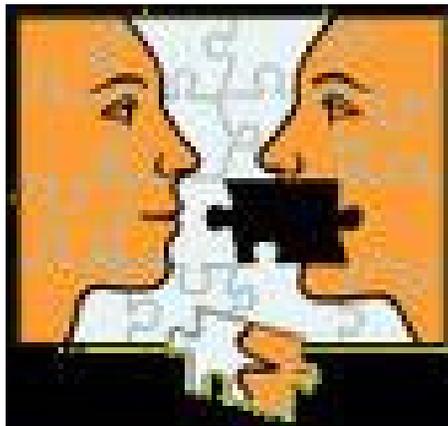




## Human Interaction and Communication



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Submitted by Amy Walker, Self-Advocate/Illinois Voices Systems Change Activist

## Red Light/Green Light

<b>Red Light! Please DON'T...</b>	<b>Green Light! Please DO...</b>
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!

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This module contains information for Direct Support Persons (DSPs) who provide supports in all types of residential living arrangements, including adults and/or to children and young adults living at home with their families and receiving home and community based services through one of the Division of DD's Medicaid Home and Community-Based Service waiver programs. The service delivery methods are participant and family directed. Direct care providers can be employees of the person and his/her family, or employed through community agencies.

### **What You Will Learn In This Module:**

- The communication process.
- How to be an active listener.
- The purpose of communication.
- Communication programs.
- How to determine and support choices.
- How to establish rapport.
- How to recognize and provide support during times of grief.
- The types of communication challenges.
- Augmentative communication devices.
- The difference between control and support.
- How information is transferred among staff
- The importance of consistency and continuity

## PEOPLE FIRST LANGUAGE

People first language is using language that puts the person first and the disability last. Using people first language is important so that we portray as positive a message as possible about people with disabilities.

"Using People First language is not political correctness, instead, it demonstrates good manners, respect, the Golden Rule, and more --- it can change the way we see a person, and it changes the way a person sees himself or herself."

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### Who should use People First Language? Everyone!!!

Staff  
Media  
Family members  
People with disabilities

Following is a set of guidelines, adapted from guidelines prepared by the Research and Training Center on Independent Living at the University of Kansas. The guidelines explain preferred terminology and offer suggestions for appropriate ways to describe people with disabilities. They reflect input from over 100 national disability organizations and have been reviewed and endorsed by media and disability experts.

1. **Do not focus on a disability** unless it is crucial to a situation. Avoid tear-jerking human interest stories about incurable diseases, congenital impairments, or severe injury. Focus instead on issues that affect the quality of life for those same persons, such as accessible transportation, housing, affordable health care, employment opportunities, and discrimination.
2. **Do not portray successful people with disabilities as superhuman.** Even though the public may admire super achievers, portraying people with disabilities as superstars raises false expectations that all people with disabilities should achieve at this level.
3. **Do not sensationalize a disability** by saying afflicted with, crippled with, suffers from, victim of, and so on. Instead say *person who has multiple sclerosis* or *man who had polio*.
4. **Do not use generic labels** for disability groups, such as "the retarded," "the deaf." Emphasize people, not labels. Say *people with intellectual disabilities* or *people who are deaf*.
5. **Put people first**, not their disability. Say *woman with arthritis*, *children who are deaf*, *people with disabilities*. This puts the focus on the persons, not the particular

functional limitation. Crippled, deformed, suffers from, victim of, the retarded, infirm, etc. are never acceptable under any circumstances.

6. **Emphasize abilities**, not limitations. For example: *uses a wheelchair/braces, walks with crutches*, rather than confined to a wheelchair, wheelchair-bound or is crippled. Similarly, do not use emotional descriptors such as unfortunate, pitiful, and so forth. Disability groups also strongly object to using euphemisms to describe disabilities. Some blind advocates dislike partially sighted because it implies avoiding acceptance of blindness. Terms such as handicapped, mentally different, physically inconvenienced, and physically challenged are considered condescending. They reinforce the idea that disabilities cannot be dealt with upfront.
7. **Do not imply disease** when discussing disabilities that result from a prior disease episode. People who had polio and experience after effects years later have a *postpolio disability*. They are not currently experiencing the disease. Do not imply disease with people whose disability has resulted from anatomical or physiological damage (e.g., person with spina bifida or cerebral palsy). Reference to disease associated with a disability is acceptable only with chronic diseases, such as arthritis, Parkinson's disease, or multiple sclerosis. People with disabilities should **never** be referred to as patients or cases unless their relationship with their doctor is under discussion.
8. **Promote that people with disabilities are active** participants of society. We know that persons with disabilities interacting with non-disabled people in social and work environments helps break down barriers and open lines of communications.

## THE IMPORTANCE OF COMMUNICATION

**Everyone communicates!** Your success as a DSP will largely depend on the positive and supportive relationship you establish with the person(s) you provide support to as well as 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 persons 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:

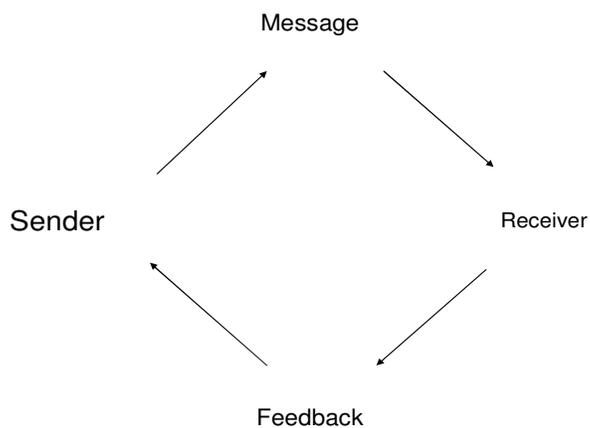
- know the person's preferred communication
- know what a person is able to communicate in all situations
- understand the communication process

Communication takes at least two people. As a result, we are partners with each other and the people we support. We each share a role in the communication process. This process includes:

- a sender
- a receiver
- a message
- feedback

**The chart below can help you** understand how the communication process works. A breakdown in communication can occur at any part of this process.

## Communication A Definition



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

### **Ways We Communicate**

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

Verbal

- 
- 

Nonverbal

- 
-

## **ACTIVITY**

**Your instructor will guide you through the next activity**

### **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, the way they act or behave is 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.

Sometimes this skill 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, it causes difficulties in interpreting the message.

### 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"> <li>▪ Elicit more info about what is causing the anger.</li> <li>▪ Initiate a more interesting activity.</li> </ul>
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; wants 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**

In addition to the tips listed earlier, you should:

- 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.
- Pull up a chair and sit down with the person to whom you are talking with. The person may not be able to stand for long periods or may use a wheelchair for mobility. You will be eye to eye with the person to whom you are having a conversation with.
- 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.
- Customize communication in order to meet the individual needs of the person according to his or her expressed preferences.

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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. These can include:
- Use mini schedules for daily routines (going to the bathroom, getting ready to eat, going to work, etc.)
- Use calendars
- Use picture boards to help with making choices
- Use picture menus

### Where to Start with Visual Supports:

- Decide what the visual supports are supposed to do
- Make the support understandable for the person
- Gather labels, make picture symbols, take photographs
- Make them durable
- Decide on location/framework



## Some Causes of Communication Challenges

The brain is very complex and for many communication disorders we do not yet understand the causes.

A few causes of communication challenges are:

**Hearing impairment** – 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** – 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 Disabilities** – some people (not all) who have intellectual Disabilities, may be slower to learn to talk and may need extra assistance.

**Autism Spectrum Disorder** – will have communication challenges. Many children with Autism or Autism Spectrum Disorder (ASD) have difficulty with social skills and their behavior and conversation 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 speech of others and many times are mistakenly thought to have a hearing problem.

### **How are communication challenges in autism treated?**

If autism or some other developmental disability is suspected, the child's physician will usually refer the child to a variety of specialists, including a speech-language pathologist. This is a professional who performs a comprehensive evaluation of the 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 people who have autism

For some people, verbal communication is a realistic goal. For others, a symbol system such as a picture exchange 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.

## **Sensory Processing and Autism**

Sensory processing is the brain's ability to make sense of the many sensations coming into it. Some people experience sensory processing disorders which can interfere with normal development and learning. Sensory processing problems are associated with conditions such as Autism, Attention Deficit Disorder (ADD), Learning Disabilities and severe and profound Intellectual Disabilities.

Some indicators of disordered sensory processing are:

- Attention problems – distractibility, fixations
- Arousal problems – hypo/hyperactivity

- Avoidance of touch or movement
- Self-stimulation – rocking, pacing, running
- Inflexibility to change
- Unpredictable explosions of emotion

After an evaluation takes place, it is determined what type of sensory input the person may require. **Some people need:**

**Vestibular Input** - such as rolling, jumping, running, etc.

**Proprioceptive Input** - sensory input comes through the persons joints by trained staff/therapists. Activities involve pushing, pulling, lifting

**Tactile Input** - lotion, rubs, vibration, etc.

### **Benefits of Meeting Sensory Processing Needs Include:**

- Decreased need to stimulate or injure self
- Improved ability to pay attention
- Improved social interaction
- Ability to handle distractions easier

Other behavioral characteristics may be present in people who are diagnosed with Autism Spectrum Disorder. These characteristics may also interfere with the communication process.

These may include:

- Decreased use of spoken language
- Poor comprehension of spoken language
- Hand or finger flapping
- Moving objects repetitively before their eyes
- Unusual responses to sound, light, or touch
- Preference for sameness
- Difficulty in transitions from one activity to another
- Concrete vocabulary (poor understanding of concepts and/or figures of speech)
- Limited, repetitive toy play
- Lack of pretend play
- Irrational fears

- Lining up of objects

<b>Sensory</b>	<b>Symptoms</b>
Auditory	<ul style="list-style-type: none"> <li>• Responds negatively to unexpected or loud noises</li> <li>• Holds hands over ears</li> <li>• Cannot walk with background noise</li> <li>• Seems oblivious within an active environment</li> </ul>
Visual	<ul style="list-style-type: none"> <li>• Prefers to be in the dark</li> <li>• Hesitates going up and down steps</li> <li>• Avoids bright lights</li> <li>• Stares intensely at people or object</li> <li>• Avoids eye contact</li> </ul>
Taste/Smell	<ul style="list-style-type: none"> <li>• Avoids certain tastes/smells that are typically part of children's diets</li> <li>• Routinely smells nonfood objects</li> <li>• Seeks out certain tastes or smells</li> <li>• Does not seem to smell strong odors</li> </ul>
Body Position	<ul style="list-style-type: none"> <li>• Continually seeks out all kinds of movement activities</li> <li>• Hangs on other people, furniture, objects, even in familiar situations</li> <li>• Seems to have weak muscles, tires easily, has poor endurance</li> <li>• Walks on toes</li> </ul>
Movement	<ul style="list-style-type: none"> <li>• Becomes anxious or distressed when feet leave the ground</li> <li>• Avoids climbing or jumping</li> <li>• Avoids playground equipment</li> <li>• Seeks all kinds of movement and this interferes with daily life</li> <li>• Takes excessive risks while playing, has no safety awareness</li> </ul>
Touch	<ul style="list-style-type: none"> <li>• Avoids getting messy in glue, sand, finger paint, tape</li> <li>• Is sensitive to certain fabrics (clothing, bedding)</li> <li>• Touches people and objects at an irritating level</li> <li>• Avoids going barefoot, especially in grass or sand</li> <li>• Has decreased awareness of pain or temperature</li> </ul>

<b>Sensory</b>	<b>Symptoms</b>
Attention, Behavior, And Social	<ul style="list-style-type: none"><li>• Jumps from one activity to another frequently and it interferes with play</li><li>• Has difficulty paying attention</li><li>• Is overly affectionate with others</li><li>• Seems anxious</li><li>• Is accident prone</li><li>• Has difficulty making friends, does not express emotions</li></ul>

## **Where Can I Get Additional Information on Autism?**

### **National Institute of Mental Health**

Phone: (301) 443-4513

E-mail: [nimhinfo@nih.gov](mailto:nimhinfo@nih.gov)

Internet: [www.nimh.nih.gov](http://www.nimh.nih.gov)

### **Autism Society of America**

Phone: (301) 657-0881

Toll-free phone: (800)3-AUTISM (28-8476)

Internet: [www.autism-society.org](http://www.autism-society.org)

### **Cure Autism Now (CAN)**

Phone: (323) 549-0500

Toll-free phone: (888)828-8476

E-mail: [info@cureautismnow.org](mailto:info@cureautismnow.org).

Internet: [www.cureautismnow.org](http://www.cureautismnow.org)

### **Autism Research Institute**

Phone: (619)281-7165

Internet: [www.autismresearchinstitute.com](http://www.autismresearchinstitute.com)

### **The Autism Program of Illinois**

Phone: 217-525-8332

Internet: [www.autismprogram.org](http://www.autismprogram.org)

## Hearing Impairments

A person with a hearing impairment 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.

Tips for communicating with persons who are hearing impaired:

- Make sure you get the person's attention before you begin to speak. Just tap the person on the shoulder if they are not facing you.
- Always look directly at the person and try to keep your face in the light away from shadows while you talk.
- Speak clearly in normal tone of voice and avoid chewing gum or smoking while you talk.
- Use short, simple sentences.
- When the person is using a sign language interpreter, don't speak directly to the interpreter. Speak directly to the person.
- If calling a person on the telephone, let the phone ring longer than usual and be prepared to repeat the reason for the call and who you are.
- If you don't have a Text Phone (TTY) you can call 711 to reach the national telecommunications relay service. This service can facilitate the call between you and the person in which you are calling using a TTY.

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## Visual Impairments

A person with visual impairments will 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.

Tips for communicating with persons who are visually impaired:

- Speak to the person when you approach him/her.
- Tell him or her who you are and don't raise your voice
- When talking in a group, remember to identify yourself and the person with whom you are speaking.
- Let the individual know when you are leaving.
- Don't attempt to lead the person without first asking for permission. Then, simply let the person hold onto your arm and let her/him control their movements.

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## Speech Impairments

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.

Tips for communicating with persons with speech impairments:

- If you don't understand something the person says, don't pretend that you do. Ask the individual to repeat what they he/she said and then repeat back to them.
- Take as much time as necessary to communicate and be patient.

- Try to ask questions that require short answers or a nod of the head.
- Concentrate and pay attention to help understand what the person was saying.
- Don't attempt to finish sentences for the person, let them speak for them self.
- After trying to understand the person repeatedly, without success, ask if you can communicate through writing as an alternative.

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## Language Impairments

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. For example, communication challenges affect:

### 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/herself or others. Attention-seeking behaviors may be learned that help him/her meet their needs.

### Examples of behaviors which can cause problems include:

- Aggression
- Self-stimulatory behavior
- Unwillingness to participate
- Withdrawal

**Note: Remember, behavior is a form of communication! It is our job to figure out what the person is trying to communicate!!**

**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.

**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 request. 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.

**Ability to Understand Time**

A person may not be able to understand the concept of time, which involves more than understanding the numbers on a clock. It also affects the understanding of day versus night; before and after; next, past and present; today and the future, etc.

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.

## Communication Tips

### How to help the person communicate more effectively:

- Teach communication skills that are functional and meaningful
- Teach communication in the context of everyday activities
- Provide multiple opportunities for communication practice throughout the day
- Arrange the environment as necessary to create the need to communicate
- Slow down when speaking
- Replace long complex sentences with short simple sentences
- Stress key words
- Use visual supports
- Use object supports
- Be consistent

### Reduce stressful speaking situations by avoiding:

- Frequent interruptions
- Frequent questions
- Excitement when speaking

Adapted from *Resource Directory of Illinois Agencies and Their Services*

## Ten Commandments on Communicating

- 1. Speak directly to the person, rather than through a companion or sign language interpreter who may be present.**
- 2. Offer to shake hands when introduced.**
- 3. Always identify yourself, and others who may be with you, when meeting someone with a visual disability.**
- 4. If you help, wait until the offer is accepted.**
- 5. Treating adults as adults.**

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- 6. Do not lean against or hang on someone's wheelchair.**
- 7. Listen attentively when talking with people who have difficulty speaking and wait for them to finish.**
- 8. Put yourself at eye level when speaking with someone in a wheelchair or on crutches.**
- 9. Tap a person who is hearing destabilized on the shoulder or wave your hand to get his/her attention.**
- 10. Just Relax**

## **TYPES OF RELATIONSHIPS**

The importance of close relationships to our lives is undeniable. We have many types of relationships. These relationships vary in closeness and purpose. One way to think about relationships is to look at them as primarily falling into one of three categories:

- **Paid Service**
- **Family**
- **Friends and Associates**

Explanations of these categories are:

**Paid Services:** Includes anyone paid to provide a service. These relationships typically have very specific purposes, roles, and boundaries. These service providers may not share your same values, beliefs, or interests. People who develop relationships with the people may experience benefits. For example, a regular customer at a restaurant, store, etc. may be treated better than a new customer.

Paid service providers may include the following:

- Health Professionals (doctors, dentists, physical therapists, etc.)  
Cashiers/clerks

Waiters/bartenders  
Gardeners/household help  
Lawyers/Police officers/firefighters/postal workers  
Personal care attendants (direct support professionals, etc.)  
Bus drivers  
Teachers  
Volunteers (Relationships that would typically be paid but are filled by an unpaid person as a method of social contribution.)

**Family:** Family relationships may include the following:

Parent/Stepparent  
Partner/spouse  
Sibling (brother or sister)  
Children/step children  
Cousin  
Niece/nephew  
In-laws  
Grandparent  
Aunt/Uncle  
Family of choice (people who are not related biologically or through adoption, or marriage, but to whom we have made long-term emotional, financial, or other commitments)

Relationships with family members can be broken; however, they usually tend to be more stable and long-term than other types of relationships. In some cases that are governed by legal requirements, this can be the result regardless of personal wishes to maintain a relationship with the person (e.g., child support, alimony, and visitation). There is often a deep-rooted sense of obligation and connection to the other family members despite differences in lifestyle, values, and preferences.

**Friends and Associates:** These are primarily relationships of choice and ones in which are based on desire to connect with the other person. These relationships vary widely in the level of intimacy, types of activities that are shared, time spent, and purpose of interaction. They are typically voluntary and reciprocal, meaning that both members contribute to each other's lives and are free to end or redefine the relationship at any point.

**Associates** are people who spend time together and interact for a commonly defined purpose and may include:

Neighbors  
Coworkers/Supervisors

Members of a social/athletic/charity or other type of group or club

Classmates

Mentors

**Friends** are people who spend time together because they want to and they enjoy each other's company. Friendships usually begin as one of the other types of relationships and evolve into friendships.

Friendships are changeable, beginning, ending, renewing, depending on the needs of the people involved. Like family relationships they are personally defined. Some people have expectations of friends that include the amount of time spent together, the types of activities engaged in, and the level of closeness. Others have few requirements of friendships.

While the needs and definitions of friendships can vary, it is important that these relationships are mutually voluntary and that both people participate and contribute to the relationship over the long term.

When you think about the categories of relationships where does the direct support person fall? Based on your relationships with the people you support, what category do you primarily fit into?

### Talking to People

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 peoples we support, you will be able to empower people to openly communicate with you and others. We should make a special note here about verbal abuse.

As we've discussed in other training courses, you must never verbally abuse a person. This type of mental abuse is defined as harm caused by an act or omission that precipitates emotional distress or maladaptive behavior in the individual, or could precipitate emotional distress or maladaptive behavior, including the use of words, signs, gestures or other actions toward or about and in the presence of individuals.

19. Recognize the ways people communicate and being 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. 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.

28. Speak directly to the individual by putting yourself at eye level.
29. Offer choices!!!!
30. Take your time.

### **Top 10 Things to Remember When Communicating**

10. **Use calendars, schedules, and checklists.** Many people having difficulty in staying on track and organizing their activities, and a visual reminder such as a calendar, schedule or checklist can be very beneficial in helping anticipate upcoming activities.
9. **Organize the environment.** This can be very helpful to 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.
8. **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.
7. **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.
6. **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 the information being communicated as well as processing the information.
5. **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.

4. **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.
3. **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.
2. **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.
1. **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.

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## 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. 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. Following is a guide to assist the DSP in the **Choice Making** process:

1. Observe the individual.
2. Identify opportunities for choice or preference.
3. Assist the individual in developing a range of choices.
4. Recognize the health, safety, financial and risk parameters associated with the choice.
5. Offer opportunities for choice.
6. Show value to the individual's choice.
7. Educate and negotiate when choices are outside of the parameters.
8. Process the choice experience with the individual.
9. Document the choice experience.

### ✓ Right to Express Emotion

As a DSP, there may be times when you will need to assist the person during times of emotional difficulty. You may need to assist the person to find healthy ways to express and deal with their emotions.

## 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?



## TYPES OF SIGN LANGUAGE SYSTEMS

### American Sign Language (ASL)

ASL is the natural language of the Deaf and also the most used form of communication among the Deaf. 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.

### 6. 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.

## Augmentative/Alternative Communication

These are devices that are specially designed, modified, or commercially available off the shelf. A person uses them to augment, assist or expand his/her communication.

### These include:

**Communication boards or books** These can be obtained commercially or home made. They may use letters, numbers, pictures, simple words, objects or other symbols which can be pointed at or isolated by some means by the person. One type of these systems that is commercially available is the PECS system.

**The Picture Exchange Communication System (PECS)** is an augmentative communication system developed to help people quickly acquire a functional means of communication (Bondy and Frost, 1994). PECS is appropriate for individuals who do not use speech or who may speak with limited effectiveness; those who have articulation or motor planning difficulties, etc. This technique was developed for use with young, nonverbal children or children with limited functional speech who have autism or other social communication challenges. Children using PECS are taught to approach and give a picture of a desired item to a communicative partner in exchange for that item.

**Electronic Devices** There are a number of commercially available devices to be used for communication. Some people have the funds to purchase high tech equipment such as tablet-PC like devices with synthetic speech and multiple input options (dynamic display devices such as Dynavox, Mercury etc.); others do not.

**The best non-speech communication strategy** (or combination of strategies) is the one which allows the person with severe communication impairment to communicate as freely as possible, in as many situations as possible, to the maximum number of people.

**Note:** It is important to be familiar with augmentative communication systems for several reasons. You should be able to understand the ways a device is used, and be able to use it yourself to communicate with any person you support. Even if you don't work with anyone at this time who uses an alternative communication device, a familiarity with such systems will enable you to recognize and feel comfortable with people who communicate in these ways should you work with them in the future.

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## DOCUMENTATION

Documentation provides a written record of events, health issues, behavioral progress, and what is important or meaningful to the persons you support. Documentation communicates consistency in supports and continuity of care of people. It ensures that the supports are provided the same way by each staff person. Effective documentation can have an impact on the person's overall quality of life, health status, behavioral progress, strengths and preferences, and other issues. For example, documentation can show if all the DSPs' responses are the same when people have seizures, need help with toileting, handwashing, etc.

Documentation completed over a long period of time provides a history of what has been going on in the person's life and the types of supports he/she has been given. It may show patterns and provide clues to the cause of challenging behaviors.

Documentation provides information that can be transferred among staff members and this can be very important in identifying and responding to many health related issues.

### RESOURCES:

Illinois Assistive Technology Program - [www.iltech.org](http://www.iltech.org)

Picture Exchange Communication System - [www.pecs.com](http://www.pecs.com)

Library Information and Services – [www.eiclearinghouse.org](http://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

*I may not remember what you said to me.*

*I may not remember what you did to me.*

*But, I will never forget how you made me feel!*

Anonymous

## **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*.

Source: <http://npi.ucla.edu/mhdd/INFO/modules/grief.htm>

## 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	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	Anger, sadness, anxiety Resentment Guilt Feeling numb Unstable emotions Profound sorrow, loneliness Intense desire to restore bond with lost one or object Depression, apathy, despairs during phase of disorganization and despair. Sense of independence and confidence as phase of reorganization evolves
Spiritual responses	Disillusioned and angry with God Anguish of abandonment or perceived abandonment Hopelessness; meaninglessness
Behavioral responses	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	Headaches, insomnia Impaired appetite, weight loss Lack of energy Palpitations, indigestion Changes in immune and endocrine system

**Resources for More Information:**

"Managing Grief Better: People With Developmental Disabilities," by S. Hollins, "THE HABILITATIVE MENTAL HEALTHCARE NEWSLETTER" May/ June 1995, Vol. 14, No. 3 and at <http://thearc.org/faqs/grief.html>

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 Disabilities & 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.