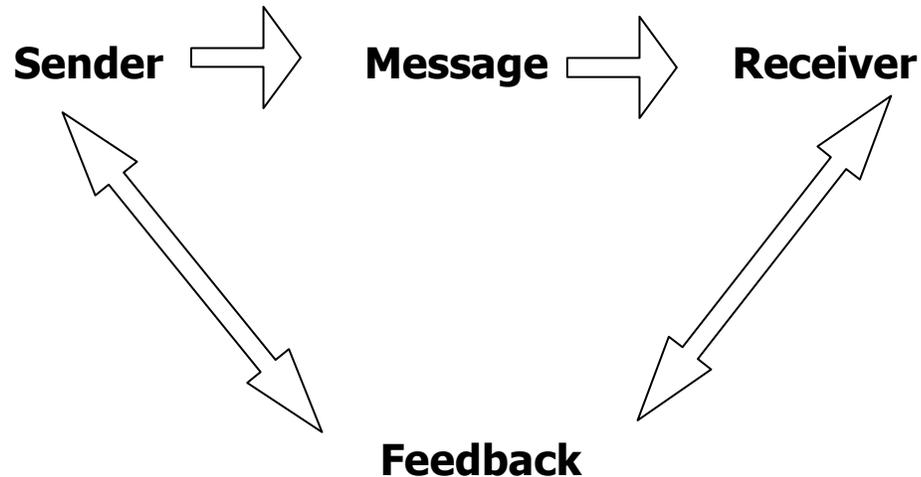


Communication is meaningful if people find the content interesting or useful, or if they feel it has a purpose. Some people that you will support may have alternative ways that they use to communicate. It is important to find out what the person's preferred mode of communication is and use it when communicating. For example, the person may understand the spoken message better when pictures are used along with speech. Information about **receptive** (what a person understands) and **expressive** (what a person says) levels of communication can be found in the person's Individual Service Plan (ISP). Communication is the tool you will use in assisting a person in identifying and achieving his/her outcomes. You cannot do this unless you:

- know the person's preferred communication
- know what a person is able to communicate in all situations
- understand the communication process

The Communication Process

The Communication Process consists of these key elements; a **message** being sent, **someone sending** the message and the **receiver** of the message. Another important element is the **feedback** cycle.



When two people interact, communication is rarely one-way only. When a person receives a message, he/she responds by a change in behavior (e.g. makes a verbal response, initiates an action, uses facial expression or body language to indicate understanding). This is called **feedback**. Feedback let's you know that the message was received exactly as intended. The critical factor in measuring the effectiveness of communication is being sure that the message was understood.

Both the sender and receiver bring a combination of the following components to the communication process:

- Non-verbal behavior (facial expression, body stance, tone of voice, etc.)
- Values (those concepts that represent their ways of trying to survive)
- Expectations
- Senses (sight, touch, hearing, etc.)
- Abilities to talk or vocalize
- Brains (the storehouse of their knowledge and experiences)
- Environments (the settings in which they live and work.)
- General communication knowledge

Non-verbal Communication

Almost all behavior is a form of communication. The behavior may be a communication attempt to gain a desired object or outcome. Or, the behavior may be a communication attempt to avoid or escape an undesirable outcome. If the person does not have any verbal means to communicate, actions or behavior may be the only means to make wants/needs known.

Communication is critical to continued human development throughout our lives. Whether you communicate verbally or non-verbally, a large part of communication is non-verbal.

By the time most of us reached our first birthday, we became experts in non-verbal communication. We spent the first year of life making wants and needs known non-verbally. The use and understanding of non-verbal communication is so automatic that many of us are completely unaware that we are using things like body language or facial expression or reading these cues to enhance words.

At times you may be confronted with challenging and confusing behaviors from the people you support. These should be handled thoughtfully and respectfully. You should remember that behavior is a person's way of communicating. Behaviors can communicate:

- happiness
- pain
- frustration
- fear
- anger
- joy



Understanding behaviors is a difficult task. Some of us express emotions differently. If someone is quiet today, does that mean he or she is unhappy, happy, or that he or she has a sore throat and it hurts to talk?

Sometimes the skill of picking up non-verbal cues is not developed during developmental learning stages. For example, a person with autism or autism spectrum disorder may never learn to use or understand non-verbal cues.

We need to remember that it is important to make sure that our verbal and non-verbal signals "match." Think about telling a person "no." To make sure that the meaning is clear your facial expression, body language, tone of voice should match the verbal expression.

When non-verbal cues do not match our words, it causes difficulties in interpreting the message.

Behavior as a Form of Communication

We have talked about positive behavior supports and the fact that behavior is a form of communication. Communication refers to all the ways we express and receive information. It is often difficult to understand what a person is trying to tell us, especially if they cannot use words. A person can be assisted by using some form of communication technology, such as a communication board. Or it can be done by making sure the person is surrounded by people who understand their communication cues or behavior. By maintaining an openness and awareness to the potential subtleties of the communication process, you will be more likely to recognize and utilize many opportunities and methods to communicate.

Ways People Communicate

We are always communicating! In fact, we cannot *not communicate*

Please list all the ways you can think of that we communicate verbally and non-verbally:

Verbal

-
-
-
-
-
-

Non-verbal

-
-
-
-
-

Communication Functions

If the Person Does This:	It Probably Means:	You Might Respond By:
Waves	Hello	Saying "Hello," waving back.
Smiles	Happy, Hello	Talking about the situation at hand that is producing pleasure Say hello, initiate conversation
Pushes you away	Want the activity to stop; angry; disinterested	Stop or modify the activity. <ul style="list-style-type: none"> ▪ Elicit more info about what is causing the anger. ▪ Initiate a more interesting activity.
Reaches for an object	Want the object	Helping them get the object, talk about it, name it, help the person manipulate it
Points to a person	They like the person; curious about the person; want interaction with the person	Calling the person over, aiding interaction with that person
Throws an object	They don't like the object; want to play with the object; don't understand the object	Removing the object Reciprocate play with the object Demonstrate function or play purpose of object
Walks up to / stands at the sink	Want a drink	Assist in obtaining a drink.
Opens the refrigerator	Wants something to eat	Assist in obtaining something to eat.
Stays in bed	Tired; not feeling well	Allowing to rest, check for illness symptoms
Cries	Sad; ill; communicating displeasure	Assessing situation to discern cause of problem.
Falls asleep at a work site	Tired; ill; bored	Assessing situation for symptoms of illness Consider sleep pattern / getting adequate sleep. Offer choice of more interesting activity.

Communication Functions (continued)

If the Person Does This:	It Probably Means:	You Might Respond By:
Runs away from support person	Playing; desire to leave situation; desire for physical activity	Reciprocating play Removing person from situation Engaging person in physical activity
Repeats a word or a person's name ("car, car, car," "mom, mom, mom," etc.)	Want the word being spoken	Taking a ride in the "car" Telephoning "mom"
Hums, Coos	Person is happy, content	Continuing activity or condition that is producing pleasure
Laughs	Person is happy, playful, teasing.	Continuing activity or condition that is producing pleasure. Reciprocating teasing, behavior, game.
Mouths objects	Desires oral, tactile stimulation; is hungry; misunderstand function of object	Substituting potentially more appropriate stimulation Offering something to eat Demonstrating proper function of the object
Paces, Rocks	Desires physical activity; bored	Engaging in physical activity. Offering alternative activities

Tips for Communicating With People Who Communicate Non-Verbally

- Use common sense. People with disabilities want to be treated the same way as everyone else.
- Offer Assistance. Do not hesitate to offer assistance. However, do not automatically give help unless the person clearly needs help or asks for it, (or unless you are directed to do so by his/her individual service plan). Ask the person if assistance is needed and how it should be given. If the person declines your help, do not insist on helping.
- Be patient. It may take them a while to answer.
- Give them your undivided attention.
- Ask them for help in communicating with them. Often, there are printed instructions on communication devices that explain how to use them.
- Tell them if you do not understand what they are trying to say. Ask them to repeat their message or tell you in a different way.
- Ask short questions that require brief answers or a head nod, to obtain information quickly.
- If you have difficulty speaking to the person:
 - Rephrase what you are telling/asking the people. Show the person an object that will describe or represent what you are telling/asking the person. Have someone who communicates successfully with the person assist you with what you are telling/asking the person.
 - Reduce distractions
 - Use **visual supports** as needed

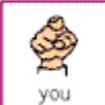


Augmentative/Alternative Communication (AAC)

Augmentative and alternative communication (AAC) includes all forms of communication (other than oral speech) that is used to express thoughts, needs, wants, and ideas. We all use AAC when we make facial expressions or gestures, use symbols or pictures, or write. People with severe speech or language problems rely on AAC to supplement existing speech or replace speech that is not functional. Special augmentative aids, such as picture and symbol communication boards and electronic devices, are available to help people express themselves. This may increase social interaction, school performance, and feelings of self-worth. AAC users should not stop using speech if they are able to do so. The AAC aids and devices are used to enhance their communication. One type of AAC is the use of Visual Supports.



Feel Something

 I	 heard	 something	 rolling	 loud	 quiet
 you	 felt	 smooth	 tinking	 heavy	 soft
 can	 not	 squeeze	 big	 hard	 little
 know	 & and	 scratchy	 bumpy	 wooden	 plastic

Visual Supports to Aid Communication

What are Visual Supports?

Visual supports are tools that are used to increase the understanding of language and to provide structure and support. They help people to understand because they are more 'permanent' than verbal language which seems transient and fleeting to many people with language difficulties.

Why use Visual Supports?

Some people develop stronger visual skills than auditory skills. Many times this is true with people who are deaf or hard of hearing or people with autism spectrum disorder. Visual supports allow people to use this visual strength to process, organize, remember, and respond to information, thereby allowing the person to more easily participate in the communication process. Visual supports also allow important information to remain accessible in the person's environment. This can greatly reduce the stress levels and inappropriate behaviors that may be exhibited when the person can't effectively

communicate or when they do not understand the expectations in the environment.

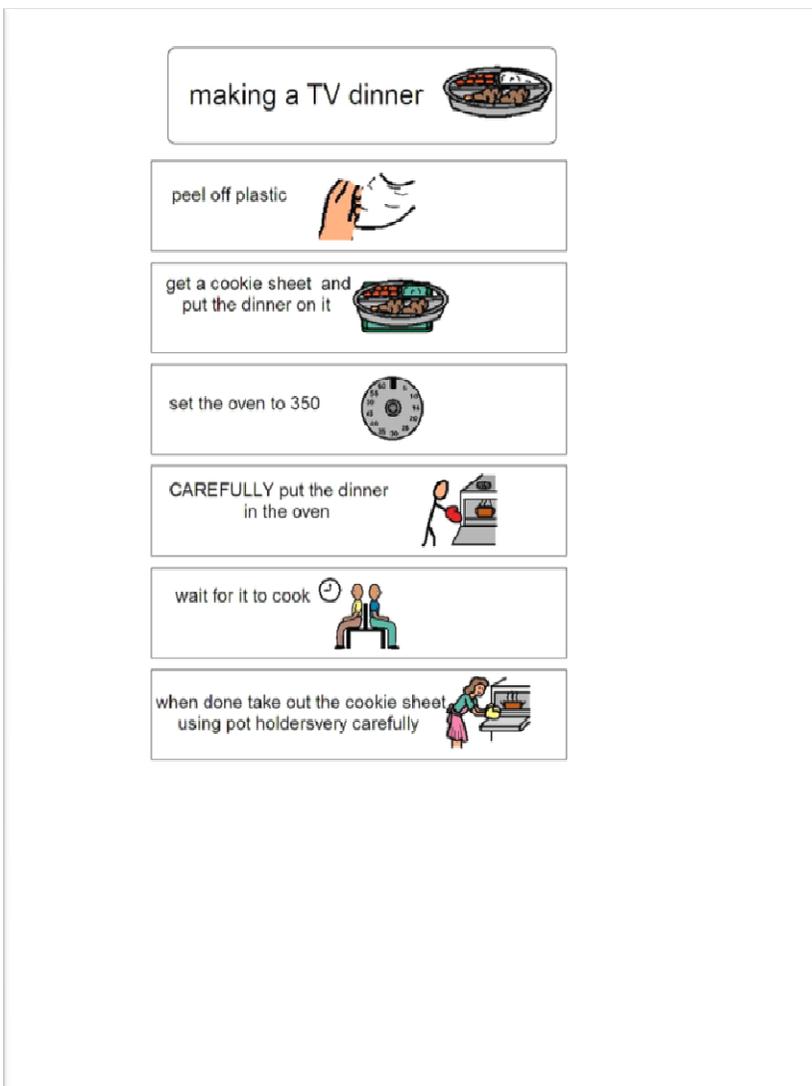
What can Visual Supports be Used for?

Visual supports are commonly used to communicate choices, organize daily schedules, give directions, explain rules or expectations and/or aide in transition.

What are some Examples of Visual Supports?

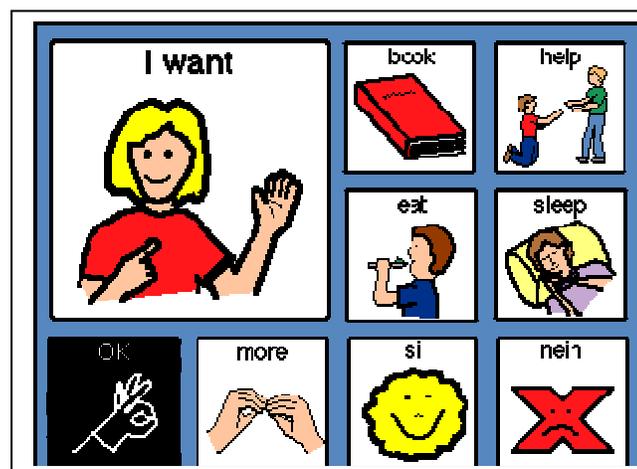
- Photographs
- Calendars
- Picture symbols
- Food labels

- Objects
- Schedules
- Written words



Where to Start with Visual Supports:

- Decide what the visual supports are supposed to do
 - **Example:** Provide choice of snack
- Choose the type of supports that best meet the needs of the person
 - **Example:** Black and white icons or color icons, digital pictures or objects
- Gather labels, make picture symbols, take photographs
 - **Example:** Picture of an apple or bag of chips, logo of McDonald's or Wendy's, etc.
- Make them durable
 - **Example:** Laminate, attach Velcro, and make multiple copies.
- Choose where the support will be used.
 - **Example:** Mount choice board on refrigerator or schedule on student's desk
- Teach and implement the support – Be consistent!



Some Causes of Communication Challenges

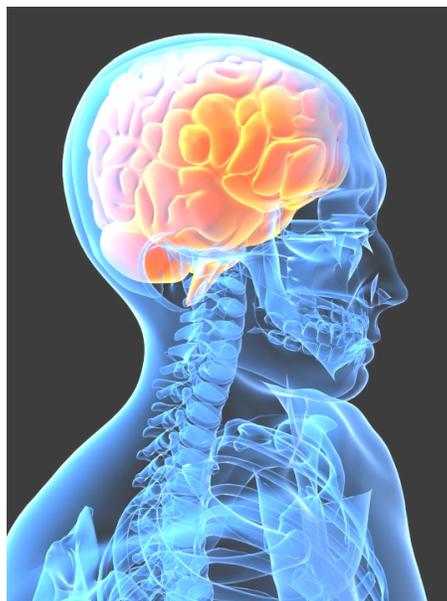
The brain is very complex and because of this, we do not yet understand the causes of many communication disorders. A few causes of communication challenges are:

Deaf/Hard-of-Hearing – full or partial hearing impairment may cause difficulty in speech and language development. An assessment of hearing is one of the first steps in the investigation of speech and hearing problems.

Physical disability – such as cleft lip and palate, or malformations of the mouth or nose may cause common communication disorders. Some disabilities such as cerebral palsy may preclude development of speech and require the use of augmentative communication methods.

Intellectual disability – some people (not all) who have intellectual disability may be slower to learn to talk and may need extra assistance.

Autism Spectrum Disorder – some people with Autism Spectrum Disorder (ASD) will have communication challenges. Many people with Autism Spectrum Disorder have difficulty with social skills and their behavior and conversational skills may be limited or inappropriate for the situation.



Communication Challenges for People with Autism and Autism Spectrum Disorder (ASD)

The communication challenges of autism vary, depending upon the intellectual and social development of the person. Some may be unable to speak, whereas others may have rich vocabularies and are able to talk about topics of interest in great depth. Despite this variation, some people with ASD may have little or no problem with pronunciation; however most have difficulty using communication effectively. Most also have problems with word and sentence meaning, intonation and rhythm.

Those who can speak often say things that have no content or information. For example, a person with autism may repeatedly count from one to five.

Others use **echolalia**, a repetition of something previously heard. One form, immediate echolalia, may occur when the person repeats the question, "Do you want something to eat?" Instead of replying with a "yes" or "no" the person will repeat the question "do you want something to eat?" every time they are requesting food.

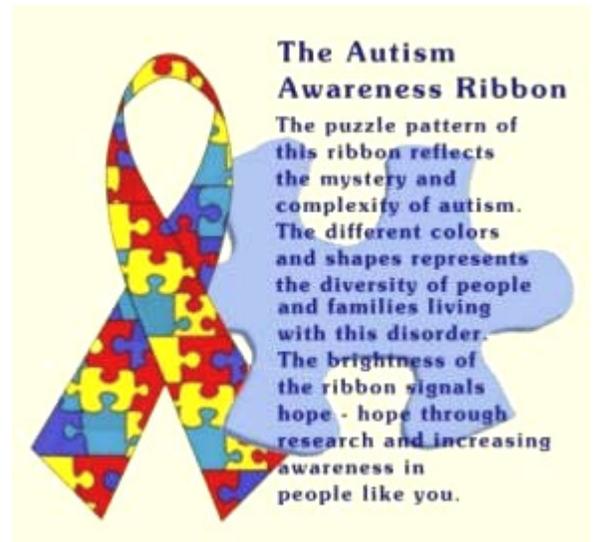
Some people may have high intelligence and may be able to speak in depth about topics they are interested in such as dinosaurs or railroads, but are unable to engage in interactive conversation on those topics.

Many people with autism do not make eye contact and have poor attention skills. They are often unable to use gestures either as a primary means of communication such as in sign language or may be unable to point to an object they want. They may not respond to the speech of others and many times are mistakenly thought to have a hearing loss.

How are communication challenges in autism treated?

If autism or some other developmental disability is suspected, the person's/child's physician will usually make referrals to a variety of specialists, including a speech-language pathologist. This is a professional who performs a comprehensive evaluation of the person or child's ability to communicate and designs and administers treatment. Here are some general guidelines regarding treatment:

- The best treatment begins early
- Treatment should be individually tailored and target both communication and behavior



- The goal of therapy should be to improve useful communication
- No one treatment method has been found to successfully improve communication in all people who have autism.

For some people, verbal communication is a realistic goal. For others, a symbol system such as a picture wallet or communication board may be the goal. Occupational and physical therapists may also work with the person to reduce unwanted behaviors that may interfere with the development of communication skills.

Some people respond to approaches such as music therapy and sensory integration therapy which strive to improve the person's ability to respond to information from the senses.



Where Can I Get Additional Information on Autism?

National Institute of Mental Health

Phone: (301) 443-4513

Toll-free phone: (866) 615-6464

E-mail: nimhinfo@nih.gov

Internet: www.nimh.nih.gov

Autism Society of America

Phone: (301) 657-0881

Toll-free phone: (800) 328-8476

Internet: www.autism-society.org

Cure Autism Now (CAN)

Phone: (323) 549-0500

Toll-free phone: (888) 828-8476

E-mail: info@cureautismnow.org

Internet: www.cureautismnow.org

Autism Research Institute

Phone: (619) 281-7165

Internet: www.autismresearchinstitute.com

The Autism Program of Illinois

Phone: (217) 525-8332

Internet: www.theautismprogram.org

Hearing Disabilities

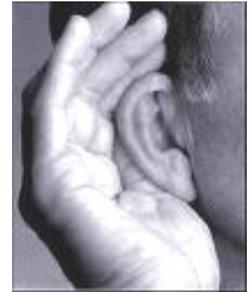
A person with a hearing disability will have problems communicating because s/he cannot hear well.

A person who experiences a serious hearing impairment at an early age may have difficulty learning to speak. Therefore, they may have difficulty in both hearing and in being understood.

Background noises make it difficult for some individuals to hear you. They cannot tell the difference between what you say and the noise.

Common reasons for hearing loss include:

- Birth defects/genetic disorders/premature birth
- Lack of oxygen during the birth process
- Illness
- Injury
- Trauma to the head and neck
- Prolonged exposure to loud sounds (e.g., machinery, guns, music and portable music players)
- Aging
- Certain types of medications

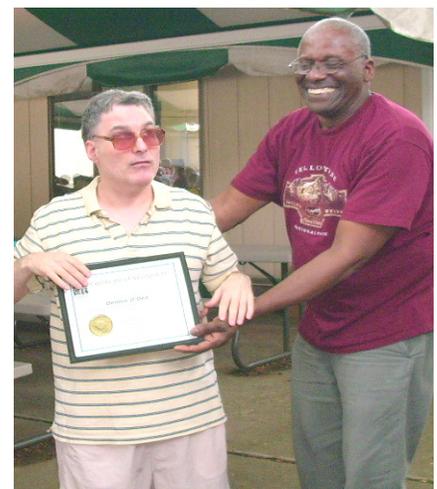


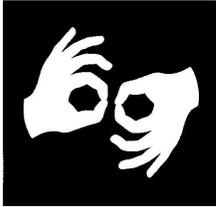
Visual Disabilities

Persons with visual disabilities often miss out on non-verbal clues. They may not be able to see the facial expressions and gestures which are a part of the message being communicated. When communicating with people with visual disabilities, be descriptive. You may have to help orientate them to their surroundings and let them know what is coming up. If they are walking, tell them if they have to step up or down, let them know if the door is to their right or left and warn them of possible hazards.

You do not have to speak loudly to people with visual impairments. Most of them can hear perfectly well.

If you are asked to guide a person with a visual impairment, offer your arm instead of grabbing theirs.





Types of Sign Language Systems

American Sign Language (ASL)

ASL is the natural language of people who are deaf and also the form of communication they use the most. However, if a signing module is included in a program, it must be understood that ASL signs will not match the speaker word for word. ASL has its own grammatical structure (different than English). ASL tends to be a visual or concept based way of communication.

Signing Exact English (SEE)

SEE follows English grammar exactly by using supplementary signs for endings such as "ing" or "ed." It would be difficult for ASL signers to follow SEE signing, although many signs are shared.

Total Communication Perspective (TC)

The total communication is a philosophy of communication and has many variations. In general, TC uses a combination of various methods and approaches to meet the person's needs. A combination of sign language, finger spelling and spoken English is often used. The type of sign language used may vary: Signed Exact English (SEE), Signed English (SE), American Sign Language (ASL), or Pidgin Signed English (PSE).

Informal (Home Made Signs)

If a non-verbal person is never taught a formal sign system, informal gesture may be developed between the individual and family or caregivers. This type of system is extremely limiting since the number of people that recognize the meaning of the gestures is very small. It is important to determine what each gesture or homemade "sign" means and then teach the formal sign to the person and parent/caregiver. However, it is important for you to try to also learn the individual's signs, as one may be unable or unwilling to change the signs one is comfortable with.

Guidelines for Using Sign Language

Be conscious of the following when you are communicating with a person in sign language:

1. Location of Signs

Always face the person to whom you are signing.

Sign with your palms out, facing the person, and be sure to gain eye contact.

Your lips should be visible. The person to whom you are signing may also read lips.

Sign with your hands in front of your chest in a comfortable manner.

Sign at eye level.

2. Facial Expression and Body Language

Facial expression and body language can completely change the meaning of a sign; all should be coordinated and used together to convey your message.

Be sure to use appropriate facial expressions as this will help the person to understand your message. For example, when signing "good," also smile and look pleased.

3. Speaking and Signing

Always speak and sign simultaneously. Recipients who are learning verbal skills should be encouraged but not forced to use speech along with the sign if at all possible.

4. Speed, Motion, and Force of Signs

The speed, motion and force with which you make the sign will all impact the meaning that the sign has.

Make all signs slowly and clearly. Be sure to repeat the sign if the person does not understand the first time.

5. Timing of the Sign

Make the various signs at the appropriate times. This will help the person to associate the sign with its meaning.

For example, sign "eat" immediately before, as well as during, mealtimes.

Other Guidelines for Using Signs

- Sign and speak to the person as much as possible each day. Consistent modeling of signs will increase the person's receptive and expressive communication skills.
- Teach language that is functional for each person. When beginning to teach signs, some persons may need various prompts. Initially, accept any approximation of signs.
- All self-initiated signs should be accepted and reinforced.
- Once a person learns a sign independently, encourage him/her to use the sign with various people in different situations. If the person knows signs for words such as "eat," "drink," or "pop," encourage him/her to produce these signs before automatically providing these items.
- Remember that repetition, consistency, continuity and appropriate reinforcement are essential in teaching signs.
- Use a "**total communication**" approach. This approach combines sign language and speech simultaneously, while also using any other mode of communication (i.e., facial expressions, pictures, amplification, gestures, etc.) to convey your message. Research has shown that this method is effective when teaching communication skills.



Problems with Speech

Some people may not speak clearly. This may be a result of:

- Physical problems such as a cleft palate (a crack or space in the roof of the mouth, leaving an opening to the nasal cavity).
- Injury or disease related to damage to the vocal chords or other structures involved in the production of speech.
- Articulation problems (speech sounds are distorted, substituted, added where they don't belong, or completely left out.)
- Weak and/or uncoordinated muscles.

NOTE: A person who has speech that is not easily understood has probably experienced frustration and humiliation. Your job is to understand what s/he means, and to be sensitive. Be careful not to embarrass the person. Aggressive behaviors may arise from this frustration, or lack of desire to communicate may arise from poor ability and prior failures.

Problems with Language

Sometimes the person may not be able to make the association between words, objects or ideas. This includes:

- The basic use of grammar
- Level of vocabulary
- Understanding what is said
- Clearly expressing oneself
- Remembering what one heard

Common Effects of Communication Challenges

Communication challenges affect all areas of a person's life. These challenges may affect:

1. The ability to control inappropriate behaviors.

A person who is unable to communicate ideas, feelings or needs and who is unable to understand their environment may express pressures and frustrations s/he feels through behaviors that cause problems for him/her or others. Attention-seeking behaviors may be learned that help him/her meet their needs.

2. The Ability to Understand Questions

If a person can't understand words like "who", "what," "where," "when," "why," "how," and "which," s/he cannot answer questions or respond to requests. The person may not respond because s/he doesn't understand what you want them to do.

We may interpret the person's lack of response as non-compliance or lack of interest. Our job is to realize why he/she is not responding and assist the person using additional cues.

3. Ability to Understand Time

A person may not be able to understand the concept of time, which is a very abstract concept. Without the ability to understand time, an individual remains concrete in his/her thinking. Time is more than numbers on a clock. Understanding time involves such concepts as:

- Day/night
- Morning/afternoon
- Week/month/year
- Seasons
- Today/yesterday/tomorrow
- Now/later/soon/next
- Before/after
- In a while
- Past/present/future
- Verb tenses



When a person has difficulty with understanding time, they can become confused or upset when their schedule changes. It is our job to help him/her anticipate and understand change.

4. Problems with Negation

People who have problems with negation are unable to understand such words as "not," "don't," "can't," "won't" or "without," and prefixes such as "un-", "dis-", or "non-". Lack of understanding of negation may lead to problems when the individual interprets what not to do as what to do.

For example, when a staff person tells an individual that plans have changed, and that s/he can't go swimming, the individual may continue to wait to go because s/he did not understand the word "can't" in the sentence.

Talking to the People you Help Support

The following are a series of communication tips. These tips will help you support and expand a person's communication skills.

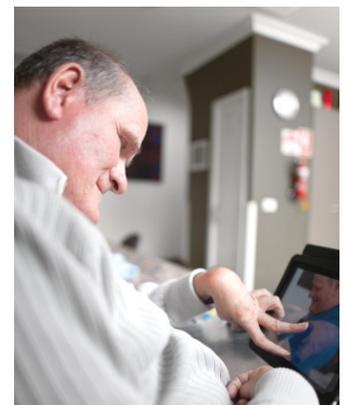
1. Talk to the people about his/her favorite subject, adding new information, and helping him/her to expand his/her interests.
2. Talk to and with the people about what is going on around him/her, such as events, people in the environment, etc.
3. Talk to and with the people about what is going to happen next, and prepare him/her for any scheduled changes in routine.
4. Talk to and with the people about the choices s/he can make that will have a positive impact on his/her life. This includes such things as choosing to wait in line, rather than shoving someone out of the way. Help him/her think about the consequences of his/her actions so that s/he can make informed choices.
5. Describe what the person is doing as s/he does it. This is known as "*parallel talk*."
6. Describe what you are doing with the person. This is known as "*self-talk*."
7. Name items in the person's environment to stimulate language development. This is known as "*naming*."
8. Repeat what the person says, making corrections in your repetition. This provides a good model without directly calling attention to errors. This is known as "*echo-correction*."
9. Repeat any of the person's utterances, adding left-out words, to create a slightly more complete thought or feeling. For example, a person might say, "No more skate," to which a staff person might reply, "You don't want to skate anymore? Okay, that's fine." This is known as "*echo-expansion*."
10. Remember that if a person doesn't understand what you're saying, saying it louder won't make it more understandable.
11. If a person doesn't understand what you're saying to him/her, rephrase your statement or question, using shorter and more direct statements.



12. Speak in a direct manner, saying what you mean. For example, if you don't want someone to do something, say "Please stop that," followed by telling them what you would like them to do.
13. Make sure people understand your style of communicating. Particularly, don't use sarcasm. Since sarcasm involves sending and receiving verbal messages that don't match the speaker's tone of voice, body language, and/or facial expression, it is difficult to interpret. Sarcasm is often viewed as an insult, even if you do not intend for it to be insulting. The use of sarcasm makes it unlikely that the people will trust you as a support person.

Likewise, don't use irony. Irony is the use of words to express something other than the literal meaning. The people may not understand that you actually mean the opposite of what you are saying.

14. Be direct when you make a request. Speak using short, direct sentences. For example, don't say "Must you do that?," when what you mean is "Please stop doing that." Likewise, don't ask "Do you have a problem?" when you mean, "What's wrong?"
15. Develop an on-going awareness of your own style of communicating. Because, in your role as a direct support person, you are in the position to influence and motivate people, your communication style becomes very important. Be aware of the methods you use to communicate, the effect these have on those with whom you communicate, and the ways your style impacts upon your relationships. Ask yourself what you can do to empower your own communication process, noting those styles, methods and skills which are limiting to you.
16. Convey respect, sensitivity, and dignity in your communication.
17. Be open to a wide range of communication methods.
18. Empower people through the use of your verbal communication skills. By being a positive role model in your communication with staff and the people we support, you will be able to empower people to openly communicate with you and others. Remember, the use of negative words, signs, gestures or other actions toward or about and in the presence of individuals can cause emotional distress or maladaptive behavior.
19. Recognize the ways people communicate and be sensitive to their communication challenges.



20. Communicate attentively with people when you are with them.
21. Make use of a range of communication methods when appropriate.
22. Use a normal tone of voice. Don't use exaggerated or unusual emphasis.
Don't shout.
23. Provide a dignified communication atmosphere by not interrupting or "talking over" the person. Give the person you support your full attention whenever possible.
24. Speak to the person in short, simple sentences if that is what s/he understands the best.
25. Be patient and allow the person adequate time to respond. Do not complete a sentence for the person before s/he is finished speaking.
26. Don't limit your verbal interaction to only telling people what to do or not to do.
27. Speak directly to the individual by putting yourself at eye level.
28. Offer **real** choices!!!!
29. Take your time.

Facilitating Communication

- **Use calendars, schedules, and checklists.** Many people have difficulty in staying on track and organizing their activities. They can benefit from a visual reminder such as a calendar, schedule or checklist which can help them anticipate upcoming activities.
- **Organize the environment.** This can be very helpful in giving people cues about what, when, and how. Too much clutter or too many items in one place can cause some people to become overwhelmed. A helpful idea is to organize the environment so that one area is for eating, one is for working, one is for activities, etc. Keep supplies handy and accessible for people to use.
- **Avoid using phrases that are abstract.** Many people have difficulty in understanding abstract thought; they interpret verbal information very literally. Be very specific about what, when, where, and how to that the information is understood. An example is asking a person to "*wait for a while*" which has no concrete meaning. A better way would be to ask a person to "*wait for 3 minutes.*" Because of difficulty in understanding abstract information, humor and sarcasm should be carefully considered before being used.
- **Avoid repeating information.** People may find it difficult to quickly interpret auditory and verbal information; repeating the information quickly may lead to frustration, anger, and aggression. Give the person time to process the information before giving a response. The use of visual cues, gestures, or physical prompts may further assist a person in understanding the information.
- **Be observant of the environment and make changes when necessary.** Environments that are very bright or very dark, noisy, or full of lots of clutter may make it difficult for people to focus on and process the information being communicated.
- **Prepare for changes or transitions.** Changes and transitions from one activity to the next can be difficult for many people. Using visual schedules, calendars, checklists and written or verbal reminders can help make transitions smoother and easier.
- **Emphasize social learning.** Some people must learn social skills that others take for granted. Social learning is done through imitation and modeling. Examples of social learning



includes turn-taking, appropriate public behavior, and using appropriate words in public. In addition, making sure that non-verbal cues match verbal communication will help the message to be processed correctly.

- **Encourage people to communicate their wants and needs.** Instead of automatically doing things for others (ordering food, helping put on or take off clothing, pushing a wheelchair), wait for people to indicate how you can best support them.
- **Ask people to repeat themselves if you don't understand what they are communicating.** It may be difficult to understand communication the first time. Don't pretend to understand as it can lead to mis-communication, anger, or frustration. Ask the person to repeat themselves until the communication is understood.
- **Have fun!** Communication should not always be about giving directions and instructions; engage in communication that is conversational to develop relationships built on dignity and respect. Encourage people to communicate their hopes and dreams, and then provide the support they need to obtain them.



Responsive Communication and Effective Listening

Develop a responsive style of communicating with people. For example, a direct response to the statement, "I don't have anything to do," would be, "Get a game." A responsive reply to the same statement would be, "It sounds like you're bored; what can we do about that?" This creates an opportunity for the person to problem solve.

Note:

By using a responsive style to communicate with people, you will empower them to exercise choice. It is through this choice process that we identify the person's hopes and dreams.

Listening Effectively

As a partner in the communication process, you need to learn to use **active listening skills**. This means that you need to use all the available clues to figure out what a person is attempting to communicate to you. In other words, be an involved partner in the communication process.

- Be aware of non-verbal communication.
- Pay attention to the tone and inflection of the person's voice.
- Don't tune-out what a person says because it doesn't seem to make sense.
- Keep in mind that the person's behavior is an attempt to communicate some need to you.
- Show you are listening by stopping what you're doing and put full attention on listening.
- Summarize the conversation.



Individual's Right to Express Emotions

The individuals you support have a right to feel upset, frustrated, angry, sad etc., and to express their feelings especially when they are in their own home! Individuals may not always know the best way to express their emotions and to communicate how they feel, what they want, and what they need. Offer empathy, comfort and support to help the individual cope with his/her feelings. Teach and model how to figure out what is going on with the individual. Teach and model ways to help the individual express his/her feelings in an acceptable way in order to achieve what s/he needs.



Communication Roadblocks

✓ **Directive Language**

Our language and behavior can build roadblocks to communication. This happens when we use language that:

- Orders
- Warns
- Commands
- Directs

✓ **Decision Making**

Another area that can cause a communication roadblock involves the understanding that a very important part of the role of the DSP is to assist the individual in making **their own** choices. You will learn more about the choice making process in the next module.

The Principles of Control vs. Support

Supporting people includes helping them accomplish what they want in life. Whenever possible, DSPs should put aside their own personal agendas and “let go” of trying to control situations. Try not to let attitudes such as the ones listed below stand in the way of promoting support instead of control:

“You should listen to me; I know better than you do what’s best.”

“If I let him get away with something once, he’ll walk all over me.”

“If you let one person do it, everyone else will want to do it, too.”

“My job is to tell you what to do. That’s why they hired me.”

“We’ve tried this before and it didn’t work.”

“I’ve known him for a long time. He’s not going to change.”

“Her IQ is the same as a child’s; she can’t make her own decisions.”

Instead, DSPs should strive to be flexible and supportive of people’s preferences and choices when planning activities and services.

Communication Professionals

Speech and language professionals work with other members of the interdisciplinary team to develop communication plans/programs for people.

A **Speech Pathologist** can help you answer the following questions:

- What communication technique/method is the person most likely to understand and/or express him/herself through?
- How can I help this person express him/herself to me?
- What is the best communication situation for the person?
- What should I do if this person doesn't understand me?

An **Audiologist** specializes in prevention, identification, assessment and non-medical treatment of hearing disorders. This may include prescribing and dispensing hearing aids.

An Audiologist can help you answer questions such as:

- How much can this person hear?
- How can I help the individual hear most effectively in a variety of listening situations (such as home, work, church)?
- How do I check this person's hearing aid to make sure it's working properly?

RESOURCES:

Illinois Assistive Technology Program – www.iltech.org

Picture Exchange Communication System – www.pecs.com

Library Information and Services – www.eiclearinghouse.org

Information on Sensory Integration – <http://www.sensoryresources.com/>

Interactive Sign Language DVD from DePaul University:
<http://asl.cs.depaul.edu/contact.htm>

Remember. . .

People will forget what you said,

People will forget what you did,

*But, people will never forget how
you made them feel!*

Maya Angelou

Supporting a Grieving Person with a Developmental Disability

Understand what grief is.

The loss of a loved one or close friend is a very profound emotional experience. Even the loss of a neighbor, co-worker, or acquaintance can cause short-term emotional trauma and may have a longer lasting effect. Grief is the mental anguish that accompanies loss, and people with developmental disabilities (no matter how severe) *do* experience grief.

Competent support of a grieving person is beneficial because:

- it quickens/hastens the person's return to normal daily routines.
- it strengthens existing emotional bonds between the person and his circle of family and friends.
- it prepares the person to better handle future losses.

Keep in mind the special needs of the grieving person.

Consider these specific factors and the unique assets and needs of the grieving person:

- mental age (cognitive, IQ, or developmental level)
- calendar age (actual age)
- previous life experiences (how sheltered or exposed s/he was to previous losses: is this a first loss? or one in a series?)
- preferred communication mode: does this person learn best through dialogue? looking at pictures? watching another person? getting the "whole picture" or details a little at a time, etc.

Consideration of these factors will guide you in every step that follows:

- Be honest about the death.
- Do not deny, hide, or minimize *what* happened, or *how* it happened.
- Provide as much detail as the person can comprehend. It may be useful to take him/her to see the places and talk to the people where pivotal events occurred.
- Help ask questions. You can figure out how much s/he already knows or understands by asking the person to draw a picture or tell a story, or act out a story with puppets, about the death. Reviewing facts and details is an important step in accepting what happened. The person may want to tell the story over and over.
- Be clear about what's going to happen next.

What is the immediate effect of the loss on this person? Exactly what will happen to the daily routine-- where s/he lives goes to school or work, her friends? Explain any changes (no matter how small) that will need to be made. Give choices wherever possible. Reassure her/him that s/he will continue to be taken care of in the specific ways she is used to, but perhaps by a different person. Then prepare the person for the funeral and mourning activities. Where will she need to go? Who will be coming from far away? What exactly will people be doing and saying?

Include the person in mourning.

Funerals and mourning rituals vary widely across cultures and religions. Provide opportunities for the person to meaningfully participate. There are dozens of ways he/she can contribute. For example, he/she can make a small board or poster of mementos of the deceased person, including photos and small items glued on, with written captions (dictated or actually written by the grieving person). He/she could also select or make a small item to be buried with the lost person. Telling a brief personal story at the memorial might be an option, or dictating it ahead of time to someone who will read it to the larger group. Offer the person a small possession of the deceased, a tangible and special reminder; ideally, the person should select the item as a keepsake.

Help the person express feelings.

Death elicits more than sadness. A person might also experience *anger* at the loss (or at doctors or others), *envy* of other people who don't have the same loss, *guilt* at having contributed to the death in some way, *regret* at actions or words one said or failed to say, *fear* at what lies ahead for the deceased person or oneself, *loneliness*, and many other emotions. Sometimes a person feels the death is a punishment for something he/she did in the relationship. Counseling can aim toward absolving the person of unrealistic guilt, expressing and dissipating anger, and gradually resolving the other distressing feelings.

Sometimes grief is experienced in physical ways, such as nausea, shortness of breath, heavy sighing or overall weakness. Disrupted sleep and eating patterns are common. Help the person understand that sadness is not only a feeling and a thought, but also a bodily reaction. Sadness and loss rarely go away, but with effective support, the person can experience moments of those feelings and still maintain their daily functioning and love of life. Look for other sources of support. If the



deceased person was a teacher, job coach, or counselor, help the grieving person locate and talk to some of the other people who experienced this loss. A group discussion or project (such as a letter to the family or poster collage) can decrease the feeling of *isolation*, or being alone with the loss.

Be alert for behavioral expressions of grief.

The following behaviors may occur for the first time, or increase in frequency or severity:

- social withdrawal
- wandering away
- aggression
- irritability
- self-injury
- loss of interest in preferred activities
- clinging

Return to the normal routines.

This does not mean that the person will feel normal or act normally. It means that life goes on, even when a person is very sad. Help the person to maintain continuity in relationships, routines, and familiar environment. Avoid additional changes in home, work, care providers, and leisure activities. The sadness and other feelings will continue to resurface for many months, both in direct comments and indirectly, such as in anger, withdrawal, distressing dreams, and possibly a reluctance or refusal to trust or get close to other people. Keep "processing" the feelings (acknowledge, express, let go, etc.).

Commemorate the loss.

Anniversaries are not just for birthdays and weddings. When the date of someone's death rolls around again on the calendar, a person can re-experience the grief. Support providers should be alert to emotional and behavioral reactions around this date. Repeating or revisiting the above activities can help. Assist the person in creating a personal ceremony or recognition on the anniversary date. Visiting the grave is an obvious activity for reflection. But consider a life-affirming activity, such as helping the person volunteer time or donate a small amount of money to a cause that was close to the heart of the deceased person. Think about commemorating the person's *life* by creating an anniversary ceremony for his *birthday*.



Symptoms of a Grieving Person

Death of a loved one is something that we will all experience at some time in our life. It is important that you provide support to individuals who are experiencing grief. The symptoms to look for are:

Cognitive responses	<ul style="list-style-type: none"> Disruption of assumptions and beliefs. Questioning and trying to make sense of the loss. Attempting to keep the lost one present. Believing in an afterlife with the lost one as a guide.
Emotional responses	<ul style="list-style-type: none"> Anger, sadness, anxiety Resentment Guilt Feeling numb Unstable emotions Profound sorrow, loneliness Intense desire to restore bond with lost one or object Depression, apathy, despair during phase of disorganization and despair. Sense of independence and confidence as phase of reorganization evolves
Spiritual responses	<ul style="list-style-type: none"> Disillusioned and angry with God Anguish of abandonment or perceived abandonment Hopelessness; meaninglessness
Behavioral responses	<ul style="list-style-type: none"> Functioning automatically Tearful sobbing; uncontrollable crying Great restlessness; searching behaviors Irritability and hostility Seeking and avoiding places and activities shared with lost one. Keeping valuables of lost one while wanting to discard them. Possibly abusing drugs or alcohol Possible suicidal or homicidal gestures or attempts Seeking activity and personal reflection
Physiologic responses	<ul style="list-style-type: none"> Headaches, insomnia Impaired appetite, weight loss Lack of energy Palpitations, indigestion Changes in immune and endocrine system

Resources for More Information:

"Developmental Disabilities and Coping with Grief, Death and Dying", visit the Boggs Center on Developmental Disabilities, Robert Wood Johnson Medical School, University of Medicine and Dentistry of New Jersey web site at:
<http://rwjms.rutgers.edu/boggscenter/projects/documents/EndofLifeResources11.11.11.pdf>

These books were written for children, but may be useful for mental health and other service providers to adapt for older persons:

Lifetimes: The Beautiful Way to Explain Death to Children. B. Mellonie and R. Ingpen. (1983, Bantam Books, Toronto)

When Something Terrible Happens: Children Can Learn to Cope with Grief, by M. Heegaard (1991, Woodland Press, Minneapolis, MN)

"Intellectual disability & Grief Following a Death Loss: Information for Families and Other Caregivers," a booklet by C. Luchterhand published by The Arc. (817) 261-6003, or visit their web site at <http://thearc.org/>

Winter Grief, Summer Grace: Returning to Life After a Loved One Dies by James E. Miller. (1995) Augsburg Press: Minneapolis, MN). This book provides inspirational short passages, photographs, and activities.

Help for the Hard Times: Getting Through Loss by Early Hipp. (1995, Hazelden: Center City, MN) This book features a large print format and cartoon drawings.