



MODULE 1 DSP NOTEBOOK



INTRODUCTION TO DEVELOPMENTAL DISABILITIES

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INTRODUCTION

Dear New DSP,

Welcome and congratulations on your new job! We want you to know that when you start working here, you will be working with people with many different hopes, dreams, abilities, disabilities, and personalities. We want you to treat us all fairly, equally, and with respect.

When you work with us, we don't want you to judge us by our disabilities, pick favorites, or nag us. You are not our parent, and we want to be treated like people. We would like you to give us more support in learning new skills and information, learning how to become a better person, and learning how to make choices for ourselves.

Lastly, we would like you to treat us the way you would like to be treated.

Sincerely,

Self-Advocates

* Adapted from a letter written by self-advocates at Sertoma Centre in Alsip, Illinois.

DIRECT SUPPORT PERSONS' ROLES AND RESPONSIBILITIES

For a variety of reasons, the role of the DSP has evolved in the past 40 years. The reasons include changes in funding sources, public policy, social values and the disability movement which advanced the services to a higher quality level.

During the institutional era, DSPs were usually called an "attendant." Often, there were too few of them to provide any kind of individualized training with the supports that would help people learn the skills they needed to become more independent. In many cases, there was only one staff person to 40-50 people, so even keeping people clean and nourished was difficult. In those days, workers were just expected to be passive caretakers, not teachers. This was in part due to the idea that individuals could not develop beyond their "fixed disability."

As the service delivery system continues to shift from large, institutional settings to smaller community-based group home settings (such as CILAs that house 8 or fewer people) DSPs are required to "wear many hats" with job roles such as cook, driver, housekeeper, teacher, and personal care attendant.

Today, the DSP assists the people they support to lead self-directed lives and to participate fully in the community. The DSP encourages attitudes and behaviors that enhance community inclusion.

One important role of the DSP is the ability to recognize and support the talents, choices and preferences of each person. The DSP is called upon to create and ensure community connections and assist people in living their lives as full citizens. This requires DSPs to provide supports that teach people the skills needed to participate in the community, as independently and fully as possible.

DSPs educate individuals so they can make informed decisions. They listen to what individuals choose and support them in attaining it.

DSPs train individuals on ways to advocate for themselves. They support individuals in achieving their goals, rather than achieving the goals for them.

The DSP reports any possible violations of abuse, neglect or any other type of harm to the authorities and team members. They train individuals to recognize, avoid, and respond to possible abuse and harmful events.



DSPs explore an individual's strengths and build supports to help the individual achieve their goals. They analyze barriers that keep people from participating in their communities and plan with community members and those they support about ways to eliminate the barriers.

The job of a DSP is complex, engaging and critically important to the quality of life for those whom they help support. Some examples of your responsibilities may include:

- Assisting and teaching individuals with daily living skills and daily personal care routines: (e.g., health, grooming, eating) and personal management needs (e.g., human development, human sexuality) by teaching skills, providing supports, and building on individual strengths and capabilities.
- Assisting with household management (e.g., meal preparation, laundry, cleaning, decorating) and maximizing people's skills, abilities and independence.
- Dealing with challenging behaviors that the people you support may demonstrate; striving to understand the difference between "behaviors" and mental health issues.
- Making sure incidents of abuse, neglect and exploitation that you observe, or have knowledge of, are reported to OIG within 4 hours.
- Immediately reporting ethical violations you witness, or have knowledge of, to supervisors.
- Promoting a partnership between yourself and the people you support by consulting with him/her and involving him/her in the support process; talking about what things they enjoy doing in the community and what they like to do for fun. Joining in with them in those fun activities if possible.
- Providing opportunities for people to be self-advocates by encouraging and assisting them to speak on their own behalf about living arrangements, work, and social relationships.
- Recognizing the importance of friends, family and community relationships to the people you support.
- Maintaining a collaborative professional relationship with the person supported and all support team members (including family/friends).
- Following ethical standards of practice (e.g., confidentiality, informed consent, etc.)
- Being aware of cultural, religious, racial, disability, and gender issues that could affect your daily practices and interactions with the people you support.
- Knowing the requirements for documentation in your organization and managing these requirements efficiently.
- Following HIPAA laws and requirements.



What Are Ethics?

Dictionary definitions of ethics include common themes such as:

- They are a system of moral principles.
- They are principles of conduct governing a person or a group.
- They are a guiding philosophy.



Today's Ethics

People with developmental disabilities continue to receive unethical treatment even today. Unfortunately, we regularly hear or see stories about people being beaten, sexually abused, neglected and financially exploited.

Ethics and the Direct Support Person

The DSP needs to be aware of and report any suspected abuse, neglect or financial exploitation of people that they help support. But, you also need to be aware of the more subtle ethical situations that may present themselves. These issues deal with how people are treated and receive supports in everyday, routine situations. DSPs must understand how to recognize and deal with these subtle ethical situations.

Some examples of these subtle situations include:

- Speaking in a harsh tone to an individual who has just spilled their juice all over the table.
- Using "if" statements on a regular basis – "If you don't clean your room you won't be able to go shopping."

Direct support ethics are guidelines. They are principles and values developed for and used by the profession.



The National Alliance of Direct Support Professionals (NADSP) Guiding Principles

NADSP, a non-profit organization, has developed a national agenda to strengthen the direct support workforce and address the guiding principles listed below. They can help DSPs make the right decisions regarding ethical dilemmas and guide them in their day-to-day work. This is critical for providing quality supports for persons served.

Person-Centered Supports. As a DSP, my first allegiance is to the person I support; all other activities and functions I perform flow from this allegiance.

Promoting Physical and Emotional Well-Being. As a DSP, I am responsible for supporting the emotional, physical, and personal well-being of the individuals receiving support. I will encourage growth and recognize the autonomy of the individuals receiving support while being attentive and energetic in reducing their risk of harm.

Integrity and Responsibility. As a DSP, I will support the mission and vitality of my profession to assist people in leading self-directed lives and to foster a spirit of partnership with the people I support, other professionals, and the community.

Confidentiality. As a DSP, I will safeguard and respect the confidentiality and privacy of the people I support.

Justice, Fairness and Equity. As a DSP, I will promote and practice justice, fairness, and equity for the people I support and the community as a whole. I will affirm the human rights, civil rights and responsibilities of the people I support.

Respect. As a DSP, I will respect the human dignity and uniqueness of the people I support. I will recognize each person I support as valuable and help others understand their value.

Relationships. As a DSP, I will assist the people I support to develop and maintain relationships.

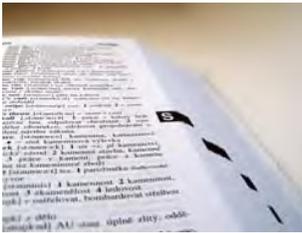
Self-Determination. As a DSP, I will assist the people I support to direct the course of their own lives.

Advocacy. As a DSP, I will advocate with the people I support for justice, inclusion, and full community participation.

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AGENCY-SPECIFIC JOB DESCRIPTION

**INSERT YOUR AGENCY-SPECIFIC
DSP JOB DESCRIPTION HERE**



Developmental Disability Definitions

A person is determined to have a developmental disability if **at least one of the two following conditions exists:**

Intellectual disability

This refers to significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested before the age of 18 years. Significantly sub-average is defined as an intelligence quotient (IQ) of 70 or below on standard measures of intelligence.

Related Condition

This is a severe, chronic disability that meets all of the following conditions:

It is attributable to-

- Cerebral palsy or epilepsy; or any other condition, other than mental illness, found to be closely related to an intellectual disability because this condition results in an impairment of general intellectual functioning or adaptive behavior similar to that of persons with intellectual disability, and requires treatment or services similar to those required for these persons.
- It is manifested before the individual reaches age 22.
- It is likely to continue indefinitely.
- It results in substantial functional limitations in three or more of the following areas of major life activity:
 - Self-care (taking care of their own basic needs);
 - Language (communicating with others);
 - Learning (ability to learn new things);
 - Mobility (getting from place to place);
 - Self-direction (motivating and guiding themselves through daily living activities);
 - Capacity for independent living (living independently including ability to earn enough money to live on).
- Children can be classified as having a developmental disability if it seems they will have these problems when they get older.

You may notice that some persons may have a diagnosis of cerebral palsy, epilepsy, or autism spectrum disorder and are not considered to be developmentally disabled. That's because if an individual has been diagnosed with cerebral palsy, epilepsy, or autism spectrum disorder, but not an intellectual disability **and** the disability is not considered to have created a **substantial handicap**, then it **cannot** be considered a developmental disability

Intellectual disabilities are the most common of the developmental disabilities, but not everyone with a developmental disability has an intellectual disability. A developmental delay occurs when the child has not reached the milestones indicated for their age group. You can read more on this topic at <http://www.med.umich.edu/1Libr/yourchild/devmile.htm>

For example, if the normal age range in which a child learns to walk is between 9 and 15 months, and the child has not begun walking by 20 months, this would be considered a developmental delay. A child can be diagnosed with a developmental delay if the child is between the ages of 3 and 9 years.

A child with a developmental disability, on the other hand, has limitations in three or more life areas (self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; or economic self-sufficiency) acquired before age 22, and these limitations are expected to continue indefinitely.

What is an Intellectual Disability?

Intellectual disability is defined as low intelligence (determined by the use of IQ tests) with impairment in adaptive behavior. This condition must begin before the age of 18 in order for the person to be considered to be intellectually disabled.

Some people with intellectual disability may:

- Have limited intellectual functioning
- Learn new things more slowly
- Have limited physical coordination
- Have increased medical issues

The general types and levels of intellectual disability you may encounter are described below:

TERM:	EQUIVALENT IQ RANGE
Mild	50 - 55 to about 70
Moderate	35 - 40 to 50 - 55
Severe	20 - 25 to 35 - 40
Profound	Below 20 - 25

Mild

People with I.Q. scores from about 50 to about 70, having substantial difficulties in at least two areas of adaptive behavior and having those difficulties first evidenced in a developmental period before adulthood are classified as having mild intellectual disability. Females are less likely than males to be identified with mild intellectual disability. Children are identified as having mild intellectual disability much more often than adults. These children often struggle with schoolwork.

Typically, persons in this category:

- Usually can attain academic skills up to about the sixth grade level.
- Can usually achieve vocational skills necessary for minimum self-support.
- Take care of all personal grooming needs.
- Can get around their neighborhood without difficulty, but cannot travel to another unfamiliar area of town by him/herself.
- Communicate complex ideas verbally.
- Participate in recreation.
- May need guidance handling money.
- Can have a career or hold a job.

About 85% of persons diagnosed as intellectually disabled are considered to be in the “Mild” range.

Moderate

People who have an I.Q. score of about 35 to about 55 are classified as having moderate intellectual disability. People with moderate intellectual disability usually have substantial adaptive behavior problems in several areas. Most persons who have moderate intellectual disability are first diagnosed with this classification in the preschool years. People with moderate intellectual disability can often learn important self-care, domestic, work and other skills; however, complete independence is not usually achievable.

Typically, persons in this classification:

- Can learn to talk or communicate, but have poor awareness of social conventions.
- Can take care of themselves with moderate supervision or less.
- Can feed, wash and dress them self; select own clothing, comb/brush own hair; prepare simple food.
- Can speak clearly and distinctly; carry on simple conversations; read words, ads, signs and simple sentences.
- Can interact cooperatively with others
- Can make minor purchases
- Can prepare foods that require mixing

About 10% of persons diagnosed as intellectually disabled are considered to be in the “Moderate” range.

Severe

People who are identified as having severe intellectual disability have IQ scores ranging from about 20 to about 40. They also have significant limitations in all areas of adaptive behavior.

People with severe intellectual disability are usually identified in first two years of life and their disability continues throughout their life. Their language and ability to communicate is usually limited; however their understanding is often better than their speaking abilities. These persons often have medical issues such as seizure disorders.

Typically, persons with this classification:

- Have deficits in motor development and speech.
- Have little or no communication skills.
- Use a spoon and fork adequately, but need help cutting with a knife.
- Can dress themselves, but cannot tie shoes
- Can indicate the need to use the restroom.
- Can wash their hands and face, but need assistance in bathing.
- Can recognize some words, but do not really read.
- Know money has value, but do not know the values of different coins.
- Can help with simple housekeeping tasks.
- Can attend to tasks for 10 minutes or more and make effort to carry out responsibilities.

About 3-4% of persons diagnosed as intellectually disabled are considered to be in the “Severe” range.

Profound

Profound intellectual disability is a classification applied to people with IQ scores between 0 and about 25. Skills vary, ranging from high and low ends of the profound disability range, but all persons within this range have major limitations in all areas of adaptive behavior. Most persons with profound intellectual disability are identified as having major disabilities in their first year of life. Significant physical and health conditions are also very common.

Typically, persons with this classification:

- Have sensory motor deficits that are obvious at an early age.
- Usually develop minimal self-care and communication skills.
- Require a highly structured environment with constant support and supervision.
- Can use spoon and fork, but often spill food
- Can put on skirt and pants, but needs help buttoning and zipping clothes
- May need assistance when using the restroom
- Can wash hands, but not very well
- Can use many gestures for communication
- Understands simple verbal communications
- Participates in group activities and can interact with others in simple play
- Do not know that money has value

About 1%-2% of persons diagnosed as intellectually disabled are considered to be in the "Profound" range.

Note: It is important to remember that new skills can be learned regardless of a person's IQ.



What is Adaptive Behavior?

The term "**adaptive behavior**" is used in the field of developmental disabilities. It means:

- The ability to function in everyday living areas such as self-help, social abilities and mobility.
- Activities the individual uses to cope with the natural and social demands of the environment which include feeding, dressing, toileting, and higher-level social interaction skills.

Examples:

–When the alarm goes off, I start getting ready for work.

(Doesn't need to be able to tell time)

–I need 2 coins that match this picture to buy a soda.

(Doesn't need to know how to count change)

–I place a screw in each of the squares on this card and then put them in a bag and staple it shut.

(Doesn't need to know how to count)



Why Do Some People Have an Intellectual Disability?

Some causes of intellectual disability are:

- Problems before birth
- Lack of adequate prenatal care
- Problems during pregnancy
- Diseases: measles, syphilis, HIV, etc.
- Alcohol/drug use/smoking by mothers or fathers (fetal alcohol syndrome/cocaine addicted babies, etc.)
- At birth problems/delivery complications
- Low birth weight
- Premature delivery
- Lack of oxygen
- Childhood infections
- Spinal meningitis, encephalitis, etc.
- Childhood injuries
- Accidents: cars, bikes, falls, lead poisoning, near drowning
- Abuse/neglect: shaken baby, malnutrition
- Poverty/Cultural Deprivation
- Genetic Disorders
- Down syndrome, phenylketonuria (PKU), Fragile X

Things that can be done to help Prevent Intellectual Disability:

- Pregnancy pre-screening tests
- Genetic counseling
- Improved pre-natal care, including avoiding smoking, drinking and drugs
- Improved childhood health care, including immunizations
- Consistent use of car safety belts and bike helmets
- Elimination of lead paint in house
- Parent education: health care, parenting skills, anger control, etc.

Mental Health Problems/Mental Illness**Are Intellectual Disability and Mental Illness the Same Thing?****No.**

A mental health disability implies psychiatric/psychological issues with behavior and emotions. Intellectual disability refers to the brain's ability to process information that is learned from the environment and its attempt to make sense of it. Intellectual disability is not a mental health disability and mental health disabilities are not intellectual - although they can occur together.

Mental health problems are severe disturbances in behavior, mood, thought processes and/or interpersonal relationships. The types of psychiatric disorders persons with intellectual or developmental disabilities experience are the same as those seen in the

general population, although the individual's life circumstances or level of intellectual functioning may alter the appearance of the symptoms.

Some of the common types are:

Thought Disorders

Schizophrenia is a disorder characterized by disorganized thought processes.

- Means “split mind” NOT “split personalities” or “multiple personalities”
- Emerges in late teens, twenties.
- Symptoms of Schizophrenia include:
 - Disorganized thoughts/speech
 - Inappropriate or flat emotions/affect
 - Avolition, lack of motivation
 - Lack of insight into illness
 - Hallucinations (seeing, hearing, smelling, feeling things that aren't there)
 - Delusions (believing things others don't believe)
 - Paranoia
- [Symptoms can come and go in cycles]
- Differentiating Schizophrenia. . .
- Use caution with:
 - Developmentally appropriate self-talk
 - Imaginary friends/fantasy play
- May be confused with hallucinations or delusions, in particular with clients with Down Syndrome or Autism Spectrum Disorder

Mood Disorders

Mood Disorders are disorders characterized by:

- Longer periods (than normally experienced) of marked shifts in emotional state
- Significant impairment in functioning
- Components of mood disorders are depression and/or mania.
- Depression
- Symptoms include:
 - Feeling excessively down, sad
 - Tearfulness
 - Trouble sleeping/sleeping too much
 - Not eating/over-eating
 - Loss of interest/pleasure in everyday activities
 - Trouble concentrating
 - Lack of goal-directed behavior
 - Irritability

Bipolar Disorder

- Periods of depression alternating with periods of mania
- Sometimes longer, slower and sometimes more rapid, drastic swings
- Presentation varies greatly.

Differentiating Bipolar Disorder

Some things can be difficult to attribute to MR, bipolar, or just a bad day:

- Poor judgment
- Distractibility
- Excessive activity

The key is to compare current behavior with previous functioning. Look for deviations from what was previously exhibited.

Anxiety Disorders

Anxiety Disorders are disorders characterized by:

- Avoidance of certain stimuli
- Autonomic arousal (feeling “hyper,” “anxious,” “shaky”)
- Excessive motor activity
- Agitation

Mania

Symptoms include:

- Feeling unusually high, elated
- Very fast, pressured speech
- Trouble staying on task, in one place
- Excessive motor activity
- Increased risk-taking, impulsive behaviors
- Irritability and/or aggressiveness
- Hyper sexuality.

Phobias

A phobia is a type of anxiety disorder. It is a strong, irrational fear of something that poses little or no actual danger. There are many specific phobias.

People with phobias try to avoid what they are afraid of. If they cannot, they may experience:

- Panic and fear
- Rapid heartbeat
- Shortness of breath
- Trembling
- A strong desire to get away.

Generalized Anxiety Disorder has the following symptoms:

- Excess anxiety and worry that is out of proportion to the situation
- Difficulty controlling the worry
- Restlessness or feeling keyed up or "on the edge"
- Being easily tired
- Difficulty concentrating
- Irritability
- Muscle tension -- shakiness, headaches
- Sleep disturbance (difficulty falling or staying asleep; or restless, unsatisfying sleep)
- Excessive sweating, palpitations, shortness of breath, and stomach/intestinal symptoms

PTSD (Post Traumatic Stress Disorder)

Post-traumatic stress disorder (PTSD) is a real illness. You can get PTSD after living through or seeing a traumatic event, such as war, a hurricane, rape, physical abuse, or a bad accident. PTSD makes you feel stressed and afraid after the danger is over. It affects your life and the people around you.

PTSD can cause problems like:

- Flashbacks, or feeling like the event is happening again
- Trouble sleeping or nightmares
- Feeling alone
- Angry outbursts
- Feeling worried, guilty or sad

PTSD starts at different times for different people. Signs of PTSD may start soon after a frightening event and then continue. Other people develop new or more severe signs months or even years later. PTSD can happen to anyone, even children.

Personality Disorders

Personality Disorders can be defined as: Enduring patterns of inner experience and outward behavior that deviate markedly from the expectation of the individual's culture. This isn't people just being "odd" or "difficult," it is:

- maladaptive
- disruptive to social, occupational, relationships
- pervasive and inflexible
- stable over time
- leads to distress or impairment

Symptoms vary widely depending on the specific type of personality disorder. Treatment usually includes talk therapy and sometimes medicine. There are many types of personality disorders. Some of them are listed below:

Borderline Personality Disorder

Symptoms include:

- Effects mood, self-image, relationships
- Mood changes quickly, easily enraged
- Create a crisis or act out in a crisis to put focus back on them
- Emotional or angry outbursts

Impulsive behavior

- Self-injury/harm
- Manipulation
- Overly dramatic, hostile, friendly
- Moves into serious relationships very quickly, moves between relationships very quickly

Avoidant

People with avoidant personality disorder are preoccupied with their own shortcomings. They form relationships with others only if they believe they will not be rejected. Loss and rejection are so painful that these people will choose to be lonely rather than risk trying to connect with others.

A person with avoidant personality disorder may:

- Be easily hurt by criticism or disapproval
- Hold back too much in intimate relationships
- Be reluctant to become involved with people
- Avoid activities or occupations that involve contact with others

- Be shy in social situations out of fear of doing something wrong
- Exaggerate potential difficulties
- Hold the view they are socially inept, inferior, or unappealing to other people

Dependent

Dependent personality disorder usually begins in childhood. However, the cause of this disorder is unknown. It is one of the most common personality disorders, and is equally common in men and women.

People with this disorder do not trust their own ability to make decisions. They may be devastated by separation and loss. They may go to great lengths, even suffering abuse, to stay in a relationship.

A person with dependent personality disorder may:

- Be extremely Have difficulty making decisions without reassurance from others
- Have problems expressing disagreements with others
- Avoid personal responsibility
- Avoid being alone
- Feel devastated or helpless when relationships end
- Be unable to meet ordinary demands of life
- Become preoccupied with fears of being abandoned
- Be easily hurt by criticism or disapproval
- passive in relations with other people

Schizoid

A person with schizoid personality disorder:

- Appears aloof and detached
- Avoids social activities that involve significant contact with other people
- Does not want or enjoy close relationships, even with family members

Anti-Social

The cause of antisocial personality disorder is unknown. Genetic factors and child abuse are believed to contribute to the development of this condition. People with an antisocial or alcoholic parent are at increased risk. Far more men than women are affected. The condition is common in prison populations. Fire-setting and cruelty to animals during childhood are linked to the development of antisocial personality.

A person with antisocial personality disorder:

- Breaks the law repeatedly
- Lies, steals, and fights often
- Disregards the safety of self and others
- Does not show any guilt

To receive a diagnosis of antisocial personality disorder, a person must have shown behaviors of conduct disorder during childhood.

People with **antisocial personality disorder** may have the following signs:

- Anger and arrogance
- Capable of acting witty and charming
- Good at flattery and manipulating other people's emotions
- Substance abuse and legal problems

Obsessive-Compulsive Disorder (OCD) and Related Disorders

- Obsessive, intrusive thoughts; sometimes relieved only by engaging in repetitive, ritualistic behavior (only temporarily relieves anxiety)
- Overwhelming need to have things a certain way

Symptoms may include:

- Hand washing
- cleaning/fear of germs
- hoarding
- touching in patterns/#s



What is a Dual Diagnosis?

Within the field of Developmental Disabilities, people with a “Dual Diagnosis” are those who have both a developmental disability along with a mental illness. Persons with a dual diagnosis can be found at all ages and levels of intellectual and adaptive functioning. Adaptive functioning includes such real life skills such as grooming, dressing, safety, safe food handling, school rules, ability to work, money management, cleaning, making friends, and personal responsibility.

In addition, individuals with intellectual disability often exhibit several different behavioral problems. The “dual diagnosis” is often missed because the person’s behavior is attributed to the developmental disability. These behaviors include pica (eating of nonnutritive substances), smearing feces, and destructive behaviors such as aggression directed at others, property destruction, and self-injurious behavior. As a result, the dual diagnosis may not be made in a timely manner.

What Treatments are Available?

Many experts agree that treatment requires a comprehensive plan with several components. After a thorough medical and neurological evaluation is made, a psychiatric evaluation can determine if medication is appropriate. Follow-up interviews are required to monitor the individual’s response to the various treatments.

Treatments for a dual diagnosis can include:

- **Medication:** (called psychopharmacology): Medication treatment is appropriate for many psychiatric disorders (such as mood disorders and psychotic disorders.) This treatment should be only a part of a comprehensive plan.
- **Therapy (called psychotherapy):** Individual or group therapy may be included in the treatment plan. Group therapies can include skills training such as social skills, assertiveness and anger management training.
- **Behavior Management:** Behavior management plans are developed to deal with problem behaviors and to teach adaptive skills. A functional analysis of behavior is conducted to determine the best approaches to use in the behavior plan. The person who is dually diagnosed is encouraged to participate in the design of the behavioral program.

Autism Spectrum Disorder



Autism spectrum disorder (ASD) is a condition that can cause significant social, communication and behavioral challenges. People with ASD handle information in their brain differently than other people. For example, people with ASD might repeat certain behaviors and might not want change in their daily routines. Many people with ASD also have different ways of learning, paying attention, or reacting to things. The disorder begins during early childhood and lasts throughout a person's life.

Social Skills

ASD can affect each person in different ways and can range from mild to severe. People with ASD share some similar symptoms, such as problems with social interaction. But there are differences in when the symptoms start, how severe they are, and the exact nature of the symptoms.

Some people with ASD might not be interested in other people at all. Others might want friends, but not understand how to develop friendships.

People with ASD might have problems with showing or talking about their feelings. They might also have trouble understanding other people's feelings. Many people with ASD are very sensitive to being touched and might not want to be held or cuddled. Self-stimulatory behaviors (e.g., flapping arms over and over, etc.) are common among people with ASD. All of these symptoms can make other social problems even harder to manage.

Other examples of social issues related to ASD:

- Not play “pretend games” (like feeding a doll)
- Avoids eye contact
- Has “flat” or inappropriate facial expressions
- Avoids or resists physical contact
- Does not share interests with others
- Is not comforted by others during distress
- Be very interested in people, but not know how to talk, play or relate to them

Communication

Each person with ASD has different communication skills. Some people can speak well. Others can’t speak at all or only very little.

People with ASD who do speak might use language in unusual ways. Some people with ASD say only one word at a time. Others repeat the same words or phrases over and over. Some people repeat what others say, a condition called *echolalia*.

People with ASD might have a hard time using and understanding gestures, body language or tone of voice. For example, people with an ASD might not understand what it means to wave goodbye. Facial expressions, movements and gestures may not match what they are saying. For instance, people with ASD might smile while saying something sad.

Other examples of communication issues related to ASD:

- Has trouble expressing needs in typical words or motions
- Appears to be unaware when other people talk to them but respond to other sounds
- Gives unrelated answers to questions
- Does not point to or respond to pointing
- Does not understand jokes, sarcasm, or teasing
- Reverses pronouns (e.g., says “you” instead of “I”)
- Talks in a flat, robot-like, or sing-song voice

Unusual Interests and Behaviors

Repetitive motions are actions repeated over and over again. They can involve one part of the body or the entire body or even an object or toy. For instance, people with ASD might spend a lot of time repeatedly flapping their arms or rocking from side to side. They might repeatedly turn a light on or off or spin the wheels of a toy car. These types of activities are known as self-stimulation.

People with ASD often thrive on routine. A change in the normal pattern of the day – like a stop on the way home from home or school- can be very upsetting to people with ASD. They might “love control” and have a “melt down” or tantrum, especially if in a strange place.

Some people with ASD might develop routines that might seem unusual or unnecessary. For example, a person may want to look into every window that he or she walks by. Not being allowed to do these types of routines might cause severe frustration and tantrums.

Other examples of unusual interests and behaviors related to ASD:

- Lines up objects
- Has to follow certain routines
- Has obsessive interests
- Gets upset by minor changes

Centers for Disease Control and Prevention; [Signs & Symptoms, Autism Spectrum Disorder], www.cdc.gov 2013.

Sensory Processing and ASD

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 disability.



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, a determination is made about 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 person's joints by trained staff/therapists. Activities involve pushing, pulling, and 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.

Sensory	Symptoms
Auditory	<p>Responds negatively to unexpected or loud noises</p> <p>Holds hands over ears</p> <p>Cannot walk with background noise</p> <p>Seems oblivious within an active environment</p>
Visual	<p>Prefers to be in the dark</p> <p>Hesitates going up and down steps</p> <p>Avoids bright lights</p> <p>Stares intensely at people or object</p> <p>Avoids eye contact</p>
Taste/Smell	<p>Avoids certain tastes/smells that are typically part of children's diets</p> <p>Routinely smells nonfood objects</p> <p>Seeks out certain tastes or smells</p> <p>Does not seem to smell strong odors</p>
Body Position	<p>Continually seeks out all kinds of movement activities</p> <p>Hangs on other people, furniture, objects, even in familiar situations</p> <p>Seems to have weak muscles, tires easily, has poor endurance</p> <p>Walks on toes</p>
Movement	<p>Becomes anxious or distressed when feet leave the ground</p> <p>Avoids climbing or jumping</p> <p>Avoids playground equipment</p> <p>Seeks all kinds of movement and this interferes with daily life</p> <p>Takes excessive risks while playing, has no safety awareness</p>
Touch	<p>Avoids getting messy in glue, sand, finger paint, tape</p> <p>Is sensitive to certain fabrics (clothing, bedding)</p> <p>Touches people and objects at an irritating level</p> <p>Avoids going barefoot, especially in grass or sand</p> <p>Has decreased awareness of pain or temperature</p>

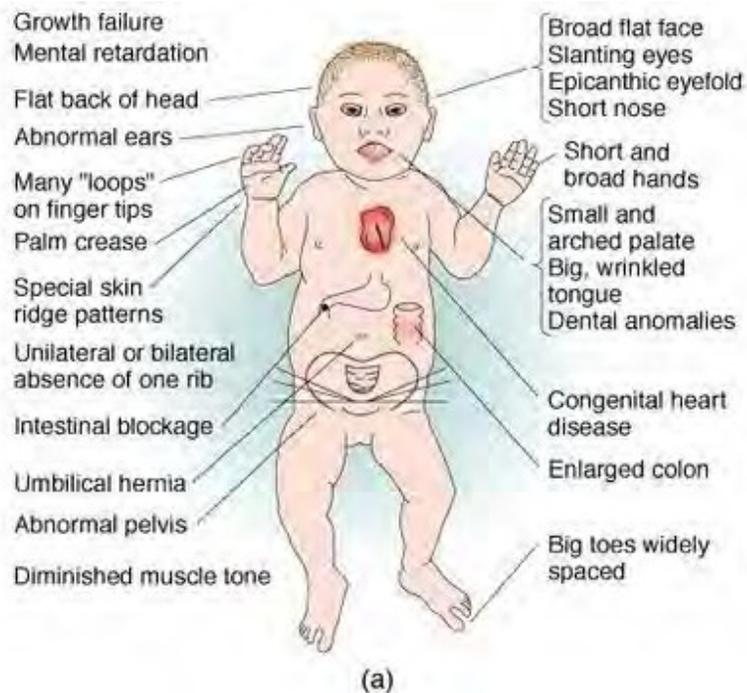
Sensory	Symptoms
Attention, Behavior And Social	Jumps from one activity to another frequently and it interferes with play Has difficulty paying attention Is overly affectionate with others Seems anxious Is accident prone Has difficulty making friends, does not express emotions

Down Syndrome

Down syndrome is a condition in which a baby is born with an extra chromosome. Chromosomes are small “packages” of genes in the body. They determine how a baby’s body forms during pregnancy and how, as the baby grows in the womb and after birth, the baby’s body functions. Normally, a baby is born with 46 chromosomes. Babies born with Down syndrome have an extra copy of one of these chromosomes. This extra copy changes the body’s and brain’s normal development and causes mental and physical problems for the baby.

Even though people with Down syndrome might have some physical and mental features in common, symptoms of Down syndrome can range from mild to severe. Usually, mental development and physical development are slower in people with Down syndrome than in those without it. Some common physical signs of Down syndrome include:

- A flat face with an upward slant to the eye, a short neck, small ears, and a large tongue
- Tiny white spots on the iris (colored part) of the eye
- Small hands and feet
- A single crease across the palm of the hand
- Small pinky fingers that sometimes curve toward the thumb
- Poor muscle tone or loose ligaments



How often does Down syndrome occur?

CDC (Centers for Disease Control) estimates that each year about 3,357 babies in the United States are born with Down syndrome. In other words, about 13 of every 10,000 babies born in the United States each year is born with Down syndrome.

What problems do people with Down syndrome have?

Babies and adults with Down syndrome can have physical problems, as well as intellectual disabilities. Every baby born with Down syndrome is different. In addition to the physical signs, some might have major birth defects or other medical problems. However, many people with Down syndrome live happy, productive lives well into adulthood.

Still, some physical problems associated with Down syndrome include:

- A birth defect of the heart
- Stomach problems, such as a blocked small intestine
- Celiac disease, a digestive disease that damages the small intestine so that nutrients from food are not absorbed well
- Problems with memory, concentration, and judgment, often called dementia
- Hearing problems
- Eye problems, such as cataracts or trouble seeing objects that are close by (far-sighted)

- Thyroid problems
- Skeletal problems

A person with Down syndrome can have an IQ in the mild-to-moderate range of intellectual disabilities. He or she also might have delayed language development and difficulties with physical coordination.

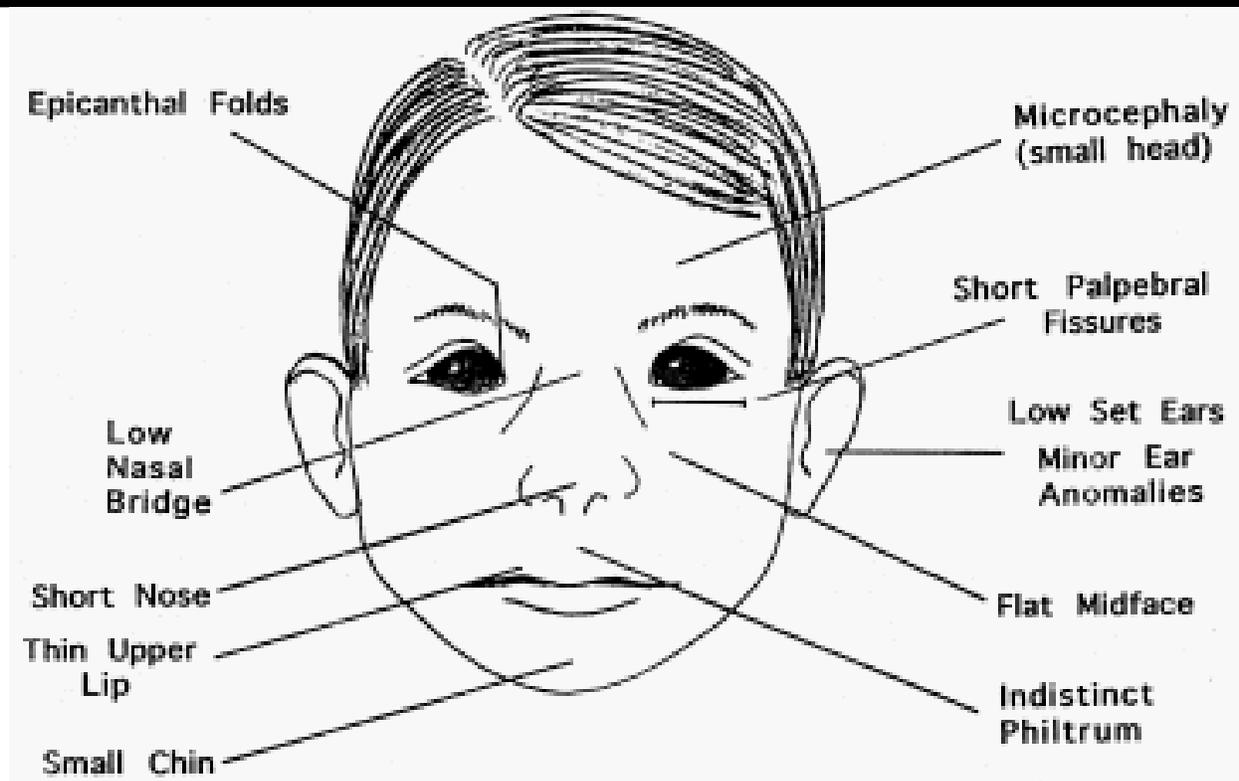
What causes Down Syndrome?

To understand Down syndrome, it is necessary to understand how a baby develops. Each baby starts developing when he or she receives 23 chromosomes from the mother's egg and 23 chromosomes from the father's sperm. When a baby has Down syndrome, an error happened when either the egg or the sperm was formed. This error caused an extra chromosome (called chromosome number 21) in the egg or sperm, so that the baby received a total of 24 instead of 23 chromosomes from one of its parents. Therefore, the baby ends up having 47 chromosomes in every cell of his or her body, instead of 46 chromosomes. This extra chromosome causes the physical signs and additional problems that can occur among people with Down syndrome. The cause of the errors that produces the extra chromosome is not known.

The age of the mother is the only factor that has been shown to increase the risk of having a baby with Down syndrome. This risk increases with every year, especially after the mother is 35 years of age. However, because younger women are more likely to have babies than older women, 80% of babies with Down syndrome are born to women younger than 35 years of age.

CDC works with many researchers to study the risk factors that can increase the chance of having a baby with Down syndrome. Following are examples of what this research has found:

- The number of babies with Down syndrome seems to be increasing, especially among mothers older than 35 years of age.
- Certain factors seem to influence how long a person with Down syndrome will live, including ethnicity, low weight at birth, and whether the baby was born with a heart defect. Death rates among Black or African-American infants with Down syndrome seem to be higher than death rates among White infants with Down syndrome.



Fetal Alcohol Spectrum Disorders

What are Fetal Alcohol Spectrum Disorders?

Fetal alcohol spectrum disorders (FASDs) are a group of conditions that can occur in a person whose mother drank alcohol during pregnancy. These effects can include physical problems and problems with behavior and learning. Often, a person with an FASD has a mix of these problems. FASDs refer to the whole range of effects that can happen to a person whose mother drank alcohol during pregnancy. These conditions can affect each person in different ways, and can range from mild to severe.

A person with FASD might have:

- Abnormal facial features, such as a smooth ridge between the nose and upper lip (this ridge is called the philtrum)
- Small head size
- Shorter-than-average height
- Low body weight
- Poor coordination
- Hyperactive behavior
- Difficulty paying attention

- Poor memory
- Difficulty in school (especially with math)
- Learning disabilities
- Speech and language delays
- Intellectual disability or low IQ
- Poor reasoning and judgment skills
- Sleep and sucking problems as a baby
- Vision or hearing problems
- Problems with the heart, kidneys, or bones

Types of FASDs

Different terms are used to describe FASDs, depending on the type of symptoms.

Fetal Alcohol Syndrome (FAS): FAS represents the severe end of the FASD spectrum. Fetal death is the most extreme outcome from drinking alcohol during pregnancy. People with FAS might have abnormal facial features, growth problems, and central nervous system (CNS) problems. People with FAS can have problems with learning, memory, attention span, communication, vision, or hearing. They might have a mix of these problems. People with FAS often have a hard time in school and trouble getting along with others.

Alcohol-Related Neurodevelopmental Disorder (ARND): People with ARND might have intellectual disabilities and problems with behavior and learning. They might do poorly in school and have difficulties with math, memory, attention, judgment, and poor impulse control.

Alcohol-Related Birth Defects (ARBD): People with ARBD might have problems with the heart, kidneys, or bones or with hearing. They might have a mix of these.

The term fetal alcohol effects (FAE) was previously used to describe intellectual disabilities and problems with behavior and learning in a person whose mother drank alcohol during pregnancy. In 1996, the Institute of Medicine (IOM) replaced FAE with the terms alcohol-related neurodevelopmental disorder (ARND) and alcohol-related birth defects (ARBD).

Source: www.cdc.gov/ncbddd/fasd/facts.html



What is Epilepsy?

Another type of developmental disability is epilepsy. A person can have epilepsy and you might not even know it by looking at them.

- Epilepsy is caused by electrical problems in the brain which cause seizures.
- Seizures can cause a short loss of consciousness or changes in how a person acts.
- Seizures may be noticeable (falling on ground, severe trembling) or barely or not noticeable (eye movements, blank stare).
- If a person has a seizure, you cannot do anything to stop it. If he/she falls, be sure the person's head is protected and wait for the seizure to end.
- When a seizure has ended, the person may feel disoriented and embarrassed. Try to ensure that he has privacy to collect himself/herself.
- Be aware that beepers and strobe lights can trigger seizures in some people.

Source: Eastern Paralyzed Veterans Association.

Epileptic Seizures

Epilepsy is a chronic disorder of the central nervous system. **Epilepsy is not a disease.**

- 10% of all persons will have a seizure at some time in their lives. This does not mean that these people have epilepsy.
- 50-80% of people with epilepsy control or prevent their seizures using anti-convulsant medications.
- 1% of people in the U.S. have epilepsy.
- 30% of people who have intellectual disability also have epilepsy

Epilepsy is often the result (symptomatic) of some other problem such as:

- Closed head injury
- Tumors
- Lack of oxygen to the brain
- Infectious disease

Epilepsy can develop at any time – the cause may not be known.

Epileptic seizure is an electrical discharge of the nerve cells in the brain which causes a change in a person's consciousness, behavior, muscle movement or sensations. These are not under the person's voluntary control.

- A seizure can take many forms depending on where it starts and where it spreads in the brain.
- Partial seizures– seizures that affect, or start in, only part of the brain.
- Generalized seizures– seizures that affect the whole brain at once.



What is Cerebral Palsy (CP)?

A condition, usually from birth, which causes problems with movement, delayed motor development, lack of coordination, and sometimes intellectual disability.

Physical Characteristics of Some People with Cerebral Palsy May Have:

- A leg that turns out
- A hand and arm that is curled up to their body
- Difficulty speaking due to slurred speech
- Difficulty walking
- Involuntary body movements

Babies born with severe CP often have an irregular posture; their bodies may be either very floppy or very stiff. Birth defects, such as spinal curvature, a small jawbone, or a small head sometimes occur along with CP. Symptoms may appear, change, or become more severe as a child gets older. Some babies born with CP do not show obvious signs right away.

What Causes Cerebral Palsy?

The cause of the majority of CP cases is uncertain. It is believed that 40% and 50% of all children who develop cerebral palsy were born prematurely. Premature infants are vulnerable, in part because their organs are not fully developed, increasing the risk of injury to the brain that may manifest as CP. After birth, other causes include toxins, severe jaundice, lead poisoning, physical brain injury, shaken baby syndrome, near drowning, and choking on toys and pieces of food.

The intellectual level among people with CP varies from genius to varying degrees intellectual disability, as it does in the general population. Experts have stated that it is important to not underestimate the capabilities of persons with CP and to give them every opportunity to learn.

The ability to live independently with CP also varies widely depending on the severity of the disability. Some persons with CP will require personal assistant services for all activities of daily living. Others can live semi-independently, needing support only for certain activities. Still others can live in complete independence. The need for personal assistance often changes with increasing age and the associated functional decline.

Associated conditions - Individuals with CP may have increased periodontal problems due to poor oral hygiene, teeth grinding or the use of Dilantin to treat convulsive disorders. Also, abnormal tongue movements and difficulty in swallowing can complicate oral health and dental service delivery. Many individuals with CP have malocclusions due to abnormal muscle functioning, such as facial grimacing, unusual chewing and swallowing patterns and tongue thrusting.

ACTIVITY:

Directions: Read over this scenario. Think about the definition of developmental disabilities you just learned. Then use what you know to answer the questions

Tom has epilepsy. His IQ is similar to an average person. However, he has seizures about twice a day. When he has a seizure he blacks out and doesn't remember anything about it when he wakes up in 5 to 10 minutes. Then he is disoriented and forgets things for a while. Because of this, he cannot live by himself, he cannot drive, he was unable to attend school, and he cannot work a regular job.

Q: Does Tom have a developmental disability?

Ted has Cerebral Palsy. His IQ is normal. He cannot walk and uses a wheel chair. He cannot speak clearly, but he uses an electronic board, called a communication board, to talk to people. He has programmed several phrases into his communication board. Ted cannot lift himself from his wheel chair.

Q: Does Ted have a developmental disability?

Q: What might Ted ask us for help with?



Positive Behavior Supports

Positive behavior supports refers to support methods that focus on prevention of challenging behavior. Positive behavior supports focus on improving quality of life. It does not focus on behavioral “compliance.” The main goal of positive behavior supports is to develop support strategies to increase behaviors that will help a person live a more independent and enjoyable life and to decrease behaviors that will interfere with a person’s ability to live independently and enjoyably.

We must also remember that a person’s behavior represents a powerful method of communication. We can help the people we support by creating a positive environment and assisting them in learning new ways to express themselves in a positive manner. Sometimes negative or aggressive behavior is the result of frustration felt by the person because they don’t have a method to communicate. The power of communication is an important tool that helps us feel that we have some control over our environment.

Good behavioral support helps people learn useful skills and gives them more control over their lives

In order for people to have control of their lives (to become self-determined) they must have a positive environment in which to learn and practice new skills. Many things are influenced by the environment: behavior, decision-making and happiness. When the person perceives the environment as positive, it will promote positive behavior, decision making and satisfaction. Many factors can help make an environment a positive one, in which people can live and learn.

Certainly one important aspect of creating a positive environment is the way we communicate with each other. Our interactions can be either positive or negative. Let’s look at the difference.

Positive Interactions

- Great work!
- Thanks for helping.
- You look really good today!
- Good to see you.

Negative Interactions

- Stop that!
- You know better than that.
- I said “NO”!
- Sit down and be quiet now!

Positive Behavioral Supports are:

- focused on prevention and learning
- respectful and individualized
- one way to protect human and civil rights

The Goals of Positive Behavior Supports are to support people with disabilities to:

- Enjoy life
- Be as independent as possible
- Live a normal life
- Overcome problem behavior

What are some Common Functions of Challenging Behavior?

Behaviors usually happen for a reason. Some reasons for challenging behaviors include:

- Behavior can be an attempt to communicate
- Behavior can be a response to some organic need
- Behavior can be an attempt to avoid something unpleasant
- Behavior can be a response to stress or too much stimulation
- Behavior can be a response to boredom or too little stimulation

It is important for staff to remember that when we create a ‘power struggle’ it is no longer about helping the people we support– it becomes about us and our feelings. Behavior supports are not about “winning”. Staff must learn to depersonalize all behavior. It is not about them.

Remember, when it comes to power struggles: **Just don’t do it!**

DSP Scenarios

Read these scenarios and discuss possible reason(s) for the display of problematic behaviors.

1. Sally, who does not speak, became angry at her roommate. First she started hitting and pinching her roommate. Then she bit her roommate. Finally, she threw things at her. Some staff were thinking that maybe she needed some medication to calm her down.

After investigation, it was found that Sally's roommate had been stealing Sally's clothes. After the stealing stopped and Sally's clothes were returned to her, Sally stopped being angry, and her 'behaviors' stopped.

2. One day Joe began throwing his food on the floor. At every meal at the group home, Joe's food ended up on the floor. When staff asked Joe why he did it, he replied "I don't know."

After investigation, it was discovered that a staff person who was new to the group home began cooking foods which Joe didn't like. The staff person hadn't bothered asking Joe what he liked to eat. Joe was afraid that if he complained, the new staff person would get mad at him and he would be punished.

3. Alicia, who has epilepsy, began having seizures more often. Alicia is on a self-medication program. Staff found that the correct amount of pills had been taken from her pill bottle. Staff were just about to make an appointment with Alicia's doctor to get her epilepsy medication increased when the DSP discovered that Alicia had not been taking her medications as she was supposed to. She had been flushing them down the toilet because she didn't like their taste.

What can be more important to a person than:

To have people really care about you – about what you think and feel?

To have someone genuinely care for you - even when you are not doing well?

To have friends?

To be able to learn without ever being afraid of making mistakes?

To know that you are a positive element in this world?

To know that your choices are respected?

Behave Gently. Be Gentle.

Adapted from Missouri Division of Mental Retardation and Developmental Disabilities
Positive Behavior Support Guidelines 2008



People First Language

People First language is speaking and writing in a way that always puts the person first and the disability last. Using People First language is important to people with disabilities and conveys respect and acknowledgement that they are viewed first as a person. The words we use to describe one another can have an enormous impact on the perceptions we and others have, how we treat one another, mutual expectations, and how welcome we make people feel.

The following set of guidelines was adapted from guidelines prepared by the Research and Training Center on Independent Living at the University of Kansas. These 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, say: “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 advocates who are blind dislike the term “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 its after effects years later have a post polio 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 a 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 help break down barriers and open lines of communications.

People First Language Activity

Please translate these statements into people first language:

He's a mongoloid.

He's a quadriplegic.

Mary is non-verbal.

Lilly is confined to a wheelchair.

Laura is autistic.

He had a behavior.

Adam is low functioning.

Connie is non-compliant.

Jane is a tube-feeder.

What is Confidentiality?

Confidentiality means sharing information only with those individuals who need to know it. That means people who need to know the information in order to perform their job duties. For example, you, as a DSP, may need access to a person's medical information. Even if someone may need to know information for their job, they may still need to get consent (i.e. a Release of Information form) in order to access that information. For example, an outside consulting agency, such as a physician's office, needs to obtain consent before having access to some information. Once a person obtains confidential information, they can only use that information for its intended purpose. For example, if you have access to a person's health information, you cannot share it with the maintenance staff.

Why is confidentiality so important?

- It is required by law
- It protects the people that you help support
- It protects you! If you don't follow the confidentiality rules, legal action may be required against you

What kind of information is considered confidential?

- Personal health information – this information should be released (only to people who need to know the information to do their jobs)
- Financial information – financial information about the person is also protected
- Living status – This includes information about who lives at a particular agency



How Can I Ensure Confidentiality?

Many times confidentiality is violated through carelessness. Here are some tips to help ensure confidentiality:

- Do not leave records out in public areas
- Keep records supervised – when not in use put records away even if you think you will need them later
- Remember that public settings are not the place to carry on confidential discussions

Electronic Information

It is important to note that the same laws and guidelines for written records also apply to electronic computer based records!

Remember, confidentiality is everyone's responsibility. You need to be aware of situations that make maintaining confidentiality difficult and then do the right thing to protect people's privacy.



The Mental Health and Developmental Disabilities Confidentiality Act can be found at:
<http://www.ilga.gov/legislation/ilcs/ilcs5.asp?ActID=1496&ChapterID=34>

Mental Health and Developmental Disabilities Confidentiality Act

Much of what you hear, see, and read and otherwise learn about the people you support is highly private, confidential information. You are responsible for protecting and safeguarding this personal information. The laws that mandate protection of confidential and personal information are contained in:

- The Mental Health Code,
- The Confidentiality Act,
- HIPAA
- The Illinois Personal Information Protection Act



Community Inclusion

Those people who are involved in their communities and interact with people in their communities are more likely to have a full and meaningful life. Many people with disabilities are unable to enjoy frequent social experiences in the communities where they live and work. To the extent possible, DSPs should support community inclusion of the persons they support. Inclusion means people are truly included and not just “present” in communities. DSPs should be prepared to educate others about accessibility and inclusion for persons they support.

The Role of the DSP in Supporting Community Inclusion

The importance of communication cannot be over-emphasized. DSPs should communicate with each other about what is happening in the community. Are there things that staff can do to help people fit in with others? Dressing fashionably, good grooming including hair and nail care, teaching the person about new fun slang words, trends, etc. will enhance and add variety to people’s social skills. Include all members of the person’s team to network and identify contacts and allies to locate employment contacts, free or low cost activities in the community such as concerts, festivals, plays, mall events, fun walks/runs and other community resources.

Community Inclusion - is an integrated setting where people of all abilities and backgrounds work, live, go to school, or play together. Community inclusion includes at least six components: Presence, choice, competence, respect, participation and belonging.

Presence - Persons participate in all settings where people without disabilities are present, including classrooms, planning meetings, businesses, neighborhoods, and community events.

Choice - Persons will have multiple life experiences from which to draw. These various experiences will help him/her make decisions on what activities that he/she wants to participate in as well as choose who will participate with them in those activities.

Competence - Persons are recognized for their strengths, contributions and, thus, have additional opportunities from which to learn.



Respect and Valued Roles: People are not seen as a “bother” but as persons who are valued by others.

Participation – People engaging with others, having a wide variety of relationships being known and knowing others, being part of the event--not just an observer.

Belonging – People's feelings are valued by others. For example, others calling just to talk or invite him/her to go to a party, out to eat, to the movies, or to just "hang out".

Inclusion is NOT:

- When volunteers spend time with people out of pity or charity.
- "Special" activities or programs only for people with similar disabilities.
- Going on a series of unrelated activities, just to get out.
- Going everywhere (work, shopping, out for a walk) in groups.
- Only going places with other people with similar disabilities.
- Only interacting with people who are paid to take care of you (staff) or people with whom you do not choose for yourself.

The Benefits of Inclusion

Some of the benefits to persons served and their families include:

- Better health.
- Increased feelings of well-being.
- Psychosocial development
- Improved esteem.
- More opportunities and access to resources.
- The protection of being known by other people. (Others are more likely to report or check on problems and become involved.)
- Greater life experience.
- Greater variety of relationships.
- Incentive to learn appropriate social behavior.

Scenarios for Discussion

Scenario #1

Fred, who is nonverbal and has a moderate intellectual disability, has had a job working at McDonalds for the last year. He has to wear a McDonald's shirt and pants to work, which he paid for himself.



Recently, Fred started ripping up his work clothes during the evening. At first they could be repaired, but when it happened three evenings in a row, they were beyond repair and his home staff bought him another pair. They tried to redirect Fred whenever he started to rip and tear his clothes, but Fred was able to sneak into his room and shred his new clothes.

When his caseworker asked his manager at McDonald's if he knew what could be the problem, his manager stated that within the last couple of weeks, high school kids had come into the restaurant and were making fun of Fred, calling him a "retard." Fred tried to avoid them, but was not successful.

Should Fred be allowed to wear his own clothes?

Should Fred quit his job?

What are some solutions to the problem?

Scenario #2

Sally attends a day school program. Sally didn't get along well with her classmates. Sally complained to her teacher, but the teacher just said, "You must get along with everybody."

As time passed, Sally got very angry. Things weren't improving at school. The more she complained, the less her teacher wanted to talk to her about it.



Finally, Sally started throwing things at her classmates. When her teacher asked her not to throw things, Sally hit her classmates. When Sally's teacher tried to intervene, Sally hit her.

Sally was expelled from her school because she was considered too dangerous.

Was this the right decision?

What were the alternative(s)?

Scenario #3

Charles is a person with a developmental disability and attends an alternative day school program in an area that has a mix of homes and businesses. Charles has complained to an aide that one of the janitors borrows his radio during lunch and plays music Charles doesn't like. Charles has asked him not to take his radio but he yells at him to mind his own business and go sit down.



This has begun to really upset Charles. When he gets upset he tries to get away from what is upsetting him. At times Charles has run into the busy street in front of his school. This has happened several times in the last few weeks and his Case Manager is concerned for his safety.

Charles understands why he is running into the street. He knows that if he can get away from the janitor he will not get so upset. He is afraid to tell his Case Manager or his parents what the janitor is doing because he thinks the janitor may then be mean to him. Charles' parents have asked his Case Manager to move him to a different classroom.

The school has said that he cannot move because they do not have another classroom with an opening.

What else would you like to know about Charles?

What are some ideas for supporting Charles?

A Credo for Support



Do Not see my disability as a problem.
Recognize that my disability is an attribute.

Do Not try to fix me because I am not broken.
Support me. I can make my contribution to the community in my own way.

Do Not see me as your client. I am your fellow citizen.
See me as your neighbor. Remember, none of us can be self-sufficient.

Do Not try to modify my behavior.
Be still & listen. What you define as inappropriate may be my attempt to communicate with you in the only way I can.

Do Not see my disability as a deficit.
It is you who see me as deviant and helpless.

Do Not try to change me, you have no right.
Help me learn what I want to know.

Do Not hide your uncertainty behind “professional” distance.
Be a person who listens and does not take my struggle away from me by trying to make it all better.

Do Not use theories and strategies on me.

Be with me.

And when we struggle with each other, let that give rise to self-reflection.

Do Not try to control me. I have a right to my power as a person.
What you call non-compliance or manipulation may actually be the only way I can exert some control over my life.

A Credo for Support (continued)

Do Not teach me to be polite and submissive.
I need to feel entitled to say “No” if I am to protect myself.

Do Not be charitable towards me.
The last thing the world needs is another Jerry Lewis.
Be my ally against those who exploit me for their own gratification.

Do Not try to be my friend. I deserve more than that.
Get to know me. We may become friends.

Do Not help me, even if it does make you feel good.
Ask me if I need your help. Let me show you how you can best assist me.

Do Not admire me. A desire to live a full life does not warrant adoration.
Respect me, for respect presumes equality.

Do not tell, correct, and lead.
Listen, Support, and Follow.

Do not work on me.
Work with me.

Credo for Support is dedicated to the memory of Tracy Latimer. Learn more about Tracy Latimer by logging on to <http://ethics-euthanasia.ca/case-study-robert-latimer/>

RESOURCES

You can find more information about developmental disabilities at these web sites:

SIU School of Medicine Library - <http://www.siumed.edu/lib/>

The Family Support Network - <http://www.familysupportnetwork.org/>

Early Childhood Intervention Clearinghouse – may request info (video tapes, books, resources) can be sent to you on any DD (217-785-1364) 800-852-4302 - <http://www.eiclearinghouse.org/>

IDHS Division of DD – <http://www.dhs.state.il.us/page.aspx?item=32253>

The ARC of Illinois - www.thearcofil.org "...committed to empowering persons with disabilities to achieve full participation in community life through informed choices"

LifeSpan – <http://www.illinoislifespan.org/>

Institute on Disability and Human Development - <http://www.uic.edu/orgs/idhd/>

Family Resource Coalition of America (FRCA) - web site: <http://www.frca.org>

The Autism Program of Illinois: www.theaustimprogram.org

The Illinois State Library: Visit their web site for more information about free tools and resources: <http://www.cyberdriveillinois.com/departments/library/home.html>

Apply online for a library card at:

http://www.cyberdriveillinois.com/publications/pdf_publications/lda137.pdf

Illinois State Library online instructions on how to order a book from the I-Share catalog:

http://www.cyberdriveillinois.com/departments/library/state_employees/pdfs/ishare_book_reques.pdf

LIST OF ACRONYMS

The acronyms below are frequently used in the field of developmental disabilities. You may want to add additional acronyms to this list as you come across them.

ADA	Americans with Disabilities Act
ADD	Attention Deficit Disorder
ADHD	Attention-Deficit Hyperactive Disorder
ASD	Autism Spectrum Disorder
ADL	Activities of Daily Living
AT	Assistive Technology
BCBA	Board Certified Behavior Analyst
CARF	Commission on Accreditation of Rehabilitation Facilities
CBTA	Competency Based Training Activity (or Assessment)
CCI	Child Care Institution
CMS	Centers for Medicare and Medicaid Services
COTA	Certified Occupational Therapy Assistant
CP	Cerebral Palsy
CILA	Community Integrated Living Arrangement
CLF	Community Living Facility
CST	Community Support Team
DCFS	Department of Children and Family Services
DD	Developmentally Disabled (or Developmental Disabilities)
DDA	Developmental Disability Aide
DHS	Department of Human Services
DOA	Department on Aging
DPH	Department of Public Health
DT	Developmental Training
DSP	Direct Support Person
DRS	Division of Rehabilitation Services
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorder
HBS	Home-Based Support Services

HCFA	Health Care Financing Administration (now known as CMS)
HCFS	Health Care and Family Services
ICAP	Inventory for Client and Agency Planning (test)
I/DD	Intellectual/Developmental Disability
IEP	Individual Education Plan
IHP	Individual Habilitation Plan
IPP	Individual Program Plan
ISP	Individual's Service Plan
IQ Test	Intelligence Quotient Test
JCAHO	Joint Commission on Accreditation of Health Care Organizations
IDT	Interdisciplinary Team
ISBE	Illinois State Board of Education
ISSA	Independent Support & Service Advocacy
MH	Mental Health
MI	Mental Illness
MR	Mental Retardation
DRS	Division of Rehabilitation Services
PAS	Pre Admission Screening Agency
OIG	Office of Inspector General
OSG	Office of State Guardian
OT	Occupational Therapist
PT	Physical Therapist
PTA	Physical Therapy Assistant
PRN	Medical shorthand for "as needed"
OJT	On-the-Job-Training
QIDP	Qualified Intellectual Disabilities Professional
RN	Registered Nurse
SEP	Supported Employment Program
SIB	Scales of Independent Behavior
SIB	Self-Injurious Behavior
SLP	Speech & Language Pathologist
SODC	State Operated Developmental Center
TBI	Traumatic Brain Injury

GLOSSARY OF TERMS

Abuse

The intentional infliction of injury, unreasonable confinement, intimidation, or punishment aimed at another, with resulting physical harm, pain, or mental anguish.

Accessible

When facilities have been adapted so that persons with physical or mental handicaps may be able to use them. Example: an "accessible van" means that there is a wheel chair lift and handrails so that persons with disabilities may be able to get in and out of the van.

Action Plan

One of many terms being used for creating a plan for people receiving services that is based on their abilities, strengths and personal desires or goals. These plans are created by support teams or circles of support (the people who know the person best and who the person would like to have participate in planning), and professionals who are only invited at the request of the rest of the support team.

Active Listening

A technique used to become fully involved in the communication process in which the listener works to understand the message, feeling and meaning of the other person communicating. It involves sensing, understanding, evaluating and responding. An active listener has an open mind and hears out the speaker, making a point of trying to understand the position of the speaker. Active listening includes verbal (saying things like "mm-hmm and okay") and nonverbal cues (such as nodding, appropriate eye contact, and attentive posture).

Advocate

A person who speaks up and is active in working toward equal rights, opportunities, and respect for another person or groups of people. Advocates can be paid or unpaid.

Airborne

Airborne/Contact Precautions are required for diseases such as chicken pox and shingles. Wear a standard isolation mask, gown, and gloves to enter the room. Place a standard isolation mask on the patient during transport.

AIDS (Acquired Immune Deficiency Syndrome)

An incurable disease caused by infection from the human immunodeficiency virus (HIV).

Alzheimer's Disease

Alzheimer's disease is the most common form of dementia among older people. It involves the parts of the brain that control thought, memory, and language. The disease usually begins after age 60, and risk goes up with age. There is some indication that people with certain disabilities such as Down Syndrome are at increased risk for onset at an earlier age. Alzheimer's disease is not a normal part of aging and currently there is no cure.

Anorexia

An eating disorder in which a person believes they are overweight even when they are thin, and they begin to starve themselves.

Assistive Technology Devices

Any items or pieces of equipment that enable people to maintain or improve their functioning, and help them to better achieve their goals. Simple pieces of assistive technology include spoons or forks with larger handles which make them easier to grip. Complex pieces of assistive technology include complex computerized communication devices.

Attention Deficit/Hyperactive Disorder (ADHD)

ADHD is estimated to affect 3 to 5 percent of all children. It is more common in boys than girls. ADHD can continue into adolescence and adulthood. People with ADHD can have trouble sitting still, planning ahead, and finishing tasks. They can be distracted by unimportant sights and sounds or unaware of what's going on around them.

Augmentative Communication

People normally interact with one another using speech as their primary mode of communication. Augmentative communication occurs when at least one of these individuals relies primarily on other modes of communication. Examples of augmentative communication are: sign language, paper and pencil, alphabet letter boards, and computer systems.

Autism-Spectrum Disorder

A disorder in which the person affected may have difficulty in both verbal and nonverbal communication and may relate to others or events in unexpected ways such as appearing disinterested, aloof, or unable to concentrate. People with autism spectrum disorder may exhibit repetitive behaviors such as rocking, banging their heads against objects, touching, or hand flapping.

Braces

An orthopedic appliance or apparatus applied to the body, particularly the torso, arms, and legs. These appliances may support the weight of the body, correct or prevent deformities, or control involuntary movements.

Barriers

Physical, emotional, or intellectual things which may get in the way of a person doing something that he or she would like to do.

Baseline

The starting point by which progress will be judged or a beginning measure against which progress can be compared.

Behavior

Something someone does that is both measurable and observable. Behavior can be influenced by consequences and relevant antecedents. Something is measurable when you can count it or express it in numbers. It is observable when you can see it, hear it, or otherwise use your senses to monitor when it happens.

Behavior Support Plans

Plans developed to let support people (staff, family, friends and others) know how best to identify, track, prevent, and respond to an individual's challenging behaviors. These plans should have an emphasis on teaching new, more appropriate, skills for communicating needs. These may also known as behavior management plans, or behavior intervention plans.

Behavioral Chain/Chaining

A behavioral chain is a series of steps of individual behaviors that, when put together in sequence, lead to the completion of a whole task. Chaining is teaching two or more steps of the chain, in sequence.

Bloodborne Pathogens

Disease-causing microorganisms in human blood. Two blood borne pathogens that can be fatal or lead to serious health problems include hepatitis B virus (HBV) and human immunodeficiency virus (HIV).

Blood Pressure

The force of the heart as it pumps blood through the arteries and other blood vessels to the rest of the body.

Bodily Fluids

Fluid that is contained in the human body utilized to maintain life and functioning.

Body Language

A way to communicate without saying any words such as our facial expressions or the pace of our speech. The same body mannerisms do not always convey the same message within cultures or families.

Case Management or Care Coordination

A person who helps the person receiving services understand his or her options and benefits regarding services.

Central Nervous System

The brain and spinal cord sending and receiving messages throughout the body.

Cerebral Palsy (CP)

A type of developmental disability resulting from damage to the brain, which results in loss of control over voluntary muscle movement in the body. There are different types of Cerebral Palsy which may affect a person differently. People with Cerebral Palsy often have difficulties with speech hearing and vision. Cerebral Palsy is sometimes combined with intellectual disability but not always. Symptoms are usually evident before age 2 and in severe cases may appear as early as three months.

Chaining

A task is a series of behaviors performed in order. This order is the behavioral chain. Chaining is a way of teaching that breaks the task into small steps that a person can perform with prompts or guidance. Reinforcement is given as needed for each step or small sequence to get the person to perform it independently. New steps in the chain are added as the person learns to complete the others well. The sequence or portions of it are taught in order until the person can complete the whole task with one initial prompt. (For example, when told: "It's time to do the dishes," the person is able to get up, find all materials, and complete all tasks, until the dishes are done.) Forward chaining is when the steps of the task are taught in order from the beginning. Another option is backward chaining. This is a way of teaching in which the final steps of the sequence are taught first. Each step is added working back to the initial action needed for the task. Backward chaining can be helpful because reinforcement is always given for the final step of the whole task.

Choice

The freedom to pick among several options. To make a decision when faced with one or more possibilities.

Chronic Disability

A chronic disability is one that is of long or indefinite length.

Circulation

The movement of blood through the circulatory system of the body. This system includes the heart, lungs, veins, and arteries.

Coercion/Coerce

Lure, trick, or manipulate someone to do something. An action or decision that is forced and not made freely.

Cognitive

Related to the ability to think.

Communication

A process of sharing information which requires both the sender and the receiver of a message to mutually agree on that message. The quality of the communication depends on both parties understanding and interpreting the same message. Communication is not only speaking words to someone but also listening, attending to body language, decoding meaning, explaining, questioning, and clarifying the information being exchanged.

Community

A group of people that are connected to each other socially, through a common need, experience, mission, culture, vision, and/or values.

Community-based employment

Traditional type of employment, where individuals are employed and paid by the company which hired them. The work takes place in the actual work setting and is performed independently or with the support of co-workers and/or support staff.

Community Inclusion

A concept that reflects the practice of sharing in community life involving at least these four aspects (1) physical presence where the individual actually lives in a typical community setting (house, apartment etc.) vs. an isolated setting such as an institution or a nursing home, (2) cultural integration where the individual exhibits locally valued lifestyles and roles (e.g., farm hand in a rural community; condominium or home owner; church or association member), (3) connections to others who are not paid as supporters. These connections include a variety of reciprocal relationships like friend, coworker, neighbor, spouse, etc.) and (4) self-determination.

Community Integrated Living Arrangement (CILA)

CILAs are the residential service for people with developmental disabilities. A CILA is a combination of supports and services individually tailored for an adult with developmental disabilities. The CILA client may live in his or her own home, in a family home, or in a community setting with no more than seven other adults with disabilities. The primary goal of CILAs is to help the individual become more independent in daily living, more involved in his or her own community and more economically self-sufficient.

Community Integration

A concept of having people with disabilities live, work and recreate in the same places as people without disabilities. Community integration is one part of community inclusion, in which people with disabilities interact in meaningful ways with people without disabilities, such as developing friendships, participating as coworkers, participating as members of community associations and boards, and being good neighbors.

Community Resources

Events, activities, people, places, services, memberships, groups, etc. available to people of a community that help enrich and add quality to life.

Competencies

The identified skills and behaviors the Direct Support Professionals needs to demonstrate on the job at a specific level of performance in order to meet job expectations.

Competency-Based Training

Is a comprehensive approach to training that aligns job skills and work expectations with job descriptions and performance evaluations as well as with the mission, vision and values of the employer.

Concise

When something is expressed in as few words as possible, while maintaining the quality of the information.

Confidentiality

The responsibility of a service provider to regard as private any information that passes between themselves and a client, unless this information poses a threat to the safety of the client or another individual or group.

Consent Form

A written document that, when completed, provides authorization for confidential information to be released or given to another person or entity within an organization for an expressed reason.

Crisis Intervention

Strategies for respectfully, effectively, and safely, interrupting dangerous or extremely disruptive behaviors. A secondary goal in crisis intervention is to resolve the crisis in ways that assist the person to be more likely to exhibit desired behaviors in the future and less likely to engage in the challenging behavior.

Culturally Competent

A person being knowledgeable, appreciative, and sensitive to a group's beliefs, values, traditions, expressions, ethnicity, culture, and race.

Daily Living Skills

Everyday tasks such as brushing teeth, hair care, personal hygiene, communication.

Day Training Programs

Day training programs are programs to help adults with developmental disabilities gain social, recreational, self-care and work-related skills.

Decontamination

To get rid of unwholesome or undesirable elements.

Decubitus ulcer

A bed sore, a skin ulcer caused by lying/sitting in one position too long so that the circulation in the skin is compromised by the pressure, particularly over a bony prominence such as the sacrum (sacral decubitus).

Dehydration

The body is lacking fluid and essential elements called electrolytes which help to regulate the body. Symptoms of dehydration are: thirst, infrequent urination, dry skin, fatigue, lightheadedness, and dark colored urine.

Deinstitutionalization

A process to reduce the number of people living in institutions by moving the people living in them to homes in the community.

Dementia

Emotional disturbance and confusion caused by a brain disorder. Condition of deterioration in a person's mental ability, affecting areas such as memory, reasoning, and emotional functioning.

Developmental Milestones

Different stages of the normal process of growth.

Dignity

Treating people with respect; the quality or state of being worthy.

Diversity

Diversity can be found in a group of people whose members differ in such things as age, race, or beliefs.

Down Syndrome

Down syndrome occurs when a baby has one extra chromosome, 47 instead of 46, in each of his or her millions of cells. In Down syndrome it is the number-21 chromosome that does not separate properly. This is referred to as Trisomy 21. It is one of the most common birth defects, occurring in all races, ethnic groups, socio-economic classes and nationalities. This extra chromosome will affect his or her life. The person may have some unique medical problems will usually have some degree of intellectual disability.

Dysphagia

Dysphagia is the medical term for the symptom of difficulty in swallowing. Dysphagia is due to problems in nerve or muscle control. Dysphagia may cause problems with nutrition and hydration and may lead to pneumonia and dehydration.

Dyslexia

A specific learning disability that affects a person's ability to read.

Eating Disorders

Bulimia or anorexia - self manipulated to vomit and/or regurgitate food intake to avoid weight gain. Both are potentially life threatening.

Echolalia

The uncontrollable an immediate repetition of words spoken by another person

Effective Communication

The transfer of comprehensive and accurate information from one person to another that results in the best outcomes for the person receiving supports.

Empowerment

The act or art of investing someone with power or the authority to act on one's own behalf or in someone's absence.

Epilepsy

A neurological disorder which affects about 1% of the population and causes people to experience seizures. Seizures are a very sudden attack on the nerve cells in the brain caused by electrical dysfunction or disturbances resulting in unconsciousness or violent movement (a neurological disorder).

Ethics or Values

The principles that an individual or group consider most important, and that influence individual or group behavior.

Exploitation

Using the resources or possessions of a child or vulnerable adult for the personal benefit, profit or gain of persons other than the vulnerable adult or child. To take advantage of a person that you have power over in a selfish or unethical manner.

Fading

Reducing the frequency or changing the timing of prompts while teaching, so that eventually the person does not need the prompts.

Fetal Alcohol Syndrome (FAS)

A disorder that is caused when a woman drinks when she is pregnant. It affects the central nervous system and causes birth defects such as intellectual disability, poor motor skills, poor eye-hand coordination, behavioral and learning problems.

Functional skills

The skills a person needs to do the ordinary tasks of day to day life. Functional skills may be an ability to read, open a door without assistance, or cook a meal.

Gestures

Informal body movements that have meaning. An example is waving good-bye. These are usually culturally shared. Usually both men and women use the same or similar gestures.

Graduated Guidance

A fading of physical prompts by gradually decreasing the amount of pressure during the procedure or the length of time the person is touched.

Graduated Risk Opportunities

The opportunity to experience small amounts of risk in order to develop the skill and knowledge necessary to make better judgments about larger risks. For instance, many young adults go on group dates and supervised dates before they go on individual dates as a way to provide graduated risk taking.

Group Home

A home, usually in a community setting, which has 2 or more people with disabilities living in it and receiving services. These homes can range in size from 2 people to 15 people and can be publicly or privately owned and operated.

Health Information

According to HIPAA, this is general information about a person's diagnosis, treatment plan, services received, and how services are paid for. This information can be exchanged orally, electronically, and in writing.

Heat Stroke

A severe and dangerous condition cause by prolonged exposure to heat.

Hepatitis

Hepatitis is inflammation of the liver commonly caused by a virus. There are several types of hepatitis, the three most common in America are: Hepatitis A (HAV), Hepatitis B (HBV), and Hepatitis C (HCV). The severity of the disease increases from Hepatitis A, which does not cause liver damage and almost always goes away after several weeks, to Hepatitis B which often becomes chronic (keeps coming back) to Hepatitis C which can result in permanent damage to the liver and possibly liver cancer.

Hepatitis B virus (HBV)

A blood-borne pathogen that can cause serious illness and death. Some people who become infected will be lifelong carriers of the disease and have the potential to infect others even when the carrier no longer has symptoms.

High Blood Pressure

A health condition, also known as hypertension, caused when the pressure of blood flow against the artery is too strong.

HIPAA

The Health Insurance Portability and Accountability Act (HIPAA) requires that you maintain the privacy of each person's personal health information. It is a federal law that must be followed. It does this by defining boundaries to how people can share personal health information verbally, writing, and electronically. If this law is not followed, civil and criminal punishments can be incurred. These punishments can include up to 10 years in prison and/or up to \$250,000 fine.

Home and Community-Based Waiver Services

A variety of services which are funded through the federal Medicaid Home and Community-Based Waiver program. It helps fund DD services provided in a number of settings including small agency run group homes, family homes, and a person's own home or apartment. How these funds are used and their availability are defined by each state's agreement with the Federal program.

Hormones

A product of living cells that circulates in body fluid and that yields specific actions in the body at a distance from its origin

Human Immunodeficiency Virus (HIV)

A blood borne pathogen that can lead to serious illness and death. Current research indicates that carriers are lifelong and can go for a long time without symptoms even when they are capable of infecting others. This virus is what cause AIDS (Acquired Immune Deficiency Syndrome).

Human Right

Rights that belong to all people. Examples are freedom from unlawful imprisonment, torture, and execution.

Human Rights Committee

A group of people who come together within an agency to review situations in which a person's rights are being restricted and to ensure that all possible steps are being taken to remove and reduce restrictions.

Hydration

Drinking the right amount of fluids, especially water.

ICF/MR

Intermediate Care Facility for People with Mental Retardation

Incontinent

Physically unable to control your bladder and/or bowel movements.

IEP/IPP/IHP/ISP

Individual Educational/Program/Habilitation/Service Plan. Individualized plans. A set of assessments, goals, strategies, and actions developed for a specific person receiving services. Traditionally the plan has been developed by a team of people involved in the person's life such as paid professionals, direct support professional, family members, and the individual receiving services. Goals focus on developing skills and achieving outcomes desired by the individual. In most states there are specific rules and regulations that require the plans and their specific content.

Inclusion

A concept that reflects the practice of sharing in community life involving at least these four aspects (1) physical presence where the individual actually lives in a typical community setting (house, apartment etc.) vs. an isolated setting such as an institution or a nursing home, (2) cultural integration where the individual exhibits locally valued lifestyles and roles (e.g., farm hand in a rural community; condominium or home owner; church or association member), (3) connections to others who are not paid as supporters. These connections include a variety of reciprocal relationships like friend, coworker, neighbor, spouse, etc.) and (4) self-determination .

Incompetency

The inability of a person to make or carry out important decisions regarding his or her affairs.

Incontinent

Physically unable to control your bladder and/or bowel movements. Independent Living Movement, whether through ILCs or as individuals, share a belief that people with disabilities must control their own lives and become a proud and organized force for removing the physical and social barriers to full inclusion of people with disabilities.

Individual Risk Management Plan

Plans that are developed by a the person and his or her support team to help DSPs know what special risks the person may experience due to his or her specific needs and how to support the person in reducing risk.

Informed Choice/Consent

A choice that is based on knowledge and understanding of the possible consequences of making that choice without any coercion.

Institution

Large public or private residential program in which 16 or more people with mental retardation and other developmental disabilities live. Institutions are most often part of state-run hospitals and usually comply with the Intermediate Care Facility (ICF/MR) standards set by the federal government.

Integrated/Integration

A setting where people of all abilities and backgrounds work, live, or play together. Although the concepts behind integration assumed that by being in the same place at the same time people would naturally begin to associate with each other, integration of environments does not always naturally lead to acceptance of each other. Also see community integration and community inclusion.

Intellectual Disability

Intellectual disability or mental retardation is identified by three characteristics. The first is major difficulty in intellectual activities such as thinking, remembering and learning new things. The second characteristic is major difficulty when compared with people of one's own age in the skills of daily community living, such as communicating with other people, taking care of one's self or one's home, or performing other types of expected activities. The third characteristic is that these difficulties were first noticed while the person was still in the developmental period.

Intelligence Quotient or I.Q.

Intelligence quotient. The numerical measure of a person's intelligence as measured by standardized tests and administered by a trained professional, often used in definitions of mental retardation.

Interest/Desire

Wanting something. A characteristic of a positive social relationship (i.e., wanting to be friends, wanting to spend time together).

Interference

To get in the way of, or impede.

Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR)

A federal funding source for funding services to people with developmental disabilities which was the first federal program targeted to monitor residential services to people with mental retardation. ICFs/MR are congregate care settings that range in size from 4 people living in a community home to several hundred living together (including units in state institutions). These programs require 24-hour supervision of the people who live in them and are guided by federal regulations.

Intimidating

To make another person feel fearful or timid.

Intervention Plan

A comprehensive written document that outlines the action steps you will take to reduce turnover and improve the retention of high quality direct support professionals including the identification of the people responsible for these steps and defined timelines for completion of each step.

Isolation

Being kept away from people and other things. Isolation can be a specific term that is used for what is known as "time-out" practices where people were taken away from everyone and everything and left alone in a stark, barren room for a period of time. This use of "isolation" is typically not allowed anymore.

Literacy

The ability to read.

Maltreatment

An act, behavior or failure to act of a family member or professional care provider that causes harm or is considered inhumane treatment of a vulnerable child or adult. Often this is referred to as abuse, neglect, verbal abuse, exploitation, caretaker misconduct, sexual abuse, and sexual exploitation.

Mandate

Something that is mandatory or required by law.

Mandated Reporting

Reporting any act that is suspected to be potential abuse, neglect, or exploitation of a person who is vulnerable (a child or adult with special needs) that is required by law because of the professional role of the reporter. In many states direct support professionals are mandated reporters.

Masturbation

Touching and stimulating of the genitals for sexual pleasure.

Medically Fragile

A person who has health conditions that make him or her more susceptible to illness and serious medical complications and therefore, typical activities or actions may be more of a risk to the person than they would be to someone without these medical issues.

Medicare and Medicaid

Federally subsidized health care plans. Medicaid programs provide medical assistance to the poor and unemployed who meet the eligibility requirement and vary greatly from state to state, while benefits for Medicare patients are mandated by the federal government.

Menopause

The time in a woman's life when menstruation ceases and fertility is ending.

Menses

A woman's menstruation, commonly called her "period."

Menstrual

Relating to the care of blood that is passed as part of a woman's reproductive cycle (menstruation).

Modeling

Demonstrating how to do something. Modeling is often combined with verbal or written instructions to ensure important steps are understood.

MRSA

MRSA infection is caused by *Staphylococcus aureus* bacteria — often called "staph." MRSA stands for Methicillin-Resistant *Staphylococcus Aureus*. It's a strain of staph that's resistant to the broad-spectrum antibiotics commonly used to treat it. MRSA can be fatal.

Natural Supports

Supports provided by family and friends; not paid care givers.

Negative Reinforcement

Taking something out the environment that makes it more likely that a behavior will occur, such as turning off the radio when someone asks.

Neglect

The failure to provide goods or care that is needed for a person's physical and/or mental health to the extent that his or her well-being is impaired or threatened.

Neurologist

A doctor who specializes in brain and nervous system disorders.

Non-verbal Communication

Any way of communicating from one individual to the other that does not include speech. Examples: hand gestures, facial expressions.

Natural Rhythm of Life

Patterns of life and conditions of everyday living that are considered to be normal by most people in our society.

Obesity

Excessively overweight by 20% or more of a person's recommended body weight.

Occupational therapists

Therapists who are knowledgeable about finding ways for people with disabilities to perform basic activities of daily living.

Oncologists

A doctor who specializes in cancer treatments.

Ophthalmologist

A physician who specializes in the diagnostic and treatment of all conditions relation to the eyes.

Optometrist

A professional who specializes in eye care and vision.

Pairing

In behavioral support, this is the process of combining primary reinforcers with events or objects that could be secondary reinforcers, for the purpose of establishing the event or object as a reinforcer. For example, combining a sip of juice (assuming the person is reinforced by the juice) with a gentle touch on the hand, in the hopes that the gentle touch will eventually become an effective reinforcer for the person.

Pap Smear

A test of the woman's cervix to check for cancer.

Pathogen

Anything that can cause a disease (especially micro-organisms such as bacteria, virus or fungus).

PECS - Picture Exchange Communication System. PECS is a structured system for training individuals with autism spectrum disorder or other severe disabilities to initiate communication by exchanging symbols for objects or activities.

Peer Support Group

People of approximately equal social status who have reciprocal relationships; friends, colleagues or others who have common bonds.

Penis

The male organ of copulation.

People-first language

Respectful forms of referring to people that avoid labeling or describing the person in terms of a diagnosis or other attributes or characteristics. In all forms of communication, including spoken and written communications the person precedes his/her diagnosis.

Person-Centered

An approach to supports and services that looks at a person's unique strengths, needs and personal goals as a basis for determining how to identify services and supports.

Personal Goals

A person's desires, wishes, or goals for him or herself, which may include relationships, activities, vocations, and other opportunities or experiences.

Pervasive Support

Pervasive support according to the disability classification system of the AAMR refers to persons who receive highly intense, constant direct support in all their life activities.

Personal Protective Equipment (PPE)

Specialized clothing or equipment worn by employees for protection against health and safety hazards. It is designed to protect many parts of the body, i.e., eyes, head, face, feet, and ears.

Physical Abuse

Any act of violence, force, or rough treatment done knowingly, recklessly or intentionally whether or not actual physical injury results.

Physical Injury

Injury to someone's physical body such as: broken bones, scratches, cuts, bruises, etc.

Physical therapist

A health care practitioner who is knowledgeable in methods of speeding up recovery or enhancing strength and flexibility after an injury.

PICA

A condition where a person eats items that are not edible and may be harmful such as dirt, paper, chemicals or cigarette butts.

Pneumonia

An infection in the lung often caused by a bacteria or virus.

Polypharmacy

Using more than one medication at the same time. This practice can cause an increased risk for side effects, interactions, and errors. In some cases it can achieve better outcomes (e.g., bipolar disorder)

Positive Behavioral Supports

The use of ongoing methods of support that prevent or diminish the use of challenging behaviors, through emphasis on quality of life, person-centered supports, and the proactive teaching of skills for success.

Positive Reinforcement

Adding something to the environment that makes it more likely that a behavior will occur, such as telling someone they did a good job.

Primary reinforcers

Biological reinforcers that do not require learning in order to be effective. Examples include: food, drink, relief from pain, sleep, etc. For people who have not learned to be motivated by social events (such as a smile or praise in response to a behavior) it may be necessary to use primary reinforcers. However, it is desirable to find or develop secondary reinforcers because primary reinforcers are things that people should have access to without needing to "earn" them and because of their use may not be practical or may add to stigma.

Primary Relationships

The most important relationships a person has.

Privacy

The right to be left alone, the condition where confidential information about an individual is not made known to others.

Prompting

Verbal, visual, or physical reminders and supports to help the person understand or remember how to perform a skill, over and above a discriminative stimulus (which is a naturally occurring prompt in the situation).

Protected Health Information (PHI)

PHI includes Social Security number, all diagnoses, treatment history, services provided and service eligibility.

Psychotropic Drugs

Drugs that affect the psychic functions, behavior or experience of a person. Use of psychotropics is sometimes the equivalent of physical restraint and procedures should ensure it is used properly and only when other positive methods are not effective; when behaviors are extreme, dangerous, or are a barrier to quality of life; and only in conjunction with a properly developed and approved behavior support plan.

Puberty

The time in the life a person when due to hormonal changes, a child's body matures and becomes capable of sexual reproduction.

Qualified Intellectual Disability Professional (QIDP)

A position defined by the federal ICF/MR regulations that requires a four year degree in a human services field and a minimum of 2 years experience working with people who have mental retardation or related conditions. The ICF/MR regulations require that a QIDP review and approve any programs developed for people receiving services.

Quality of Life

A person's overall life experience. People are thought to have a high quality of life if in addition to having their basic needs, such as food, shelter, and safety met, they also have opportunities for personal growth, choice, new experiences, and enjoyment of fulfilling personal relationships. A poor quality of life is one in which basic needs are not met, or people are isolated, lonely, bored, or frustrated on a regular basis.

Reinforcement

The relationship between a behavior and a consequence, in which the presentation of the consequence increases the likelihood that a behavior will occur again in the future. Reinforcement can be positive (something is added to the environment) or negative (something is removed from the environment).

Relationship

Kinship/connections created and maintained through good communication, acceptance of differences, good listening skills, kindness, common courtesies, and flexibility.

Replacement Behaviors

Specific appropriate behaviors that have the same function as challenging behaviors. These behaviors are meant to replace the challenging behavior by teaching an appropriate alternative for communicating and having a need met.

Respite Care

Service that pays for outside help to take care of a family member with a developmental disabilities who lives in the family home. This allows the parent or family member to take a break from care giving and go shopping, out with friends, etc.

Rights Violation

An action that denies or prevents the person from making their own choices or access to their belongings or otherwise infringes upon their human rights.

Risk

Unknown or understood parts of a situation that may be harmful. The possibility or likelihood that loss or damage will occur.

Risk Management

Making choices that make necessary risk less likely to be harmful. For example, wearing a helmet while riding a motorcycle.

Secondary reinforcers

Reinforcers that a person finds valuable. They can include special events, interactions, privileges, recognition, items, etc.,. These could be such things as going to a movie, park, concert, someone saying "you did a great job", tokens, awards, etc..

Sedentary

Lacking exercise or activity.

Segregated

An environment where only people with a certain characteristic work, live, or play.

Seizures

A sudden, violent involuntary series of contractions of a group of muscles caused by an attack on the nerve cells in the brain. Symptoms include uncontrollable twitching, blackouts, snorting, foaming at the mouth, and/or blinking.

Self-Abuse

Behavior that is injurious to one's self: physical, mentally, emotionally, psychologically, spiritually, financially, etc.

Self-Administer

A person who has the ability to take their own medications, nutritional supplements, etc. in a safe and effective manner after training.

Self-Advocate

A person with a developmental disability who is speaking out for his or her own rights or for the rights of all people with developmental disabilities.

Self-Care Skills

The basic ways that people take care of themselves and their hygiene.

Self-Determination

Living one's life based on one's own choices and preferences, and without undue influences or interference from others.

Self-Direction

The ability of people to lead themselves in carrying out age-appropriate activities. A limitation is self-direction means that a person needs unusually great amounts of assistance, supervision and reminders in order perform the activities that are typically performed by someone of the person's age or cannot perform those activities at all.

Self-Injurious Behaviors

(SIB) behaviors that are harmful to oneself, including deliberate self-injury, such as hitting oneself, or repeatedly rubbing an area of skin until it bleeds, etc.

Self-Stimulation or Stereotypic Behaviors

Repetitive, sometimes odd-looking behaviors that people engage in such as rapid flapping of hands, sniffing objects inappropriately, pacing, spinning, or rocking.

Sensory Impairments

Sensory impairments exist when people have substantially below average abilities to see, hear, taste and feel.

Sexual Abuse

Any sexual behavior, sexual contact or intimate physical contact between an employee and an individual, including an employee's coercion or encouragement of an individual to engage in sexual behavior that results in sexual contact, intimate physical contact, sexual behavior or intimate physical behavior. "Sexual abuse" also includes an employee's actions that result in the sending or showing of sexually explicit images to an Individual via computer, cellular phone, electronic mail, portable electronic device, or other media with or without contact with the individual; or, an employee's posting of sexually explicit images of an individual online or elsewhere whether or not there is contact with the individual. "Sexually explicit images" includes, but is not limited to, any material which depicts nudity, sexual conduct, or sadomasochistic abuse, or which contains explicit and detailed verbal descriptions or narrative accounts of sexual excitement, sexual conduct, or sadomasochistic abuse.

Sexually Transmitted Disease

A disease that is given from one person to another person through contact with sexual organs or sexual fluids.

Shaping

Prompting and rewarding behaviors that are more like the desired behavior at each step, with the desired outcome being to teach a new behavior.

Signs and Symptoms

Signs are what you can see; Symptoms are what the person tell us. "My stomach hurts" is a symptom. Flinching when the doctor presses on your stomach is a sign. This is important to know, because some individuals with DD might not be able to describe their symptoms.

Speech Language Pathologist or Therapist

A professional who specializes in the study of communication disorders such as speech, language and voice for the purposes of diagnosis and treatment.

Standard (Universal) Precautions- Standard Precautions (previously known as Universal Precautions by the CDC), are an approach to infection control. These precautions apply to all blood, body fluids, secretions and excretions (urine & feces), whether or not they contain visible blood. They also apply to mucous membranes and where there is a cut or abrasion. Standard Precautions protect both the individual being assisted and the DSP. Standard Precautions include the use of disposable gloves and hand washing.

Supported living

A residential service model that tailor services to meet individual needs.

Tardive Dyskinesia (TD)

Abnormal involuntary movements caused by long-term use of anti-psychotic agents.

Task analysis

Breaking down a complex skill, behavior, or activity into individual steps.

Telecommunications Device for the Deaf (TDD) – A telephone system that allows deaf or individuals who have hearing impairments to communicate by typing and receiving messages through a monitor.

Tics

A persistent trait of character or behavior demonstrated by such things as repetitive phrases, sudden and jerky movement of the head, arms, and other body parts.

Traumatic Brain Injury (TBI)

Traumatic Brain Injury is any injury cause to the brain that damages parts of it. The effects from traumatic brain injury can be mild to severe but often causing changes in a person's personality and abilities. Short term memory is often affected.

TTY/TTD – a device that enables hearing- or speech-impaired users to transmit and receive typed-in exchanges over phone lines.

Unethical

Actions that are considered wrong or self-serving to the detriment of others. Actions that are in conflict with established moral or ethical codes.

Universal Precautions

An approach to infection control designed to prevent transmission of blood-borne diseases such as AIDS and hepatitis B in health care settings. These guidelines were developed in 1987 by the Centers for Disease Control and include recommendations for use of gloves, masks and protective eyewear.

Urinary Tract

All organs and ducts involved in the elimination of urine from the body.

Vaccine

A fluid that is used to prevent a particular disease or illness

Vagina

The female opening that monthly menstrual blood passes out of the body through.

Verbal Abuse

Any communication that diminishes a person's dignity or self-worth or cause the person emotional anguish or pain.

Viral

Related to virus, which is a type of germ that causes infection and is spread through the air and by touching contaminated surfaces such as doorknobs, another persons' hand, and countertops. Viruses include the common cold and flu.



HUMAN RIGHTS

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Introduction from Self-Advocates

We would like DSPs to remember that we have rights. Some of the rights that are most important to us include the following:

I have the right to speak up for myself.

I have the right to eat whatever I want.

I have the right to sit where I want at lunch.

I have the right to use the microwave!

I have the right to talk to whomever I want.

I have the right to go where I want to.

I have the right to date who I want.

I have the right to go to school.

I have the right to look at my own files.

I have the right not to be abused and to call the police if I am abused.

Submitted by: Stephanie W., self-advocate, Melissa R., self-advocate, Sean J., self-advocate, Cindy T., self-advocate, Judy D., self-advocate, and Donald J., self-advocate

My name is Glen and I am 57 years old. I lived at home until I was 7 then I moved to Dixon State School. I was there for 21 years. Then I moved to the state hospital at Anna. I lived in a bunch of different places including Elgin State Hospital and Howe. Ten years ago I moved into a CILA [Community Integrated Living Arrangement]. I like to shop. When I was young I did not get to leave to go shopping. I got to go to a few parties but that was it. I did not get to pick what food I ate. Now I do. Now I get to go to church. A man from my church picks me up every Sunday. I go shopping a lot. I like to buy CD's and word search books. I like to listen to all kinds of music. When I was younger I was not allowed to talk on the phone with my family. Now I talk to my mom every week. When I was young I was not allowed to visit my family. Now I visit on holidays and my birthday. When I was young I slept in a room with a bunch of other people in bunk beds. Now I have my own room with a TV, CD player, cable and a VCR. I have lived in my home for ten years.

Submitted by: Glen M., self-advocate

Rights Guaranteed to Persons with Disabilities

The U.S. Constitution guarantees the following rights to each citizen, regardless of ability:

- Access to the courts and legal representation
- Free association
- Right to contract, own, and dispose of property
- Equal educational opportunity
- Equal employment opportunity
- Equal protection and due process
- Fair and equal treatment by public agencies
- Freedom from cruel and unusual punishment
- Freedom of religion
- Freedom of speech and expression
- Privacy
- Services in the least restrictive environment
- Right to vote



Division of Developmental Disabilities Mission Statement:

The Division of Developmental Disabilities in Illinois will provide quality, outcome-based, person-centered services and supports for persons with developmental disabilities and their families. The system of services and supports in Illinois will enhance opportunities for persons to make real choices and receive appropriate, accessible, prompt, efficient, and life-spanning services that are strongly monitored to ensure individual progress, quality of life and safety.

Source DHS website direct link: <http://www.dhs.state.il.us/page.aspx?item=29761>

Rights of Individuals Receiving Support in Illinois:



- Right to services in least restrictive environment
- Right to normalized living conditions
- Right to dignity and respect
- Right to freedom from discomfort and deprivation
- Right to appropriate clinical, medical and therapeutic services
- Right to vote
- Right to religious worship
- Right to private communication
- Right to free association
- Right to physical exercise
- Right to seasonal, clean, neat clothing
- Right to manage personal funds
- Right to bed, dresser and storage area
- Right to privacy
- Right to public media (i.e. newspapers, television, radio, magazines)
- Right to adequate nutrition
- Freedom from unnecessary medication and mechanical, chemical or physical restraints

Source: Developing Staff Competencies for Supporting People with Developmental Disabilities. Gardner and Chapman.

The Evolution of Human Rights for People with Developmental Disabilities

Historically, society has tended to isolate and segregate people with disabilities. Many early institutions were simply warehouses where people were sent for a variety of reasons; not all of which were related to mental illness or mental retardation. Very few ever received any form of individualized treatment or habilitation.

People with disabilities were considered to have no rights up until the early 1960's when a series of landmark declarations, court decisions and legislative acts began to make a crucial difference in the civil rights of persons with developmental disabilities. Some of these are summarized below:



- 1963 - The enactment of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), conceived by President Kennedy, Eunice Kennedy Shriver, and Dr. Robert Cooke. This Act resulted in better understanding, professional education, access and safety in institutional facilities. Later, changes were made to the DD Act, as conceived by Dr. Elizabeth Boggs, Dr. Elsie Helsel, and others. These changes focused on the efforts of families, professionals, and state agencies to improve supports for all people with developmental disabilities. Today, the programs emphasize legal services, advocacy, and capacity building at the state and local levels. The focus is on listening to people with developmental disabilities as self advocates, and helping people with developmental disabilities and their families obtain the information, assistive technology, and supports they need in order to make more informed choices about how and where to live and work, and be active and involved citizens in their communities.

As a result of the landmark court decision in 1970, **Wyatt vs. Stickney**, we recognized that persons with mental retardation are citizens who have "rights" under the constitution. This case resulted in the establishment of 49 Principles of service, which include the requirement to establish a seven-person Human Rights Committee to review all habilitation plans to ensure that the human rights of the residents were preserved. It also resulted in the establishment of:

- Qualified Intellectual Disabilities Professionals (QIDPs)
- A "Right to Treatment"
- Staff to client ratios
- Physical plant features/dimensions

- Development of behavior plans

In 1971, the United National issued its "Declaration of the Rights of Mentally Retarded Persons." This declaration provided expectations for higher standards of living, principals of dignity, and worthiness of persons with developmental disabilities.

- 1974 - A televised documentary made by journalist Geraldo Rivera exposed the living conditions of children and adults at the Willowbrook School in New York City. The fallout from this scandal set in motion a major deinstitutionalization program across New York State. Plymouth Center for Human Development was the first institution in the country to close under federal court order because of the deplorable conditions and abuse. It also brought about needed repairs and reforms at the institutions that continued to operate.
- 1984 - The Health Care Finance Authority (HCFA) is ordered to begin in-depth surveys in Intermediate Care Facilities for People with Mental Retardation (ICF/MRs) to see if the level of care mandated by Medicaid rules was actually being provided. The findings of these surveys brought about a wave of closures and decertifications.



Note: Although there have been major improvements in the last 45 years, discrimination against persons with disabilities continues to be a serious social problem. Discrimination continues in such critical areas as employment, housing, public accommodation, education, transportation, communication, recreation, institutionalization, health services, voting and access to public services. It is our responsibility to make sure these rights are protected for the persons we support. This is especially true when it comes to providing an environment that is free from abuse and neglect and free from the fear of abuse and neglect.

Sources: http://www.mncdd.org/dd_act/dd-act.html Connecticut Developmental Disabilities Council, Ed Preneta, Executive Director, and the Texas Developmental Disabilities Council, Roger Webb, Executive Director.

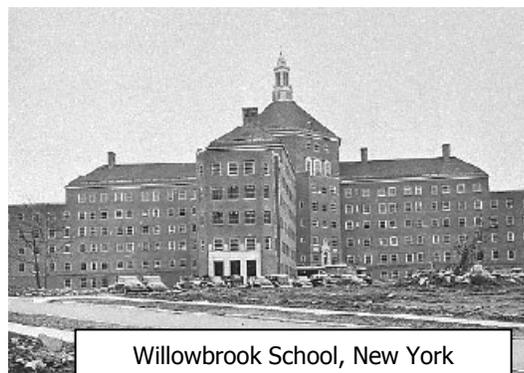
Baker, Steve and Tabor, Amy *Human Rights Committees*, High Tide Press, Homewood, Illinois, 2006

How this evolution of rights for people with developmental disabilities has changed the DSP's role:

Over the last 40 plus years, the role of direct support persons has changed as the disability movement succeeded in bringing about higher quality services for people with developmental disabilities.

During the institutional era, there were usually too few DSPs to provide the individual attention to people that would allow them to learn skills for independence. In many cases, there was only one staff to 40-50 people. Workers were not expected to teach people skills; they were simply expected to be passive caregivers. It was sometimes difficult for DSPs to just keep people clean and fed.

People moving away from institutions and group settings has resulted in the DSPs' role evolving to include emphasis on recognizing and supporting the talents, choices and preferences of people as the key to a satisfactory lifestyle. DSPs now create and ensure people have community connections and assist them in living their lives as citizens with human rights. This requires the DSP to provide supports that teach people the skills needed to participate in their community, as independently and fully as possible.



Rules and Codes

There are now laws that ensure that people with developmental disabilities have the right to considerate, safe, and respectful supports that are free of mental, physical, sexual, and verbal abuse, neglect, and exploitation. They also have the right to be free from seclusion and only put into restraints if they are an immediate danger to themselves or others.

Laws are required to ensure that individuals with developmental disabilities never again experience abuse and neglect as they did in the past. Human rights are required by various rules and codes, while others are specified by agencies. Major rules and codes protecting the rights of persons with disabilities are:

- Mental Health & Developmental Disabilities Confidentiality Act
- Mental Health & Developmental Disabilities Code
- Rule 115 (Community Integrated Living Arrangements)
- Rule 119 (Developmental Training)
- Rule 120 (Medicaid Home and Community-Based Waiver Program for Individuals with Developmental Disabilities)
- Rule 50 (Abuse & Neglect Reporting)
- Department of Human Services Regulations (e.g., requirements in grant funding contract)
- Department of Public Health Regulations (e.g., 77 Illinois Administrative Code which requires DSP training; formerly known as "developmental disability aide" training).

Role of an Advocate

What is an advocate?

An advocate is someone who helps others speak up for themselves, or listens carefully to what another person says, and speaks up for that person's needs and wants.

DSPs should act as advocates for the people they support. Ways that DSPs should be advocates are as simple as encouraging the person to be as independent as possible; helping the person shop for his/her own clothes; deciding on a weekly menu; choosing the Friday night video; increasing opportunities for community socialization and encouraging him/her to personalize their living area. Allow people additional time to do things for themselves rather than doing it for them. As an advocate, you actively work to ensure the protection of the human rights of the individual you support.



Some other ways that you can help support people's rights are:

- Assist people in understanding their rights
- Honor the choices that people make
- Always communicate in a respectful manner
- Protect people's privacy (For example, knocking before entering the bedroom)
- Recognize that people who victimize people with disabilities must be held accountable for their actions
- Represent the best interest of people who cannot speak for themselves by working hard to find an alternative way of understanding desires/needs

There are a number of advocacy groups in Illinois and across the nation that provide assistance and information to people with disabilities in a variety of settings: mental health facilities, residential programs, community placements, and nursing homes. Issues addressed by advocacy groups can include, but are not limited to: help with admission and discharge from hospitalization, adequate treatment, and refusal of unwanted services and confidentiality of records. Illinois' advocacy groups as well as other nationwide advocacy groups are listed in the Appendix section of this curriculum.

The Right to Dignity and Respect through Positive Interactions

Agencies should use positive approaches when providing services. Dehumanizing practices are prohibited. Personal freedoms should not be unduly restricted. When necessary to ensure health, safety, and welfare, limitations on personal freedom are subjected to careful ethical review through a Human Rights Committee.

The types of interactions that are used when providing support must convey dignity and respect. No one should have to live or work with someone who curses, yells, mocks, or otherwise treats him or her cruelly. The basic rule of thumb is “treat others as you would want to be treated.”

Likewise, it is not the role of the DSP to **make** someone perform a task. The role of the DSP regarding programming that is specified in the ISP (Individual Service Plan) is to provide gentle teaching and **not to let any interaction become a power struggle.**



Sample Empowerment Worksheet

Rephrase the statements below to reflect positive interaction:

1. Go take a bath.

2. That is how things are done here.

3. Why would you waste your money on . . .

4. Because I said so!

5. I told you that you wouldn't like that job!

6. Those clothes don't match . . . go change.

7. You have behaved so badly lately that you don't deserve to do to the . . .

8. Time for you to go to bed.

9. This isn't a goal you want to work on, but the team wants you to.

10. These are the people I am inviting to your team meeting.

The Right to Intimacy



Having a developmental disability does not alter the right of a person to express his or her desire to have intimacy. Intimacy is very personal. It is often a reflection of a person's need for closeness with others. It is particularly difficult to judge the "appropriateness" of another's social choices. The person's desires for social relationships, marriage and potential parenthood should be understood by the organization.

People with developmental disabilities have the right to and deserve acceptance of their sexuality. The people involved in a sexual relationship must both be consenting adults. Consent is always seen as informed consent. Some people may need support to deal with unwelcome sexual behaviors and to report this when they need assistance.

The organization should understand what sexuality means for the person. What opportunities exist for this expression? What supports are needed? (education, counseling, privacy). The person should receive sexuality education that will help them understand and be prepared for the risks, and possible results of sexual behavior. Results and risks of sexual behavior include pregnancy, sexually transmitted diseases, emotional attachment, etc. Staff should listen and watch carefully for issues that people may express, and help them get appropriate help as needed. Staff should also not be judgmental and try to impose their own personal values on people. It is also important that staff respect the privacy of people they support to discuss and express their sexuality. Most agencies have specific policies and procedures addressing sexuality. As a DSP you should ensure that these policies are followed while also ensuring that the person remains safe and their rights are protected.

A high percentage of people with developmental disabilities experience sexual abuse in their lifetime. A main factor contributing to the high prevalence is sexual abuse is the lack of sexuality education provided to them.

The Right to Privacy

The reasonable expectation for privacy is a constitutional right. All citizens have the right to keep certain parts of their lives private. The right to privacy includes having time alone and keeping certain possessions private. Each person has their own preferences for privacy. Some people like to be alone when upset or when they just want to relax. Others like to be with people much of the time and don't like much time alone. For people who live in group settings, being able to respect this right may be a challenge. The first step in supporting people's privacy is to get to know the person and what their individual preferences are and then help support those preferences.

Another important aspect to privacy is **confidentiality**. Remember, whenever you speak or write about someone's personal information, you should be concerned about sharing information with those that do not need to know.

Free Access to the Telephone

The telephone is often the person's usual way to maintain contact with friends and family. People's homes should include access to a telephone that offers privacy. People have the right to make and receive phone calls privately. People who experience disabilities which make it difficult to use the telephone should be able to use alternative types of communication. Some people may need a telephone with larger buttons for calling, telephones with pictures of the people they typically call on each pre-set dial pad key, or pre-set phone numbers for each dial pad key and a corresponding directory; i.e. 2 = mom; 3 = brother Don, etc.



The Right to Freedom of Movement

Each person has the right to move about in their environment and this freedom should be the same as all citizens. If, however, this freedom is restricted due to safety reasons, due process rights should be given. Freedom of movement can be limited in many ways.

Some examples of limitations of freedom of movement are: "one-to-one" supervision, door buzzers to monitor movement, etc.

The Right to Free Association

As a Constitutional right, people with intellectual disabilities are free to choose with whom they want to spend time. They should be encouraged to seek relationships with coworkers, neighbors and others they may meet in the community. Supporting a person's right to have relationships also provides opportunity to learn how to interact in social situations.

Cultural Competency and Client Rights Information

From The Cultural Dimensions Guide for Providers of Services for People with Developmental Disabilities (Advocacy Center for the Elderly and Disabled, New Orleans, Louisiana):



The word "culture" is used to refer to a group of people who have experiences in common, whether the group is a nation, a community, or a small group within a community. Within the broad "American culture" of the United States, there are separate cultural groups; even within local communities there are cultural differences. "Culture" is composed of aspects of life which are human-made: skills, tools, folkways, and customs. The effects of culture on a person are pervasive; one's tone of voice, even choice of words may be influenced culturally.

It is essential that when you are representing and promoting the rights and interests of someone, that the person's cultural background is recognized and considered. It is important that the rights and desires of the **person** are being represented and not those of the advocates.

Reminders:

- Seek to understand your own culture as well as other cultures.
- Remember the diversity of different cultures.
- Remember the extent of cultural influence on individual behavior and perceptions.

Discussion Activity: Client Rights, Cultural Competency and Staff/Agency Responsibilities

- Does a person have the right to include 20 family members in a service plan meeting, even if a staff member doesn't think it is necessary or appropriate?
- Does a person, or his/her family, have the right to refuse certain aspects of service or treatment that conflict with their religious beliefs?
- Think of an area where you have some beliefs related to a certain population or person. Where does that belief come from and what proof do you have to support it?
- A person in a group home can only eat food that is kosher. Where/how do we get that food? Do you know what 'kosher' means?
- A person requests private, quiet time five times per day to pray. The person's service plan indicates he cannot be unsupervised. What do we do?
- Is it okay for a person to wash his hair only once per week?
- You are talking to a person about a 'behavior' that is problematic to others in the house. The person is looking at the ground and her lap, not at you, while you are talking. What are your thoughts?

Source: Clearbrook

The Choice Making Process and Personal Freedoms

Giving people the opportunity to make choices in their lives is one way the DSP can help people achieve **self-determination or personal freedom**. The issue of choice and control over one's life are vital aspects of the quality of life for all people.

Many individuals with developmental disabilities have lived in environments where options for making choices are limited and where they had little exposure to an assortment of experiences that can make a basis for decision making. **Real choices** are significant when the person has **experienced** the options from which to choose.

Like other people, individuals with developmental disabilities deserve the opportunity to make choices in a graduated fashion. No one should be put in situations which allow the person to make major risky decisions, without the benefit of previous experience and learning. They should be exposed to and assisted in making small choices with small amounts of risk. Then the person can gradually make bigger and bigger choices that involve more risk when provided with the appropriate training and assistance. Remember, when risk increases, so does the need for support.

Here are some tips that can help you assist with choice making:



- Get to know the person.
- Identify opportunities for choice or preference.
- Assist the person in developing a range of choices.
- Recognize the health, safety, financial and risk parameters associated with the choice.
- Offer opportunities for choice.
- Show you value the person's choice.
- Educate and negotiate when choices are outside of the parameters.
- Process the choice experience with the person.
- Document the choice experience.
- Offer alternative means to express choice, if needed.

Individuals cannot achieve the outcomes they want unless they are given opportunities to make choices. Making a choice can be broken down into a three-tiered process:

1. The individual must first be exposed to a variety of situations & events.
2. The individual is then allowed the opportunity to indicate preference.
3. S/he then makes a choice.

Guardianship

Family members are not automatically named the legal guardian for their relative with a disability. When children with disabilities reach age 18, they may have a guardian appointed. In all cases, the court will make a determination as to the need for guardianship and who should serve as guardian. A family member may petition the court to be named guardian or the person may express a preference as to his/her guardian. If the person expresses a preference, the judge will give consideration to the person with a disability. However, the judge appoints whoever will make the best guardian and act in the best interest of the person with a disability, regardless of how they are related to each other.

Copies of guardianship papers must be in the person's file.

Guardianship is needed when a person is unable to make and communicate responsible decisions regarding his or her personal care or finances due to a mental, physical or developmental disability. A mental, physical or developmental disability and nothing more is not sufficient cause for the appointment of a guardian. The fact that a person is elderly, mentally ill, developmentally disabled, or physically disabled does not necessarily indicate the need for guardianship. The extent to which a guardian is allowed to make decisions for a ward is determined by the court based on a thorough clinical evaluation and report.

Duties of a guardian include:

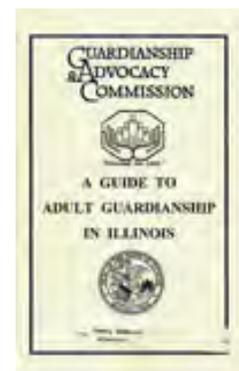
- Advocate for the person's wants.
- Visiting the individual
- Ensuring appropriate residential placement
- Being a part of the Interdisciplinary Team Process
- Approving the ISP/IPP/IHP
- Giving informed consent for medical treatment
- Monitoring supports the person receives
- Visiting the person and reviewing their records on a regular basis
- Protecting the person's rights
- Approval of psychotropic medications
- Making informed decisions for the person.

Types of Guardianships

There are several types of guardianships available under the Illinois Probate Act.

Guardianships can take following forms:

1. **Limited Guardianship** - used when the person with disabilities can make some, but not all, decisions regarding his/her person and/or estate. "Guardianship shall be ordered only to the extent necessitated by the individual's mental, physical and adaptive limitations." A limited guardian makes only those decisions about personal care and/or finances which the ward cannot make. **The powers of a limited guardian must be specifically listed in the court order.** The ward retains the power to make all other decisions regarding his/her person or estate. Limited guardianship may be used to appoint a limited guardian of the person, a limited guardian of the estate, or both.
2. **Plenary Guardianship** - used when the "individual's mental, physical and adaptive limitations" necessitate a guardian who has the power to make all important decisions regarding the individual's personal care and finances. Plenary guardianship may be used for the person, the estate, or both.
3. **Guardianship of the Person** - used when a person, "because of his disability, lacks sufficient understanding or capacity to make or communicate responsible decisions regarding the care of his person." The guardian of the person makes decisions regarding the "support, care, comfort, health, education . . . maintenance, and . . . professional services" (such as educational, vocational, habilitation, treatment and medical services) for the person under guardianship who is called a ward.
4. **Guardianship of the Estate** - used when the person "because of his disability...is unable to manage his estate or financial affairs." A guardian of the estate makes decisions about management of the ward's property and finances.
5. **Temporary Guardianship** - used in an emergency situation. Temporary guardianship can last no longer than 60 days and is a means to assure that the person who evidences need for guardianship receives immediate protection.
6. **Successor Guardianship** - used upon the death, disability, or resignation of the initially appointed guardian, when guardianship is still needed.
7. **Testamentary Guardianship** - used by parents of a person with disabilities and designates, by will, a person who assumes the guardianship appointment upon the death of a parent. The designated person must still be appointed by the court before he/she can serve as guardian. The court will consider the designated



person but is not bound by the testamentary designation. It can appoint someone else if the proposed guardian is found to be inappropriate.

Source: <http://gac.state.il.us/guardfaq>

Behavior Management Committees (BMC) and Human Rights Committees (HRC)

What Is a Behavior Management Committee (BMC)?

The BMC serves important functions within your agency. The people who serve on this committee may include self-advocates, professional staff, and board members, and other people who know the person the best. The committee has responsibility for reviewing behavior plans for technical effectiveness. These plans must then be reviewed by the HRC to ensure that the behavior management plan does not unduly restrict an individual's rights. A summary of BMC duties are:



- Review behavior plans for technical effectiveness.
- Provide impartial, professional reviews of completed plan.
- Reinforcement of schedules, functional analysis, treatment integrity, etc.
- After a behavior plan is reviewed and approved by the BMC and informed consent obtained from guardian, it then goes to the Human Rights Committee for review.

What is a Human Rights Committee (HRC)?

The HRC may include a group of individuals with a diversity of backgrounds and a broad range of experiences-- both from within and outside of the agency/facility. They should not be all of the same people who are on the BMC. These people are charged with the responsibility of protecting the rights of the individuals whom the agency/facility supports. Behavior plans must be endorsed by the HRC before implementation.

One of the issues the HRC faces is the prevention of abuse and neglect.

Staff and persons supported are encouraged to inform the HRC chair of questionable situations that could lead to abuse and/or neglect. The HRC may then decide to contact to the QIDP or executive director in an effort to discourage and prevent the occurrence of abuse and neglect.

BMC and HRC Role Related to Behavior Treatment Plans

1. After a plan is reviewed by the BMC and approved, the plan then goes to the HRC for rights review. Plans which do not receive approval from the BMC should not go to the HRC.
2. The HRC can endorse the plan as written, send it back to BMC for revisions, or endorse the plan with conditions.
3. Plans must be approved by the BMC and endorsed by the HRC before implementation.

There is a definite process that must take place before someone's rights are restricted. Your agency has policies and procedures which address the process for implementing a restrictive program; however, there is generally a similar chain of approval that is followed. First, a meeting is held by the person's Interdisciplinary Team (IDT). If the team determines that no other less restrictive measure can be found, the restrictive program is recommended. The team then requests approval of the program/restriction from the Behavior Management Committee. This committee examines the technical aspects of the restrictive program. If approved by the Behavior Management Committee, approval is finally sought from the Human Rights Committee. The Human Rights Committee may approve the program; however it is only approved for a limited amount of time because any restriction of rights should always be considered as a temporary measure. The team must continually attempt to use other programmatic/behavioral measures which would take the place of the restriction that was posed.

Documentation which supports the continued need for restriction must be presented to the Human Rights Committee at regular intervals to prove that they continue to be necessary. Documentation is a very important part of this process and that is a very important part of your role as a DSP. The restrictions must also be a part of the person's record and be found in the Individual Service Plan (ISP). We will learn more about this plan in a future module.

Activity - Losing an Important Thing in Your Life

Your instructor will guide you through the next activity. When completing the activity think about:

- Human Rights Issues
- Human Rights Violations
- Human Rights Questions
- Human Rights Situations

A Few Words about Risk

The world in which we live is not always safe, secure and predictable . . . Every day that we wake up and live in the hours of that day, there is a possibility of being thrown up against a situation where we may have to risk everything, even our lives. This is the way the real world is. We must work to develop every human resource within us in order to prepare for these days. To deny any person their fair share of risk experiences is to further cripple them for healthy living.

- Robert Perske

In working with young people and/or people with a disability there is a need, through planning, to minimize possible harm. It is not possible to eliminate risk, only to formulate strategies to minimize it. Allowing someone to undertake or engage in a risky activity does not make you negligent. Failing to take any steps to minimize foreseeable harm could be. This is called '**dignity of risk**'.



The ideal for individuals with a disability is to live a life which is as typical as possible to their nondisabled peers. All people take risks.

When a staff member is uncertain, they should discuss the situation with other staff, a supervisor or seek guidance from management.

From "Duty of Care, Critical Thinking and Ethics"

Facilitated by Dr Caroline Ellison

New Mexico Developmental Disabilities Supports Division- Meaningful Day

Please visit the below web site to read "And Yet More Information - *A FEW WORDS ABOUT DIGNITY OF RISK*."

<http://www.health.state.nm.us/DDSD/meaningfullife/documents/AYMAFEWWORDSABOUTDIGNITYOFRISK.pdf>

The “**Dignity of Risk**” recognizes that:

- The world is not always safe and secure.
- Learning new things is an important part to being human and having a full life.
- The main way people learn is to try new things.
- When people try new things, they take risks, including the risk of emotional and physical pain.
- Keeping people from experiencing risks keeps them from learning and therefore from full lives.

Respecting people requires providing them with opportunities to have choices, take chances, and make mistakes. Of course we need to start out with **small** risks. After learning has taken place, we can increase the amount of risk in a graduated fashion.



“Freedom is not worth having if it does not include the freedom to make mistakes.”

Mahatma Gandhi

Activity: Read and Discuss The Dignity of Risk:

The Dignity of Risk

What if...

- ...you never got to make a mistake
- ...your money was always kept in a envelope where you couldn't get to it?
- ...you were always treated like a child?
- ...your only chance to be with people different from you was with your own family?
- ...the job you did was not useful?
- ...you never got to make a decision?
- ...the only risky thing you could do was act out?
- ...you couldn't go outside because the last time you went out, it rained?
- ...you took the wrong bus once and now you can't take another one?
- ...you got into trouble and were sent away and couldn't come back because they always remembered that you were "trouble"?
- ...you worked and got paid \$0.46/hour?
- ...you had to wear your winter coat when it rained because it was all you had?
- ...you had no privacy?
- ...you could do part of the grocery shopping but you weren't allowed to do any, because you weren't able to do all of the shopping?
- ...you spent three hours each day just waiting?
- ...you grew old and never knew adulthood?
- ...you never got a chance?

Human Rights Scenarios for Discussion

Directions: Read the scenarios below. Then identify and discuss which rights may have been violated. **Review agency/facility rights, identify and document which specific agency right(s) were violated.**

Human Rights Scenario 1:

Three staff members from the accounting department at an agency that serves people with developmental disabilities are sitting in the staff lunchroom. A DSP enters the lunchroom and while she is heating up her lunch begins to talk about Joe a person in her work group. She tells the people from accounting that Joe has been “acting up” all day long, cussing her out and throwing work and that she can’t wait for the day to end.

Human Rights Scenario 2:

The QIDP was visiting a residential site when he observed the afternoon shift staff watching the Super Bowl and ignoring an individual who was trying to get their attention. When the Q asked the person what was going on, he said he wanted someone to take him to church but nobody would even talk to him about it.

Human Rights Scenario 3:

When the Q asked staff why they were not helping this individual, they responded that he attended a Catholic Church across town. No one wanted to take him because they would miss part of the football game. They wondered why he didn't go earlier in the day with everyone else to the Lutheran Church down the block. One staff stated that he couldn't tell the difference anyway.

- **Which rights were violated?**
- **How can we correct this situation?**

Human Rights Scenario 4:

Susan has lived in your agency for several years. Her current service plan does not allow her to leave the facility unescorted. She has requested that she be allowed to leave the facility without staff to go to a local store for a soda each day.

The team is concerned for her safety because she has never been out on her own and the store is several blocks away. Also, she would have to cross two busy streets.

Safety Issues in this Scenario:

This scenario demonstrates the challenge between balancing high quality supports, keeping people safe, teaching people to access their community and ensuring individual rights protection. How do we find the balance between allowing Susan to exercise her rights but at the same time ensuring her safety? Things to consider:

- What safety issues are there?
- Do we know if she is able to cross street safely?
- Do we know if she can count change for purchases?
- What are her socialization skills with strangers?
- What additional supports may she need?
- How do we prepare her to exercise her choice while minimizing the risks?

Human Rights Scenario 5:

A QIDP and a DSP are standing in the hallway talking about a person with a disability on the QIDP's caseload. The QIDP is informing the DSP that the person is on a new medication and may be experiencing some side effects.

- **Which rights were violated?**
- **How can we correct this situation?**

Human Rights Scenario 6:

The QIDP was supervising the agency's fun day carnival when she observed a staff member sliding on the giant inflatable slide and ignoring an individual trying to get her attention. When the QIDP asked the person what was going on, he said he wanted to go to the library and read but nobody would even talk to him about it.

When the QIDP asked staff why they were not helping this person, they responded that the library was on the other side of the field inside the building and they didn't want to miss part of the carnival. They wondered why he didn't go to the library earlier in the day with the rest of his group. One staff stated he didn't know what he wanted to do and he couldn't read anyway.



Abuse and Neglect Recognition, Prevention and Intervention



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INTRODUCTION

I am a human being!

We are people, and we have feelings!

We want to learn more and grow every day that we're doing something.

We participate in the community, we learn, and we try new things.

Treat me fair!

Treat me with respect.

Treat me nice and kind.



Stop it if someone hits me.

When people go out into the community, they should be treated as equally as possible—like regular people.

Get rid of the word "inappropriate"!

Anonymous self-advocates Illinois Voices

Your Legally Mandated Responsibilities

You are a Required Reporter: All DHS and community agency employees are required by Rule 50 to report allegations of abuse, neglect and financial exploitation to the Office of Inspector General (OIG).

HOTLINE NUMBER: 1-800-368-1463

Any employee who suspects, witnesses, or is informed of an allegation of abuse or neglect must report it immediately (**NO OPTION!**).

- "Suspects" means you have a suspicion based upon information or an observation,
- "Witnesses" means you saw or heard it, or
- "Informed of" means you were told about it (like hearsay or an anonymous letter), whether or not you think it actually happened.
- You are a required reporter 24 hours a day, seven days a week, NOT only when you are at work.

Every allegation must be reported to the OIG Hotline within **four hours** of the time it was first discovered by the staff.

For abuse/neglect, "employee" means any person who provides services at the facility or agency on-site or off-site. The service relationship can be with the individual or with the facility or agency.

Also, "employee" includes any employee or contractual agent of the community agency involved in providing or monitoring or administering mental health or developmental services. This includes, but is not limited to: owners, operators, payroll personnel, contractors, subcontractors, and volunteers.

Remember, for reporting purposes...

- You are an "employee" 24 hours a day, seven days a week.
- Volunteers and contractors are employees.
- Employees are accountable if they commit abuse or neglect on their personal time.
- An employee who quits or is fired will still be investigated by OIG for abuse or neglect allegedly committed while an employee.

Illinois Rule 50 Definitions

Abuse

Abuse is any physical abuse, sexual abuse, mental abuse or financial exploitation inflicted on an individual other than by accidental means.

So, abuse can be one of four things:

1. Physical Abuse
2. Sexual Abuse
3. Mental Abuse
4. Financial Exploitation



Physical Abuse is defined as an employee's non-accidental and inappropriate contact with an individual that causes bodily harm. Physical abuse includes actions that cause bodily harm as a result of an employee directing an individual or person to physically abuse another individual. Bodily harm is defined as any injury, damage, or impairment to an individual's physical condition or making physical contact of an insulting or provoking nature with an individual. To be reportable, the contact must have been caused by a non-accidental and inappropriate means.

Note: Bodily harm is not always visible. For instance, bodily harm could be a slap that doesn't leave a visible injury or a kick that does leave a visible injury. They are both wrong AND must be reported to OIG.

Sexual Abuse is any sexual behavior, sexual contact or intimate physical contact between an employee and an individual, including an employee's coercion or encouragement of an individual to engage in sexual behavior that results in sexual contact, intimate physical contact, sexual behavior or intimate physical behavior. "Sexual abuse" also includes an employee's actions that result in the sending or showing of sexually explicit images to an individual via computer, cellular phone, electronic mail, portable electronic device, or other media with or without contact with the individual; or, an employee's posting of sexually explicit images of an individual online or elsewhere whether or not there is contact with the individual. "Sexually explicit images" includes, but is not limited to, any material which depicts nudity, sexual conduct, or sadomasochistic abuse, or which contains explicit and detailed verbal descriptions or narrative accounts of sexual excitement, sexual conduct, or sadomasochistic abuse.

Sexual Contact is defined as inappropriate sexual contact between an employee and individual involving an employee's genital area, anus, buttocks or breasts(s) or an individual's genital area, anus, buttocks or breasts(s). Sexual contact also includes sexual contact between individuals that is coerced or encouraged by an employee. There is no such thing as consensual sexual activity between an employee and an individual. Any sexual activity between an employee and an individual is reportable to OIG.

Examples of Sexual Abuse:

- Pressuring an individual to have sex with another individual.
- Encouraging the individual to masturbate in front of others.
- Taking nude photographs of an individual.

Mental Abuse is defined as the use of demeaning, intimidating, or threatening words, signs, gestures, or other actions by an employee, about an individual and in the presence of an individual or individuals that results in emotional distress or maladaptive behavior, or could have resulted in emotional distress or maladaptive behavior, for any individual present.

- Mental abuse is still mental abuse even if the individual's mental or physical condition keeps him/her from getting upset.
- Mental abuse is verbal or nonverbal and includes not intervening when an individual faces an upsetting situation.

Note: Mental abuse is not always face-to-face with that individual, but at least one individual must be present at the time.

Examples of Mental Abuse

- Cursing at an individual. A curse that is not derogatory of the individual is still reportable if the individual becomes upset by it, so it's best not to curse at all near individuals.
- Joking about or making fun of an individual's condition or diagnosis. For example: Making a derogatory comment about an individual with profound intellectual disability or a hearing impairment, who doesn't react. **Remember . . .** If someone does something harmful, you must report it regardless of whether the individual appears to get upset by it or not.

Financial exploitation is taking unjust advantage of an individual's assets, property, or financial resources through deception, intimidation, or conversion, for the employee's, facility's, or agency's own advantage or benefit.

Examples of Financial Exploitation

- Taking an individual's umbrella for the weekend because of a forecast for rain. You have benefitted from your personal use of an individual's property.
- As the payee, an agency decides to divert all of an individual's Social Security funds from his account in order to pay the agency's rent.

Neglect is defined as an employee's, agency's, or facility's failure to provide adequate medical care, personal care, or maintenance, and that as a consequence, causes an individual pain, injury, or emotional distress, results in either an individual's maladaptive

behavior or the deterioration of an individual's physical condition or mental condition, or places an individual's health or safety at substantial risk.

Example of Neglect

If a co-worker is assigned one-to-one (arms length) supervision to prevent an individual from eating inappropriate objects, yet the co-worker leaves him alone, you should report your co-worker for neglect if the individual then:

- Eats anything harmful;
- Reasonably could have eaten anything harmful;
- Became upset because he was left alone; or
- Acts out and needs to be on one-to-one longer as a result.

Egregious neglect is a finding of neglect as determined by the Inspector General that represents a gross failure to adequately provide for, or a calloused indifference to, the health, safety, or medical needs of an individual, and results in an individual's death or other serious deterioration of an individuals' physical or mental condition.

Questions and Answers

Question: What about multiple allegations? If an individual makes multiple allegations of abuse or neglect every day, do you have to report all of them?

Answer: You should report each one as a new allegation. But you must also try to get specifics - names, dates, and times - so OIG can verify that each allegation has already been reported.

Question: What about false allegations? If an individual makes an allegation of abuse or neglect that you know is not true, do you still have to report it?

Answer: Yes

Question: What about recanted allegations? If an individual alleges that he or she was abused or neglected, and then, before you call to report it, he or she admits to just making it up, do you have to still report it?

Answer: Yes. Remember . . .

- If you are told about abuse or neglect, you must report it.
- If you witness abuse or neglect, you must report it.
- If you just suspect abuse or neglect, you must report it.

Question: What about "screening?"

Answer: You are not allowed to screen allegations.

Screening means intentionally not reporting an allegation or omitting or changing any information in the allegation. Your supervisor is not allowed to screen. If the policy says you are to report allegations to your supervisor, you should do so. However, if your supervisor fails to report it to OIG, you are still responsible to report it. You are still a Required Reporter.

Additional Definitions

Accidental

The law does not require reporting harm that is caused only by "accidental means." Accidental implies that you did not make a conscious decision to act or fail to act.

Examples:

Backing into someone is an accident.

Tripping over your shoes is an accident.

Hitting someone back is **not** an accident.

Cursing an individual you don't know is present is **not** an accident.

Aggravating Circumstance

A factor that is attendant to a finding and that tends to compound or increase the culpability of the accused. Examples: Aggravating circumstances are those that classify the abuse or neglect as more severe, like:

Using something as a weapon to inflict harm;

Causing a severe injury;

Allegation

An allegation is any assertion, complaint, or suspicion you have that abuse or neglect of an individual may have occurred. You do not have to prove or even believe an allegation to report it. Allegations are never assumed true or false: If you hear of an allegation from an individual who frequently lies, you are still required to report it. Allegations have no statute of limitations: If you hear of an allegation that may have occurred ten or twenty years ago, you are still required to report it.

Imminent Danger

A preliminary determination of immediate, threatened or impending risk of illness, mental abuse, or physical injury or deterioration to an individual's health that requires immediate action.

Maltreatment

Maltreatment encompasses all forms of inappropriate interactions, employee misconduct, abuse and neglect. Maltreatment may range from mild forms (e.g., using an unnecessarily loud tone of voice with a person served) to severe forms such as employees hitting a person served. Please refer to your agency's policy on maltreatment. There is good reason to believe that, left unaddressed, mild forms of maltreatment/inappropriate interaction

might lead to more severe, reportable forms of abuse and to a negative influence on the home/work environment.

Mitigating Circumstance

A condition that is attendant to a finding that does not excuse or justify the conduct in question, but may be considered in evaluating the severity of the conduct, the culpability of the accused, or both the severity of the conduct and the culpability of the accused.

Required Reporter

A Required Reporter is any employee who suspects, witnesses, or is informed of an allegation of abuse or neglect. **Remember: you are a Required Reporter.** You must report any alleged abuse or neglect that you:

- See,
- Hear,
- Read, or
- Suspect.

You do not need to believe an allegation is true to report it. Even outlandish and far-fetched allegations - those that cannot be true - must be reported.



You must report it immediately. All allegations must be reported to OIG within four hours.

You must cooperate fully with every OIG investigation. Failure to do so can result in you being disciplined or discharged.

Remember, agency policies should include those that prohibit retaliation against an employee who acts in good faith reporting any suspicion of abuse and neglect in their duties as a required reporter.

You can be fired and prosecuted if you abuse or neglect someone.

When an incident occurs... What you should **NOT** do:

- **Do not** remove anything.
- **Do not** wash or clean anything.
- **Do not** handle anything that might be evidence.
- **Do not** search for evidence yourself.

Examples:

An individual who is bleeding alleges to you that an employee hit him with a mop in the kitchen.

Potential evidence:

- the clothing worn by the accused and the victim,
- any mop or broom in the kitchen, and
- potentially anything in the kitchen.

What you should **NOT** do?

- move or pick up anything off the floor, or
- clean blood off anything in the kitchen or mop the floor.

An individual alleges to you that he just had sex with an employee in a storage room.

Potential evidence:

- the clothing of either person,
- towels or sheets in his bedroom, and
- anything in the storage room.

What you should **NOT** do:

- enter the room or let other staff enter it, or
- allow the individual to shower or change.

Since June 13, 2006, intentionally reporting an allegation late—or not reporting it at all—is a Class A misdemeanor.

If you are convicted, it is punishable by:

- up to one year in jail
- and/or a \$2,500 fine.



Allegations of crimes should be reported to the most appropriate law enforcement agency, especially if an immediate response is critical.

Reporting Immediately Inform Your Supervisor or Call:

OIG (Office of Inspector General) Hotline-800-368-1463

Reporting for: Adult victims age 18 through 59 living in facilities under the jurisdiction of the Department of Human Services including State Operated Developmental Centers (SODCs); State Operated Mental Health Centers; Community Integrated Living Arrangements (CILAs); Developmental Training (DT) sites; domestic living situations (such as private homes, unlicensed residential settings, and board and care homes whose physical or mental disability impairs his or her ability to seek or obtain protection from abuse, neglect or exploitation).

IDPH (Illinois Department of Public Health) Hotline-800-252-4343

Reporting for: Long-Term Care Facilities (Skilled Nursing; Intermediate Care); Hospitals; Community Living Facilities; Assisted Living Facilities; Sheltered Care Facilities; State Operated Developmental Centers (SODCs); State Operated Mental Health Centers

DCFS (Department of Child and Family Services) Hotline- 800-25-ABUSE

Reporting for: Children (aged 17 years and younger) In all situations including children who live in a home/family environment; in public or private residential agencies or institutions, including state operated developmental disability or mental health facilities; or attend day care centers, schools or in situations where children are in contact with adults who are responsible for their welfare.

Department on Aging Hotline – 866-800-1409

Reporting for: Individuals 18-59 with a disability living in a domestic living situation and Individuals 60 years of age or older who reside in domestic living situations and are alleged to be abused, neglected or financially exploited by another individual.

QUICK REFERENCE FOR PHYSICAL ABUSE, SEXUAL ABUSE, MENTAL ABUSE, NEGLECT, OR FINANCIAL EXPLOITATION REPORTING

<u>If</u> the consumer is:	<u>And</u> you suspect that the perpetrator of the abuse/neglect is:	<u>Then</u> you should call/inform:
Under 18, living in a private home in the community	A family member or caregiver	Your supervisor DCFS HOTLINE 1.800.252.2873
Under 18 and enrolled in any of your agency's programs (non-ICF residential, day programs, etc. included)	A staff member from your agency	Your supervisor DCFS HOTLINE 1.800.232.2873
Under 18 and enrolled in any of your agency's programs (non-ICF residential, days program, etc. included)	A family member or caregiver	Your supervisor DCFS HOTLINE 1.800.232.2873
Age 18 and over enrolled in any of your agency's programs (non-ICF residential, day programs, etc. included)	A staff member from your agency	Your supervisor OIG HOTLINE 1.800.368.1463
Age 18 and over enrolled in any of your agency's programs (non-ICF residential, day programs, etc. included)	A family member or caregiver	Your supervisor OIG HOTLINE 1.800.368.1463
Age 18 and over living in a setting funded, licensed, or certified by DHS, but not run by your agency (i.e., individual attends your agency's day program, lives in CILA at another agency)	A third-party staff member	Your supervisor OIG HOTLINE 1.800.368.1463
Between 18 and 59 and living in a private home in the community	A family member or caregiver	Your supervisor DOA HOTLINE 1.866.800.1409
Age 18 and over living in a nursing home or facility (ICF included) run by your agency	A staff member from your agency	Your supervisor DPH HOTLINE 1.800.252.4343
Age 18 and over living in a nursing home or facility (ICF included) not run by your agency	A third-party staff member	Your supervisor DPH HOTLINE 1.800.252.4343
Age 60 and over NOT in a nursing home (living in private home in community)	A family member or caregiver	Your supervisor DOA HOTLINE 1.866.800.1409

- **IF THERE IS IMMEDIATE DANGER or A MEDICAL EMERGENCY, CALL 911 and then inform your supervisor.**
- **In cases of inappropriate staff conduct or inappropriate staff interactions, inform your supervisor.**
- **DPH may also require reporting of serious injury. ALL client deaths should be reported to your supervisor, and then to appropriate agency, regardless of whether abuse/neglect is suspected.**
- **DHS OIG now accepts referrals of abuse/neglect allegations of the 18+ individuals with a disability still in school with an IEP.**
- **In accordance with the Child Care Act of 1969, "Adult student with a disability" means an adult student, age 18 through 21, inclusive, with an Individual Education Program, other than a resident of a facility licensed by the Department of Children and Family Services.**

Source: Modified Clearbrook tool

What Is Reportable?

Abuse, Neglect, Death and Serious Injury

You must report to your **AGENCY** incidents or allegations of: Abuse, Neglect, Death, Serious Injury and Inappropriate Interactions. For example:

- If you **observe** an incident of abuse, neglect;
- If you **are told** of an incident of abuse, neglect; or
- If you **believe** there may have been an incident of abuse or neglect.

OIG must be contacted within 4 hours for:

- **Any allegation of abuse**
- **Any allegation of neglect**
- **Any injury or death of an individual that occurs within a facility or community agency when abuse or neglect may be suspected.**



To ensure an investigation by OIG, someone must call OIG's Abuse and Neglect Hotline at **1-800-368-1463**. Each allegation of abuse and neglect must be reported to the OIG hotline within **4 hours** of the initial discovery.

**Follow Your Agency's Policy on Reporting Abuse, Neglect, and Financial Exploitation but Remember...
The Allegation must be reported within 4 hours of Discovery.**

Did You Know . . .

- The rate of abuse ranges from a low of 25% to a high of 83% for all people with a disability.
- The perpetrators are often not strangers but rather caregivers or someone else who is close to the person with a disability.
- More than 90 percent of people with DD will experience sexual abuse at some point in their lives. (Valenti-Hein & Schwartz, 1995)
- 49 percent will experience 10 or more abusive incidents. (Valenti-Hein & Schwartz, 1995)
- Only 3 percent of sexual abuse cases involving people with disabilities will ever be reported. (Valenti-Hein & Schwartz, 1995)
- Staff who engage in inappropriate interaction usually do not intend to cause any harm to the individual. These persons are generally kind and caring caregivers. However, their actions can result in injury to the individuals they support.
- Isolated incidents of inappropriate interaction can become a habit.
- Inappropriate interaction may require corrective action by you or the agency or facility.
- Inappropriate interactions tend to escalate over time and become more ingrained, more severe, more pervasive acts and may well lead to abuse and neglect.



Some Examples of Inappropriate Interaction

Language

Talk about someone in their presence

Use labeling

Use phrases like "had a behavior"

Uses terms such as "low grade", "retarded", "ignorant"

Uses degrading nicknames

Raising volume of voice

Saying "Them" or "Hey You"

Saying "Shut up"

Practice

Lining up

Herding

Hovering

Grabbing by wrists or clothing

Controlling supplies

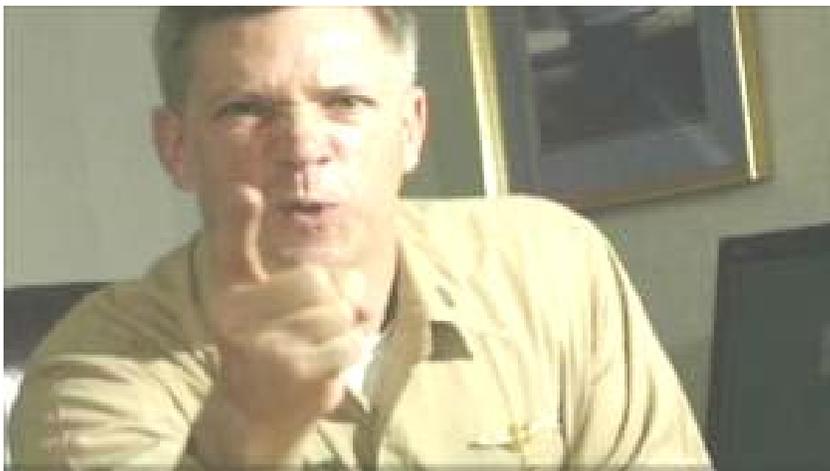
Limiting choices

Threatening possessions

Demanding

Shouting orders

Using TV as substitute caregiver



What is “Maltreatment?”

The term “maltreatment” applies to a wide range of negative interpersonal interactions. For our purposes, it will serve as the term that will include acts or omissions by employees involving individuals that are improper or inappropriate as well as acts or omissions that are abusive, negligent or exploitative. The term “maltreatment” includes OIG reportable acts as well as **acts not reportable to OIG but that may be considered inappropriate. This type of maltreatment is sometimes called “inappropriate interactions”.**

Please refer to your agency’s policy on “Maltreatment” or “Inappropriate Interactions”

Possible Indicators of Maltreatment

- **Physical indicators** are any type of visible, physical marking that a person can observe.
- **Verbal indicators** are any type of words or sounds that a person can hear, including sign language.
- **Behavioral indicators** are any type of behavior or action that a person can observe.
- **Circumstantial indicators** are any type of current or past behavior, words or actions of the caregiver.

Be aware that it is possible that the signs that you are observing are not always indicators of maltreatment.

How Do I Determine if What I am Seeing is Maltreatment?

- The better you know the individuals that you support and the better you know the environment in which you work, the easier it will be for you to figure out what the indicators mean.
- It is possible that an indicator may be caused by something other than maltreatment.
- Indicators do not have to be reported to OIG until there is a determination that the indicator supports reasonable suspicion of abuse or neglect.
- Recognition of indicators is a **form of prevention**.

Possible Physical Indicators of Maltreatment

- Physical marks on the individual's body (e.g., cuts, bruises, burns, bites)
- Physical marks that are on areas of the body that are difficult to injure (e.g., bruises, burns, cuts on the back)
- Physical marks that are unusual for the specific individual
- Physical marks that no one can explain how they happened
- Blood, semen or other physical markings on the individual's clothing, bedding, towels, or in other areas of the environment
- Torn or missing clothing



Possible Verbal Indicators of Maltreatment

- Statements by an individual (e.g., complaints of being poorly treated, complaints of not liking an employee)
- Unusual or prolonged crying, screaming, or other form of noise made by the individual
- Unusual or prolonged crying, screaming, or other form of noise made by the individual only with a particular employee
- Sudden changes in mood, especially depression
- Engages in sexualized behavior (e.g., an unprompted or unexplained drawing of genitalia.)

Possible Behavioral Indicators of Maltreatment

- Negative changes in behavior patterns (e.g., increased aggression, sudden withdrawal from others and activities, return to engaging in old behavior challenges, changes in sleeping habits, changes in eating habits.)
- Unusual or more extreme displays of fear (e.g., fear of being alone, fear of being with specific persons, fear of being touched, fear of going to a particular place, fear of specific objects.)
- Sudden changes in mood (i.e., increased irritability, sadness, anger, apathy, fear.)
- Negative changes in behavior patterns, unusual or more extreme displays of fear, sudden changes in mood only when specific persons are present or only after being with specific persons.
- Avoids specific persons (e.g., the individual doesn't want to be around an employee that she had previously enjoyed being with.)
- Avoids specific places for an unknown reason
- Exhibits negative changes in behavior patterns (e.g., difficulty sleeping or other sleep disturbances, develops an eating disorder in which the individual refuses/restricts food intake or gorges/is obsessed with food, regression to engaging in old behavior patterns.)
- Unusual or more extreme displays of fear (e.g., fear and resistance towards physical examination.)

Remember: It is possible that the behavioral signs that you are observing are not always indicators of maltreatment. The signs may be due to other factors: the person may be physically sick, emotionally ill, experiencing a side effect of medication, may have experienced a sad event in his/her life, or some other unknown reason.

When you observe behavioral signs it is best to check it out to find out what the problem really is. It is also important to document all your observations.

Scenarios for Discussion

Discuss the following scenarios with regard to actions taken and implications of abuse.

Scenario 1

- Tom is a staff person working with Melanie, a person she helps support.
- As part of an approved behavioral program, when Melanie gets upset she goes to her room to relax.
- Melanie is upset right now and is yelling in the dining room.
- Tom says in a loud angry voice (and with a threatening pose) "Melanie you need to go to your room, now!"
- Melanie becomes even more upset and refuses to go to her room.
- Tom grabs her by the arms and gives her a shake and says, "GO TO YOUR ROOM!"



Scenario 2

- Charlotte is a very picky eater but loves dessert.
- She has no weight concerns and does not have any dietary restrictions, but Rita, a staff person, is concerned that Charlotte will only eat junk food.
- At dinner, to motivate Charlotte to eat her meal, Rita tells Charlotte, "Eat your meal or you won't get your dessert".
- Charlotte ate her whole meal.



Caregiver Warning Signs

Here are some warning signs that may indicate the potential for maltreatment on the part of the caregiver:

- Negative caregiver behavior (i.e., aggression, hostility, anger, disrespect, apathy, callousness, etc., towards self and others)
- Previous history of maltreating others
- Alcohol or drug abuse
- Negative attitudes that devalue self and others
- Past history of threatening to harm the individual
- Joking about harming the individual
- Finding humor in the pain and suffering of the individual



Sexual Abuse

Possible Physical Indicators of Sexual Abuse

- Bruises in genital area
- Genital discomfort
- Torn or missing clothing
- Unexplained genital abnormalities
- Unexplained pregnancy
- Unexplained blood on underwear

It is possible that what you are observing is not an indicator of maltreatment. Genital discomfort could be a urinary tract infection or yeast infection. Bruises could be related to hemophilia or diabetes. The individual's wound could be the result of self-injury. It is important to document all you see.

Possible Verbal Indicators of Sexual Abuse

- Unexplained unusual knowledge or new words of a sexual nature that the individual had not previously known
- An interest in a new sex-related topic that cannot be explained

- Discloses or talks about the sexual abuse

It is possible that what you are hearing is not an indicator of maltreatment. However, when you hear a possible verbal indicator it is best to check it out to find out what the problem is. It is important to document all your observations.

Possible Behavioral Indicators of Sexual Abuse

- Avoids specific persons (e.g., the individual doesn't want to be around an employee that she had previously enjoyed being with.)
- Avoids specific places for an unknown reason
- Exhibits negative changes in behavior patterns (e.g., difficulty sleeping or other sleep disturbances, develops an eating disorder in which the individual refuses/restricts food intake or gorges/is obsessed with food, regression to engaging in old behavior patterns.)
- Unusual or more extreme displays of fear (e.g., fear and resistance towards physical exams.)
- Sudden changes in mood, especially depression
- Engages in sexualized behavior (e.g., an unprompted or unexplained drawing of genitalia.)



Possible Circumstantial Indicators of Sexual Predator

- Excessive or inappropriate eroticism (i.e., the employee brings pornographic material to work, seems preoccupied with sex.)
- Perpetrates other forms of abuse.
- Seeks isolated contact with individuals.
- Has a personal history of sexual abuse.
- It is possible that the circumstantial indicators that you are observing are not indicators of maltreatment.
- It may be a "one time problem" that is not typical for the individual.
- It is also possible that you are observing a typical pattern of behavior for the individual.
- It is also possible that the individual's history has no impact on their present behavior.
- Whenever you observe circumstantial indicators it is best to check it out to find out what the problem really is.

When someone tells you they have been sexually abused, FIRST, respond to person's immediate needs, THEN report incident to OIG within the required time frame.

WHAT TO DO When Someone Tells You They Have Been Sexually Abused and WHAT TO SAY When Someone Tells You They Have Been Sexually Abused

A DSP can use these guidelines if an individual says they have been sexually abused. The guidelines and contact information can be put near the phone, on an index card or on a sheet of paper.

When Supporting Victims of Sexual Abuse:

- Provide Privacy
- Explain Options
- Support Choices
- Ensure Safety

<u>DO</u>	<u>DON'T</u>
<ul style="list-style-type: none"> ✓ Believe ✓ Respect ✓ Support ✓ Assist 	<ul style="list-style-type: none"> ✓ Doubt ✓ Judge ✓ Blame ✓ Punish

Say:	I believe you. I'm sorry this happened to you.
Ask:	How can I help you? What do you need right now?
Tell:	We have a crisis center in town that can help you on the phone or in person.
Help:	Would you like to call them? I can help you with that.
Protect:	What would make you feel safe right now? Let's make a safety plan.

For more information on this topic, please call the Rape Crisis Center at 800-656-4673 or visit the Illinois Department of Human Services website at www.dhs.state.il.us or the Illinois Coalition Against Sexual Assault at www.icasa.org



WHAT AM I REALLY SEEING?

John reports to his supervisor that he is concerned about Fred, a person at the home. Fred has always had a tendency to tease his friends and lose his temper; however, this behavior has been more frequent over the past two weeks. While helping Fred in the restroom, John noticed dark stain marks on his underwear. When asked about the marks, Fred reported that his buttocks have been itchy. John concluded that Fred needs to wipe himself better and instructed Fred on proper hygiene. Recently, Fred complained that his bottom was sore. Fred agreed to show John his buttocks. John observed several scratches and redness around the anal area. John tells his supervisor that he is unsure what all of this information means.

Indicator Exercise: What Am I Really Seeing?

- What indicators are present in this scene?
- What are possible explanations for these indicators?
- What type(s) of maltreatment might be occurring?

What are the requirements for reporting deaths?

Deaths that must be reported to OIG are as follows:

- Deaths occurring on-site in any residential or non-residential program;
- Deaths within 14 days of discharge or transfer from a residential program; and
- Deaths within 24 hours after deflection from a residential program.

A death must be reported to OIG within 24 hours of the staff becoming aware of it. If the death may be suspected to be the result of abuse or neglect by staff, however, the death must be reported within four hours.

Reporting to Law Enforcement

Allegations of crimes should be reported to the most appropriate law enforcement agency, especially if an immediate response is critical. However, the allegation must still be reported to OIG within the time required if it involves a death or alleged abuse or neglect of an individual with disabilities.



By law and interagency agreement, OIG reports criminal allegations to the Illinois State Police or local law enforcement. OIG also may work with law enforcement agencies in investigating allegations of abuse or neglect of individuals with disabilities.

Question: When an incident occurs, what you should do?

- Ensure the safety of all individuals.
- Notify your supervisor or investigative staff that there may be evidence.
- Document everything you see and do.
- Avoid entering an area where the act allegedly occurred.
- Write out a statement, if requested.

OIG – Investigative Findings

An allegation may be . . .

Unfounded

There is no credible evidence to support the allegation.

Unsubstantiated

There is credible evidence, but less than a preponderance of evidence to support the allegation.

Substantiated

There is a preponderance of the evidence to support the allegation.



Discussion Activity: What Happens If You Are Accused Of Abuse or Neglect?

Persons under investigation may be placed on administrative leave pending the outcome of the investigation.

- What feelings would you have towards the client or staff who made the accusation?
- How might you feel about being placed on administrative leave?



Substantiated Findings and the Health Care Worker's Registry

(formerly known as NURSE AIDE REGISTRY)

The Department of Public Health maintains a registry that, among other things, identifies health care workers that have had substantiated findings of abuse and neglect made against them. The Office of Inspector General (OIG) reports to the Health Care Worker Registry the names of employees who are substantiated to have committed physical abuse, sexual abuse, egregious neglect or financial exploitation unless there is still pending a grievance or a petition filed under 20 ILCS 1305/1-17(s)(3). Referral to the Health Care Worker Registry applies to all employees (which includes owners/operators, contractors, subcontractors, and volunteers). Substantiated findings of mental abuse and non-egregious neglect are never reported to the Health Care Worker Registry.



Perpetrators whose names are placed on the Health Care Workers Registry:

- Are ineligible for employment in the field of human services in Illinois.
- Are prohibited from being employed in providing, administering, or monitoring services.

After the name of a person is referred to the Health Care Worker Registry, he or she may request removal using the 20 ILCS 1305/1-17(s)(6) petition process no more than once per twelve month period.

False Reporting of Abuse or Neglect

As with other inappropriate behaviors, sometimes individuals do make false allegations against DSPs or other staff. Below are guidelines on handling questionable and/or false allegations.

- Thorough documentation of your actions, your co-worker's actions, and those of the clients you support will help safeguard you in the event a false report is made against you.
- Reports made by individuals with a documented history of making false accusations must be taken seriously and reported.
- You have little way of knowing whether or not the individual is telling the truth this time.
- Individuals with a known history of making false reports are at increased risk because perpetrators know they are easy targets and it is likely that the report will not be taken seriously.
- All incidents should be addressed clinically and through a behavior management program and/or training.

False Reporting of Abuse and Neglect Activity

Directions: After reviewing your agency's policy on false reporting, write the answers to these questions based on the discussion.

What role do you have in reporting and investigating the allegation at your agency or facility?

What can you do to minimize the negative impact on individuals and the home/work environment while an investigation is being conducted?

What can you do to maintain confidentiality while the investigation is being conducted?

Recognition is a Form of Prevention

- Early recognition of maltreatment may prevent escalation into more severe and prolonged forms of maltreatment.
- Early recognition allows the community agency or facility an opportunity for early intervention with the offending employee. Perhaps the person can be retrained. Perhaps the person should be terminated.
- Early recognition may stop the individual from being harmed any more than he already has been and may prevent further victimization.
- Early recognition can prevent the bad actions of one person from contaminating the rest of the employees and home or work environment.





Recognition Activity

Directions: Working in small groups, for each of the following scenarios, write in the first column "yes" if you would report this to your supervisor or "no" if you would not. If you wrote yes in the first column, in the second column, write what type of maltreatment you think has occurred.

Choose from: Physical Abuse, Sexual Abuse, Neglect, Mental Abuse, Financial Exploitation or Other.

Did maltreatment occur?	Yes/No?	What Type?	Report to
OIG			
1. An employee does not cut up a client's food as prescribed in his/her ISP and the client chokes.			
2. An employee shoves a client to get the client to stop asking to go on an outing.			
3. An employee yells, "Don't touch that stove, it's hot!" at a client.			
4. A client trips over a crack in the sidewalk and falls, spraining his ankle.			
5. When a client asks for juice rather than coffee, an employee says, "Drink that or you get nothing."			
6. An employee calls a client "lazy" and the client cries.			

Did maltreatment occur?	Yes/No?	What Type?	Report to OIG
7. An employee encourages two clients to fight so they can "figure it out on their own."			
8. An employee slaps a client in the face in response to the client kicking the employee in the leg.			
9. One employee says to another employee about a client "Oh he drives me nuts, he's such a stupid jerk." The employees are alone in a room.			
10. An employee does not notify anyone or assist the client with changing herself when he notices that client has soiled her pants.			
11. An employee makes a client sit out of work after that client complained about the employee to his Q.			
12. An employee makes a client wait to go to the bathroom to change soiled pants, saying, "You should have told me sooner that you needed to go to the bathroom."			
13. An employee observes that a client cut her hand and is bleeding heavily, but does not attend to that because that employee is talking with another employee about his weekend.			
14. An employee chooses not to follow a client's behavior plan (giving that client his daily \$1 for pop) even though he met the criteria, because he called the employee a name. This results in the client becoming aggressive.			

Did maltreatment occur?	Yes/No?	What Type?	Report to OIG
15. An employee says to a client, "Do that again and you'll be sorry."			
16. An employee 'borrows' a client's wristwatch because his is broken.			
17. You hear an employee swear at a client. The client shies away.			
18. You see an employee take money from a client's envelope that holds his incentive pay for his behavior plan.			
19. An employee does not read the medication labels and puts too many pills in the client's pill cup. Although the client tries to protest, the employee orders the client to take the pills. The client is hospitalized.			
20. An employee demands each individual pay one dollar upon returning from a day program, claiming "for services rendered."			
21. You see a bruise on a client that was not there the day before and looks like a handprint.			
22. A client tells you that a staff at her group home touched her "down there."			
23. You hear an employee say, "You should be ashamed of yourself" to a client who has just hit another client.			

Did maltreatment occur?	Yes/No?	What Type?	Report to OIG
<p>24. A client reports to program on a very cold snowy day wearing shorts, flip-flops, and no coat or gloves. His toes and fingers are purple. The client lives at home with his elderly mother.</p>			

Source: Clearbrook, Arlington Heights, Illinois

Prevention

Here are some tips you can use when faced with a stressful situation:

Thought Stopping

In order to diffuse a situation, you, as the DSP, can engage in a four-step process called "thought stopping."

The four steps are:

- *Stop!*
- *Think!*
- *Relax!*
- *Reconsider!*

When faced with a stressful situation, you may only have a few seconds to use thought stopping, but that may be enough time to prevent the wrong action.

- Part of "reconsidering" is assessing the situation to determine what the best way is to diffuse the situation.
- Use your detective skills and try to figure out what is bothering or upsetting or somehow affecting the person.
- Teach, model and reinforce assessing and diffusing a situation at your home/work environment.

Strategies for Diffusing a Situation

- Ask a person what's going on!
- Calmly talk to the person about what happened.
- Calmly explain to the person what the options are for doing something differently.
- Give the individual readily available choices for how to handle the situation.
- Create a diversion - direct the individual's attention to something or someone else that is enjoyable for the individual.
- Have the individual engage in physical exercise to release pent-up emotions.

- Join the individual in the activity.
- Support the individual in taking a quiet rest period to relax.
- Change your tone of voice.
- Change the surroundings.
- Don't engage in a power struggle with the person.
- Play calming music.

Teamwork

- Teamwork is easier said than done.
- Effective teamwork requires that each person compromise or bend a little in order to complete the work in the best possible way for everyone.
- Teamwork requires putting aside personality differences or negative personal feelings about a co-worker. The individuals you support should never suffer because you do not like a co-worker.



What are some characteristics of an ideal situation when it comes to teamwork?

How can you promote effective teamwork?

Creating & Maintaining a Respectful, Healthy, Environment



Directions:

In your group answer the following questions:

How would you describe the perfect respectful, healthy, engaging environment?

What does it look like?

What does it sound like?

What does it feel like?

The Impact You have on People You Help Support

I've come to the frightening conclusion that I am the decisive element in a resident's life. It is my personal approach that creates the climate. It is my daily mood that makes the weather. I possess a tremendous power to make a resident's life miserable or joyous. I can be a tool of torture or an instrument of inspiration. I can humiliate or humor, hurt or heal. In all situations, it is my response that decides if a crisis will be escalated or de-escalated and a resident humanized or de-humanized.

Haim Ginott



Attitude

The attitude that you bring to work each day directly impacts the individuals that you support and your job performance.

Your attitude can contribute to creating a trust-producing, healthy, engaging environment or can contribute to creating a negative, hostile, fearful, destructive environment.

- What are some examples of how you feel when you have a good attitude? That is, how does a good attitude make you feel?

- What are some things that can happen in your life that might cause you have a bad attitude at work?

- What are some examples of how you feel when you have a bad attitude? That is, how does a bad attitude make you feel?

- What are some things you personally can do either before or after work to help you have a good attitude for work?

- What are some things you can do during work that can help you keep your emotions in check?

Stress and Burnout

Providing supports to persons with developmental disabilities can be very rewarding. However, the day-to-day responsibilities and sometimes demanding work can end up taking a toll on both your body and your mind causing stress and burnout. People who are "burned out" may experience fatigue, stress, anxiety, and depression. When ignored, stress can lead to irritability that may lead to abuse and neglect. From the very start of your role as a DSP, you should build in ways to be a DSP to yourself!

What is Stress?

Stress is a reaction to changes that require you to adjust or respond. Our bodies are designed to feel stress and react to it. Not always a bad thing, stress keeps us alert and ready to escape danger.



It's not always possible to avoid change or the situations that can cause stress; as a result, you can begin to feel overwhelmed and unable to cope.

When it persists, stress can affect the body's immune system, leading to illness.

When you are not sure of the exact cause of your stress, it may be helpful to know the warning signs. Once you can identify these signs, you can learn how your body responds. Then you can take appropriate steps to reduce the stress.

What Are the Warning Signs of Stress?

Your body sends out physical, emotional, and behavioral warning signs of stress.

Emotional warning signs:

- Anger
- Inability to concentrate
- Unproductive worry
- Sadness
- Frequent mood swings

Physical warning signs:

Stooped posture

- Sweaty palms
- Tension headaches
- Neck pain
- Chronic back pain
- Chronic fatigue
- Weight gain or loss
- Problems with sleep

**Behavioral warning signs:**

- Over-reacting
- Acting on impulse
- Using alcohol or drugs
- Withdrawing from relationships
- Changing jobs often

What Can Be Done to Reduce Stress?

Finding ways to reduce stress will help lessen the long-term emotional and physical toll of caregiving.

Tips for managing stress include:

- Keep a positive attitude. Believe in yourself.
- Accept that there are events you cannot control.
- Be **assertive** instead of **aggressive**. "Assert" your feelings, opinions, or beliefs instead of becoming angry, combative, or passive.
- Learn to relax.
- Exercise regularly. Your body can fight stress better when it is fit.
- Stop smoking.



What Are the Symptoms of Burnout?

The symptoms of DSP burnout are similar to the symptoms of stress and depression.

They include:

- Withdrawal from friends, family and other loved ones
- Loss of interest in activities previously enjoyed
- Feeling blue, irritable, hopeless, and helpless
- Changes in appetite, weight, or both
- Changes in sleep patterns
- Getting sick more often. Flare-up of your own medical problems or a new illness
- Feelings of wanting to hurt yourself or the person for whom you are caring
- Emotional and physical exhaustion, chronic fatigue
- Rough handling of the persons with the disability

How Can I Prevent Burnout?

Here are some steps you can take to help prevent DSP burnout:

- Find someone you trust -- such as a friend, co-worker, or neighbor -- to talk to about your feelings and frustrations. Look beyond those old beliefs that asking others for a favor is a sign of weakness, or that others should know when and how to help.
- Set aside time for yourself, even if it's just an hour or two. This should happen regularly in small ways, like a phone call to a friend, a relaxing bath, or a walk on a nice day; and occasionally in a big way, like a night out with friends, or even a vacation. Remember, taking care of yourself is not a luxury. It is an absolute necessity for DSPs.
- Talk to a professional. Most therapists, social workers, and clergy members are trained to counsel individuals dealing with a wide range of physical and emotional issues.
- Know your limits and do a reality check of your personal situation.
- Recognize and accept your potential for DSP burnout.

- Develop new tools for coping.
- Remember to lighten up and accentuate the positive.
- Use humor to help deal with everyday stresses.
- Stay healthy by eating right and getting plenty of exercise and sleep.
- Accept your feelings. Having negative feelings -- such as frustration or anger -- about your responsibilities or the person for whom you are caring is normal. It does not mean you are a bad person or a bad DSP.
- Join an organization. There are organizations that support DSPs and there are coalitions of organizations that work to improve the quality of human service support by making the direct support workforce stronger.

The National Organization for Direct Support Professionals can be found at: **<http://www.nadsp.org>**. Sharing your feelings and experiences with others in the same situation can help you manage stress, locate helpful resources, and reduce feelings of frustration.

Supporting the Emotions of People with Developmental Disabilities

It is important that you understand the emotions of the person you serve by keeping in mind:

- Persons served must interact with multiple caregivers and must respond to the directions of many people.
 - Persons served must deal with the inconsistencies in how his/her support programs are implemented.
 - How frustrating and confusing every day can be for the people you support.
- 
- The people you support experience the same emotions that you and I experience (joy, sorrow, anger, frustration, fear, boredom, loneliness, excitement).
 - People's reactions to things that happen to them in life are often no different from how you and I react.
 - The people 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.
 - People may not always know the best way to express their emotions and how to communicate how they feel, what they want and what they need.

Supporting the Emotions of People with Intellectual Disability

SCENARIO I

Shirley has been looking forward to her work holiday party for two months. She told her boyfriend that she would wear a new dress, and have her hair done at a beauty shop. Shirley lives in a group home with five other ladies. Ready for the party, Shirley walked down the hall from her bedroom towards the living room. Florence, another resident at the home, came out of her room with an open stick of lipstick in her hand. Florence tripped and collided with Shirley, leaving a line of red lipstick across the front of Shirley's dress and her hair in a mess. Shirley became upset and threatened to hit Florence. Shirley began to cry and tried to rip off her dress.



If you were Shirley, how would you react in this situation? How would you feel?

How would you want others to react?

If you were the caregiver involved, how would you approach this situation with Shirley?
Florence?

Supporting the Emotions of People with Developmental Disabilities

SCENARIO II

Bill and Mary had spent a good day together. To top off the day they were going to a party sponsored by Mary's work. They were excited about getting dressed up and going to the party. Bill had a glass of orange juice in his hand when he went into the bedroom to get last minute directions from Mary.

As he walked into the room, Mary was rushing out of the room. They accidentally bumped into each other, spilling juice on Mary.

If you were Mary, how would you react in this situation? How would you feel?

How would you want your spouse to respond to you?

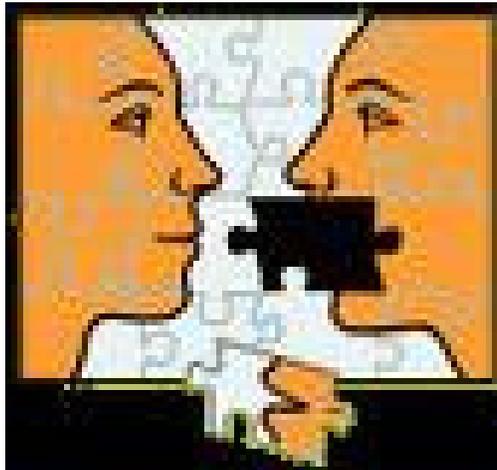
It's Not Your Job to Punish or Control

Remember. . .

- ✓ **Punishment or control leads to a power struggle**
- ✓ **Everyone loses in a power struggle!**
- ✓ **The person is humiliated, fearful and hurt**
- ✓ **Other people become afraid**
- ✓ **You may lose control**
- ✓ **The environment becomes a negative, hostile, and fearful place for everyone!**



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.

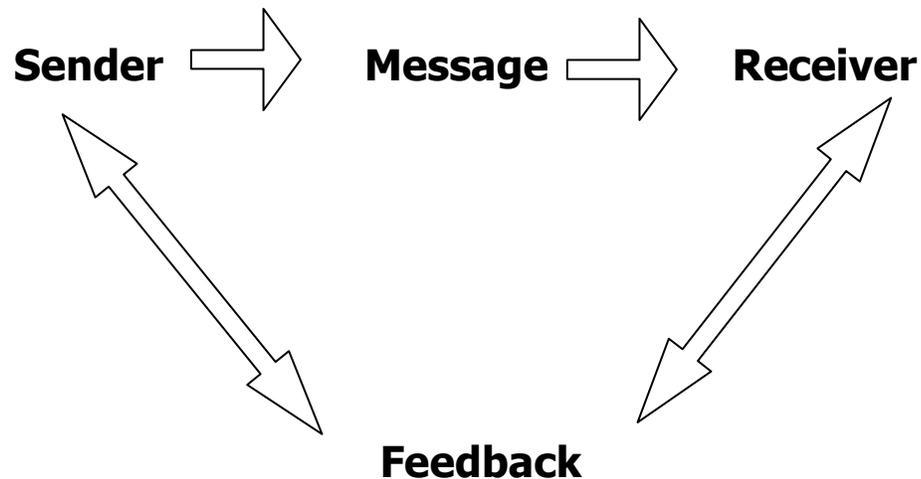


Communication is meaningful if people find the content interesting or useful, or if they feel it has a purpose. Some people that you will support may have alternative ways that they use to communicate. It is important to find out what the person's preferred mode of communication is and use it when communicating. 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

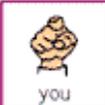


Augmentative/Alternative Communication (AAC)

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.

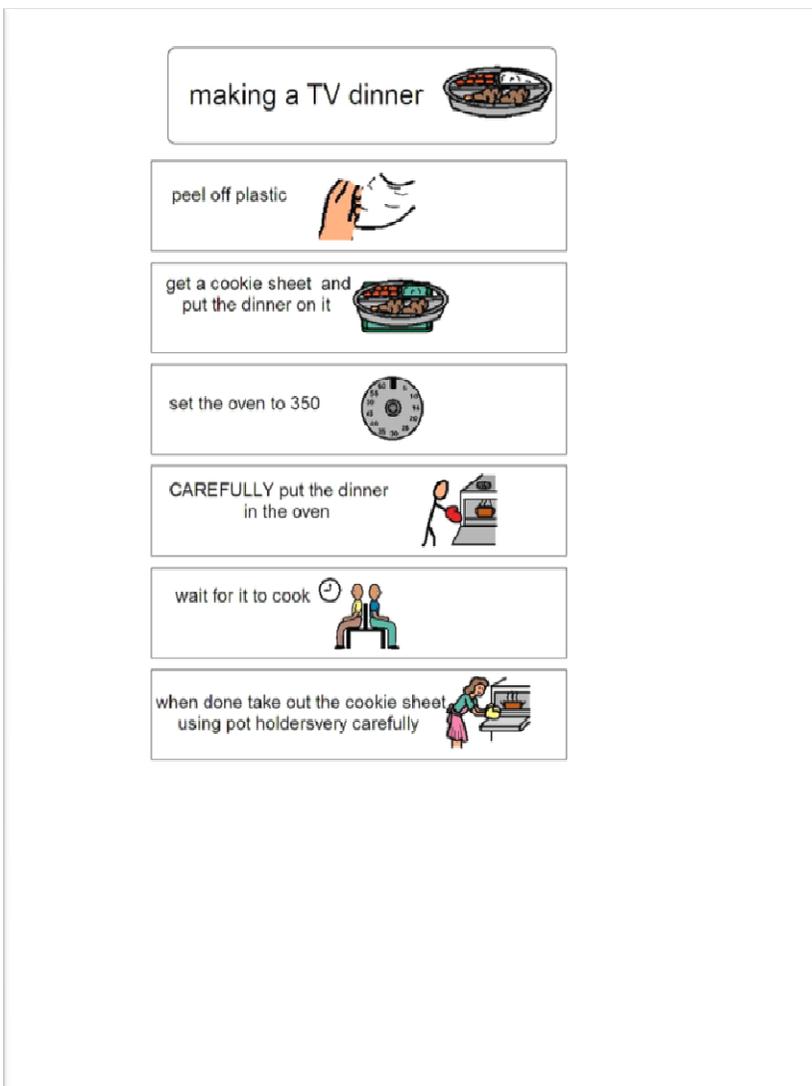
What can Visual Supports be Used for?

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?

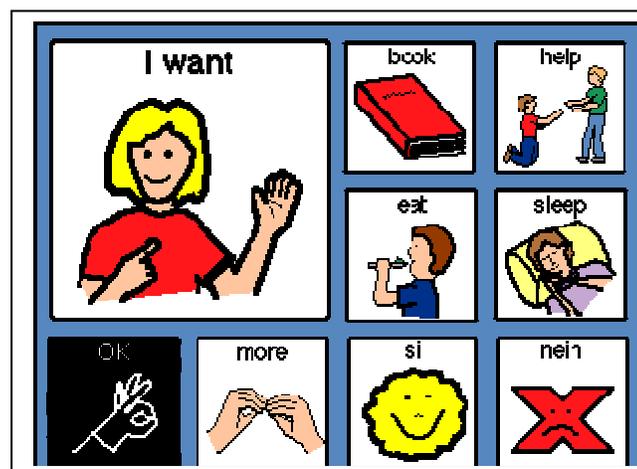
- Photographs
- Calendars
- Picture symbols
- Food labels

- 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

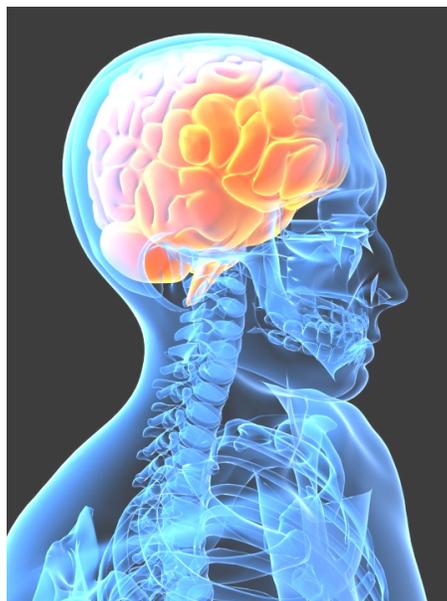
The brain is very complex and because of this, we do not yet understand the causes of many communication disorders. A few causes of communication challenges are:

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.

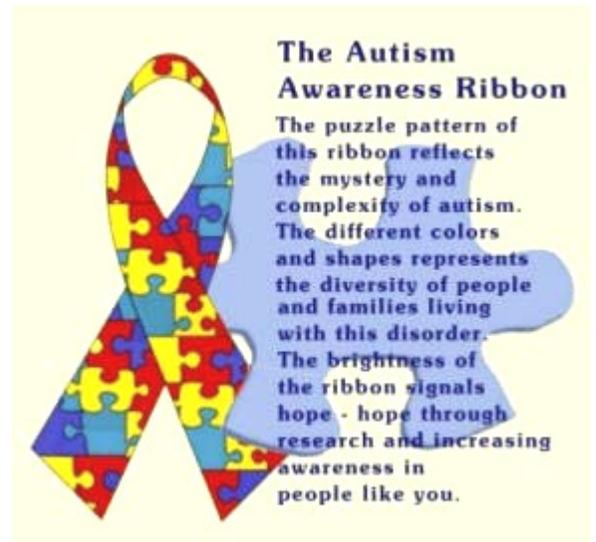
Some people may have high intelligence and may be able to speak in depth about topics they are interested in such as dinosaurs or railroads, but are unable to engage in interactive conversation on those topics.

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

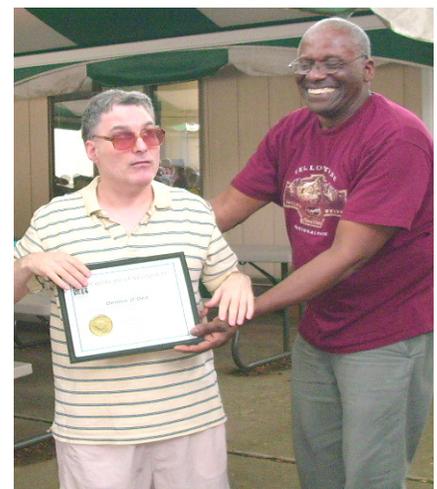


Visual Disabilities

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.

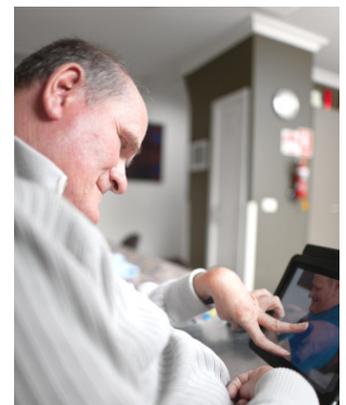
1. Talk to the people about his/her favorite subject, adding new information, and helping him/her to expand his/her interests.
2. Talk to and with the people about what is going on around him/her, such as events, people in the environment, etc.
3. Talk to and with the people about what is going to happen 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.



MODULE 5 DSP NOTEBOOK



INDIVIDUAL SERVICE PLAN DEVELOPMENT AND IMPLEMENTATION

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INTRODUCTION

"My name is April. This year I ran my own ISP meeting by myself. To get ready for the meeting I told my staff at my house what was important to me and they made a list for me. I told staff the most important things first.

We talked about me moving to a new house. This was most important to me. I invited people to my meeting. I told my house manager that I wanted to have food at my meeting so he brought some. I was a little shy at first but then I told everyone what I wanted."

Submitted by April, self-advocate from Chicago Heights, IL



What is the Individual Service Plan (ISP)?

The Individual Service Plan (ISP) is the written details of the supports, activities, and resources required for the individual to achieve personal goals. The Individual Service Plan is developed to articulate decisions and agreements made during a person-centered process of planning and information gathering. The general welfare and personal preferences of the individual are the key consideration in the development of all plans.

The individual and his/her team are responsible for developing the individual plan of support. These teams, called interdisciplinary teams (IDT), are composed of people who care about and know the individual. The team may also ask specialists, consultants, or specific provider staff to contribute to the plan by completing evaluations, or by observing and collecting information that is basic to the preparation of the plan.



The IDT is ultimately responsible for assessing and documenting each person's:

- Personal choices and preferences.
- Significant health care, mental health or behavioral needs and related maintenance needs.
- Safety and financial skills.

The teams translate this information into goals and objectives, which are then contained within the written plan. The plan results in outcomes that maintain or change services or supports to reflect what is most important to and most important for the individual in their daily life.

Service plans could be known as:

IPPs' Individual _____ Plans

ISPs' Individual _____ Plans

IHPs' Individual _____ Plans

IEPs' Individual _____ Plans

These are probably the most common names for service plans.

Description of Individual Service Plan for Adults

Although each agency has its own ISP format, there are some basic elements and information contained in almost all plans as listed in the **Appendix** of this Module.

Note: Because of their highly individualized nature, not all service plans contain all the components listed. Some plans may have additional information not listed in the Appendix.

Life Goals

Individual Service Plans should reflect the goals of the individual served. Because we are all different and unique people, each person's ISP should be unique and address the needs and desires of the person.



To begin the process, we must first learn how a person **wants** to live. In your role as a DSP, you can continually encourage people to experience new things. This enables the person to exercise greater choice in life because they have the experience to do so. After we learn what a person wants, we can then decide what needs to be done to help the person move toward that life.

Good plans are rooted in what is important to the person, while taking into account all the other factors that impact the person's life.

Life Changes

Just as people change, service plans need to be revised to reflect growth, new interests and desires. Service plans are reviewed a minimum of once per year at Individual Service Plan meetings. Sometimes these meetings are called *annuals*.

More and more, agencies are getting away from that practice and holding meetings to discuss these plans on an *as needed basis*.

In a year's time, much in your own life changes. This includes developing new interests and desires, changing where you live or work, who your friends are, etc.

ISP Scavenger Hunt

Directions: Work with your assigned group to find the answer to as many of the following questions as possible.

1. Where is the following information found in the ISP? *Use page number(s) to indicate the location(s).* **Note** - it may be in more than one location.

Assessment results		Personal Preferences	
Background/Historical		Personal Rights	
Communication Style		Personal Values	
Education		Personality	
Financial		Recent Life Changes	
Goals		Social Relationships	
Interests & Activities		Strengths & Weaknesses	
Learning Style		Vision for the Future/dreams	
Medical/Dental/Nutritional		Vocation	
Personal Description			

2. How does this person communicate?
3. List one of this individual's favorite activities.
4. List one of this individual's goals.
5. How will this goal be achieved?
6. When is this goal to be met?
7. What responsibility do you as a DSP have in supporting the individual in achieving this goal?
8. Does this person have a behavior management (intervention) plan? If so, what is

your role in implementing it?

9. What is this individual's current medical condition? What can you do to support his/her health?
10. Name a recent life change.
11. List five things below that you would like to know more about in order to provide support to this individual:
 - 1.
 - 2.
 - 3.
 - 4.
 - 5.

What Makes A Good Service Plan?

How do you know that the ISP you just reviewed is an accurate reflection of the person?
Things to check for:

- It was unique to this individual
- Focused on abilities
- Showed the person's choices and preferences
- Was respectful
- People significant to the individual were involved
- Identified social connection
- Maintained confidentiality
- Hopes/Dreams/Goals are a priority to the individual
- Hopes/Dreams/Goals are realistic
- Hopes/Dreams/Goals are precise & measurable
- Hopes/Dreams/Goals state how they are to be met



The plan should include a personalized statement of the person's expectations for the future and state who will be responsible for providing the supports and services to reach those goals. Additionally, the plan should address natural supports and connections for people with other citizens of the community.



What is the IDT?

The Interdisciplinary Team (IDT) consists of at least the person, parents (except when the person or the person's guardian does not desire them to participate), the guardian, as well as representatives of disciplines and services necessary to identify the person's needs and to design services and alternatives to meet them. At least one member of the team must be a Qualified Intellectual Disabilities Professional (QIDP).

The IDT process assesses the strengths and needs of persons with mental disabilities with input from the person requesting and/or receiving services and from those providing services. The IDT works to develop and implement the person's service plan.

Who Makes Up the Interdisciplinary Team?

A number of people are involved in developing the ISP. The most important member of the team is the person being served and there should never be a meeting without the person. Its primary purpose is to assist the individual with developmental disabilities in making decisions about life goals.

Members:

The **person supported** and the team of **professionals**, who usually include the following:

- QIDP
- Psychologist/Psychiatrist
- Social Worker
- Doctor/Nurse
- DSP
- Nutritionist
- OT/PT
- Teacher
- Residential Representative
- Day Program Representative
- Vocational Rep/Job Coach



Note: It is usually the DSP who works most closely with the person being supported. Your role is vital to the team.

Non-Professionals

- Friends
- Family
- Guardians
- Co-Workers



The DSP's Role in the Interdisciplinary Team Process (IDT)

Your role with the IDT is to assist the QIDP in determining the best course of action for the persons you will be supporting. How will you do that? By getting to know the persons you support and learning their likes and dislikes, documenting your observations, and making recommendations about what you think should be included in their plans. You may be asked to document certain behaviors. It will be up to you to report your observations about the wants and needs of the person. Others can then develop a plan, with the person's input, to meet their wants and needs in order to support change in the person's behavior. This is not an easy job.

How will you know what supports are needed by the persons with whom you will be assisting? First, build a relationship with them and get to know them as a person. In order to do this it is very important to understand that you need to listen to people objectively, without judgment. This is essential to the service planning process. In fact, one of the most important roles of the DSP is the day-to-day getting to know the people they support and what they want, then representing that to other members of the team.

Remember, your role is vital in developing and implementing the ISP.

When implementing the ISP it is important that you...

- **Be Consistent** - Lack of consistency leads to confusion.
- **Offer a sufficient number of trials - Individuals** may need a lot of practice to attain their goals. Look for opportunities to practice and reinforce learning in natural settings and across environments. (E.g., Spending and counting money at Wal-Mart; using a napkin at McDonalds; etc.)
- **Understand the ISP** - You need to understand your role in each area of the ISP.
- **Implement the ISP in positive manner** - Offer praise and encourage the individual using positive body language and tone. Treat the individual with dignity and in a non-condescending manner. Explain rather than demand or threaten. Support the individual in achieving his/her goals.
- **Document all required behaviors, successes and concerns related to the ISP** – The ISP is constantly changing to meet the needs, goals and desires of the individual for whom it is written. Documentation will help identify those areas that need adjustment.

NOTE: Be sure to communicate with your supervisor when a goal is not working, or you are having a difficult time with the implementation of a goal.

Family Involvement

Don't underestimate the importance of family involvement. Family members can provide a wealth of information useful in the planning process. Also, they act as a natural support system for the individual and give meaning to his/her life. We should respect and use them as resources.



At times, family members may not acknowledge their relatives as adults or may resist implementing portions of the service plan. The more involvement they have in the planning process, the less likely this will be a concern for them.

Your responsibilities include helping family members:

- see their relative as a person with dreams, hopes, and skills;
- understand the individual's strengths aptitudes, and competencies;
- identify how they can serve as resources and supports for the individual's active participation in community life; and
- respect the person's life goals and achievements.

People should be selected for the team based on their expertise, interest, connection, and respect for the person for whom the planning is intended.

Information from the team members can be in the form of assessments, reports, anecdotes or test results.

The person with a developmental disability is by far the most important member of the IDT.

What Is Person-Centered Planning?

Person-Centered Planning is a set of approaches designed to assist someone to plan their life and supports. It is used most often as a life planning model to enable individuals with disabilities, or otherwise requiring support to increase their personal self-determination and improve their own independence.

It is important to remember that a person-centered plan is a means **not** an end. The person-centered plan is a process, not a piece of paper. The life that a person wants is the outcome, **not** the plan that describes it. Person-centered planning is a written planning tool giving a description of where the person wants their life to go and what needs to be done to get there.

We've talked a bit about what person-centered planning is, but sometimes knowing what it **isn't** makes things even clearer. A person-centered plan **isn't**:

- ❖ Stagnant (it must be revisited and re-evaluated)
- ❖ Limited to available services
- ❖ Unrealistic
- ❖ A written plan, separate from a process
- ❖ A mystical quick or easy process.



Person-centered planning involves: keeping the focus on the **person** and his/her abilities. Person-centered planning means **individually** tailoring things for the person.

It starts with the person at the center and grows outward. It utilizes available **resources** to assist the person in obtaining his/her goals and objectives. It incorporates what is important to the person. It focuses on the **strengths** of the person, not the person's deficits or limitations or those of the system.

At all times we should demonstrate **respect** and **dignity** in all that we do to support a person with a developmental disability. This includes protecting the person's **confidentiality**.

QUIZ - What Is Person-Centered Planning?

(Fill in the blanks with the information from the previous page.)

Person-centered planning involves:

- keeping the focus always on the _____ and his/her abilities.
- _____ tailoring things to the person.
- planning for the person utilizing available _____ to assist the person in obtaining his/her goals and objectives.
- incorporating what is important to the person. It focuses on the _____ of a person, not the deficits or limitations, nor those of the system.
- demonstrating _____ and _____ in all that we do to support a person with a developmental disability.
- protecting the person's _____.

Remember what we learned about **people first language**. The way we speak shows respect or a lack of respect for an individual. We should focus on an individual's strengths, not their problems. Our words should reflect this focus. The ISP should also reflect this and be written in people first language.

**Individual First,
Disability Last!**



Definitions

Age-appropriate - programs, possessions, settings and activities which are appropriate for a person's chronological age.

Age Appropriate Activities include:

- Preparing Meals
- Reading newspaper
- Completing crossword
- Playing checkers
- Listening to music

Choice - exposing the individual to an assortment of experiences that could serve as a basis for decision making. (John is given a chance to taste whole wheat bread as well as white bread and then make a choice.)

Preference - an individual's personal choice after being exposed to an assortment of things or experiences. (John indicates he prefers whole wheat bread to white bread. How does he know? Because he has tasted both.)



Natural Rhythm of Life

In our society the majority of people typically go to work or school during the week with weekend activities more relaxed and focused on leisure and social activities. For most people, this is the natural rhythm of life. People with disabilities should be offered the same conditions as are offered to other citizens to live as normal a life as possible. Rhythm of life includes natural rhythm of a day, a week, a year and the life cycle itself. Included in this natural rhythm of life are certain life conditions such as housing, employment, exercise, recreation and freedom of choice.

As part of this natural rhythm of life, people with disabilities should be:

- Enjoying meals with others in restaurants and at picnics
- Working in regular industries
- Supported in regular homes and apartments
- Seen moving almost everywhere in our neighborhoods
- Worshipping in regular churches, synagogues, and mosques
- Cheering for their favorite local athletic teams
- Going on vacations to break up routines

Community Inclusion

Community inclusion is an integrated setting where people of all abilities and backgrounds work, live, go to school, or play together. Community inclusion includes at least six components: Presence, choice, competence, respect, participation and belonging.

Presence - Persons participate in all settings where people without disabilities are present, including classrooms, planning meetings, businesses, neighborhoods, and community events.

Choice - Persons will have multiple life experiences from which to draw. These various experiences will help him/her make decisions on what activities he/she wants to participate in as well as choose who will participate with them in those activities.



Competence - Persons are recognized for their strengths, contributions and, thus, have additional opportunities from which to learn.

Respect and Valued Roles: People are seen as a person--as well as a being valued by others, not seen as a bother.

Participation – Persons engaging with others, having a wide variety of relationships, being known and knowing others, being part of the event--not just an observer.

Belonging – People's feelings are valued by others. For example, when others call just to talk or invite him/her to go to a party, out to eat, to the movies, or to just "hang out."

Inclusion is NOT:

- When volunteers spend time with people out of pity or charity.
- "Special" activities or programs only for people with similar disabilities.
- Going on a series of unrelated activities, just to get out.
- Going everywhere (work, shopping, out for a walk) in groups.
- Only going places with other people with similar disabilities.
- Only interacting with people who are paid to take care of you (staff) or people with whom you do not choose to be with.

The Benefits of Inclusion

Some of the benefits to persons served and their families include:

- Better health.
- Increased feelings of well-being.
- Psychosocial development
- Improved esteem.
- More opportunities and access to resources.
- The protection of being known by other people. (Others are more likely to report or check on problems and become involved.)
- Greater life experience.
- Greater variety of relationships.
- Incentive to learn appropriate social behavior.



The Role of the DSP in Supporting Community Inclusion

Residential staff can support inclusion by:

- Offering choices.
- Providing training to develop the person's skills for future inclusionary activities.
- Supporting people's participation at actual community and social events. As much as possible, try to promote people's individual participation in community activities rather than as part of a group. People may have trouble making new friends and being looked at as an individual if they arrive in a group.
- Researching information about community resources and sharing this information with persons served.
- Helping people learn social skills and other skills as needed.
- Analyzing inclusion barriers and helping the person overcome these barriers.
- Using a respectful tone of voice and friendly words when addressing individuals in public.
- Not speaking for or about the person. Problem behaviors should be dealt with as discretely as possible.
- Being prepared for questions about the person's disability. Plan ahead and discuss how the person would like information shared, if at all. Each person has a different "comfort level" regarding privacy. Pay particular attention to, and do your best to support, each person's unique needs and expectations.

Module 5 DSP Notebook Individual Service Plan Development & Implementation

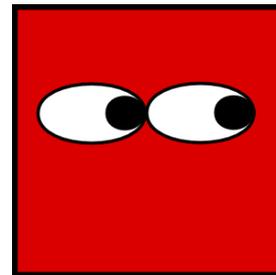
- Trying to help people fit in with others by assisting them in their dressing, grooming and communication skills.
- Making sure the person has the training and skills necessary to become independent. For instance, training the person how to use the bus can pay off in a lifetime of inclusion and freedom from relying on staff for every transportation need.
- Being prepared to advocate for and educate others about the benefits of inclusion.
- Understanding when to get involved and when to stay out of the person's relationships. Instead of sheltering people from potential dangers by isolating them, support staff should help the person manage risks in real and sometimes complex situations.
- Teaching daily living, vocational, and educational skills in natural settings in a functional and empowering way.
- Networking to find contacts and allies in the community who may have information about social or vocational opportunities.
- Developing strategies to minimize persons' risks and barriers and help the person understand the importance of making good choices that will reduce such risk.
- Ask individuals to go with you to any community group speaking engagements you may present at. Individuals can explain what his/her life was like before coming to the community program they participate in and how the program has impacted his/her life.
- Allow individuals to order their own food, etc. when in public.
- Ensure that the people have access to opportunities and education to facilitate building and maintaining relationships.
- Provide information about human, legal, civil rights and other resources and assist individuals to use information for self-advocacy and decision-making about living, working, and social relationships.

Resources Available for Vocational Opportunities

In your role as DSP, you may be asked to assist with vocational opportunities. DSPs can support people who are seeking vocational opportunities by first helping them research community resources that could provide those vocational opportunities. When these are identified, DSPs can assist with the application process.

Tips for researching community resources:

- Look in the local newspaper or weekly shopper
- Contact the Chamber of Commerce for a list of organizations, groups and clubs and contact those
- Contact the local tourism office
- Look in the yellow pages
- Ask family, friends and co-workers
- Contact the local community education office
- Search the Internet
- Contact the local library
- Contact out the local park and recreation office
- Check out local volunteer agencies
- Check with public schools and colleges





Teaching Functional Skills

Functional Skills are those tasks that most people do on a regular basis as part of their daily living routine. If a person is unable to perform these tasks, someone would probably need to do it for him or her. Consider all the things that must be done for the person served and find ways to get them more involved, even if initially it is only a small part of the task. This type of teaching is sometimes called "Active Treatment". The types of skills that need to be taught depend on each individual's needs and wants. The skills may range from teaching someone to brush their teeth or make their own breakfast to learning how to search for and find a job or use public transportation. The goal of teaching is to add skills that will improve the person's independence and quality of life. In order to determine if your interactions with the individual are "functional", ask yourself these questions:

- Did the person **LEARN** something as the result of your interactions that will allow the individual to function more **INDEPENDENTLY**?
- Did the individual **INCREASE HIS/HER SKILLS** as a result of the services you provided?
- Did the activities help **PREVENT THE LOSS** of skills the person already had?

Tips for Teaching Functional Skills

- Encourage the person to do as much as possible for themselves
- Know each person's goals and objectives and consistently implement formal and informal training
- "Teach" people rather than "do" for them
- Get people actively involved in the routine of the home (doing chores, making choices, etc.)
- Do things *with* people not *for* them (One noted teacher/author on this subject jokes that staff fingerprints should never be found within areas where individuals served receive **quality** services. That's because individuals served are performing all the tasks, not staff, even if they are doing it with hand-over-hand guidance.)
- Use language stimulation techniques throughout the day
- Offer opportunities for choice
- Be a good role model
- Look at every interaction as an opportunity to *teach* something

Stimulation Activities Compared To Real Activities

Teaching Functional Activities also means assisting people in identifying and experiencing **real** activities. Consider how to incorporate real activities into lives of the people you support. Write your ideas for “real” activities which promote the same stimulation effects.

Stimulation Activities	Real Activities
Smelling different bottled scents.	
Touching stuffed animals.	
Feeling a soft cloth on your face or mouth.	
A paid staff member talking to you as a scheduled activity.	
Going for a ride in the van with the group.	
Touching a variety of baby toys in a bag.	
Catching a ball in the yard at the group home.	
Sorting different shaped blocks.	
Walking up and down a hallway.	

Learning Styles

We all have a preferred way of learning and learn in a variety of ways--by seeing, hearing, touching, doing, etc. People with developmental disabilities are just like us.

They have preferred ways of learning too. In order for DSPs to identify and use various instructional strategies, and effective teaching techniques, it is important to understand different learning styles. Often times we learn using a combination of ways, although, we usually have one preferred way of learning. In each person's ISP you will find information on which learning style is most effective to teach new tasks.

The three primary learning styles are: **visual, auditory, and kinesthetic.**

Visual learners tend to learn by looking, seeing, viewing, and watching. Visual learners need to see an instructor's facial expressions and body language to fully understand new information. They tend to sit at the front of the room to avoid visual distractions. They tend to think in pictures and learn best from visual displays. During a lecture or discussion, they tend to take detailed notes to absorb information.



Auditory learners tend to learn by listening, hearing, and speaking. Auditory learners learn best through lectures, discussions, and brainstorming. They interpret the underlying meaning of speech by listening to voice tone, pitch, and speed and other speech nuances. Written information has little meaning to them until they hear it. They benefit best by reading text out loud and using a tape recorder.



Kinesthetic learners tend to learn by experiencing, moving, and doing. Kinesthetic learners learn best through a hands-on approach and actively exploring the physical world around them. They have difficulty sitting still for long periods of time, and easily become distracted by their need for activity and exploration.



Module 5 DSP Notebook Individual Service Plan Development & Implementation

The table below shows some of the methods that appeal to visual, auditory, and kinesthetic learners. Training should take into account all three styles.

VISUAL	AUDITORY	KINETHESTIC
PowerPoint slides	Lectures	Role plays
Videos/Slideshows	Group discussions	Simulations
Flip charts	Informal conversations	Practice demonstrations
Readings	Stories and examples	Writing/Note taking
Demonstrations	Brainstorms	Activities

Knowing people's preferred learning style will help us develop appropriate learning strategies. Let's look more closely at some ways in which we assist people with developmental disabilities in learning a new task.

Task Analysis

Any skill can be thought of as a chain of small steps. These small steps are identified by completing a **Task Analysis**. Each step, or link in the chain, serves as a cue to do the next step. Sometimes a task an individual is learning is too complicated for the person to learn all at once (e.g., brushing your teeth). Therefore, we break the task down into *teachable steps*. This allows the learner to develop multi-step, complex skills that would otherwise be difficult to acquire. Identifying the step-by-step sequence does this. This requires a task analysis.



How Does Task Analysis Work?

- Determine what task you want the student to perform.
- Figure out what steps will be required to complete the task.
- Teach the student one step until the student displays mastery of it.
- Decide what order to teach the steps in. You might want the person to master the last step, then second to last and so on until the entire task can be done independently. Or vice versa, you can work from the first step to the last. This is known as **chaining**. We will learn more about this later.
- As each part of the process is learned, add it to the chain until the task can be completed independently.

You should note that much of our own learning is done in steps. Many of the things we learn, remember, and do are done in this process.

For example, the Task Analysis for teaching someone how to eat with utensils might look something like this:

- 1) Sit in seat at table
- 2) Identify fork and knife
- 3) Pick up fork with less dominant hand
- 4) Pick up knife with dominant hand
- 5) Put fork into meat or other food to hold in place
- 6) Use knife to cut meat or other food into bite-sized pieces
- 7) Remove fork from food
- 8) Put knife down on plate
- 9) Pick up fork with dominant hand
- 10) Use fork to pick up one piece of bite-sized food
- 11) Raise fork with food on it to mouth
- 12) Open mouth
- 13) Put food into mouth
- 14) Close mouth
- 15) Put fork down onto plate
- 16) Chew food
- 17) Swallow food
- 18) Start process again.



Author: Tom McIntyre at www.BehaviorAdvisor.com; Retrieved June 27, 2011

Task Analysis Activity

Your instructor will guide you through the next activity. After completion, please consider the following questions:

1. What happens when each staff does a task differently when helping a person with a developmental disability learn to do a task?
2. Why is it important to do a program plan the way it is written?
3. What should staff do if the program plan doesn't seem to be working?

Also consider. . .

- Is there more than one way to do the same thing?
- What happens if each of you does a task differently with an individual?
- Why is it important to implement an individual's training plan the way it is written?

Techniques for Teaching New Skills

By building one step onto another learned step in the sequence, a strong chain can be created. This is called **CHAINING**. There are two kinds of chaining, forwards and backwards. You'll learn more about these later.

Shaping

Shaping is a way of adding behaviors to a person's repertoire. Shaping is used when the target behavior does not yet exist. In shaping, what is reinforced is some approximation of the target behavior.

For example: *In playing the game "Hot & Cold," you hide a prize and then reinforce any movement that takes the player closer to the prize. Each of those successive movements is a closer approximation of the desired behavior. If the prize is under the couch and the player is moving toward the couch, every time the player takes a step toward the couch, you are yelling "hotter," and you are reinforcing the behavior. If the player moves away from the couch, you would yell "colder" (non-reinforcing).*

Chaining

Chaining is the process of working forward or backward, step-by-step, to accomplish a task. For example:

- **Forward chaining** is a procedure that teaches a task from start to finish. It involves teaching people one step at a time, working forward step by step to accomplish a simple task.
- **Backward chaining** involves teaching the last step first.



Modeling

Modeling is a training method in which the individual learns by observing another perform the behavior that is to be learned.

Prompting

Prompts are signals or cues to perform in a specified manner.

- **Verbal** prompts use words to initiate, continue or complete a task
- **Gestural** prompts use a hint or suggestion without using physical contact
- **Physical** prompts use physical touch to initiate, continue or complete the task
- **Hand-Over-Hand** is a physical prompt that involves actual physical guidance

Fading

Fading involves reducing the amount of information given in order to decrease dependence.

Remember, as staff members you are always teaching, whether it is by active involvement with the individual or by modeling appropriate behavior with staff and/or individuals. (Dale DiLeo, *Enhancing the Lives of Adults with Disabilities*.)

Discovering Reinforcers

A reinforcer is any stimulus or event that when it follows a behavior, increases the probability that the behavior will occur again. Positive and personal reinforcers include actions, consequences, or rewards that can cause an increase in desired behavior. Activities or incentives can be used, for example, to promote lifestyle changes such as increased exercise in free-time activities; healthy snacks, etc. When choosing personal reinforcers, it is important to:

- Get to know the person well
- Ask the person to help choose the type of reinforcers he would like to earn
- Observe what the person enjoys doing



Positive Reinforcement

A stimulus that, when added to the environment as a consequence of a behavior, results in an increase (frequency, duration, or intensity or maintenance) of that behavior.

Effective Reinforcers

- Are age-appropriate and are provided immediately after the behavior has occurred
- Are paired with a clear verbal description of the behavior
- Are varied enough to maintain interest.

Types of Reinforcers

- **Primary** (substances that sustain life - food, water, etc.)
- **Secondary/Social** (conditioned reinforcers that are generalized from primary reinforcers - money, social interactions, tokens, etc.)

A smile, comment and/or compliment can go a long way toward increasing or maintaining positive behavior!

Negative Reinforcement

A behavior is more likely to occur again because the behavior allows a person to stop something that the person dislikes or finds unpleasant. A negative reinforcement is anything that, when taken away contingent on a response, tends to increase the probability or rate of that response.

For Example: *Driving in heavy traffic is a negative condition for most of us. You leave home earlier than usual one morning and don't run into heavy traffic. You leave home earlier again the next morning and again you avoid heavy traffic. Your behavior of leaving home earlier is strengthened by the consequence of the avoidance of heavy traffic.*

PERSONAL REINFORCERS EXERCISE

Identify 3 items that are usually primary reinforcers for you:

1. _____
2. _____
3. _____



Identify 3 secondary/social reinforcers for you:

1. _____
2. _____
3. _____

Documentation

Documentation means “Providing a written record of an action, event, item, issue, or thought that is important or meaningful.”

It is important to remember that the things you record are **legal documents!**

The following tips can help you document important information so that it will be accurate and meaningful to those who may need it now, or later.

- Do not sign a document that has inaccurate information.
- If two people witnessed an incident, each person should make separate reports or entries. You should never document for another person or from another person’s perspective.
- Always include the date (day, month, and year) on all documents.
- Always include the time of day on all documents using a.m. or p.m. for all times.
- Be careful about using abbreviations or acronyms that some people may not understand.
- Ensure the privacy of people on all documents. When referring to another person in an individual’s document you may want to describe the relationship to the person (e.g., coworker, roommate, another staff person, cousin, sister) and the person’s initials.
- Always use your signature.

Completing Documentation in a Timely Manner

It is important to document events as soon as possible after things happen so you can remember all the details of what occurred. Your recollection of the events that happened will not be as clear and accurate if you wait even a day or two after the occurrence. This also results in poor communication with co-workers, family members or guardians, and the people you support.

If there is no documentation about a situation, other people providing supports may not have all the necessary information needed to make the best decisions when handling the situation afterwards.

If you forget to document something on the day it happened, it is important to begin your documentation with a statement that indicates your entry was made some time after the event occurred. This is usually called a “late entry.”

The Benefits of Good Documentation

Keep in mind that the report you are writing may later be read by people who do not know the persons involved. They should be able to easily understand the situation despite the fact that they do not know the people involved.

Examples of OBJECTIVE Documentation:

- He was crying and his hands were visibly trembling afterwards.
- She stated that she didn't know what to do.
- I have never encountered a similar situation while working with this individual.

Examples of SUBJECTIVE Documentation:

- He was so upset afterwards.
- She didn't know what to do.
- Something funny was going on.

Always include the four W's:

NOTE: The examples used here are for reporting suspected abuse, neglect and exploitation.

- **Who** - This includes everyone involved.
- **What** - Start at the beginning and explain step by step until the end of the incident.
- **When** - Note the exact time, day/month/year and hour including a.m. or p.m.
- **Where** - The exact location, address, inside or outside, what room?

WHO?

- Who is the suspected perpetrator?
- Who is the suspected victim of abuse, neglect, or exploitation?
- Who are the individuals that witnessed the incident?
- Who else may have been involved in the incident?



WHAT?

Document what happened step-by-step. Start at the beginning of the incident and include all details until the end of the incident. Report only the facts and write an objective description of your observations in your report. Do not write your feelings, opinions, and attitudes. Also do not make judgments about the situation.



Here is an example:

December 9, 2010. At 9:00AM this morning, I heard a sound from the back bedroom. I went to the back room and knocked on the door. The staff person said, "We are OK, don't worry." I asked if I could come in. The staff person said, "yes." I opened the door and saw Amy sitting on the floor on the right side of her bed. Amy was crying and holding her wrist. I asked Amy if she was OK. Amy stated, "My wrist hurts." I then examined Amy's wrist. There were no visible signs of injury. Two hours later, I examined Amy's wrist and there was visible bruising about 2 inches in diameter."

- Report only the facts and objective descriptions of your observations in your report.

- Do not write feelings, opinion, attitudes or judgments. Include any other important statements and details, such as your relationship to the victim.

WHEN?

Note the exact time of the incident, including the month, day, year, and time of day with a.m. or p.m. noted.



WHERE?

- Note where the incident occurred
- Outside or inside
- The address of the place of the incident
- The exact room the incident took place
- The exact place in the room where the incident took place



Types of Documentation

Depending on the situation, agency procedures, and local and state laws, you may need to document for any number of reasons. Here are some possible types of documentation you will be doing:

- Health related documentation
- Personal goals and individual program documentation
- Behavioral support plan documentation
- Incident and accident documentation

You may also be required to provide verbal reports or faxed or e-mailed copies of reports to certain external agencies or people. It is important for you to be familiar with the right place to document and report these types of incidents.

Ensure people’s privacy in documents. Refer to their relationship with the person such as, “coworker,” “roommate,” etc., and then use initials to identify them.

Things **not** to document are:

- Complaints about other staff
- Disagreements you have with agency policy
- Your own personal problems
- Negative comments made by other co-workers
- Negative comments about people served



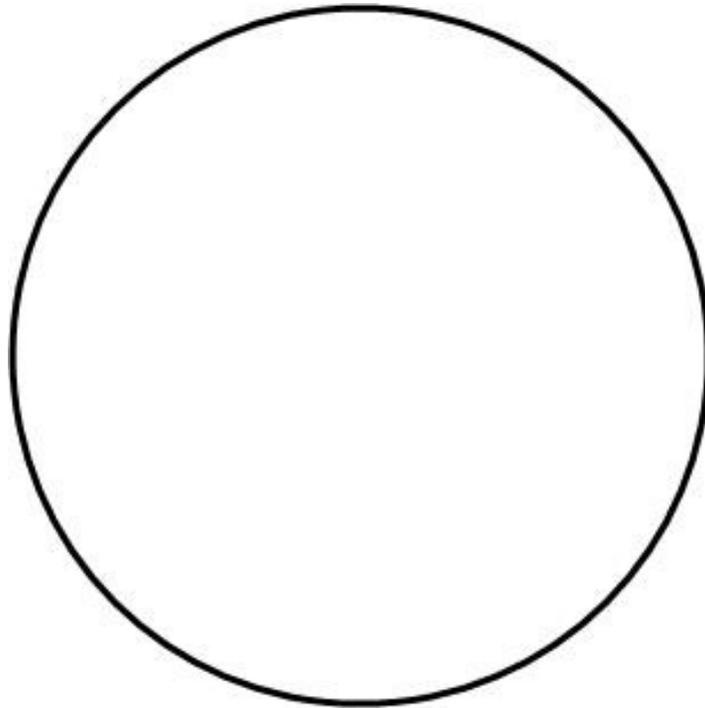
Documentation Scenario

You are a DSP working the afternoon shift at one of the CILA homes. You are working alone on this particular day. You have assisted the 3 women with the evening meal and now it's time to clean up the kitchen. One of the women, Linda, begins to wash the dishes and Marley begins drying the dishes. The other lady wants to go watch TV. You went into the other room to turn down the volume of the TV. Marley starts telling Linda that she does not know how to do dishes. While you were out of the room you heard arguing and loud voices in the kitchen. As you walk into the kitchen to see what's happening, you see Linda slap Marley and Marley drops the dish. Marley begins to cry and calls Linda a "Stupid jerk." You separate the women, help them to calm down and help get the kitchen cleaned up. Now it's time to write the progress/service notes on this situation.

Linda's file:

Marley's file:

A Penny Is.....?



Martin Luther King said:

“I have a dream.”

He didn't say:

**“I have an annual plan with
quarterly goals and objectives.”**

Inclusion News, 1997-1998



Sections of the Service Plan

Most service plans contain the following information:

Personal Description- This section describes the person. It goes beyond the old way of describing a person (e.g., 25-yr. old black male with Down syndrome).

Medical/Dental/Nutritional- This section contains a summary of significant medical issues. This includes any medication the person takes and the reasons. There may be nutritional information mentioned here, as well.

Background/Historical- This is a summary of significant events that have happened in the individual's life. These events may be a clue as to what shaped who the person is today.

Social Relationships- Here is where details of the person's social life are outlined. Important people are mentioned, as well as all types of relationships (e.g., family, friends, work, staff members). Some of these relationships may be positive and others not. Sometimes we draw maps to show how these people are related. These show graphically, the connections between people. This area would indicate whether the person prefers to be with people or by himself/herself.

Goals/Objectives- This section identifies the areas targeted for development. The information for this section is gathered through interviews, assessments, and on-going interactions with the person. Goals can be from any area, but they need to be important to the person, not necessarily the staff providing input into the plan. We must set goals in various areas to obtain funding. This includes economic self-sufficiency, daily living skills, and community integration. We look at what the person wants to learn and prioritize short and long-term goals based on the person's preferences.

Interests and Activities- This is where we learn what interests the person outside of work and home responsibilities. Leisure activities, hobbies, sports, or just about any other interest can be listed in this section.

Personal Values- This section makes a statement about what is important to the person. This is useful to know because often times we are motivated by what we value the most.

Personality, Feelings, & Emotions- We need to know these things about the person in order to develop a supportive environment. Therefore, getting to know the person is essential.

Sources of Comfort and Discomfort- This section will outline what things provide comfort as well as, discomfort to the person. You may want to remember that we can never know everything about a person. So, this section may have information only known to the staff who wrote it. Further, as people grow and change, this area of the plan may have to undergo change. Again, you will learn much about the person as you interact with him/her.

Assessments- The results of assessments or tests may be included here. For example, PT/OT, IQ, speech and language, etc.

Strengths and Needs- Here we learn about the abilities as well as areas which require support.

Vocation- This section will describe the kinds of work the individual likes to do or would like to do.

Education- A summary of the person's educational background as well educational goals.

Financial - This area discusses financial information about the person including sources of income and needs for the future.

Communication Style- The best way to communicate with the person would be spelled out here. People can and do communicate in a variety of ways and it is important for you to understand how to communicate with each person you will be working with.

Learning Style- How the person learns is outlined. This includes strategies you can use to work most effectively given the person's specific situation.

Personal Rights- In this area, we would learn which rights are most important to the person. Also, what, if any, rights restrictions might be in place and details of the situation.

Recent Life Changes- Anything that has recently occurred in a person's life which may have an effect on his/her day-to-day functioning should be noted here. This is another area that would be updated continually.

Vision for the Future- Just as we have dreams and hopes for the future, so do people we support in our programs. You need to get to know the person. This will assist you in identifying his/her hopes and dreams. Then you can assist the person in realizing them.

Each ISP is tailored to the individual. Therefore, not all service plans contain all of these components. Some plans may have additional information not listed here.

Additional Information: Service Plans are developed and signed by the individual or guardian, the QIDP, and all service providers. Service Plans explain significant changes in services or providers and indicate that the individual, family members and Service Facilitator participated in the decision process regarding these changes.

Service Plans contain at least one measurable goal. Service Plans contain an explanation of instructional methods for assisting the individual in moving toward accomplishment of his/her goal(s) and a way to monitor the individual's progress in achieving the goal. It also contains the name(s) or role(s) of the person(s) responsible for assisting the individual in achieving the goal.



Introduction to Basic Health & Safety

Module 6

Agenda for Module 6 - Basic Health and Safety

Section 1: Introduction to Basic Health & Safety

Section 2: Human Growth & Development

Section 3: Vital Signs and Symptoms

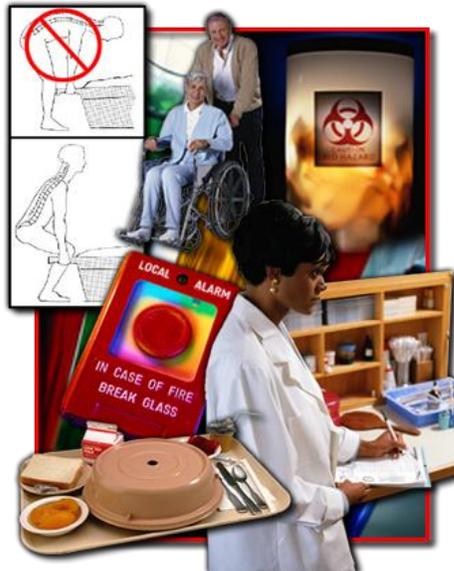
Section 4: Wellness

Section 5: Assisting with Activities of Daily Living

Section 6: Environmental & Individual Safety



Introduction to Basic Health & Safety



Module 6, Section 1

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These are the things we would like you to know about for Health and Safety. There are rules in our houses like don't overload the outlets, unplug stuff like the TV, and use bathmats. We do not like it when staff grabs at us as they are helping us or yells at us to get ready for bed. We may have something that we want to finish doing. Ask us.

~ Melissa R., self-advocate,

~ Sean, J., self-advocate

~ Veronica Pierson, self-advocate

Exercise is important to me. We do jumping jacks nearly every morning. On Fridays, we do exercises with a video tape. I was very excited to join a group that learns a little about exercising called Yoga. I think it is cool. Sometimes we practice breathing in through our nose and out through our mouth. We learn about relaxing.

~ Joe G., self-advocate



I think I have done a really good job at the group home. I have lost weight and am at my goal weight now. I do really well at controlling my food and at budgeting my money. I still need to learn what I can eat and what I can't eat, and picking healthy choices. I have learned a lot, but have not tried to do it completely on my own.

~ Anna T., self-advocate

Principles of Support

Some persons with developmental disabilities are more vulnerable to injuries than others. When necessary precautions are not taken, it can be devastating to the health and well-being of a person you support, for the home in which he/she lives, or for the agency that provides the service. Each year, thousands of accidents occur, some fatal, that could have been prevented by taking specific precautions. It is the responsibility of the direct support person to ensure that appropriate precautions are taken based upon the needs of the individual.

Direct Support Persons (DSPs) should follow and teach the people they support these guidelines for basic health and safety. It is important to be mindful of each person's dignity.

Safety

- Assist people who might fall.
- Clean up spills on the floor.
- Pick up things dropped on the floor.
- Unplug electrical appliances when not in use.
- Limit use of extension cords.
- Put a mat on the floor in bathroom when getting in and out of tub/shower.
- Straighten throw rugs.
- Remove items blocking entrances, exits, and walkways.



Privacy

- Close door to bathroom or bedroom when assisting a person.
- Do not discuss personal issues where others can hear.
- Do not tell others private information (especially medical information).
- Respect the person's personal space and personal belongings.
- Knock first and wait for a response before entering a room.

Dignity

- Show respect to people.
- Realize that each person is different and has different needs, preferences, etc.
- Try to prevent situations which could cause embarrassment for people.
- Respect the person's religious and cultural beliefs, even if they are not yours.
- Ask before assisting and wait for a response.

Communication

Talk with and listen to people, their families and other team members.
Communicate respectfully to people and use people-first language.
Speak in words the listener will understand.
Explain what you are doing before and while you are doing it.
Ask permission before doing something to/with a person. Wait for a response.

Independence

Encourage people to do things for themselves.
Do not do things for people if they are capable, even if it takes longer.
Use the least prompting necessary to achieve the desired outcome.
Teach people to speak up for their choices.
Teach people to speak up for their rights.

Infection Control

Wash hands as circumstances require.
Wear gloves as circumstances require.
Cover your mouth when sneezing/coughing, and teach people to do the same.
Do not use glasses/utensils unless they are clean.
Disinfect commonly used items.

Confidentiality Is Everybody's Business**Confidentiality and HIPAA**

DSPs may observe and have access to a person's protected health information (PHI) or other confidential or sensitive information about the person. PHI includes names, addresses, diagnoses and treatment of individuals, their mental and physical condition and even the fact that the person receives services and the types of services that they receive. The Health Insurance Portability and Accountability Act (HIPAA) mandates that PHI can only be shared with and made available to authorized people and for authorized uses. HIPAA compliance requires a culture of privacy in your agency and your personal commitment. DSPs must protect people's PHI, for example by:

- Restricting access to areas where PHI is available and keeping cabinets locked where PHI is stored.
- Shredding documents containing PHI before discarding them.
- Avoiding conversation involving PHI or confidential information unless conducted in secure areas away from unauthorized people.
- Exercising caution and care when faxing, emailing or telephoning PHI or other confidential information to ensure it is not released to unauthorized people.
- Not leaving confidential papers where others can see them.

How Germs Are Spread



Direct Contact

Germs are spread from one person directly to another person

What are the ways this can happen?

- One person with an infection, such as a contagious rash or open/infected sore or wound, touches another person
- Body fluids (feces, urine, blood, saliva, etc.) get into an open wound
- Insect bite

Indirect Contact

Germs are spread from one person to an object then to another person.

What are some examples of this?

- Eating food that has been contaminated by someone's dirty hands.
- Handling soiled linen or equipment.
- Using soiled utensils, cups or contaminated water.

Droplet Spread

Germs are spread through the air. Droplets generally do not remain in the air very long, and generally travel short distances of 3 feet or less, but often that is far enough to contaminate others.



Controlling the Spread of Germs

Hand washing is one of the most important (and easiest) practices used to prevent the spread of germs and the transmission of bloodborne pathogens. Hands or other exposed skin should be thoroughly washed as soon as possible following an exposure incident. Use soft, antibacterial soap, if possible. Avoid harsh, abrasive soaps, as these may open fragile scabs or other sores. Hands should also be washed immediately (or as soon as feasible) after removal of gloves or other personal protective equipment. Because hand washing is so important, you should familiarize yourself with the location of the hand washing stations or facilities nearest to you.



When to Wash Your Hands:

- When you come to work
- **Before** touching:
 - Food
 - A person's medicine
 - Kitchen utensils and equipment
 - Someone's skin that has cuts, sores or wounds
 - Before putting on disposable gloves
- **After:**
 - Using the bathroom
 - Sneezing, coughing or blowing one's nose
 - Touching one's eyes, nose, mouth or other body parts
 - Touching bodily fluids
 - Touching someone's soiled clothing or bed linens
 - Providing assistance with medications
 - Removing and disposing of used disposable gloves
 - Touching anything else that could be contaminated with germs
 - Smoking

How to Wash Your Hands

- Gather supplies, if necessary
- Wet hands under warm water
- Apply soap
- Wash for at least 20 seconds (Sing "Happy Birthday or say you're A, B, C's twice)
- Scrub all surfaces, especially cuticles, under nails and around and under rings
- Rinse hands from the wrist down
- Use paper towel to dry
- Use paper towel to turn off faucet and open door if it has a handle
- Discard towel in waste basket

- Nails should be kept trimmed and clean.

Note: Jewelry should not be worn on the job. Watches should be worn high enough on the wrist as to not interfere with the hand washing process.

Alcohol-Based Hand Rubs

As part of good hand hygiene, it is often appropriate to use alcohol-based hand rubs. When using an approved alcohol-based hand rub:

Apply the product to the palm of one hand (using the volume recommended by the manufacturer) and rub your hands together.

- Be sure that you cover all surfaces of your hands and fingers.
- Rub your hands together until they are dry, at least 15 seconds.
- Use soap and water when your hands look dirty; otherwise, you can use an alcohol-based hand rub.

Alcohol kills germs and leaves them on your hands. Wash with soap and water every 3-5 times of using "hand-rubs".

Other Issues with Hand Hygiene

To maintain good hand hygiene, pay close attention to your fingernails:

- If you have natural nails, keep them short
- Wash hands after taking gloves off
- Change gloves when switching from one person to another or from one task to another
- Change gloves if they become torn
- Dispose of gloves in a proper container
- Be sure to remove rings and watch before putting on gloves.

Ways to Prevent Germ Transmission Exercise

Directions: List ways you know to prevent germ transmission.

Bloodborne Pathogens

Exposure to bloodborne pathogens in the workplace is a major concern to workers and employers. **The Occupational Safety and Health Administration (OSHA)** has a standard to address this concern. The Bloodborne Pathogens Rule requires both employers and workers to prevent the spread of bloodborne diseases.

What is a Bloodborne Pathogen?

Bloodborne pathogens are germs which may be present in blood that are capable of causing disease. Bloodborne pathogens are an important consideration in dealing with blood and other potentially infectious materials. Materials include human body fluids, unfixed tissue or organs, and HIV/HBV-containing cell or tissue cultures.

How Are People Exposed to Bloodborne Pathogens?

You can be exposed to a bloodborne pathogen by performing a task or being in an area where you might come in contact with blood or other potentially infectious materials.

What Happens If You Are Exposed to a Bloodborne Pathogen?

Even one exposure to a bloodborne pathogen can lead to serious and disabling diseases such as:

- HIV
- Hepatitis
- MRSA (Methicillin Resistant Staphylococcus Resistant Aureus)

You may not know you are infected with a bloodborne disease at the time of exposure. You may not realize it until years later.

Does Everyone Exposed to a Bloodborne Pathogen Become Infected?

Whether or not you become infected depends on:

- The number and strength of the germs
- Your resistance to disease
- The germ having an entrance into your body



Above is an example of a biohazard cleanup kit containing absorbent powder, towelets, biohazard bag with tie, surface cleaner, gloves, scoop, and dry paper towel

The following source control measures are part of the etiquette as well:

- Covering the mouth and nose with a tissue when coughing
- Disposal of used tissues
- Use of surgical masks on the coughing person as appropriate
- Hand hygiene after contact with respiratory secretions
- Keeping a distance of more than 3 feet from a person with a respiratory infection, which can be accomplished through such measures as having separate common waiting areas for persons with respiratory infections

AIDS and HIV

AIDS, or Acquired Immune Deficiency Syndrome, is caused by a virus called the human immunodeficiency virus, or HIV. Once a person has been infected with HIV, it may be many years before AIDS actually develops. HIV attacks the body's immune system, weakening it so that it cannot fight other deadly diseases. AIDS is a fatal disease, and while treatment for it is improving, there is no known cure. AIDS is the result of a long process that begins with HIV infection. HIV destroys the body's immune system, allowing cancers, pneumonia and other infections to develop.



Estimates on the number of people infected with HIV vary. The Centers for Disease Control and Prevention (CDC) estimated in 2011 that 50,000 people are infected with HIV every year in the United States, and more than 1.1 million persons were living with HIV/AIDS. These numbers could be higher, as many people who are infected with HIV may be completely unaware of it.

The HIV virus is very fragile and will not survive very long outside human body. It is primarily of concern to employees providing first aid or medical care in situations involving fresh blood or other potentially infectious materials. It is estimated that the chances of contracting HIV in a workplace environment are only 0.4%. However, because it is such a devastating disease, all precautions must be taken to avoid exposure.

AIDS infections occur essentially in three broad stages. The **first stage** is when a person is actually infected with HIV. After the initial infection, a person may show few or no signs of illness for many years. Eventually, in the **second stage**, an individual may begin to suffer swollen lymph glands or other lesser diseases which begin to take advantage of the body's weakened immune system. The second stage is believed to eventually lead to AIDS, the **third and final stage**. In this stage, the body becomes completely unable to fight off life-threatening diseases and infections.

Symptoms

Symptoms of HIV infection can vary, but often include weakness, fever, sore throat, nausea, headaches, diarrhea, a white coating on the tongue, weight loss, and swollen lymph glands.

HIV CAN be contracted by:

- blood transfusions
- contact with blood/bodily fluids
- homosexual or heterosexual contact
- Intravenous (IV) drug users who share needles

NOTE: An unborn baby may contract it from its mother (though the risk is lowered with appropriate prenatal treatment), and babies can contract it through breast-feeding.

HIV CANNOT be contracted by:

- telephones, doorknobs, toilet seats, or mosquito bites
- shaking hands, hugging, being coughed or sneezed on
- eating food prepared by an HIV positive person.
- **by donating blood.**

NOTE: The risk of contracting HIV from a blood transfusion is extremely low. The blood supply is carefully tested.

How do you get infected with HIV?

HIV is transmitted through blood, semen or vaginal fluid. HIV cannot be transmitted by holding hands, hugging, kissing or sharing food and household items. The virus does not survive outside of the body on surfaces like door knobs, toilet seats, drinking fountains, telephones or in swimming pools. There haven't been any cases of the virus being transmitted by insects or food handlers.

Some people have become infected with HIV after receiving blood transfusions. The nation's blood supply has been screened for HIV since 1985 so today it is extremely rare to get HIV from a blood transfusion.

HIV primarily is spread through bodily fluids via:

- Unprotected sexual intercourse
- Sharing needles and syringes when injecting drugs or steroids
- Infected mothers to their child during pregnancy, birth or sometimes breast feeding

What are the symptoms of HIV?

Symptoms of HIV may not appear for 10 years or longer. You can be infected with HIV and still look and feel well. Once you are infected, you always carry the virus and you can infect others.

HIV symptoms usually are long-lasting and persistent. They may include:

- Fever, chills or night sweats
- Swollen glands in the neck, armpits or groin area
- Frequent diarrhea
- A thick white coating or spots on the tongue or in the throat
- Mouth sores
- A dry cough, sometimes with shortness of breath
- Unexpected weight loss
- Pink or purple blotches on or under the skin
- Persistent vaginal yeast infections

Is there a test for HIV?

There are tests that detect whether the body's immune system has produced disease-fighting antibodies against the virus. If HIV antibodies are in your body, you will test positive for HIV. A positive test is not a death sentence. It doesn't mean a person has AIDS. Knowing your HIV antibody status is the key to obtaining proper medical care. Right now there isn't a cure for AIDS, but there are many effective treatments which, when given early, can prolong and improve the quality of life for people with HIV and AIDS. HIV testing is available through all county health departments.

How can I protect myself from HIV?

The best advice is don't have sexual intercourse and don't shoot drugs, or to have sex with only uninfected partners.

Having sex is a choice you make. But you should know that every time you have sex with a new partner, you may increase your chances of being exposed to HIV and other sexually transmitted diseases.

You can reduce your risk of infection by:

- Talking to your partner about HIV/AIDS
- Practicing safer sex where there is no exchange of semen, vaginal fluids, or blood
- Correctly using a latex condom **every** time you have sex
- Not using needles or syringes that another person might have used

What should a person with HIV/AIDS do?

If you are infected with HIV, you should seek medical care. Treatment is available to slow the progression of HIV in the body and to treat complications related to AIDS. Your doctor, county health department or a local HIV/AIDS service organization can provide additional information about medications and counseling. The progression of HIV to AIDS may be slowed by living a healthy lifestyle. If you are HIV-positive, eat a balanced diet, exercise regularly, get plenty of sleep, reduce stress from your life and do not use alcohol or other drugs.

What can I do for a friend or family member with HIV/AIDS?

People with HIV/AIDS need support and friendship. They may feel alone, frightened and unsure of their relationships and future. Fortunately, there are organizations which help people with HIV/AIDS and their families deal with the medical, financial and emotional problems associated with the disease. A blood-borne disease is one that can be spread by contamination by blood.



Hepatitis B (HBV)

"Hepatitis" means "*inflammation of the liver*," and, as its name implies, Hepatitis B is a virus that infects the liver. While there are several different types of Hepatitis, Hepatitis B is transmitted primarily through "blood to blood" contact. Hepatitis is another bloodborne pathogen. Hepatitis B initially causes inflammation of the liver, but it can lead to more serious conditions such as cirrhosis and liver cancer.

There is no "cure" yet for HBV, but there are several new promising treatments that were not available until recently. These treatments slow down liver damage caused by HBV, meaning there is less chance of developing a serious liver disease later on. It is important to note, however, that there are different kinds of hepatitis, so infection with HBV will not stop someone from getting another type.

The Hepatitis B virus is very durable, and it can survive in dried blood for up to seven days. For this reason, this virus is the primary concern for employees such as housekeepers, custodians, laundry personnel and other employees who may come in contact with blood or potentially infectious materials in a non first-aid or medical care situation.

Symptoms:

The symptoms of HBV are very much like a mild "flu". Initially there is a sense of fatigue, possible stomach pain, loss of appetite, and even nausea. As the disease continues to develop, jaundice (a distinct yellowing of the skin and eyes), and a darkened urine will often occur. However, people who are infected with HBV will often show no symptoms for some time. After exposure it can take **1-9 months** before symptoms become noticeable. Loss of appetite and stomach pain, for example, commonly appears within 1-3 months, but can occur as soon as 2 weeks or as long as 6-9 months after infection.

Modes of Transmission of Bloodborne Pathogens

Bloodborne pathogens such as HBV and HIV can be transmitted through contact with infected human **blood** and **other potentially infectious body fluids** such as:

- **Semen** (the viscid, whitish fluid from the male)
- **Vaginal secretions** (fluid from the female cervix)
- **Cerebrospinal fluid** (colorless liquid that surrounds the brain and spinal cord)
- **Synovial fluid** (fluid that lubricates and cushions the joint)
- **Pleural fluid** (fluid between the pleural membranes of the lung and the inner chest wall)
- **Peritoneal fluid** (fluid in the gastrointestinal organs)
- **Amniotic fluid** (fluid which surrounds the fetus)
- **Saliva** (in dental procedures)
- **Any body fluid that is visibly contaminated with blood**

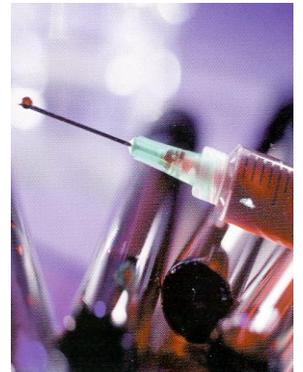
It is important to know the ways exposure and transmission are most likely to occur in your particular situation, whether providing first aid to someone, handling blood samples for a nurse, or cleaning up blood anywhere.

HBV and HIV are most commonly transmitted through:

- Sexual Contact
- Sharing hypodermic needles
- From mothers to their babies before, at and after birth through breastfeeding
- Accidental puncture from contaminated needles, broken glass, or other sharp objects (sharps)
- Contact between broken or damaged skin and infected body fluids
- Contact between mucous membranes and infected body fluids

Accidental puncture from contaminated needles and other sharps can result in transmission of bloodborne pathogens.

In most work or laboratory situations, transmission is most likely to occur because of accidental puncture from contaminated needles, broken glass, or other sharps; contact between broken or damaged skin and infected body fluids; or contact between mucous membranes and infected body fluids. For example, if someone infected with HBV cuts their finger on a piece of glass, and then you cut yourself on the now infected piece of glass, it is possible you could contract the disease. Anytime there is **blood-to-blood contact** with infected blood or body fluids, there is a slight potential for transmission. Unbroken skin forms an impervious barrier against bloodborne pathogens.



However, **infected blood can enter your system through:**

- Open sores
- Cuts
- Abrasions
- Acne
- Any sort of damaged or broken skin such as sunburn or blisters

Bloodborne pathogens may be transmitted through the **mucous membranes** of the

- Eyes
- Nose
- Mouth

For example, a splash of contaminated blood to your eye, nose, or mouth could result in transmission.

Methicillin Resistant *Staphylococcus aureus* (MRSA)

MRSA related terms:

***Staphylococcus aureus* (SA)**, often simply referred to as “staph”, is a bacteria commonly found on the skin or in the nose of healthy people. Staph bacteria can cause infections, and when they do, these are often referred to as “staph infections”. About 25-30% of the population is colonized with staph, that is to say they are carriers of the staph bacteria but it causes no infection.

Methicillin Resistant *Staphylococcus aureus* (MRSA), refers to a specific type of staph that is resistant to the antibiotic methicillin as well as several other similar antibiotics. Only about 1% of the population is colonized with MRSA.

Colonization of an individual with MRSA is different than infection with MRSA. An MRSA infection is an active disease process. MRSA infections may be in the form of an abscess, a boil, a cellulitis, or a more serious infection such as infection of the blood, lungs, urine, or a surgical wound.

People at Risk

MRSA infections can occur in any geographic location and on any part of a person’s body. Most people who acquire MRSA infection in the community get infections of the skin. Close skin-to-skin contact, openings or cuts in the skin, crowded living conditions, poor hygiene, and contaminated items and surfaces are the main cause of MRSA spread in the community.

Prevention of Community Acquired MRSA

- Clean your hands. Use soap and water or alcohol based hand rub frequently to maintain hygiene.
- Maintain a clean environment. Establish routine cleaning procedures for frequently touched surfaces.
- Keep cuts and scrapes covered until healed. Maintaining cleanliness of a wound will decrease the chances of acquiring a skin infection through any opening in the skin.

If someone in the home has MRSA infection...

- Cover the wound. Wounds that are draining should be covered with clean dry bandages until healed.
- Maintain infections precautions. When changing bandages, disposable gloves should be worn and hands should be washed with soap and water after the bandage changes. Soiled bandages should be bagged and disposed of in the regular trash.
- Maintain clean linens and towels. Linens should be changed and washed when soiled and on an established routine basis. Towels should only be used once.
- Avoid sharing personal items such as washcloths, razors, clothing, etc.

MRSA infection and the workforce

Unless specifically directed by a physician, individuals do not need to be routinely excluded from work or otherwise isolated due to MRSA infection. Individuals may continue to participate in activities as long as the wound can be covered and contained with a clean dry bandage, and appropriate hygiene measures are maintained. Exclusion from activities may be necessary if the wound cannot be adequately covered or wound drainage cannot be contained.

For more information regarding MRSA in the community, visit www.cdc.gov/mrsa

Clostridium difficile (C diff.)

Clostridium difficile (klos-TRID-e-uhm dif-uh-SEEL), often called *C. difficile* or *C. diff*, is a bacterium that can cause symptoms ranging from diarrhea to life-threatening inflammation of the colon. Illness from *C. difficile* most commonly affects older adults in hospital or long term care settings and typically occurs after using antibiotic medications.

In recent years, *C. difficile* infections have become more frequent, more severe and more difficult to treat. Each year, tens of thousands of people in the United States get sick from *C. difficile*, including otherwise healthy people who are not hospitalized or taking antibiotics.

Mild illness caused by *C. difficile* may get better if you stop taking antibiotics. Severe symptoms require treatment with a different antibiotic.

Some people who have *C. difficile* never become sick, though they can still spread the infection. *C. difficile* illness usually develops during or shortly after a course of antibiotics. But signs and symptoms may not appear for weeks or even months afterward.

The most common symptoms of mild to moderate *C. difficile* disease are:

- Watery diarrhea three or more times a day for two or more days
- Mild abdominal cramping and tenderness

In severe cases, *C. difficile* causes the colon to become inflamed (colitis) or to form patches of raw tissue that can bleed or produce pus (pseudomembranous colitis). Signs and symptoms of severe infection include:

- Watery diarrhea 10 to 15 times a day
- Abdominal cramping and pain, which may be severe
- Fever

- Blood or pus in the stool
- Nausea
- Dehydration
- Loss of appetite
- Weight loss

Mayo Clinic; accessed 10/24/11; <http://www.mayoclinic.com/health/c-difficile/DS00736>

Universal Precautions

Universal Precautions for bloodborne pathogens are part and parcel of Standard Precautions. It is an approach used in infection control. Universal precautions treat all blood and other potentially infectious materials as if they are known to be infected with bloodborne diseases. It treats all blood and other potentially infectious materials as if they were known to be infected with bloodborne diseases. Blood and other materials can carry pathogens that cause serious diseases. Materials include human body fluids, unfixed tissue or organs, and HIV/HBV-containing cell or tissue cultures. The intent of Universal Precautions is to protect the healthcare worker from bloodborne diseases. DSPs must become familiar with key elements of an effective infection control program.

- Use good workplace practices and follow Standard Precautions.
- Wear Personal Protective Equipment (PPE) and use respiratory protection as indicated.
- Receive the hepatitis B vaccination series and other vaccinations when they are offered.
- Wash your hands with soap and water frequently.
- If you are exposed to blood or other potentially infectious materials, you should take immediate actions to cleanse the area, tell your supervisor, have any medical follow-up indicated by the exposure and a post-exposure evaluation.
- Practice good housekeeping by observing established practices, schedules, and procedures for cleaning and disinfecting work areas at your agency.
- Follow recommended practices for handling contaminated clothing and laundry at your home or agency.
- Bag soiled linens (including isolation linens) in single blue plastic bags. Double-bag laundry if the outside of the first bag is visibly soiled.

In work areas where exposure is likely, **do not:**

- eat, drink, or put objects in your mouth.
- apply cosmetics, lip balm, or contact lenses.

Transmission Based Precautions Beyond Standard Precautions are

- Contact Precautions

- Droplet Precautions
- Airborne Precautions.

Personal Protective Equipment

Probably the first thing to do in any situation where you may be exposed to bloodborne pathogens is to ensure you are wearing appropriate personal protective equipment (PPE). For example, you may have noticed that emergency medical personnel, doctors, nurses, dentists, dental assistants, and other health care professionals always wear latex or protective gloves when working directly with patients. This is a simple precaution they take in order to prevent blood or potentially infectious body fluids from coming in contact with their skin. **To protect yourself, it is essential to have a barrier between you and the potentially infectious material or fluids.**

Rules to follow:

- Always wear PPE in exposure situations.
- Remove PPE that is torn or punctured, or has lost its ability to function as a barrier to bloodborne pathogens.
- Replace PPE that is torn or punctured.
- Remove and dispose of PPE before leaving the work area.

If you work in an area with routine exposure to blood or potentially infectious materials or fluids, the necessary PPE should be readily accessible to staff. Contaminated gloves, clothing, PPE, or other materials should be placed in appropriately labeled bags or containers until it is disposed of, decontaminated, or laundered. It is important to find out where these bags or containers are located in your area before beginning your work.

Gloves

Gloves should be made of latex, nitril, rubber, or other water impervious materials. If glove material is thin or flimsy, double gloving can provide an additional layer of protection. Also, if you have cuts or sores on your hands, you should cover these with a bandage or similar protection as an additional precaution before putting on your gloves. You should always inspect your gloves for tears or punctures before putting them on. **If a glove is damaged, don't use it!** When taking contaminated gloves off, do so carefully. Make sure you don't touch the outside of the gloves with any bare skin, and be sure to dispose of them in a proper container so that no one else will come in contact with them.

Gloves are an essential element of infection control. Remember:

- You should wear gloves any time you are at risk of coming in contact with blood or other potentially infectious materials or fluids (e.g., dirty laundry).
- You should wear gloves that cover your wrists.

- If you are wearing an isolation gown, your gloves should cover the cuffs of the gown.

Wear disposable gloves when...

- Cleaning the rectal or genital area
- Assisting with mouth care
- Assisting with shaving
- Cleaning toilets
- Cleaning up urine, feces, vomit or blood
- Helping with menstrual care and disposal of sanitary supplies
- Performing wound care or first aid
- Handling soiled linen
- When assisting with bathing (optional)

Always wash your hands before putting on gloves and always check them for damage.



Removing Gloves

Gloves are made for one-time use and must be removed and disposed of properly after a single use.

Removing gloves properly is essential to protecting yourself and others from the risk of infection. Remove gloves so that the inside part of the glove is turned toward the outside. This is because the outside of the glove is soiled, and taking the gloves off inside out will keep the germs contained within the gloves.

Disposing of gloves properly is equally essential. Gloves contaminated with blood should be disposed of in a regulated waste container. Uncontaminated gloves may be disposed of in a regular waste container. Immediately after removing gloves, wash your hands with soap and water.

Goggles

Anytime there is a risk of splashing or vaporization of contaminated fluids, goggles and/or other eye protection should be used to protect your eyes. Again, bloodborne pathogens can be transmitted through the thin membranes of the eyes so it is important to protect them. Splashing could occur while cleaning up a spill, during laboratory procedures, or while providing first aid or medical assistance.

Face Shields

Face shields may be worn in addition to goggles to provide additional face protection. A face shield will protect against splashes to the nose and mouth.

Aprons

Aprons may be worn to protect your clothing and to keep blood or other contaminated fluids from soaking through to your skin.

Normal clothing that becomes contaminated with blood should be removed as soon as possible because fluids can seep through the cloth to come into contact with skin. Contaminated laundry should be handled as little as possible, and it should be placed in an appropriately labeled bag or container until it is decontaminated, disposed of, or laundered.

Gowns

Sometimes gowns and/or personal protective equipment are worn to keep from transmitting pathogens from a patient's room to another area of the hospital (refer to your agency's policies). If this is the case, remove the gown before leaving the patient's room and WASH YOUR HANDS.

Remember to use universal precautions and treat all blood or potentially infectious body fluids as if they are contaminated. Avoid contact blood or potentially infectious body fluids whenever possible, and whenever it's not possible, wear personal protective equipment.

If you are working in an area where there is reasonable likelihood of exposure, **you should never:**

- **Eat**
- **Drink**
- **Smoke**
- **Apply cosmetics or lip balm**
- **Handle contact lenses**

No food or drink should be kept in refrigerators, freezers, shelves, cabinets, or on counter tops where blood or potentially infectious materials are present.

Decontamination and Sterilization

All surfaces, tools, equipment and other objects that come in contact with blood or potentially infectious materials or fluids must be decontaminated and sterilized as soon as possible. **Equipment and tools must be cleaned and decontaminated before servicing or being put back to use.** Decontamination should be accomplished by using a solution of 5.25% sodium hypochlorite (household bleach/Clorox) diluted between 1:10 and 1:100 with water. **The standard recommendation is to use at least a quarter cup of bleach per one gallon of water.**

If you are cleaning up a spill of blood, you can carefully cover the spill with paper towels or rags, then gently pour the 10% solution of bleach over the towels or rags, and leave it for *at least 10 minutes*. This will help ensure that any bloodborne pathogens are killed before you actually begin cleaning or wiping the material up. By covering the spill with paper towels or rags, you decrease the chances of causing a splash when you pour the bleach on it.

If you are decontaminating equipment or other objects (be it scalpels, microscope slides, broken glass, saw blades, tweezers, mechanical equipment upon which someone has been cut, first aid boxes, or whatever) you should leave the disinfectant in place for *at least 10 minutes* before continuing the cleaning process. Of course, any materials you use to clean up a spill of blood or potentially infectious materials must be decontaminated immediately, as well. This would include mops, sponges, re-usable gloves, buckets, pails, etc.

Sharps

Far too frequently, housekeepers, custodians and others are punctured or cut by improperly disposed needles and broken glass. This, of course, exposes them to whatever infectious material or fluids may have been on the glass or needle. For this reason, it is especially important to handle and dispose of all sharps carefully in order to protect yourself as well as others.

Needles

- Needles should never be recapped.
- Needles should be moved only by using a mechanical device or tool such as forceps, pliers, or broom and dust pan.
- Never break or shear needles.
- **Needles must be disposed of only in labeled sharps containers.**
- Sharps containers must be closable, puncture-resistant, leak-proof on sides and bottom, and must be labeled or color-coded.
- When sharps containers are moved from the area of use, the containers must be closed immediately before removal or replacement to prevent spillage or protrusion of contents during handling or transport.

Broken Glassware

Broken glassware that has been visibly contaminated with blood must be sterilized with an approved disinfectant solution before it is disturbed or cleaned up.

- Glassware that has been decontaminated may be disposed of in an appropriate sharps container.
- Broken glassware must not be picked up directly with the hands. Sweep or brush the material into a dustpan.
- Uncontaminated broken glassware may be disposed of in a closable, puncture resistant container such as a cardboard box or coffee can.

By using Universal Precautions and following these simple engineering and work practice controls, you can protect yourself and prevent transmission of bloodborne pathogens.

Needles must be disposed of in sharps containers.

Improperly disposed needles can injure housekeepers, custodians, and other people.



Isolation Procedures

Sometimes a physician may order a person to be put in "isolation". Isolation procedures are sometimes necessary for medical conditions. General isolation precautions should be used for methicillin-resistant *Staphylococcus aureus* (MRSA), Vancomycin-resistant Enterococci (VRE), Respiratory Syncytial Virus (RSV), chicken pox, shingles, lice, *Clostridium difficile* (C-diff), etc. DSPs should wear gloves to enter the room and remove gloves and wash hands before leaving the room. Patient equipment (for example, a stethoscope, digital thermometer, etc.) must always be disinfected, or have their use dedicated to only the isolation room. Check your agency policy for the correct disinfectant.

Standard precautions have now been revised to include these new areas of protection:

- Respiratory hygiene and cough etiquette
- Safe injection practices

Standard precautions apply to the following:

- blood, all body fluids, secretions and excretions regardless of whether or not they contain visible blood
- Non-intact skin – this may not always be obvious
- Mucous membrane.
- Gloves
- Masks, eye protection, face shields
- Fluid resistant non-sterile gowns, as needed. Remember: Overdoing is better than not doing.
- Patient care equipment handling
- Linens handling
- Bloodborne pathogen exposure - needles and sharps.
- Hand washing whether or not gloves are worn. Wash hands immediately after removing gloves, between all patient contacts and as needed.
- Mouth pieces, resuscitation bags and other ventilation devices.

Note: Always assume certain areas of the body are colonized with disease causing microorganisms that, if transmitted to others, could cause disease and protect yourself accordingly. These areas include mucous membranes, moist areas of the body, broken skin, anything wet coming from the body, and any medical devices that drain fluids from the body.

OJT Practice Activity #16: Hand washing

Name _____

Date _____

Attention: Remember to wash your hands:

- When coming to work
- Before and after any contact with an individual
- Before handling any food
- After going to the bathroom
- After coughing or sneezing
- After smoking
- Before and after wearing disposable gloves
- Before going home



Supplies:

- Sink
- Warm water
- Soap
- Paper towel

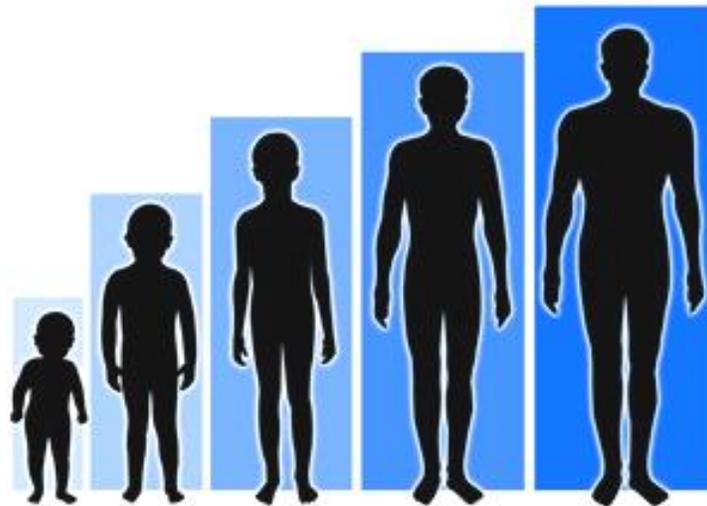
Steps	Partner Check	Instructor Check
Turn on water and adjust temperature.	<input type="checkbox"/>	<input type="checkbox"/>
Wet your hands and wrists.	<input type="checkbox"/>	<input type="checkbox"/>
Apply soap.	<input type="checkbox"/>	<input type="checkbox"/>
Rub your hands together to make soap.	<input type="checkbox"/>	<input type="checkbox"/>
Hold your hands lower than your elbows.	<input type="checkbox"/>	<input type="checkbox"/>
Wash your hands vigorously and thoroughly. Include wrists, palms, back of hands, nails and between fingers.	<input type="checkbox"/>	<input type="checkbox"/>
Rinse your wrists and hands, keeping them below your elbows.	<input type="checkbox"/>	<input type="checkbox"/>
Pat dry your wrists and hands with a clean paper towel.	<input type="checkbox"/>	<input type="checkbox"/>
Use towel to shut off faucet and open door.	<input type="checkbox"/>	<input type="checkbox"/>
Throw towel away.	<input type="checkbox"/>	<input type="checkbox"/>

OJT Practice Activity #21: Removing Disposable Gloves

Steps	Partner Check	Instructor Check	Illustration
Partially remove first glove by pinching the glove at the wrist being careful to touch only the outside surface.	<input type="checkbox"/>	<input type="checkbox"/>	
Pull glove toward the fingertips without completely removing it. The glove is now inside out.	<input type="checkbox"/>	<input type="checkbox"/>	
With partially gloved hand, pinch the exterior of the second glove. Remove second glove.	<input type="checkbox"/>	<input type="checkbox"/>	
Pull the 2nd glove toward the fingertips until it is inside out. Remove it completely.	<input type="checkbox"/>	<input type="checkbox"/>	
Finish removing both gloves. Grasp both gloves with your free hand. Touch only the clean interior surface of the glove.	<input type="checkbox"/>	<input type="checkbox"/>	
After removing both gloves, discard gloves in an appropriate container.	<input type="checkbox"/>	<input type="checkbox"/>	
Wash hands thoroughly.	<input type="checkbox"/>	<input type="checkbox"/>	



Human Growth and Development



Module 6, Section 2

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Developmental Milestones for Babies

At age one month, most children can...

- Raise their heads slightly when lying on their stomachs
- Briefly watch objects
- Make "noise in throat" sounds
- Pull away from a cloth or blanket on their faces

At age three months, most children can...

- Lift their heads and chests when lying on their stomachs
- Show vigorous body movement
- Follow a moving person with their eyes
- Recognize a bottle or breast
- Smile when someone speaks to them



At age six months, most children can...

- Sit with minimal support
- Roll from their backs to their stomachs
- Turn to locate and identify sounds
- Transfer objects from hand to hand and from hand to mouth
- Respond to friendly speech with a smile or coo

At age 12 months, most children can...

- Pull themselves up to stand and may step with support
- Pick things up with a thumb and one finger
- Nod their heads to signal "yes"
- Give affection
- Say two or three words

At age 2, most children can...

- Hand over toys upon request
- Kick a large ball
- Turn pages in a book (two or three at a time)
- Ask for items by name
- Recognize a familiar picture and know if it is upside down
- Use two or three words together, such as "more juice"

At age 3, most children can...

- Walk up stairs while holding the railing
- Stand momentarily on one foot
- Open doors
- Unbutton large buttons
- Verbalize toilet needs
- Stack objects of different sizes

A delay in any of these areas could be a sign of a developmental problem.

Factors Which Contribute to a Variety in Rate of Development

- Sex of the person
- Gland function or dysfunction
- A lack of proper nutrition
- Genes
- Rate of intellectual development
- Health status (sickly)
- Exposure to fresh air or pollutants
- Birth order of child in family in relation to siblings
- Level of motivation or drive
- Presence or absence of parents' attitudes: encouragement, interest or not
- Environmental stimuli
- Drugs or alcohol



Stages of Normal Human Development

<u>Stage</u>	<u>Characteristics</u>
Newborn	Senses are developed. Infants are attracted to the human face and can follow a moving light. Uses rooting reflex to obtain nourishment.
Infant	Grasp reflex of hands and toes. Imitation begins: motor (banging, tongue, peek-a-boo) and vocal (da, da, da)
Toddler	Knows environment and can make simple changes to it, such as getting someone's attention for the purpose of play, knowing that things which disappear still exist. Learns objects have names. Learns cause and effect relationships. Variety and repetition are keys to learning.
Young child	Communication skills improve. Learns best by doing. Learns abstract reasoning. Becomes more independent of caregivers. Likes to play with peers.
Pre-pubescence	Feels more secure interacting with same sex friends. Secondary sex characteristics appear, but the reproductive organs are not yet fully developed. Marked by growth spurts and marked changes in body proportions. (Varies by heredity) Girls' growth spurts are between 8-12 years and growth gradually declines until age 17 or 18. Boys begin their growth spurt between 10-15 years. Growth peaks between 14.5-15.5 years with growth gradually declining until age 20 or 21.
Pubescence	The first phase of adolescence when sexual maturation occurs. It climaxes when girls first menstruate and boys show the presence of live sperm in the urine.
Adolescence	Boys' testes and penises grow and nocturnal emissions occur. Pubic hair, underarm and facial hair begins to grow. Girls' reproductive organs grow and mature (breasts, uterus, ovaries, vagina, etc.) Pubic hair and widening of hips occur. Both sexes may experience acne, finicky appetites, increased desires to be alone, more easily bored, increasingly clumsy or awkward, heightened emotions, loss of self confidence and excessive modesty. Thinking shifts from concrete to abstract. Emotions are often intense, uncontrolled, and seemingly irrational. They are attempting to develop masculine or feminine social roles. Personalities and morals develop. Enjoys interacting with the opposite sex.

Adulthood Male and female roles established. More mature interest in opposite sex. Instinct is to have a family and settle down. Focus may be on marriage and raising children.

Old age Increased risk of bone fractures, loss of strength and muscle power. Osteoporosis or other types of ill health may interfere with ease of living. Life stressors may impact health. Skin becomes dry and wrinkled. May have more time to develop or pursue interests and hobbies.

People with Developmental Disabilities – Motor experience may be limited because of physical, psychological, or sociological issues. Person may have been raised in overly-structured, restrictive environment. This may inhibit exploration and reduce the person's opportunity to develop more varied perceptions and associations. Interpretations of environment may be unusual because of lack of normal set of experiences. The person may exhibit characteristics of a certain stage, even though their chronological age may be older.

Remember, a person with a developmental disability may have normal physical development, but have significant delays in cognitive or emotional development.

Stages of Language Development

1. **Babbling:** The first stage of language development is known as the babbling or cooing stage. During this period, which typically lasts from the age of three to nine months, babies begin to make vowel sounds such as *oooooh* and *aaaaaah*. By five months, infants typically begin to babble and add consonant sounds to their sounds such as *ba-ba-ba*, *ma-ma-ma* or *da-da-da*.
2. **Single Words:** The second stage is known as the one-word stage of language development. Around the age of 10 to 13 months, children will begin to produce their first real words. While children are only capable of producing a few, single words at this point, it is important to realize that they are able to understand considerably more. Infants begin to comprehend language about twice as fast as they are able to produce it.
3. **Two Words:** The third stage begins around the age of 18 months, when children begin to use two word sentences. These sentences usually consist of just nouns and verbs, such as "Where daddy?" and "Puppy big!"
4. **Multi-word Sentences:** Around the age of two, children begin to produce short, sentences that have a subject and predicate. For example, a child might say "Mommy is happy" or "Want more milk."

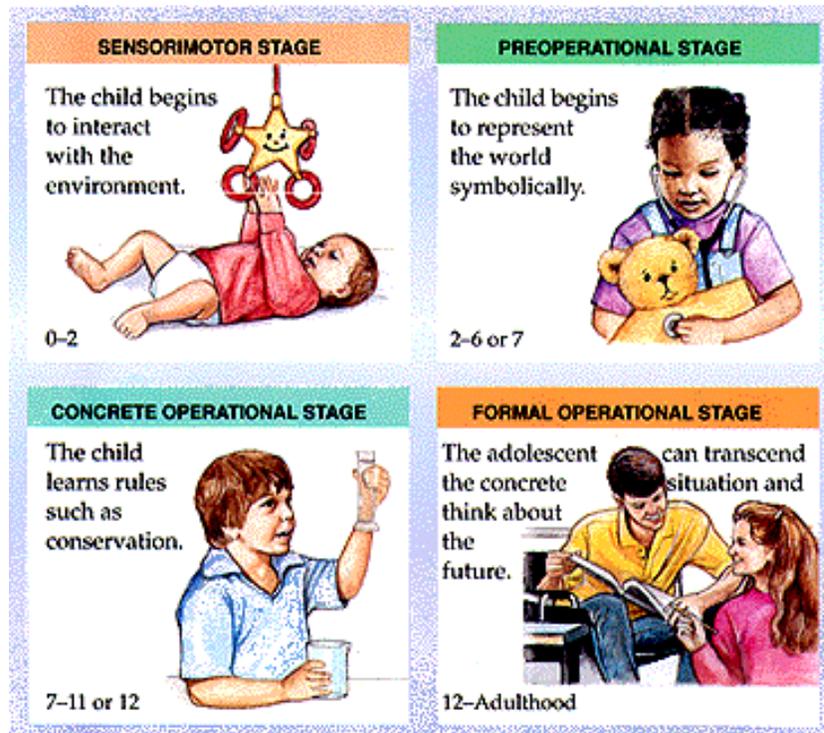
As children age, they continue to learn more new words every day. By the time they enter school around the age of five, children typically have a vocabulary of 10,000 words or more.

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Berk, L. E. (2006). Chapter 9 - *Child Development* (8th ed). Pearson.

Bjorkland, B. R. (1995). Language development and cognition. In David F. Bjorkland (Ed.), *Children's thinking: Developmental function and individual differences*. Pacific Grove, CA: Brooks/Cole.

Piaget's Developmental Ladder



Child psychologist Jean Piaget described the mechanism by which the mind processes new information. He said that a person understands whatever information fits into his established view of the world. When information does not fit, the person must reexamine and adjust his thinking to accommodate the new information. Piaget described four stages of **cognitive development** and relates them to a person's ability to understand and assimilate new information.

Stage 1: Sensorimotor

The child is incapable of solving problems. If something is not seen, it has ceased to exist. Around 18 months the child realizes the object has fallen and will search for it. The child can form a plan to retrieve it, but success tends to be a trial and error process. For example, a 20 month old may finally figure out how to open a door by turning the doorknob after many attempts, but may forget the next day and have to re-solve the problem.

Stage 2: Preoperational

By age 2, the child can use language to control the environment and help solve problems. The child can sing a song, tell what happened and can understand some opposites. However, s/he cannot understand abstract concepts, such as death or honesty.

Stage 3: Concrete Operations

From age 6-12, the child can see complex relationships, classify objects and put in order, solve simple arithmetic problems, and read. S/he still has difficulty dealing with hypothetical situations.

Stage 4: Formal Operations

This stage begins at about age 12 and continues throughout life. The person can project into the future and set up long range goals. They are more sensitive to the needs of others and can understand abstract concepts, isolate a problem, review it systematically and test possible solutions. They are no longer gullible and do not believe in fanciful stories.

Human Senses

- Hearing - ears



- Seeing - eyes



- Tasting - tongue



- Touching - skin, fingers



- Smelling - nose



Aging and People with Developmental Disabilities

People with Developmental disabilities are living longer now than ever before. This is because of improved medical technology and greater access to medical care. 12% of all people with developmental disabilities are over the age of 65 years. As a DSP, you will play a very important role in supporting people as they become older. You may be the first person to notice some of the subtle signs of aging, so it is important that you know what some of these signs may be. People with developmental disability need support and understanding by people that are compassionate and properly trained so they can live their lives with dignity and quality.

Just as with typical aging, people with developmental disabilities experience reductions in functional vision, hearing and balance. Depending on the nature of the person's disability, even minor deterioration of these senses can cause major life changes. Some of these changes may include:

Vision Changes

Vision Changes associated with aging include:

- Inability to see things clearly
- Difficulty seeing in the dark
- Difficulty in situations with reflected light or glare
- Loss of visual field (tunnel vision)

Indicators of a Visual Problem include:

- Rubbing eyes
- Squinting
- Shutting or covering one eye
- Tilting head forward
- Redness of eyes or around eyes
- Stumbling
- Hesitancy on a step or curb
- Holding objects close to eyes
- Sitting close to TV
- Changes in color perception (especially greens, blues and violets)

Support Strategies for Vision include:

- Getting regular eye exams
- Using high contrast colors (black on white, for example), non glare lighting and surfaces
- Providing increased lighting, using night lights
- Organizing belongings and keeping their locations consistent

Hearing Changes

Hearing changes associated with aging include:

- Decreased ability to locate the source of sound
- Decreased ability to detect sound or speech due to increased ear wax
- Decreased ability to understand speech (even though hearing environmental sounds may seem to be fine)
- Loss of hearing for high pitched sounds

Indicators of hearing loss include:

- Turning TV up loud
- Speaking loudly
- Inappropriate response to questions
- Confusion in noisy situations
- Self injurious behaviors

Support Strategies for hearing include:

- Getting regular exams with a hearing professional to check for wax, disease, gradual hearing loss
- Hearing aid if indicated
- Reducing background noise
- Speaking slower using lower pitched voice
- Facing the person when speaking with light on your face

Sense of Smell/Nose

As people age there is a decrease in nerve fibers in the nasal area. Mucous membranes become dry and people are less sensitive to odors.

Support Strategies for the sense of smell include:

- Using smoke detectors
- Exercising additional care if using propane stoves or water heaters
- Discarding food after recommended time, checking for spoilage
- Assisting with the awareness of body odor or over-use of fragrances

Sense of Touch/Skin

With aging there is a decrease in the elasticity and thickness of the skin. There is less blood supply and a decrease in the function of the sweat glands.

Protecting the Skin:

- Minimize use of harsh soaps and be sure to rinse well.
- Be sure to dry well and use moisturizers
- Reposition frequently if mobility is limited
- Check skin frequently for problems
- Clearly label hot and cold water and monitor water temperatures
- Use sun protection

Age related Muscle or Skeletal Changes

As people age changes in bones and muscles also occur. These changes include:

- Decrease in muscle mass (amount of muscle)
- Decrease in joint mobility
- Decrease in strength of bones (become more porous or sponge-like)
- Shortening of the spinal cord
- Increased likelihood of developing arthritis

Special Down syndrome Concerns:

While many of the issues with aging probably will not be of concern until the person is into their 50's or 60's, certain developmental disabilities such as Down syndrome, exhibit a special set of concerns. Research has shown that a significant number of individuals with Down syndrome over the age of 35 years develop Alzheimer's disease. The initial signs may just be very subtle changes, such as a decrease ability to carry out activities of daily living, but may eventually lead to more serious, life-changing problems. These signs appear much earlier than the general population for people with developmental disabilities and progress more rapidly. Some people may experience a new onset of seizure disorders.

Other age-related problems for people with Down syndrome include:

- Increased risk of heart valve disease later in life
- Joint problems of neck, knee, and hip
- Increased incidence of being overweight

References:

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http://www.nsn.com/graying_of_disabled_america.htm ; accessed 12/4/2011

Brown, Sharan; Watson, Kathleen, Malony Esther "Supporting People with Developmental Disabilities During the Aging Process"; accessed 12/4/2011.

Characteristics of Sexual Development

Male Development

Increased body hair

Hair around genitals

Growth of beard

Growth of hair under arms

Lowering of voice

Nocturnal emissions (wet dreams)

Erections

Interest in opposite sex

Acne

Development of larger muscles
& broader shoulders

Mood swings

Female Development

Increased body hair

Hair around genitals

Appearance of menses

Growth of hair under arms

Appearance of breasts

Interest in opposite sex

Ability to become pregnant

Acne

Mood swings

Need to wear sanitary napkins
or tampons

Abdominal cramps

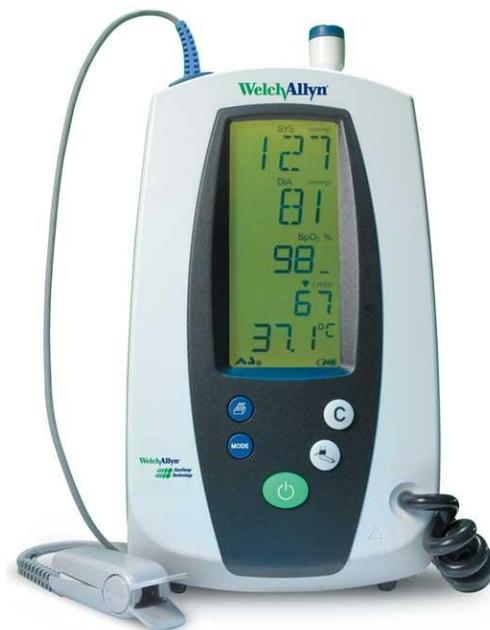
Sexuality Terms Worksheet

Directions: Draw a line from the word in the left-hand column to the correct description on the right.

Penis	Small, erectile organ near the opening of the vagina.
Vagina	Male sex gland which produces sperm.
Testes	Canal in the female that receives the penis during intercourse. Also, the fetus passes through it at birth.
Genitals	Male sex organ, also used for urination.
Clitoris	External sex organs.
Intercourse	Stimulation of the genitals through manipulation or means other than intercourse.
Masturbation	Sexual union of two people in which the penis is inserted into a body orifice of the other.
Ejaculation	Outer covering of skin at the tip of the penis.
Scrotum	Expulsion of semen from the male body.
Foreskin	Pouch of skin that hangs behind the penis and contains the testes.
Uterus	Opening where solid waste leaves the body.
Anus	Place in a woman's body where the fetus develops: the womb.



Vital Signs & Symptoms



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Assessing Health Needs

People with developmental disabilities have the same health issues that everybody else does. They have colds, the flu, stomach aches, etc. Your role regarding assessing health needs involves listening, questioning, observing and documenting. DSPs are the first-line of preventing illness, identifying illness by observing symptoms and working with your agency's team to manage symptoms and address illnesses.

Listening: Listen to what people say, such as:

- My stomach hurts
- I have a headache
- I don't feel well
- My tooth hurts

Questioning: You might ask questions, such as:

- Are you sick?
- Does it hurt somewhere? Show me.
- Can you tell me about it?

Observing: You might notice the following:

- Groaning
- Holding stomach/head, etc.
- Throwing up
- Discolored skin
- Change in behavior



Signs and Symptoms

Though signs and symptoms describe the same conditions, they are very different in many ways. **Signs** are what a doctor sees. **Symptoms** are what the patient experiences. Listening to the people you help support and helping them express their feelings can be very helpful for medical personnel who are trying to diagnose and treat medical conditions. Doctors rely on symptoms to help diagnose medical conditions.

Although the patient notices symptoms, it is other people (DSPs, nurses, physicians) that notice the signs. **Signs** are considered to be objective because they can be felt, heard or seen. Bleeding, bruising, swelling and fever are examples of **signs**.

Symptoms are subjective in the sense that they are not outwardly visible to others. It is only the patient who perceives and experiences the symptoms. For example, a high temperature, a rapid pulse, low blood pressure, and bruising can all be called **signs**. Chills, shivering, fever, nausea, shaking and vertigo are **symptoms**.

You Should Document these Signs and Symptoms if observed:

Wound

pain
swelling
redness
tenderness
pus and/or red streaks

Ears

pain
pulling at ear
redness
fever
diminished hearing
drainage

Teeth

pain
refusal to eat
facial or gum swelling
gum bleeding
fever

Digestive System

abdominal pain
vomiting
loose stools
constipation
fever

Toxic Shock Syndrome

vomiting
fever
pain in one or both sides of mid back
vomiting
chills
diarrhea
nausea
rash, especially during menstruation

Throat

pain with swallowing
refusal to eat
redness
whitish patches at back of throat
hoarse voice
fever or skin rash

Eyes

redness
swelling of the eyelid(s)
eyes burning or painful
discharge
could be allergy if discharge is clear
infection likely if discharge is
yellowish or greenish

Respiratory System

cough
phlegm (mucous)
shortness of breath
wheezing
fever

Urinary Tract

difficult urination, loose stools
pain or burning
change to urine color (clear to cloudy,
light to dark yellow)

Vaginal Infection

unusual discharge
itching, burning
unusual odor

Reporting Guidelines for Signs & Symptoms

When documenting information about signs and symptoms, be sure to include any of the following:

- State what the individual claims is wrong
- Describe how the individual appears physically
- State when the symptoms first began or were noticed
- Describe any changes in the individual's eating habits
- Describe any changes in the individual's behavior
- Describe any vomiting, diarrhea or urinary problems
- Report any recent history of similar symptoms.
- Provide list of current medications
- Provide list of known allergies
- Describe any visible bleeding or swelling, how much and how fast
- Describe any lack of movement or inability to move body parts
- If injured, describe how it happened
- Describe size of wound or injury
- Report pulse, temperature and blood pressure
- State only the facts, not opinion



Subjective vs. Objective Documentation

One of your responsibilities will be to report your observations in progress notes. Any medically-related issue which comes up on your shift must be communicated to the nurse and/or other staff. Remember to be objective when reporting and report only the facts.

When you are documenting signs or symptoms, be sure to write only objective facts, such as size, shape, level of pain, etc., not your opinion or a conclusion that you have made based on the symptoms.

Objective Documentation is writing what you can see, hear, touch or smell.

Subjective Documentation is given by the individual, family members, or others. They include experiences, such as feelings they have or what the individual describes to you, such as pain.

Subjective and Objective Documentation Quiz

DIRECTIONS: Read each documentation example. Determine which is subjective and which is objective and tell why you think that.

Example #1:

John must have fallen out of bed because he said his arm hurt. It's probably not broken.

Example #2:

John had three bruises on his right arm. They measured 4" x 3" each. The bruises were reddish in color and swollen in appearance.

Documentation Tips and Rules

Remember, records are considered legal documents. Therefore:

Sign your name the same way each time, using your legal name.

- Include your title and the date with your signature
- Never use “white out”
- Draw a single line through all unused space.
- Use blue or black ink (per agency requirements)
- Write legibly
- Report objectively (keep feelings out)
- Put information in chronological order
- Protect confidentiality
- Use proper names.
- Draw a single line through errors; initial; then write corrections (if applicable)
- Follow your agency’s guidelines when referring to other staff or individuals in documentation



Documentation Exercise

Instructions: Read the following scenario. Then write a sample progress note based on what you might see.

Mary is a 32 year old woman with mild mental retardation who lives in a group home. She approached you, the authorized DSP, and stated that she had a sore throat and wanted some Tylenol. As you get the medication, you notice she also has a runny nose and is coughing. You give her two Tylenol tablets, as the doctor had previously recommended for pain, according to the PRN Protocol.

Write your progress note here:

Behavior as an Indicator of Illness

A person's behavior sometimes may indicate that they are not feeling well. List some behaviors that could indicate that a person is not feeling well. (See the next page for behaviors to look for.)

General Activity Level

-
-
-
-
-
-
-

Specific Behaviors

-
-
-
-
-
-
-

Body Positioning

-
-
-
-
-

Types of Behaviors that Can Indicate Illness

General Activity Level:

- Quiet
- Restless
- Drowsy
- Alert
- Nervous
- Calm
- Overactive

Specific Behaviors

- Refusing to eat
- Crying
- Holding stomach
- Rubbing elbow
- Jerking movements
- Limping
- Hitting face or head

Body Positioning

- Outstretched
- Twisted
- Bent over
- Cramped
- Fetal position (legs and arms drawn in toward the body)

Common Health Problems for Individuals with Developmental Disabilities

There are **four major health issues** that are more common in people with developmental disabilities than in the general population. These 4 major health issues can lead to severe morbidity and even death. They are frequently referred to as the “fatal four” risks:

- ❖ Aspiration
- ❖ Dehydration
- ❖ Constipation
- ❖ Epileptic seizures

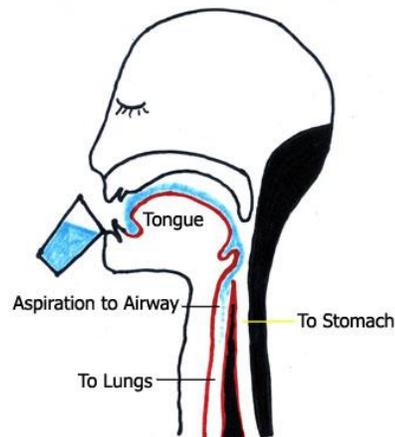
Aspiration, dehydration and constipation may be dangerous conditions that often go unrecognized. Many of the symptoms are subtle and persons with developmental disabilities may not be able to express their discomfort or give indications that they are not feeling well.

Dysphagia/Aspiration

Dysphagia is the medical term which means difficulty swallowing. Aspiration is when bits of food, fluid, saliva or other materials are inhaled into the lungs. Aspiration often happens as a consequence of dysphagia. These two important medical problems are often not recognized promptly in people with developmental disabilities. The following information is meant to increase the awareness of these issues and help to recognize the signs and symptoms of these serious medical conditions.

Factors that place individuals at risk for aspiration:

- ❖ Being fed by others
- ❖ Inadequately trained caregivers assisting with eating/drinking
- ❖ Weak or absent coughing/gagging reflexes, commonly seen in persons who have cerebral palsy or muscular dystrophy



- ❖ Poor chewing or swallowing skills
- ❖ Gastroesophageal reflux disease (GERD, GER) which can cause aspiration of stomach contents
- ❖ Food stuffing, rapid eating/drinking and pooling of food in the mouth
- ❖ Inappropriate fluid consistency and/or food textures
- ❖ Medication side effects that cause drowsiness and/or relax muscles causing delayed swallowing and suppression of gag and cough reflexes
- ❖ Impaired mobility that may leave individuals unable to sit upright while eating
- ❖ Epileptic seizures that may occur during oral intake or failure to position a person on their side after a seizure, allowing oral secretions to enter the airway

Mealtime behaviors that may indicate aspiration

- ❖ Eating slowly
- ❖ Fear or reluctance to eat
- ❖ Coughing or choking during meals
- ❖ Refusing foods and/or fluids
- ❖ Food and fluid falling out the person's mouth
- ❖ Eating in odd or unusual positions, such as throwing head back when swallowing or swallowing large amounts of food rapidly
- ❖ Refusing to eat except from a "favorite caregiver"

Signs and symptoms that may indicate aspiration

- ❖ Gagging/choking during meals
- ❖ Persistent coughing during or after meals
- ❖ Irregular breathing, turning blue, moist respirations, wheezing or rapid respirations
- ❖ Food or fluid falling out of the person's mouth or drooling
- ❖ Intermittent fevers
- ❖ Chronic dehydration
- ❖ Unexplained weight loss
- ❖ Vomiting, regurgitation, rumination and/or odor of vomit or formula after meal

Interventions for aspiration

- ❖ Chin-down position
- ❖ Nectar-thickened liquids
- ❖ Honey-thickened liquids
- ❖ Dental soft diet
- ❖ Pureed diet

Individuals who exhibit these behaviors or who are at risk for dysphagia and aspiration should be seen by a medical provider for further assessment and treatment as indicated. The assessment generally consists of a swallowing evaluation done by a speech language pathologist.

Constipation

Constipation is when an individual has difficulty passing stool; the stools are hard, dry and often look like marbles. The frequency of bowel movements varies greatly from person to person. Bowel movements are considered normal as long as the feces is soft; normal sized and is passed easily out of the bowel.

Factors that place individuals at risk for constipation:

- ❖ Neuromuscular degenerative disorders that impair the central nervous system's response for the need to eliminate
- ❖ Spinal cord injuries or birth defects that affect neural responses needed for elimination such as spina bifida
- ❖ Individuals with muscle weakness who lack the strength and tone needed for adequate bowel function
- ❖ Diets that do not contain enough fiber and fluids
- ❖ Poor swallowing skills with aspiration risk making it difficult to eat and drink adequate amounts of fiber and fluid
- ❖ Inadequate or inconvenient access to the bathroom
- ❖ Immobility and poor body alignment that does not allow for optimum positioning for bowel elimination
- ❖ Poor bathroom habits and routines or lack of privacy and time for using the bathroom
- ❖ Medications that slow down gastric motility or draw too much fluid from the GI tract.
- ❖ Hemorrhoids or other conditions that make bowel elimination painful
- ❖ History of frequent bowel stimulant use leading to decreased bowel reactivity
- ❖ Repression of the urge to defecate due to psychiatric issues

Signs and symptoms of constipation

- ❖ Spending a lot of time on the toilet
- ❖ Straining and grunting while passing stool
- ❖ Refusing to eat or drink
- ❖ Hard, small, dry feces
- ❖ Hard, protruding abdomen (usually this is an emergency)



- ❖ Vomiting digested food that smells like feces (This is an emergency)
- ❖ Bloating and complaints of stomach discomfort

Interventions for Constipation issues

- ❖ Dietitian consultation regarding the type of food, texture, fiber content and fluid requirements to enhance elimination
- ❖ Implement an individual constipation protocol and train caregivers how to identify constipation symptoms, what to do if they occur and who to notify

Observations that should prompt concern

- ❖ No bowel movement for more than three days
- ❖ Last two bowel movements were hard and/or small
- ❖ In the last three days, only small bowel movements recorded

Dehydration

Dehydration occurs when an individual does not drink enough fluids. Fluids are needed for temperature control, chemical balance and for cells to make energy and get rid of waste products. Dehydration occurs when the body loses more fluid than is replaced.



Factors that place individuals at risk for dehydration

- ❖ Unable to access fluids without assistance
- ❖ Needing assistance with drinking
- ❖ Dysphagia with coughing and choking during meals
- ❖ Food, fluid and saliva falling out of a person's mouth
- ❖ Frequently refusing food and fluids
- ❖ Suppression of thirst mechanism that results in the inability to recognize thirst
- ❖ Unable to effectively communicate thirst to caregivers
- ❖ Medical conditions where fluid loss can potentially cause dehydration, such as kidney disease or diabetes
- ❖ Conditions where the individual loses body fluids, such as drooling, diarrhea, sweating and vomiting
- ❖ Taking medications that affect body fluid balance, such as diuretics

Signs and symptoms that an individual may be dehydrated

- ❖ Dry skin and poor skin elasticity
- ❖ Extreme thirst
- ❖ Dry, sticky mucous
- ❖ Lethargy and decreased alertness
- ❖ Fever
- ❖ Increased heart rate and decreased blood pressure
- ❖ Decreased urination, dark colored urine and concentrated urine smell.

Interventions for Dehydration

- ❖ Offer fluid intake if the individual is alert and able to drink safely
- ❖ If unable to take fluid safely, call health care professional for administration of intravenous fluids

Seizure Disorder (Epilepsy)

Epilepsy is a disorder of the brain that is characterized by recurring seizures. Individuals with developmental disabilities are more likely to have epilepsy because of an underlying brain dysfunction. Head injuries, brain tumors, and brain congenital abnormalities are some causes of epilepsy. The clinical expression of an epileptic seizure varies according to where it starts in the brain.

Factors that place individuals at risk for epilepsy

- ❖ Prenatal and postnatal brain injury, such as trauma, anoxia, infection
- ❖ Congenital brain malformations
- ❖ Brain tumors, clots, hemorrhage, and aneurysms
- ❖ Traumatic brain injuries

Immediate interventions when an individual has a seizure

- ❖ Stay with the person and guide gently away from or prevent access to dangerous areas
- ❖ Do not place anything in the person's mouth
- ❖ Move objects away from the person to prevent injury
- ❖ Only move the person if in an unsafe area such as a roadway or stairwell
- ❖ If in water, keep the person's head above the water
- ❖ Don't restrain the person's movements
- ❖ Pad under the person's head, arms and legs
- ❖ Keep track of how long the seizure lasts



After the seizure

- ❖ Loosen clothing
- ❖ Check for injuries and treat appropriately
- ❖ Document the seizure on a seizure calendar or record
- ❖ Allow the person sufficient time to recover before returning to activities

General interventions

- ❖ Keep an accurate description of seizures and track all seizures in a consistent manner
- ❖ Monitor for medication side effects
- ❖ Keep the environment safe. Precautions must be considered when bathing/swimming if there has been a seizure in the past 12 months or antiepileptic medications have been changed within the last 6 months
- ❖ Individualized seizure protocol with caregiver trainings

A couple more things about Epileptic Seizures

It is possible for some seizures to be overlooked as behaviors and/or cognitive symptoms.

Behaviors:

- Yelling or screaming
- Aimless wandering
- Argumentativeness

- Appearing drunk
- Repeating the same word or phrase over and over
- Non-directed violence or lashing out

Cognitive:

- Confusion
- Lapses of memory
- Cloudiness of thinking
- Hallucinations

Seizures MAY be the cause of some of these conditions

Treating Epilepsy

- Doctors rely on accurate reporting of events to help in arriving at a correct diagnosis.
- It may only be possible to sort out seizures from behaviors through the use of an EEG, a test which measures brain waves.
- CT or MRI scans may reveal growths, scars or other physical conditions that may be causing a seizure.
- Epilepsy is treated mostly with medication
 - There are many different medications. One may work for some people but not for other people.
 - Anti-epilepsy drugs are only effective when the correct amount is maintained in the blood stream, so taking the correct dosage at the correct time is important.
- Be sure to report any possible side effects from medications
 - Side effects can include: Double/blurred vision, clumsiness, drowsiness, nausea, dizziness, irritability, tremor, confusion, insomnia.
 - More serious side effects include: Skin rash, hives, bruising, hypersensitivity, drunken behavior, increased seizures.

Common anti-convulsant medications include Dilantin, Phenobarbital, Mysoline, Tegretol, Klonopin, Depakene.

Reporting Seizures

Remember to document:

- Time of the seizure
- Any drug or alcohol use
- Parts of the body affected
- Types of movement

- Antecedent conditions
- Impairment in consciousness
- Changes in skin color
- Any resulting injuries
- Condition after the seizure
- Any difficulty with recall
- Who the seizure was reported to

www.oregon.gov/DHS/spd/provtools/.../ddmanual/companion.pdf

The following is an example of a Seizure Report Form. Please be sure to become familiar with your agency seizure reporting form.

SEIZURE REPORT FORM

Name: _____ Agency: _____

Name: _____

Date of Birth: _____ Seizure Date: _____ Seizure Time: _____

I. Pre-seizure State

- A. Duration: Seconds _____ Minutes _____ Not Known
- B. Activity engaged in: _____
- C. Environment: Noisy Crowded Hot Cold Bright lights Other: _____
- D. Behavior: Hyperactive Confused Calm Lethargic Other: _____

II. Seizure

- A. Duration: Seconds _____ Minutes _____ In Progress Not Known
- B. Warning: Yes No Not known First Movement: _____
If yes, describe: _____
- C. Stayed awake: Yes No Not known
- D. Responsive to environment: Yes No Not known

E. Body Movement	Yes	No	NK		Yes	No	NK
Head rolled forward				Right arm jerked			
Head rolled backward				Left arm relaxed			
Head rolled left				Left arm stiff			
Head rolled right				Left arm twitched			
Facial twitching				Left arm jerked			
Pupils dilated				Trunk relaxed			
Pupils constricted				Trunk stiff			
Eyes rolled left				Trunk jerked			
Eyes rolled right				Right leg relaxed			
Eyes rolled upward				Right leg stiff			

Other Common Health Issues

Incontinence and Urinary Tract Infections (UTI)

Some people that you help support, like millions of others, may experience the frustration and embarrassment of urinary tract infections, otherwise known as UTIs. When this happens, clothing gets wet, odors develop, and the person gets uncomfortable. Being incontinent is beyond the person's control and dealing with it as a professional requires understanding, kindness and patience.

Urinary Incontinence

This is the inability of the person to contain urine in the bladder. The extent can range from an occasional leakage of urine, to a complete inability to hold any urine.



Common Causes of Incontinence

There are a number of reasons someone you support may be incontinent. Incontinence can develop suddenly, be only temporary or be ongoing. Some causes of sudden or temporary incontinence include:

- Urinary tract infection or inflammation
- Prostate infection or inflammation
- Stool impaction from severe constipation which causes pressure on the bladder
- Side effects of medications

Causes that may be more long term include:

- Spinal injuries
- Alzheimer's disease
- Enlarged prostate
- Neurological conditions (multiple sclerosis)
- Weakness of the sphincter (the round muscle of the bladder responsible for opening and closing it)
- Bladder cancer
- Cognitive disability

Fecal Incontinence is loss of control of the bowels. This may lead to stool leakage from the rectum. Muscle damage is a common cause of fecal incontinence. Damage to the nerves that are responsible for rectal sensation is also a common cause.

Diseases such as diabetes, spinal cord tumors and multiple sclerosis can cause nerve injury which can cause fecal incontinence.

Interventions for Fecal Incontinence

- ❖ Adequate fluid intake daily
- ❖ Regular exercise
- ❖ Positive mental outlook

Pressure sores

What is a pressure sore?

A pressure sore is an injury to the skin and the tissue underneath it caused by pressure to the area when you stay in one position too long without shifting your weight. This can happen if a person uses a wheelchair, or if they are confined to bed. However, even people who are able to walk still can get pressure sores when they become ill or injured and must stay in bed. When a person's position doesn't change often enough, the constant pressure against the skin reduces the blood supply to the area and the tissue in that area dies. Sometimes as little as two hours of this constant pressure can trigger skin damage. Even the weight of sheets and blankets can cause pressure sores on toes. Pressure sores can also be called **bed sores** or **decubitus ulcers**.



Is a pressure sore serious?

Pressure sores can be extremely serious, depending on how much tissue has been damaged. Although the pressure sore can start as simply an area of reddened skin, it can quickly turn into an open sore that can eventually go deep into the muscle and bone. If not treated properly, they can become infected and lead to an infection that may be fatal.

Where can pressure sores occur?

Pressure sores can happen anywhere on your body. They are most common over a bony or firm area. Bony areas include:

- Elbows
- Ankles
- Hips
- Heels
- Shoulders and shoulder blades
- Back
- Back of the head

What causes pressure sores?

One or more of the following commonly causes pressure sores:

- **Pressure:** Pressure on the skin can hurt the skin and the layers of tissue underneath the area. When the tissue does not get enough blood, tissue can become damaged and even die. Damage to the tissue and skin from pressure can begin after one or two hours of staying in one position.

- **Shearing, rubbing, or friction:** Shearing happens when the skin is dragged across a surface. For example, being moved up in bed may cause skin shearing if the skin is pulled across the bed surface. A person may have friction on their skin, which is when the top layer of skin is removed. This may cause the skin to turn red, or feel like it is burning
- **Moisture:** Moisture makes the skin spongy, increasing the risk of pressure sores. Moisture can be due to incontinence, not drying properly after bathing or sweating. Be sure that the person is never left in a wet bed or wet clothes.

Preventing Pressure Sores

It is important to remember: Pressure **sores are much easier to prevent than to heal**. Take care to protect skin from friction, shearing and other stress. Do **not** massage (rub) the skin over bony areas.

Here are some ways to help prevent pressure sores.

- Check skin several times a day for redness over bony areas
- Keep skin dry
- Keep skin clean
- Change positions frequently (at least every hour)
- Protect the skin over bony areas
- Use special equipment and pads
- If in bed, keep bottom sheet free of wrinkles
- If in a chair or wheelchair, have person sit up straight (shift weight from one side to the other every 15 minutes)
- Make sure feet are supported
- Ask the nurse about exercises that can be done in the chair (exercising helps blood flow to the skin)

Allergies and allergic reactions

The symptoms of **allergy** include sneezing and wheezing to itching and tearing. This occurs when your body reacts to what is normally a harmless substance. The results can range from mild congestion to death. Allergens (pollen, dust, mites, mold spores, animal dander, etc.) enter through the nose causing discharge of histamine. The histamine causes sneezing, nasal congestion and nasal discharge.

Medications include antihistamines, nasal steroid sprays, and decongestants. Other treatments include salt water nasal sprays, allergy



shots, and air filters. Some allergic reactions include **contact dermatitis** (red, itchy, blistering skin) and **hives** (itchy, red welts and swelling).

Allergic reactions may occur due to **medications**. This occurs if a person's immune system reacts to the presence of a foreign substance. The body attempts to get rid of the substance. Symptoms may be serious. They could include anaphylactic shock (which can lead to death), anxiety, hives, palpitations, shortness of breath, skin rash, swelling or wheezing.

Eczema

Eczema can be caused by an allergic reaction. It produces an inflammation which causes the skin to become itchy and scaly, with dry, red patches of skin. This often occurs behind the knees, in the folds of the elbows and wrists, and on the neck, ankles and feet. The itching worsens with heat, stress or abrasions to the areas from scratching.

Medications to treat eczema include topical ointments, oral steroids, antibiotics, and antihistamines.

Asthma

Asthma occurs when the airways narrow as a result of irritation and inflammation. It causes repeated bouts of wheezing, shortness of breath, chest tightness, and coughing, especially at night or early morning.

Treatments of asthma include avoiding known irritants or triggers (cigarette smoke, dust and strong chemical odors) and taking medications to reduce airway inflammation.

Diabetes

Also called: "Sugar", Adult onset diabetes, Non-insulin dependent diabetes

Diabetes is a disease in which your blood glucose, or sugar, levels are too high. Glucose comes from the foods you eat. Insulin is a hormone that helps glucose in the blood to be absorbed by your cells. Glucose enables cells to provide energy. With Type 1 diabetes, your body does not make insulin. With Type 2 diabetes, the more common type, your body does not make insulin or use it well. Without enough insulin, the glucose stays in your blood.

Over time, having too much glucose in your blood can cause serious problems. It can damage your eyes, kidneys, and nerves. Diabetes can also cause heart disease, stroke and even the need to remove a limb. Pregnant women can also get diabetes. This is called gestational diabetes.

Symptoms of Type 2 diabetes may include fatigue, thirst, weight loss, blurred vision and frequent urination. Some people have no symptoms. A blood test can show if a person has diabetes. Exercise, weight control and sticking to a nutritional meal plan can help control diabetes. People need to monitor their glucose level and take medicine if prescribed by a physician.



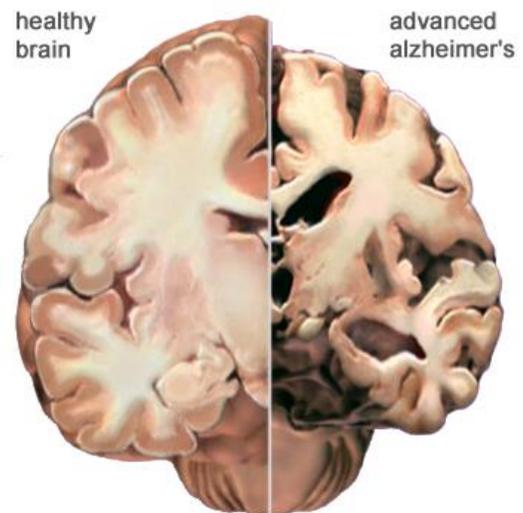
Alzheimer's Disease and Dementia in People with Developmental Disabilities

Alzheimer's disease is age related, that is, it affects primarily older adults. Except for people with Down syndrome, adults with developmental disabilities are at the same risk for Alzheimer's disease as other adults in the general population.

Studies have shown that the rate of occurrence of Alzheimer's disease among people with developmental disabilities is about the same as the general population (about 6% of persons age 60 or older). However, the rate among people with Down syndrome is much higher. For people with Down syndrome over age 40, about 25% will be diagnosed with Alzheimer's disease. This rate jumps to 65% for those with Down syndrome age 60 and older.

Adults in general are at greater risk of having the disease if they:

- Are over 60 years old
- Have Down syndrome
- Have had some form of severe or multiple head injury
- Have a family history of Alzheimer's disease



The early symptoms of Alzheimer's disease in the general population often include:

- **Language problems.** The person cannot find the right word or name for a familiar person, place or object. This is not the same as taking longer to recall a word. It is far more than the "occasional" slip of a name that everyone experiences.
- **Loss of recent memory.** The person may forget that he or she just had breakfast or has left something cooking on the stove, or may check and recheck that the bed has been made. However, recall of events from the distant past is often unaffected.
- **Loss of a sense of time and place.** The person may become more and more confused about what day it is, or forget the route to well-known places.
- **Decline in activities of daily living.** The person may exhibit an unexplained loss of activities of daily living (ADL) skills. What once was an easy task for the person may now be difficult.

- **Personality changes.** These may be so slight that, at first, they are difficult to notice. Some people become more quiet and withdrawn. In other cases, they may become more and more restless. Some persons may start to get angry over little things or have sudden changes of mood for no apparent reason.

As the disease progresses, memory losses become even more pronounced. There may be specific problems with language abilities. Persons affected may have difficulty naming objects or with maintaining a logical conversation. They may have difficulty understanding directions or instructions and become disoriented as to time of day, where they are and with whom they are with. They may also begin to experience loss of self-care skills, including eating and using the toilet. Severe changes in personality may become obvious and social behavior may be marked by suspiciousness and delusions.

Supporting People with Alzheimer's disease

Here are some tips for supporting people with Alzheimer's disease:

Communication

Trying to communicate with a person who has Alzheimer's disease can be a challenge. Both understanding and being understood may be difficult.

- Choose simple words and short sentences and use a gentle, calm tone of voice.
- Avoid talking to the person with Alzheimer's like a baby or talking about the person as if he or she weren't there.
- Minimize distractions and noise—such as the television or radio—to help the person focus on what you are saying.
- Make eye contact and call the person by name, making sure you have his or her attention before speaking.
- Allow enough time for a response. Be careful not to interrupt.

Bathing

While some people with Alzheimer's disease don't mind bathing, for others it is a frightening, confusing experience. Advance planning can help make bath time better for both of you.

- Plan the bath or shower for the time of day when the person is most calm and agreeable. Be consistent. Try to develop a routine.

- Respect the fact that bathing is scary and uncomfortable for some people with Alzheimer's. Be gentle and respectful. Be patient and calm.
- Tell the person what you are going to do, step by step, and allow him or her to do as much as possible.
- Prepare in advance. Make sure you have everything you need ready and in the bathroom before beginning. Draw the bath ahead of time

Dressing

For someone with Alzheimer's, getting dressed presents a series of challenges: choosing what to wear, getting some clothes off and other clothes on, and struggling with buttons and zippers. Minimizing the challenges may make a difference.

- Try to have the person get dressed at the same time each day so he or she will come to expect it as part of the daily routine.
- Encourage the person to dress himself/herself to whatever degree possible. Plan to allow extra time so there is no pressure or rush.
- Allow the person to choose from a limited selection of outfits. If he or she has a favorite outfit, consider buying several identical sets.
- Arrange the clothes in the order they are to be put on to help the person move through the process.
- Hand the person one item at a time or give clear, step-by-step instructions if the person needs prompting.
- Choose clothing that is comfortable, easy to get on and off, and easy to care for. Elastic waists and Velcro® enclosures minimize struggles with buttons and zippers.

Eating

Eating can be a challenge. Some people with Alzheimer's disease want to eat all the time, while others have to be encouraged to maintain a good diet.

- View mealtimes as opportunities for social interaction and success for the person with Alzheimer's. Try to be patient and avoid rushing, and be sensitive to confusion and anxiety.
- Aim for a quiet, calm, reassuring mealtime atmosphere by limiting noise and other distractions.
- Maintain familiar mealtime routines, but adapt to the person's changing needs.

- Give the person food choices, but limit the number of choices. Try to offer appealing foods that have familiar flavors, varied textures, and different colors.

Exercise

Incorporating exercise into the daily routine has benefits for both the person with Alzheimer's disease and the caregiver. Not only can it improve health, but it also can provide a meaningful activity for both of you to share.

- Think about what kind of physical activities you both enjoy, perhaps walking, swimming, tennis, dancing, or gardening. Determine the time of day and place where this type of activity would work best.
- Be realistic in your expectations. Build slowly, perhaps just starting with a short walk around the yard, for example, before progressing to a walk around the block.
- Be aware of any discomfort or signs of overexertion. Talk to the person's doctor if this happens.
- Allow as much independence as possible, even if it means a less-than-perfect garden or a scoreless tennis match.

Medications

Medications are used to enhance the quality of life for people. The benefits are many. Medicines can treat and cure many health problems, but they must be taken properly to ensure that they are safe and effective. Many medicines have powerful ingredients that interact with the human body in various ways. However, whenever medications are used, the potential for unwanted effects and reactions is always present. As a direct support staff person, you will need to watch for these effects and reactions so that good decisions regarding medication use can be made.



Medication Effects

The effects of medications can fall into two general categories: **therapeutic** (which are the desired effects) and **side effects**. The therapeutic effect is what the drug is intended to do for the person. The side effect is a part of the action of the drug that is not part of the goal of the medication.

Therapeutic Effects

In order to understand how medications work therapeutically, we need to understand how they affect the workings of the human body. Medications can generally be placed in four categories. These are:

Depressing. When a drug has this effect, it slows down cellular processes. An example of this is the use of antihistamines which slow down the body's production of histamine which is produced in reaction to irritations.

Stimulating. Stimulants are drugs that arouse activity in the brain and central nervous system, speeding up communication between the two. Stimulants usually increase alertness and physical activity. Your everyday coffee is a stimulant from which many people have formed an addiction.

Destroying cells. Medications in this category destroy certain harmful cells. Antibiotics are an example of this type of drug. Antibiotics kill microorganisms that cause disease.

Replacing substances. These medications are designed to replace a substance that the body is not producing naturally. An example of this type of medication is insulin which is taken by people who have diabetes.

Medication Side Effects and Interactions

As a DSP, it is important that you are aware of potential side effects of medications and watch the person you support to see if any side effects occur. If you observe a side effect, you must be sure to follow your agency's procedures for documenting and reporting the information. Your documentation is very important because it will help the doctor decide what to do about the medication causing the side effects. However, if a severe reaction occurs and the person appears to be in a life-threatening situation, medical attention is needed immediately. Seek medical advice before administering another dose of a medication when you have observed a side effect. You can get information about the side effects from the prescribing doctor or pharmacist. When a medication is filled, a list of potential side effects usually accompanies the medication.

The causes of side effects may be influenced by things that are under our control:

- Sometimes when a drug is used in combination with another drug or with certain kinds of foods, the interaction can result in side effects that neither drug would cause if used alone.
- Certain foods can decrease the beneficial effects of some medications.
- Alcohol and caffeine often interact undesirably with medications
- Remember that alcohol is an ingredient in many cough syrups, mouthwashes, shaving lotions, deodorants etc.
- There is a greater risk of undesirable side effects when a number of drugs are used at the same time.

Tardive Dyskinesia (TD)

TD is a movement disorder that is a side effect of medications, usually psychotropic drugs (antipsychotic or neuroleptic). When these medications are prescribed for a long period of time or are discontinued, TD symptoms may appear. TD is characterized by repetitive, involuntary, purposeless movements such as grimacing, tongue protrusion, lip smacking, puckering and pursing, and rapid eye blinking. Rapid movements of arms, legs and trunk may be noticed. Other TD symptoms include the involuntary movement of fingers as though playing an invisible guitar or piano, and making repetitive sounds such as humming or grunting. The muscles of respiration and speech can be impaired by TD too. In the worst cases, a person with TD will thrash about continually.

Antipsychotic medications that may cause TD include Thorazine, Prolixin, Haldol, Loxitane, Serentil, Moban, Trilafon, Orap, Compazine, Serapsil, Mellaril, Navane, and Stelazine. Antidepressant medications associated with TD are Asendin and Triavil. Medications for gastrointestinal problems related to TD are Reglan and Compazine. Penergán (for coughs). A combination medication associated with TD is Etrafon.

Factors that Affect Drug Action

Following are some factors that may affect how well a drug works in a specific person.

Weight – The size of the person. A larger dose may be needed for a larger person. A smaller person may require a smaller dose.

Age – Age may change how a medication works. For example, the body processes of elderly persons may be slower which may take a drug longer to work.

Diet – Some drugs are affected by the amount or kind of food eaten. Some medications need to be taken on an empty stomach. For other medications, certain foods need to be avoided. It is important to know this information when assisting someone with their medications.

Gender – Females generally require smaller doses than males.

Race – Race can affect drug action since body chemistry and stature among different races can vary.

Tolerance – The therapeutic effects of some medications are lessened in some individuals after prolonged use. Therefore, a person who has used a drug for a long time may need larger doses than when the medication was first prescribed in order to get the same therapeutic effects.

www.tpub.com/content/armymedical/md0913/md09130057.htm

Why would anyone not want to take medications?

A person may resist taking medications for any number of reasons such as:

- Expectation that the medication should work faster; therefore, they must not be working
- Side effects are intolerable
- Feel that the medication is too expensive
- The medication is inconvenient to take
 - Time of dosage
 - Size of the pill
- Want to exert their right of control over their life
 - Uses the taking of medication as a bargaining chip to get other privileges

Things to remember when helping people accept the fact that medication can help them.

- A change in medication may be confusing to a person whether it is a change in brand or change in type of medication. Remind the person of the reasons for the change and reassure them.
- When unpleasant side effects occur report these and confirm with the doctor that the benefits of taking the medication outweigh the negative side effects.
- If a person resists taking a medication, review the protocol for such an occurrence and follow it. The protocol should be documented.

Examples of Medications and Their Uses

Anticonvulsants

Purpose: Controls seizures

Phenobarbital	Lamictal
Dilantin	Tegretol
Depakene	Depakote
Klonopin	Mysoline
Neurontin	Keppra
Topamax	

Non-Steroidal Anti-Inflammatory

Purpose: Reduces pain, fever, inflammation.

Bayer Aspirin
Ibuprofen (Motrin, Advil)
Naproxen (Anaprox, Aleve, Naprosyn)
Ketoprofen (Orudis)
Nabumetone (Relafen)

Anti-Anxiety Drugs

Purpose: Alleviates anxiety often displayed as agitation.

BuSpar	Librium
Ativan	Xanax
Valium	

Asthma

Purpose: Opens passages to the lungs.

Theo-Dur	Primatene Mist
Slo-Bid	
Proventil	

Antidepressants

Purpose: Reduces symptoms of depression.

Elavil	Prozac
Trofanil	Paxil
Wellbutrin	Desyrel
Zoloft	Remeron
Lexapro	Effexor

Diuretics

Purpose: Helps eliminate water, sodium and chloride from the body.

Lasix	Bumex
Dyazide	Zaroxolyn
Maxzide	Dyrenium
Hydrodiuril	

Antipsychotics

Purpose: Reduces symptoms of various psychoses (i.e., schizophrenia, manic depression, etc.)

Thorazine	Risperdal
Prolixin	Haldol
Mellaril	Navane
Seroquel	Clozaril
Abilify	Geodon
Invega	

Antihistamines

Purpose: Alleviates allergies, cold and hay fever symptoms.

Dimetane	Allegra
Benadryl	Claritin
Tavist	Zyrtec

Anti-Seizure

Use the following 2 pages (Example of a Written Insert, etc.) to answer these questions.



What is the medication supposed to do?

In what forms does this drug come?

If I take this medicine once a day and I miss a dose but don't remember until the next day, should I take two doses?

Should I take this medication with food?

Is there anything I should avoid eating or drinking while taking this drug? If so, what?

1. What are the common side effects?
2. Why shouldn't I store this drug in the bathroom?
3. If I take these drugs, I should inform my doctor. What are they?
4. Where would be a good place to store this medication?
5. What can I do to decrease gum enlargement?

Example of a Written Insert Accompanying a Drug Dispensed by the Pharmacist

Medication: Dylantin (Phenytoin - Oral)

USES: This medication is used to treat seizures and epilepsy.

HOW TO TAKE THIS MEDICATION: Take with food or milk if stomach upset occurs. Capsules should be swallowed whole unless otherwise directed. The tablets must be chewed thoroughly before swallowing. The suspension must be shaken well before measuring each dose. This medication must be taken as prescribed. Do not stop taking this drug suddenly without consulting your doctor, as seizures may occur. It is important to take all doses on time to keep the level of medication in your blood constant. Do this by taking doses at the same time(s) each day. Do not skip doses. While taking this medication, lab tests may be done, especially in the first few months, to check if the drug is working properly.

SIDE EFFECTS: May cause drowsiness, dizziness, or blurred vision. Use caution performing tasks that require alertness. Other side effects include stomach upset, headache, muscle twitching, or sleep disturbances. These should subside as your body adjusts to the medication. Notify your doctor if seizures occur or if you develop severe nausea and vomiting, joint pain, swollen or tender gums, sore throat, uncoordinated movements, unusual bleeding or bruising, uncontrolled side-to-side eye movements or skin rash while taking this medication. May cause enlargement of the gums. This can be minimized by maintaining good oral hygiene with regular brushing, flossing and massaging of the gums.

PRECAUTIONS: This drug should be used during pregnancy only if clearly needed. Discuss the risks and benefits with your doctor. Small amounts of phenytoin appear in breast milk. Consult with your doctor before breast-feeding. Use of alcohol and other sedative type medications can lead to extreme drowsiness. Try to limit their usage. This medication may decrease the effectiveness of oral contraceptives. Consult your pharmacist or doctor about other methods of birth control. Be sure your doctor knows your complete medical history.

DRUG INTERACTIONS: Inform your doctor about all the medicine you use (both prescription and non prescription) especially if you take a blood thinner (Coumadin), Cimetidine (Tagamet) for stomach problems, Disulfiram (Antabuse) for alcoholism, oral antifungal medications, or Xanthine drugs (i.e., theophylline) to treat asthma as the dosage may need to be adjusted. Limit caffeine usage.

NOTE: It is recommended persons wear or carry medication identification indicating which drugs they are taking. Do not change from one product brand to another

without consulting your doctor or pharmacist. Products made by different companies may not be equally effective.

MISSED DOSE: If you miss a dose and take one dose daily, take as soon as you remember unless you do not remember until the next day. In that case, skip the missed dose and resume your usual dosing schedule the following day. If you take several doses daily and should miss a dose, take as soon as remembered unless it is within 4 hours of the next dose. In that case, skip the missed dose and resume your usual schedule. Check with your doctor if you miss doses for more than 2 days in a row. Do not double the dose to catch up.

STORAGE: Store at room temperature away from moisture and sunlight. Do not store in the bathroom.

OJT Activity #17: Measuring a Radial Pulse

Steps	Partner Check	Instructor Check
Assemble materials (clock/watch with second hand or digital second counter).		
Wash hands.		
Identify person.		
Greet person.		
Provide for person's privacy.		
Explain to the person how you will be taking the vital signs.		
Obtain permission to take the person's pulse.		
Grasp the right/left wrist between your thumb and four fingers.		
Place your 2nd & 3rd fingers on the wrist, palm side of hand up, closest to the thumb.		
Count pulse for 15 seconds and multiply by four.		
Assess the strength and rhythm of the pulse. (see NOTE below).		
Write down the results.		
Attend to person's comfort and safety.		
Thank individual for cooperating.		
Wash hands.		

Follow this example when documenting the pulse rate in the progress notes: Radial pulse-76, strong & regular.

Note: The average pulse rate for an adult is 72-80 beats per minute. The rhythm is routinely described as follows:

- Strong - normal rhythm
- Bounding - unusually strong rhythm
- Thready - pulse beats are weak
- Irregular - pulse beats do not have a regular rhythm.
- Regular - regular rhythm

OJT Activity #17: Measuring a Carotid Pulse

Steps	Partner Check	Instructor Check
Assemble materials (clock/watch with second hand or digital second counter).		
Wash hands.		
Identify person.		
Greet person.		
Provide for person's privacy.		
Explain to the person how you will be taking the vital signs.		
Obtain permission to take the person's pulse.		
Run your four fingers down the Adam's apple on the front side of the neck.		
Slide your first three fingers into the crevice next to the Adam's apple.		
Count pulse for 15 seconds and multiply by four.		
Assess the strength and rhythm of the pulse. (see NOTE below).		
Write down the results.		
Attend to person's comfort and safety.		
Thank individual for cooperating.		
Wash hands.		

Follow this example when documenting the pulse rate in the progress notes: Radial pulse-76, strong & regular.

Note: The normal pulse rate for an adult is 72-80 beats per minute. The rhythm is routinely described as follows:

Strong - normal rhythm

Bounding - unusually strong rhythm

Thready - pulse beats are weak

Irregular - pulse beats do not have a regular rhythm.

Regular - regular rhythm

OJT Activity #17: Measuring a Brachial Pulse

Steps	Partner Check	Instructor Check
Assemble materials (clock/watch with second hand or digital second counter).		
Wash hands.		
Identify person.		
Greet person.		
Provide for person's privacy.		
Explain to the person how you will be taking the vital signs.		
Obtain permission to take the person's pulse.		
Place your first three fingers on the inner surface of the upper arm.		
Count pulse for 15 seconds and multiply by four.		
Assess the strength and rhythm of the pulse. (see NOTE below).		
Write down the rate and rhythm.		
Attend to person's comfort and safety.		
Thank individual for cooperating.		
Wash hands.		
Report anything abnormal to supervisor or nurse.		

Follow this example when documenting the pulse rate in the progress notes: Radial pulse-76, strong & regular.

Note: The normal pulse rate for an adult is 72-80 beats per minute. The rhythm is routinely described as follows:

Strong - normal rhythm

Bounding - unusually strong rhythm

Thready - pulse beats are weak

Irregular - pulse beats do not have a regular rhythm.

Regular - regular rhythm

OJT Activity #18: Measuring the Respiratory Rate

Steps	Partner Check	Instructor Check
Assemble materials (clock/watch with second hand or digital second counter).		
Wash hands.		
Identify person.		
Greet person.		
Provide for person's privacy.		
Explain to the person how you will be taking the vital signs.		
Obtain permission to take the person's pulse.		
Appear to be taking the person's pulse, begin counting respirations.		
Count the rise and fall of the chest as one respiration. Count rate for 30 seconds and multiply by 2. (see NOTE below)		
Write down the rate and rhythm.		
Attend to person's comfort and safety.		
Thank individual for cooperating.		
Wash hands.		
Report anything abnormal to supervisor or nurse.		

Follow this example when documenting the respiration rate in the progress notes: Respiration - 16.

Note: The average normal respiratory rate for an adult is 16-20 respirations per minute.

OJT Activity #19: Taking a Manual Blood Pressure

Equipment needed: Blood pressure cuff that is the right size for the individual, stethoscope, alcohol wipes, and watch/clock with second hand.

Steps	Partner Check	Instructor Check
Locate blood pressure cuff, stethoscope and alcohol wipes.		
Wash hands.		
Identify and greet person.		
Explain to the person how you will be taking the vital signs.		
Obtain permission to take the person's pulse.		
Provide for the person's privacy.		
Open the alcohol wipes and wipe off the ear pieces of the stethoscope.		
Discard used wipes.		
Ask individual to sit or lie down. Uncover either upper arm of individual. (Do not use an arm that has an injury or paralysis, etc.) Do not constrict blood flow to arm.		
Place stethoscope ear pieces in your ears.		
Support the person's forearm on a firm surface near heart level. Position the palm up.		
Verify that the cuff is deflated and reading at zero.		
Wrap cuff around person's arm so lower edge of cuff is at least one inch above bend of inside elbow. Place rubber cushion of cuff so the center is over artery in center of inner arm.		
Place flat side of stethoscope diaphragm over individual's brachial pulse.		
Tighten the valve (screw attached to the bulb at the end of the tube) on the blood pressure cuff inflation mechanism until it is closed.		
Grasp the bulb in the palm of your hand.		
Position yourself so that your eyes are level with the mercury or the dial.		

Steps	Partner Check	Instructor Check
Using a pumping action, inflate the blood pressure cuff (while feeling the pulse) up to 30-40 mm past where you feel the pulse disappear using bulb.		
Observe pressure dial.		
Do not touch cuff or tubes. Hold firmly so there is not space between stethoscope and skin, but with as little pressure as possible.		
Release the valve by loosening the screw slowly while carefully observing the dial attached to the bulb.		
Note the dial reading when you first hear a regular thumping sound through the ear pieces of the stethoscope. This is the systolic reading.		
Continue to let air out slowly. The sounds will become dull and disappear.		
Note the number when you hear the last sound. This is the diastolic reading. (see NOTE below)		
Deflate cuff completely.		
Repeat after 1-2 minutes.		
Completely deflate cuff. Remove ear pieces of stethoscope from ears.		
Remove cuff from individual's arm.		
Attend to person's comfort & safety.		
Thank the person for cooperating.		
Open the alcohol wipes and wipe off ear pieces of stethoscope.		
Wash hands.		

Follow this example when documenting the blood pressure reading in the progress notes: B/P-120/80.

Note: Normal systolic (top number) is 110-120. Normal diastolic (bottom number) is 60-80.

Please determine if a specific arm should not be used for blood pressure (broken arm, mastectomy, etc)

OJT Activity #20: Taking an Oral Temperature

Equipment needed: Disposable plastic probe cover
Electronic thermometer*
Probe attachment
Pen and paper

Steps	Partner Check	Instructor Check
Assemble materials (electronic thermometer, disposable plastic probe cover, probe attachment, pen and paper).		
Wash hands.		
Identify and greet the person.		
Provide for person's privacy		
Explain to the person how you will be taking their temperature.		
Obtain permission to take the person's temperature with the electronic thermometer.		
Ask if the person has eaten, drank, or smoked in the last ten minutes. If so, wait ten minutes before taking the temperature.		
Plug the probe into the base of the thermometer.		
Check the connection of the probe to the base of the thermometer.		
Explain to the person you are about to insert the thermometer into their mouth, under the tongue, and then do so. Instruct the individual to close their mouth.		
Wait for buzzer to sound.		
Remove probe.		
Read the thermometer. (see NOTE below)		
Write down the temperature.		
Discard used probe cover.		

Return probe to proper storage place.		
Attend to person's comfort and safety.		
Thank the person for cooperating.		
Wash hands.		
Report abnormal temperatures to the supervisor/nurse.		

Follow this example when documenting the electronic temperature in the progress notes: Oral Temp- 98.6⁰

Note: Normal oral temperature is 98.6⁰ (37⁰ C), but may vary by individual.

OJT Activity #22: Taking an Axillary (Armpit) Temperature

Equipment needed: Electronic thermometer
 Probe cover
 Probe attachment
 Pen and paper

Steps	Partner Check	Instructor Check
Locate the electronic thermometer and plastic probe cover sheaths.		
Wash hands.		
Identify and greet the person.		
Provide for person's privacy		
Explain to the person how you will be taking their temperature.		
Obtain permission to take the person's temperature with the electronic thermometer.		
Plug the oral probe into the base of the thermometer.		
Cover the probe with the plastic probe cover sheath.		
Assist the person in loosening their clothing around the armpit.		
Using a paper towel, pat dry the axilla where the thermometer will be placed.		
Place the end of the probe in the center of the person's armpit.		
Once the thermometer has been put into place, have the person hold their arm tightly against the chest.		
Leave the thermometer in place until the thermometer buzzer sounds or temperature registers.		
Remove the thermometer from the person's armpit.		
Read the thermometer.		
Discard the plastic sheath.		
Write down temperature. (see NOTE below)		

Assist the person with clothing adjustment.		
Attend to the person's comfort & safety.		
Thank the person for cooperating.		
Return the probe to its stored position.		
Wash hands.		
Store thermometer.		
Report any abnormal temperature to the supervisor/nurse.		

Follow this example when documenting the electronic temperature in the progress notes: Axillary Temp- 98.6°

Note: Normal axillary (armpit) temperature is 97.6° (36° C), but may vary by individual.

OJT Activity #61: Measuring Weight

Attention: Recording of weight may be requested by physician or dietitian.

Always explain what you will be doing with individual, ask permission and discuss steps as you are doing them.

Ensure privacy and confidentiality for this procedure.

Discuss what you are going to do with consumer. Use the least prompting necessary.

Record results in agency-preferred location.

Weigh at the same time of the day to ensure accurate comparison.

Equipment needed: Scale

Steps	Partner Check	Instructor Check
Determine which person you will be weighing.	<input type="checkbox"/>	<input type="checkbox"/>
Ensure privacy.	<input type="checkbox"/>	<input type="checkbox"/>
When charting measurements assure that weights are taken at the same time each day.	<input type="checkbox"/>	<input type="checkbox"/>
Have the person take off heavy shoes or outer clothing.	<input type="checkbox"/>	<input type="checkbox"/>
Train or assist person to place scale on flat surface, if not already there.	<input type="checkbox"/>	<input type="checkbox"/>
Train or assist individual to step on scale. Verify that he/she is not holding onto anything.	<input type="checkbox"/>	<input type="checkbox"/>
Train or assist individual to read number on scale.	<input type="checkbox"/>	<input type="checkbox"/>
Train or assist individual to step off scale.	<input type="checkbox"/>	<input type="checkbox"/>
Train or assist individual to return scale to the proper storage location.	<input type="checkbox"/>	<input type="checkbox"/>
Record the results and give them to your OJT trainer.	<input type="checkbox"/>	<input type="checkbox"/>



Wellness



Module 6, Section 4

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Wellness

Wellness is more than being without disease. It is a way of living or a lifestyle that helps people reach their potential for health and independence. There are a number of ways to achieve wellness. Many experts tell us that exercise and diet are very important components in pursuing wellness. Medical management alone has not proven to be effective in meeting the health needs of people with developmental disabilities.



Choosing active leisure activities can promote wellness and also significantly reduce stress and anxiety. Active recreational activities are particularly important in promoting physical and mental health. However, statistics show that many people with developmental disabilities do not have active life styles and also require, as most of us do, further education on choosing healthy foods.

The Center for Disease Control's Healthy People 2010 progress report compared people without disabilities to those with developmental disabilities. The report found that individuals with developmental disabilities are more likely:

- Obese
 - 45% of males; 56% of females were found to be obese. This is substantially higher obesity rates than the general population which is 33% for men and 36% for women.
- Exercise less frequently.

In earlier research, it was found that more than 75% of female adults with developmental disabilities were obese (Rimmer et al., 1993). Frey and Rimmer (1995) also found much higher rates of obesity among American adults with developmental disabilities compared to German adults with developmental disabilities. The incidence of obesity among the American sample was 43%, compared to only 16.7% of the German subjects. The investigators concluded that one of the major reasons for the differences in obesity between the two countries was lifestyle. The German cohort was more involved in regular physical activity and relied less on vehicular transportation to get to places.

Accessed 8/11/11; http://www.ncpad.org/disability/fact_sheet.php?sheet=117

In addition, poor dietary choices often contribute to overall health concerns such as weight management, high cholesterol, etc.

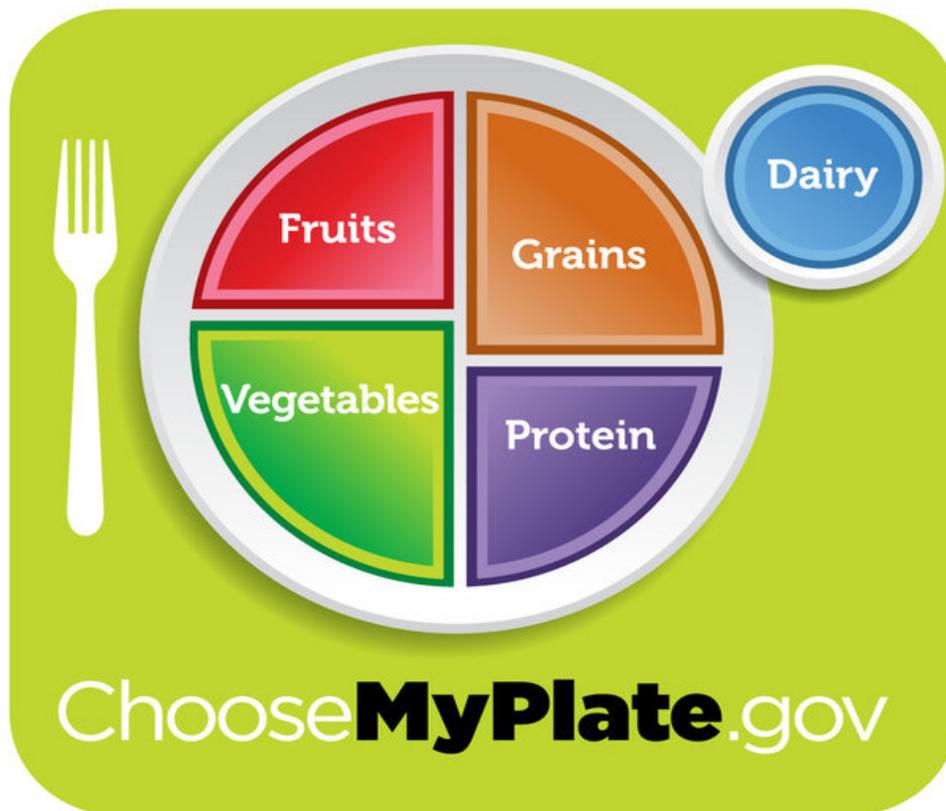
Some general tips on healthy eating include:

- Enjoy your food, but eat less.
- Avoid oversized portions
- Make half your plate fruits and vegetables
- Make at least half of your grains whole grains
- Drink water instead of sugary drinks

Other research shows that people with developmental disabilities are more likely to:

- Have chronic health conditions
- Make more emergency room visits
- Have feelings of loneliness or isolation

Healthy Eating



The new Food Plate icon was introduced in 2011. It replaces the USDA's 2005 Food Pyramid. The food plate is meant to be a simpler and more straightforward tool to educate and inform people about the basic food groups and portion sizes. The plate is divided into sections: grains, protein, fruits, vegetables and dairy. It also demonstrates the $\frac{1}{2}$ of the plate should consist of fruits and vegetables.

Part of your job as a DSP will be to help people you support make healthy dietary choices. The following page offers some tips on how to build a healthy plate.

How to Build a Healthy Plate

Eat more whole grains

Any food made from wheat, rice, oats, cornmeal, barley or other cereal grain is a grain product. Bread, pasta, oatmeal, breakfast cereals, tortillas and grits are examples. Grains are divided into two subgroups: whole grains and refined grains. Whole grains contain the entire grain kernel, - the bran, germ, and endosperm. People who eat whole grains as part of a healthy diet have a reduced risk of some chronic diseases.

Add more vegetables to your day

Eating vegetables is important because they provide vitamins and minerals and most are low in calories. Choose vegetables that are red, orange or dark green. They are full of vitamins and minerals. It's always a good idea to have some veggies like carrots or celery prepared and ready to snack on.

Focus on fruits

Like vegetables, fruit can add much to an overall healthy diet and can help people reduce the risk of some chronic diseases. Fruits provide nutrients vital for health, such as potassium, dietary fiber, vitamin C and folate (folic acid). Most fruits are naturally low in fat, sodium and calories. None have cholesterol.

Cut back on foods high in solid fats, added sugars and salt

Choose foods and drinks with little or no added sugars. For example, choose 100% fruit juice instead of fruit-flavored drinks. Be sure to eat fewer foods that are high in solid fats. Make major sources of saturated fats – such as cakes, pizza, cheese, hot dogs occasional choices, not every day foods. Also, look out for salt (sodium content) in the foods you buy.

Use food labels to help you make better choices

Most packaged foods have a Nutrition Facts label and an ingredients list. Use these tools to make smarter food choices quickly and wisely. Choose foods with lower calories, saturated fat, trans fat and sodium.

Nutrition and Special Diets

Many individuals with developmental disabilities are able to eat all foods and food textures. This type of diet is referred to as a “general diet”. However, some individuals need modified or special diets that must be ordered by a health care professional. A dietitian or feeding specialist may determine dietary requirements but the physician (health care professional) must sign the order. A diet order may specify calorie content, food restrictions and/or consistency requirements.

Caloric Level

The calorie level may be identified as a number or numerical range or may be described with words or phrases. Examples:

- 3000 calorie general diet
- 1200 – 1400 calorie general diet
- Reduced portion general diet

The terms “low calorie” and “reduced portions” should be defined, such as low calorie = 1800 calories. Otherwise, they are not measurable and are confusing for caregivers.

Food Texture and Consistency

The texture prescribed in a diet order should be based upon the individual’s chewing and/or swallowing ability. Foods offered to the individual must follow the texture ordered. Offering foods that are not allowed can result in choking, aspiration, pneumonia or even death.

Mechanical or Mechanical Soft Texture

Food is usually chopped, ground, grated or diced and is of a soft, easy to chew consistency. Size of bites and consistency of food pieces may vary slightly for each individual and should be identified, such as nickel size pieces, dime size pieces or coleslaw consistency. The term “bite size” is not recommended as it means different things to different caregivers. Items such as raw vegetables, peanuts, popcorn or hotdogs are not allowed on a mechanical soft diet.

Pureed Texture

Pureed foods are processed in a food blender to create a smooth consistency. The food is blended until soft and smooth, usually by adding liquids or by using food thickeners to create a specific consistency, such as mashed potato or pudding consistency. Pureed foods should be served separated on a plate so that the individual food flavors remain distinct. Some individuals need the consistency of pudding while others need a looser consistency. Caregivers need to have clear written instructions and demonstrations on how the food needs to be prepared.

Textures of Fluids

Fluids are most commonly thickened with a commercial thickener, such as “Thick it” or “Thick n Easy”. There are four common fluid consistencies:

- **Thin = water, milk, juice, coffee, soft drinks, etc.**
- **Nectar thick = prune juice, apricot and peach nectars, etc.**
- **Honey thick**
- **Pudding thick**

Adapted from: Oregon Department of Human Services; “DHS Developmental Disabilities Nursing Manual”, Accessed 1/3/12
http://www.oregon.gov/DHS/spd/provtools/nursing/ddmanual/all_sections.pdf?ga=t

What kinds of Foods are in each Food Group?

Grains

What foods are in the grain group?

- bulgur (cracked wheat)
- oatmeal
- whole cornmeal
- brown rice



Refined grains have been milled, a process that removes the bran and germ. This is done to give grains a finer texture and improve their shelf life, but it also removes dietary fiber, iron, and many B vitamins. Some examples of refined grain products are:

- white flour
- de-germed cornmeal
- white bread
- white rice

Whole grains:

brown rice
buckwheat
bulgur (cracked wheat)
oatmeal
popcorn

Ready-to-eat breakfast cereals:

whole wheat cereal flakes
muesli
whole grain barley
whole grain cornmeal
whole rye
whole wheat bread
whole wheat crackers
whole wheat pasta
whole wheat sandwich buns and rolls
whole wheat tortillas
wild rice

Refined grains:

cornbread*
corn tortillas*
couscous*
crackers*
flour tortillas*
grits
noodles*

*Pasta**

spaghetti
macaroni

pitas*
pretzels

Ready-to-eat breakfast cereals

corn flakes

white bread
white sandwich buns and rolls
white rice.

Less common whole grains:

amaranth
 millet
 quinoa
 sorghum
 triticale

*Most of these products are made from refined grains. Some are made from whole grains. Check the ingredient list for the words “whole grain” or “whole wheat” to decide if they are made from a whole grain. Some foods are made from a mixture of whole and refined grains.

Some grain products contain significant amounts of bran. Bran provides fiber which is important for health. However, products with added bran or bran alone (e.g., oat bran) are not necessarily whole grain products.

Vegetables

- Eat more dark green veggies
- Eat more orange veggies
- Eat more dry beans and peas

**What foods are in the vegetable group?**

Any vegetable or 100% vegetable juice is a member of the vegetable group. Vegetables may be raw or cooked; fresh, frozen, canned, or dried/dehydrated; and may be whole, cut-up, or mashed.

Vegetables are organized into 5 subgroups, based on their nutrient content. Some commonly eaten vegetables in each subgroup are:

Dark green vegetables

bok choy
 broccoli
 collard greens
 dark green leafy lettuce
 kale
 mesclun
 mustard greens
 romaine lettuce
 spinach
 turnip greens
 watercress

Starchy vegetables

corn
 green peas
 lima beans (green)
 potatoes

Other vegetables

artichokes
 asparagus
 bean sprouts
 beets
 Brussels sprouts

Orange vegetables

acorn squash
 butternut squash
 carrots
 hubbard squash
 pumpkin
 sweet potatoes

Dry beans and peas

black beans
 black-eyed peas
 garbanzo beans (chickpeas)
 kidney beans
 lentils
 lima beans (mature)
 navy beans
 pinto beans
 soy beans
 split peas
 tofu (bean curd made from soybeans)
 white beans

cabbage
 cauliflower
 celery
 cucumbers
 eggplant
 green beans
 green or red peppers
 iceberg (head) lettuce
 mushrooms
 okra
 onions
 parsnips
 tomatoes
 tomato juice
 vegetable juice
 turnips
 wax beans
 zucchini

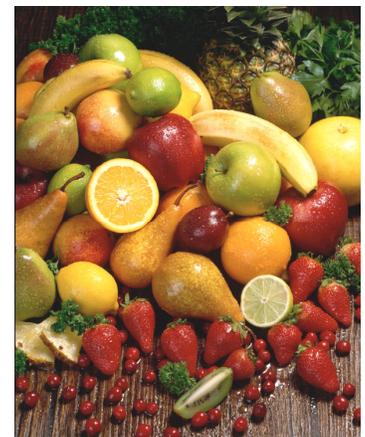
Fruits

- Eat a variety of fruit
- Choose fresh, frozen, canned, or dried fruit
- Go easy on fruit juices

What foods are in the fruit group?

Any fruit or 100% fruit juice counts as part of the fruit group. Fruits may be fresh, canned, frozen, or dried, and may be whole, cut-up, or pureed. Some commonly eaten fruits are:

Apples
 Apricots
 Avocado
 Bananas



Mixed fruits:
 fruit cocktail

Nectarines
 Oranges
 Peaches

Berries:

strawberries
blueberries
raspberries
cherries

Grapefruit
Grapes
Kiwi fruit
Lemons
Limes
Mangoes

Melons:

cantaloupe
honeydew
watermelon

Pears
Papaya
Pineapple
Plums
Prunes
Raisins
Tangerines

100% Fruit juice:

orange
apple
grape
grapefruit

Proteins

Go lean on protein

- Choose low-fat or lean meats and poultry
- Bake it, broil it, or grill it
- Vary your choices - with more fish, beans, peas, nuts and seeds.

What foods are included in the meat, poultry, fish, dry beans, eggs, and nuts (proteins) group?

All foods made from meat, poultry, fish, dry beans or peas, eggs, nuts, and seeds are considered part of this group. Dry beans and peas are part of this group as well as the vegetable group.

Most meat and poultry choices should be lean or low-fat. Fish, nuts, and seeds contain healthy oils, so choose these foods frequently instead of meat or poultry.

Some commonly eaten choices in the Meat and Beans group, with selection tips, are:

Meats*

Lean cuts of:
beef
ham

Dry beans and peas:

black beans
black-eyed peas
chickpeas (garbanzo beans)

Fish*

Finfish such as:
catfish
cod



lamb	falafel	flounder
pork	kidney beans	haddock
veal	lentils	halibut
	lima beans (mature)	herring
Game meats:	navy beans	mackerel
bison	pinto beans	pollock
rabbit	soy beans	porgy
venison	split peas	salmon
	tofu (bean curd made from soy beans)	sea bass
Lean ground meats:	white beans	snapper
beef	<i>bean burgers</i>	swordfish
pork	garden burgers	trout
lamb	veggie burgers	tuna
<i>Lean luncheon meats</i>		Shellfish such as:
<i>Organ meats:</i>	tempeh	clams
liver	texturized vegetable protein (TVP)	crab
giblets		crayfish
	Nuts & seeds*	lobster
Poultry*	almonds	mussels
chicken	cashews	octopus
duck	hazelnuts (filberts)	oysters
goose	mixed nuts	scallops
turkey	peanuts	squid (calamari)
ground chicken and turkey	peanut butter	<u>shrimp</u>
	pecans	
	pistachios	Canned fish such as:
Eggs*	pumpkin seeds	anchovies
chicken eggs	sesame seeds	clams
duck eggs	sunflower seeds	tuna
	walnuts	sardines

***Selection Tips**

Choose lean or low-fat meat and poultry. If higher fat choices are made, such as regular ground beef (75 to 80% lean) or chicken with skin, the fat in the product counts as part of the discretionary calorie allowance.

If solid fat is added in cooking, such as frying chicken in shortening or frying eggs in butter or stick margarine, this also counts as part of the discretionary calorie allowance.

Select fish rich in omega-3 fatty acids such as salmon, trout, and herring, more often.

Liver and other organ meats are high in cholesterol. Egg yolks are also high in cholesterol, but egg whites are cholesterol-free.

Processed meats such as ham, sausage, frankfurters, and luncheon or deli meats have added sodium. Check the ingredients and try to limit sodium intake. Fresh chicken, turkey, and pork that have been enhanced with a salt-containing solution also have added sodium. Check the product label for statements such as “self-basting” or “contains up to ___% of ___”, which mean that a sodium-containing solution has been added to the product.

Sunflower seeds, almonds, and hazelnuts (filberts) are the richest sources of vitamin E in this food group. To help meet vitamin E recommendations, make these your nut and seed choices more often.

Dairy

Get your calcium-rich foods

- Go low-fat or fat-free
If you don't or can't consume milk, choose lactose-free products or other calcium sources.



What foods are included in the milk, yogurt, and cheese (milk) group?

All fluid milk products and many foods made from milk are considered part of this food group. Foods made from milk that retain their calcium content are part of the group, while foods made from milk that have little to no calcium such as cream cheese, cream, and butter, are not. Most milk group choices should be fat-free or low-fat.

Some commonly eaten choices in the milk, yogurt, and cheese group are:

Milk*

All fluid milk:
fat-free (skim)
low fat (1%)
reduced fat (2%)
whole milk

flavored milks:
chocolate
strawberry

Cheese*

Hard natural cheeses:
cheddar
mozzarella
Swiss
parmesan

soft cheeses
ricotta
cottage cheese

lactose reduced milks
lactose free milks

Milk-based desserts*
Puddings made with milk
ice milk
frozen yogurt
ice cream

processed cheeses
American

Yogurt*
All yogurt
Fat-free
low fat
reduced fat
whole milk yogurt

Selection Tips

Choose fat-free or low-fat milk, yogurt, and cheese. If you choose milk or yogurt that is not fat-free or cheese that is not low-fat, the fat counts as part of the **discretionary calorie** allowance. See section below.

If sweetened milk products are chosen (flavored milk, yogurt, drinkable yogurt, desserts), the added sugars also count as part of the **discretionary calorie** allowance.

For those who are lactose intolerant, lactose-free and lower-lactose products are available. These include hard cheeses and yogurt. Also, enzyme preparations can be added to milk to lower the lactose content. **Calcium-fortified foods and beverages such as soy beverages or orange juice may provide calcium, but may not provide the other nutrients found in milk and milk products.**

Discretionary Calories

What are discretionary calories?

You need a certain number of calories to keep your body functioning and provide energy for physical activities. Think of the calories you need for energy like money you have to spend. Each person has a total calorie "budget." This budget can be divided into "essentials" and "extras."

With a financial budget, the essentials are items like rent and food. The extras are things like movies and vacations. In a calorie budget, the "essentials" are the minimum calories required to meet your nutrient needs. By selecting the lowest fat and no-sugar-added forms of foods in each food group you would be making the best nutrient "buys." Depending on the foods you choose, you may be able to spend more calories

than the amount required to meet your nutrient needs. These calories are the “extras” that can be used on luxuries like solid fats, added sugars, and alcohol, or on more food from any food group. These are your “discretionary calories.”

Each person has an allowance for some discretionary calories. But, many people have used up this allowance before lunch-time! Most discretionary calorie allowances are very small, between 100 and 300 calories, especially for those who are not physically active. For many people, the discretionary calorie allowance is totally used by the foods they choose in each food group such as higher fat meats, cheeses, whole milk, or sweetened bakery products.

You can use your discretionary calorie allowance to:

- Eat more foods from any food group than the food guide recommends.
- Eat higher calorie forms of foods - those that contain solid fats or added sugars. Examples are whole milk, cheese, sausage, biscuits, sweetened cereal, and sweetened yogurt.
- Add fats or sweeteners to foods. Examples are sauces, salad dressings, sugar, syrup, and butter.
- Eat or drink items that are mostly fats, caloric sweeteners, and/or alcohol, such as candy, soda, wine, and beer.



For example, assume your calorie budget is 2,000 calories per day. Of these calories, you need to spend at least 1,735 calories for essential nutrients, if you choose foods without added fat and sugar. Then you have 265 discretionary calories left. You may use these on “luxury” versions of the foods in each group, such as higher fat meat or sweetened cereal. Or, you can spend them on sweets, sauces, or beverages. Many people overspend their discretionary calorie allowance, choosing more added fats, sugars, and alcohol than their budget allows.

Source: United States Department of Agriculture, Updated October, 2008.

Activity: Reducing Fat in the Diet

Directions: Write in substitutes that would result in less fat in the diet.

Instead of:	Choose:
Whole milk	_____
Ice cream	_____
Butter, margarine	_____
Regular cheese	_____
French fries, hash browns	_____
Sour cream	_____
Tuna packed in oil	_____
Cooking oil, lard, shortening	_____
Fatty meats	_____
Vegetables in cream or butter sauce	_____
Potato chips	_____

How to Read Food Labels

The labels on canned, packaged and frozen foods tell you what's really in the foods you eat.

Comparing labels will help you choose foods that are low in fat, cholesterol, sodium (salt), and calories. Reading food labels is a big step toward eating with nutrition in mind. Look for the "Nutrition Facts" label on packaged foods.

1. Serving Size

Look at this closely. This is the amount of food in 1 serving. If you eat more, you get more of everything on the label, including fat and cholesterol.

2. Total Fat

This number tells you how much trans fat is in 1 serving. Choose foods with a low number for total fat.

3. Saturated Fat

This number tells you how many grams (g) of saturated fat are in 1 serving. Saturated fat raises your cholesterol most. Look for foods that have little or no saturated fat.

4. Trans Fat

This number tells you how much trans fat is in 1 serving. Trans fat raises your cholesterol just like saturated fat.

5. Cholesterol

This number tells you how much cholesterol is in 1 serving. You should eat less than 300 milligrams (mg) of cholesterol a day.

6. Calories from Fat

This number tells you how many calories from fat are in 1 serving. Look for foods with few calories from fat.

7. % Daily Value

A large number means 1 serving contains a lot of that ingredient. Look for foods that have low numbers for total fat, saturated fat, trans fat, cholesterol and sodium.

8. Sodium

This number tells you how much sodium is in 1 serving. Choose foods with low numbers for sodium. Or look for foods that say Low Sodium or Sodium Free.

9. Dietary Fiber

This number tells you how much fiber is in 1 serving. Look for foods that are high in fiber

Nutrition Facts	
Serving Size 1 cup (240g)	
Servings Per Container 2	
Amount Per Serving	
Calories 100	Calories from Fat 20
% Daily Value*	
Total Fat 2g	3%
Saturated Fat 0g	0%
Trans Fat 0g	
Cholesterol 0mg	0%
Sodium 70mg	3%
Total Carbohydrate 17g	6%
Dietary Fiber 3g	12%
Sugars 5g	
Protein 4g	
Vitamin A 70%	Vitamin C 20%
Calcium 15%	Iron 8%

*Percent Daily Values are based on a 2,000 calorie diet. Your Daily Values may be higher or lower depending on your calorie needs.

Food Label Exercise

Directions: Complete this exercise.

1. What do labels tell you about calories?
2. What, if anything, does the order of ingredients tell you?
3. What did you learn from the label about fat, cholesterol, sodium and fiber?
4. What else can you learn from food labels?

Food Allergies

A food allergy occurs when the body sees the food as abnormal (as it does with bacteria, viruses and toxins). It produces antibodies and histamine. This produces the symptoms of the allergy.

The problem is diagnosed by an allergist who performs tests to check the person's responses to suspect foods. Food allergies are not contagious.

Treatment includes antihistamines, bronchodilators to open tight airways, cortosteroids to reduce the immune response, epinephrine to minimize the allergic response and prevent anaphylaxis (a life threatening condition). People with severe food allergies may carry either an EpiPen or an AnaKit which contain epinephrine to prevent anaphylaxis. It is injected into the person. If an individual in your care demonstrates a severe allergic response, a medical professional should be contacted immediately.

Typical foods that some people are allergic to:

- Fish
- Milk and other dairy products
- Peanuts and peanut oil
- Shellfish, such as shrimp and crab
- Soy tree nuts, such as walnuts
- Wheat
- Whitefish



What are the symptoms?

- Itching in the mouth
- Vomiting
- Diarrhea
- Abdominal distress
- Hives or rash
- Shortness of breath or wheezing
- Reaction can be mild to fatal
- May occur within a few minutes to an hour after eating the food

Cooking Methods

Baking

Besides breads and desserts, you can bake seafood, poultry, lean meat, vegetables and fruits. For baking, place food in a pan or dish surrounded by the hot, dry air of your oven. You may cook the food covered or uncovered. Baking generally doesn't require that you add fat to the food.

Braising

Braising involves browning the ingredient first in a pan on top of the stove, and then slowly cooking it covered with a small quantity of liquid, such as water or broth. In some recipes, the cooking liquid is used afterward to form a flavorful, nutrient-rich sauce.

Roasting

Like baking, but typically at higher temperatures, roasting uses an oven's dry heat to cook the food. You can roast foods on a baking sheet or in a roasting pan. For poultry, seafood and meat, place a rack inside the roasting pan so that the fat in the food can drip away during cooking. In some cases, you may need to baste the food to keep it from drying out.

Sautéing

Sautéing quickly cooks relatively small or thin pieces of food. If you choose a good-quality nonstick pan, you can cook food without using fat. Depending on the recipe, use low-sodium broth, cooking spray or water in place of oil.

Steaming

One of the simplest cooking techniques is steaming food in a perforated basket suspended above simmering liquid. If you use a flavorful liquid or add seasonings to the water, you'll flavor the food as it cooks.

Stir-frying

A traditional Asian method, stir-frying quickly cooks small, uniform-sized pieces of food while they're rapidly stirred in a wok or large nonstick frying pan. You need only a small amount of oil or cooking spray for this cooking method.

Using herbs and spices

Creating meals using spices and herbs is one of the best ways to add color, taste and aroma to foods without adding salt or fat. Choose fresh herbs that look bright and aren't wilted, and add them toward the end of cooking. Add dried herbs in the earlier stages of cooking. When substituting dried for fresh, use about one-half the amount.

Healthy Cooking Activity

This exercise is a guide to cooking healthy meals. Please complete this exercise.

Choices:

Bake

Broil

Boil

Fry

Stir Fry

Steam

Grill

What are the healthiest ways to cook these foods?

- Raw vegetables -
- Meat -
- Canned vegetables -
- Potatoes -

What is the least healthy way to cook foods?

Physical Activity

Another great way to stay healthy is to add physical activity into everyday life. By becoming more physically active, the people you help support will lower their chances of developing many types of illnesses. By lowering the risk for these illnesses, the risk of unplanned hospitalizations also decreases.

You can encourage people to be more physically active and support them in finding out which activities they like best. Some people you help support may need additional assistance as they work to add physical activity into their lives. For example, a person with cerebral palsy or another developmental disability that makes moving difficult may find it hard to include exercise in his or her life. This does not mean the person cannot make healthy lifestyle choices. It just means that he/she will require extra support from you and those around him/her.

For example, you could help this person learn about exercises that can be done while in bed or sitting in a wheelchair. You can support individuals to make choices that add physical activity to their daily lives. In addition to formal exercise plans, you can encourage each person, as much as they are able to:

- Walk or propel their wheelchair instead of asking for transportation help from their support person if the destination is within a reasonable distance
- Ask their support person to park at the far end of parking lots and walk or propel their wheelchair to their destination
- Take the stairs instead of the elevator unless the person uses a wheelchair
- Whenever possible physically move during the day such as getting up to change the television channel instead of using a remote control



Remember to talk to the individual's doctor before they start any new exercise plan. A doctor will be able to tell you which exercises are right for the individuals you support and how to help each person to exercise safely.

Physical Fitness Activities

Physical fitness activities contribute to wellness. Different people like different activities. Here is a list of potential benefits from regular exercise:

- relieves tension and stress
- provides enjoyment and fun
- stimulates the mind
- helps maintain stable weight
- controls appetite
- boosts self-image
- improves muscle tone and strength
- improves flexibility
- lowers blood pressure
- relieves insomnia
- increases good cholesterol (HDL)
- lowers bad cholesterol (LDL)
- reduces the risk of diabetes

An hour long fitness program should employ the 3-2-1 principle. That is, 30 minutes on cardiovascular activity, 20 minutes on strength and 10 minutes on flexibility.

Note: No exercise program should begin without a health checkup and approval by a physician



People with developmental disabilities often do not get enough exercise. Ensuring that individuals receive sufficient exercise is part of the DSP's role. This exercise quiz may give you some ideas on helping the individuals with an exercise program.

Accessed 8/4/11; Florida Developmental Disabilities Council, Inc. "Increasing Wellness and Reducing Secondary Health Conditions for Individuals with Developmental Disabilities."
<http://www.nacdd.org/documents/The%20Fit%20Club.pdf>

Increasing Physical Activity for Older Persons with Developmental Disabilities

As a DSP, you may notice that many older persons with developmental disabilities are now receiving services. The trend toward longer life for all Americans is also true for people with developmental disabilities. As we have noted, research has shown that

many adults with intellectual disabilities are physically inactive. The combination of a low fitness level and health problems associated with aging puts the people at risk for disease, loss of independence and injury. An inactive, or sedentary, lifestyle is a major contributor to these problems.

The University of Chicago Center on Aging has made some recommendations to begin to address exercise for older persons with developmental disabilities. Of course, approval from a physician should be obtained before starting any exercise program. However, there are some simple ways to increase daily activity throughout the day.

These include:

- Changing TV channels manually by getting up and down.
- Taking stairs and park further away from buildings
- Doing stretches while TV shows are on commercial breaks
- Start to walk short distances (five minutes) two or three times a day and increase gradually
- Shooting baskets!

Find ways to keep fitness fun! Motivation will be a challenge for persons that have been sedentary. To do this you can:

Change routines often to avoid boredom.

Take before and after pictures.

Work together with a group of friends who can motivate each other.

Develop motivators that add to the fitness program such as a trip to a park for a walk or to the beach for a swim.

For people who use wheelchairs, encourage activities that use upper body strength as much as possible. Things like weight lifting and swimming may be appropriate.

DD SafetyNet; Accessed 8/11/11

Concerns of Older Adults

Many people with developmental disabilities are living longer than ever before. For the most part, elderly people with developmental disabilities have the same age-related concerns as other older adults. Some of these are:



Risk Factors

decrease in muscular strength

decrease in joint flexibility

decrease in vision

decrease in hearing

Possible Intervention Strategies

strength training exercises, assistive devices (canes, walkers, handrails)

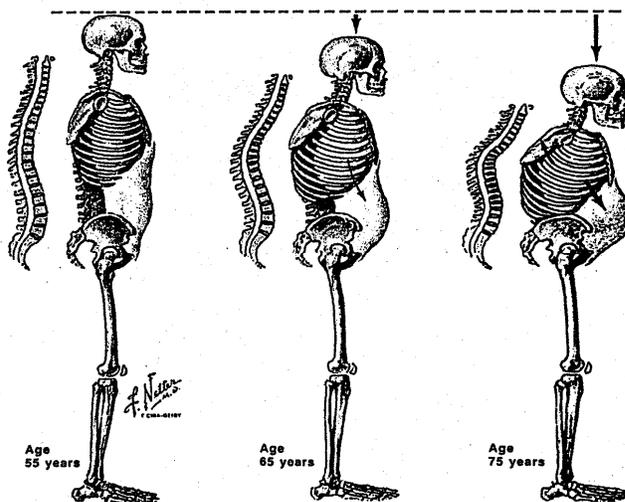
active lifestyles
stretching exercises

increased room lighting, reduced glare, eye glasses, surgical treatments

removal of ear wax, hearing aids

Another health-related issue that comes with age for some people is osteoporosis. Below are pictures of how the spine changes with the disease and factors that increase the risk for developing this condition.

Skeletal Changes with Osteoporosis



Factors That Increase Risk of Osteoporosis & Fractures

Genetic or Medical Factors

Light-colored skin
Previous fractures that occurred easily
Female relatives with osteoporosis
Being thin (especially if you are short)
Chronic diarrhea or surgical removal of part of the stomach or small intestine
Kidney disease with dialysis
Use of thyroid hormone in high doses
Dilantin or aluminum containing antacids
Daily use of cortisone

Lifestyle Factors

High alcohol use
Smoking
Lack of exercise
Lack of Vitamin D from sun, diet or pills
Very high protein diet
High salt diet
Never having borne children
High caffeine use
Not enough calcium in diet

EXERCISE QUIZ

Please fill in the blanks below:

Examples of cardiovascular activity:

Examples of strength training:

Examples of flexibility training:

Recreation Considerations for People with Epilepsy

The following tips are ways that people with epilepsy can help improve their safety during recreational activities:

- When exercising, take frequent breaks, stay cool, and save the greatest exertion for the coolest part of the day.
- Exercise on soft surfaces if you can -- grass, mats, wood chips.
- Review the risks carefully before taking up sports which could put you in danger if you were suddenly unaware of what you were doing.
- Wearing a life vest is a good idea when you are on or close to water.
- Swimming can be safe and fun for everyone, but if you have seizures avoid swimming alone.
- Tell lifeguards and friends you swim with what kind of seizures you have, how to recognize them, and what to do if you have one. Make sure they swim well enough to help if you need it.
- Wear head protection when playing contact sports or when there is an added risk of falling or head injuries.
- If you ski or hike, go with a buddy; you may need someone to get help if you have a seizure in remote areas.
- Consider use of a safety strap and hook when riding the ski lift.



www.epilepsyfoundation.org

Alzheimer's Disease and Physical Activity

The Alzheimer's Association recommends physical activity to possibly preserve cognitive (mental) function for people with Alzheimer's disease. Persons with the disease have many of the same health problems and emotional needs as everybody else and derive the same benefits as their peers with a regular exercise program. In fact, recent studies from Washington University in St. Louis have shown that walking and other forms of aerobic exercise may actually ward off the onset of Alzheimer's disease pathology in the brain.



The easiest, safest, and most readily available physical activity for a person with Alzheimer's disease is walking. It channels a tendency for restlessness and wandering which are characteristic of the disease into a beneficial activity. If possible, combine it with a purposeful activity, such as walking a dog, pushing a person in a wheelchair, walking to the store to buy a newspaper or groceries, or picking up trash in the neighborhood. Many shopping malls have organized "mall walking" programs that offer structure, incentives, T-shirts, and social opportunities, as well as a safe, climate-controlled, stimulating, and traffic-free environment. Such programs are a perfect activity for persons with dementia if they have an activity companion.

Make sure the person with Alzheimer's Disease is wearing a Medic Alert (<http://www.medicalert.org/>: 1-800-432-5378) or Safe Return (<http://www.alz.org/>, 1-800-272-3900) ID bracelet or medallion or has other identifying information on his or her person, in case he or she gets lost when walking alone or if he or she gets separated from a walking partner.

Accessed 8/11/11 "Exercise May reduce Alzheimer's disease brain changes"
www.physorg.com/

Visiting the Doctor

If this is the first visit, schedule a pre-office visit if possible. This gives the individual an opportunity to see the waiting room office, exam rooms and examination equipment in advance. This may help alleviate anxiety if the person seems especially worried.

Preparing for the Visit

Prior to the doctor's appointment explain any procedures that will occur. This will help lessen fear and hopefully make the exam go more smoothly. You can use a variety of teaching methods to help meet the learning needs of the person you help to support. Some methods you might use are:



Verbal Instruction

If a person easily understands verbal explanations, that is all that may be needed.

Pictures

If verbal instructions are not enough, pictures may help. You can even take photographs of the equipment to be used, where the visit will take place and who some of the people are that will be involved.

On Site Visit

Before the visit, arrange a visit to show the person firsthand what the office/exam room looks like and maybe even meet some of the people involved.

Making the Visit

You may be asked to accompany a person to visit the doctor or dentist. Guidelines for things you should do before, during and after the visit are listed below.

- The DSP will need to take information about the individual, including a list of acute and chronic health conditions, current medications (strength and dosage), allergies, immunizations, list of all health care providers, names and telephone number of pharmacy, guardianship status, health insurance information (if applicable), etc. with them to the appointment. This should all be in the person's **health history**.
- Make a list of questions, and concerns. Check with parent or guardian if available. Note any changes in health status.
- Prepare the individual for the visit. Discuss the purpose of the visit and what is expected to happen during the visit, such as blood tests, blood pressure, etc.

- Take something for the individual to do in case there is a long waiting period before seeing the doctor. Discuss with the receptionist how best to schedule the appointment to minimize the wait.
- Provide the doctor with the gathered information at the appropriate time. Return with documentation of what the doctor says (e.g., temperature, blood pressure, diagnosis, what happens next, new or changed prescriptions, next visit, etc.).
- Assist in having the doctor speak directly to the consumer. If the doctor says something the consumer doesn't understand, rephrase it for him/her.
- Explain procedures the doctor is going to do to the consumer before or while it is being done.
- Ask the doctor questions if there is something you do not understand.
- After the visit, ask the consumer if he/she has any questions about the visit and explain what will happen next.
- Make sure the prescription(s) is/are filled.
- Provide information to other authorized persons following the appointment.

Key Elements of a Health History

Whenever a person exhibits unusual symptoms, you may want to check to see if there is a history of this or something related. A place where all relevant medical information is kept is called a health history. Each person must have a documented health history. Key elements are listed below. These elements can help you know what kinds of information you might expect to find in the person's health history.

- Information about past and present illness
- Family history
- History of medications
- Name, address, and telephone number of physicians and dentist
- Name of any other regular medical specialist or healthcare providers and contact information
- Any allergies to medications
- Physician reports
- Results of any laboratory or medical testing done in the past 12 months
- Behavioral incident reports
- Family information, including emergency contacts
- Guardianship information (name, address, and telephone number), as appropriate, including court papers



Visiting the Dentist

As with visiting the doctor, schedule a pre-office visit. This gives the individual an opportunity to see the waiting room office, exam rooms and examination equipment in advance. This may help alleviate anxiety if the individual seems especially worried about the visit. You can even prepare the person for the visit by doing things with the person, such as practicing opening mouth and using a mouth mirror. Talk about the teeth and what the dentist may be doing.



- Take something for the individual to do in case there is a long waiting period before seeing the doctor. Discuss with the receptionist how best to schedule to minimize the wait.
- Provide verbal support to the individual while getting into and out of chair, as needed. Tell the individual when any movements of the chair or light are anticipated.
- Ask the dentist to speak in lay terms to the person, such as cleaning and fixing a broken tooth, rather than scraping and composites.
- Explain procedures the dentist is going to do to the person before or while it is being done.
- Ask the dentist questions if there is something you do not understand.
- Try to anticipate the tolerance threshold of the individual. It is much better to have two short, successful visits than one long visit which results in trauma.
- Make and record information about the next appointment.
- After the visit ask the person if he/she has any questions about the visit.
- Record information about the visit and next appointment in the appropriate place.

When to seek non-routine dental care:

People with developmental disabilities might have some dental issues (described below) that you are not familiar with.

Dental Issues

Periodontal (gum) disease - Affects the tissues and structures surrounding and supporting the teeth. Most dentists and hygienists agree that this may occur at an earlier age in individuals with developmental disabilities. It is not unusual to find

advanced gum disease...swollen, bleeding gums, loose teeth due to bone loss, and gum infection in a young adult with special needs. Malformed or poorly arranged teeth, tooth grinding, poor health and some medications contribute to development of gum disease. It is very important to brush, floss and clean the teeth, gums and tongue daily.

Tube feeding - Individuals who are tube-fed can build up deposits on their teeth more than those who chew food. The reasons for this are not clearly understood. It is very important to brush, rinse and stimulate the mouth area daily of people who are being tube-fed in order to maintain good oral health. Brushing bacteria from the tongue is still necessary to prevent infections, such as thrush. Thrush is a fungus infection that causes a whitish growth and sores in the mouth.

Effects of Medications - Individuals with special needs are frequently prescribed medications to be taken over a long period of time. Some medications reduce the flow of saliva leading to a dry mouth. This promotes tooth decay and cracks in lips. Rinsing the mouth with water after each dose is advised. Aspirin dissolved in the mouth before swallowing provides an acid environment that can lead to decay. Dilantin is widely used to control seizure disorders. Many individuals who receive this drug over an extended period of time will develop enlarged and overgrown gum tissues which make brushing and flossing more difficult and less effective. Some experience gum enlargement. The onset of gum overgrowth most often occurs within the first year of using Dilantin.

Sugar Content of Medications - Liquid medications contain up to 84% sucrose with most having more than 40% sugar content. These are often given before a rest time or at bedtime. When asleep, the decrease in salivary flow does not allow the liquid to wash away. The sugary solution stays in the mouth, leading to tooth decay. If possible, give the medication while the individual is awake and have him/her rinse the mouth or brush immediately after a dose. Also, ask your pharmacist if a sugar-free medication is available.

Dry Mouth - May occur from mouth breathing and medications. Mouthwash containing alcohol may lead to dehydration of an already dry mouth. Offering lots of water will help insure adequate hydration of the body.

Drooling - Excessive drooling is often seen in persons with disabilities who have poor oral-muscular control, not necessarily because of an excessive amount of saliva production. Facial chapping may occur (Occupational Therapy, OT) may reduce the incidence of drooling.

Pouching (food retention in the mouth) - Pouching is a habit found in some persons with developmental disabilities. Storing of food in the cheek or palate may be done to prolong the taste of food or medicine or because of oral-muscular dysfunction. Help avoid pouching by:

- Inspecting the mouth after giving food or medications to remove any remaining material.
- Giving liquid medication, rather than pills.
- Giving medication with fluids to encourage swallowing.
- When a medication can be crushed without adversely affecting the drug's absorption, it can be given along with artificially sweetened applesauce or pudding.

Self Injurious Behavior - Lip biting after taking a local, oral anesthetic may occur in individuals who do not understand the sensation of a local anesthesia. Prevention is not always possible and caregivers must closely watch these individuals. Chronic lip biting can result in large sores requiring the use of antibiotic therapy to prevent secondary infection. If this persists, the dentist may recommend an appliance or even tooth extraction(s) as a remedy. Severe root exposure due to scraping the gum tissue with a fingernail may come from a behavior developed by some individuals. Positive behavior support skills or use of a mouth guard to cover the teeth may be needed to decrease the behavior. Use of a mouth guard would require approval by the agency's Human Rights Committee

Dental Implications of Down syndrome - The tongue may appear large, giving an open mouth appearance. There is evidence that the tongue is actually of normal size but appears large and protruding due to a narrow nasopharynx and enlarged tonsils and adenoids. A high palate becomes a place to pocket food and may be hard for the individual or caregiver to keep clean. Proper care of this area includes frequent brushing. Good oral hygiene is necessary to prevent gum disease. Cardiac abnormalities may require preventative antibiotic treatment before dental treatment.

Canker Sores - Injuries to the mouth, infection, female hormones or stress can also cause individuals with developmental disabilities to have canker sores. These are painful, open sores in the mouth and cheek that can take 7-10 days to heal. The dentist (or doctor) can provide a topical medication (or a prescription for an over-the-counter medication) to ease the pain. People who have canker sores should chew their food slowly and use a soft bristle toothbrush to avoid injury to the inside of the mouth.

Risk Factors - There are a variety of risk factors which can lead to a mouth, teeth or throat problem for any person. There are also additional risk factors for some people with developmental disabilities that call for close observation by caregivers and frequent regular check ups.

Poor habits or techniques of oral hygiene, such as not brushing or flossing correctly or often enough can also lead to difficulties.

- A poor diet, like not eating well-balanced and nutritious meals or frequent snacking on sweets.
- Not seeing a dentist regularly for check ups and professional teeth cleaning.
- Smoking or drinking alcohol to excess. These can damage teeth, gums and other mouth tissues.
- Motor impairments which limit the ability to chew or swallow properly and/or to care for teeth.
- Insensitivity to pain or inability to identify it to a caregiver.
- The side effects of medications such as gums growing onto the teeth.
- A fear of dentists or doctors or the dental examination process.
- Taking liquid medicines (high in sugar) without brushing or rinsing afterwards.

Prevention - There are ways to avoid the special dental concerns of people with developmental disabilities.

- Good dental hygiene, such as brushing and flossing at least twice daily.
- A proper diet and avoiding sugary snacks.
- Use of fluoride (toothpaste, mouthwash) and sealants (plastic covers applied to the molars).
- A dental check-up or cleaning at regular (6-12 month) intervals.
- Keep an accurate and complete health history for the dentist.
- Follow/encourage good eating habits, avoiding sugary and starchy snacks without brushing (or at least rinsing) afterwards.
- Deal effectively with anxiety about dental and medical services where it interferes with being seen and treated properly.
- Assist with eating or modify (cut up, mash) food if the person is prone to eating too quickly, not eating properly or has a poor gag reflex.



Women's Annual Exams

When getting an annual physical, the women you support may receive a pelvic exam. It is important to prepare the individual for this invasive and sometimes embarrassing event. The following guidelines may give you some insight as to the discussion you may want to have before the examination.

The doctor will examine the uterus, cervix, fallopian tubes, and ovaries by inserting a lubricated, gloved fingertip inside the vagina with the other hand on the abdomen.

The whole procedure takes less than five minutes and is virtually painless.

The adolescent girls and women that you are supporting may have menstrual periods every month that may require your assistance. You may need to train the women on the use of sanitary napkins, mini pads, or tampons. The guidelines below may be helpful when you assist with this and to point out areas that need to be mentioned to a doctor.

Note: You may be asked to chart the monthly periods for a particular female if that information is required by a physician.



Module 6, Section 5

DSP NOTEBOOK



Assisting with Activities of Daily Living

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Cognitive disabilities can affect personal care activities in a number of ways. People with cognitive disabilities may have some or all of the following needs:

- Need for consistency in personal care routines.
- Reminders to perform personal care tasks or the consequences of not performing them.
- Encouragement or acceptance when they are unwilling or refuse to do personal care tasks.
- Reminders of how to do activities when they are physically capable of doing them.
- Assistance in making changes to their homes and the spaces they use to complete personal care so they can complete these activities more easily.



Assisting with Meals

There may be times when you will need to assist someone with eating, or may actually be feeding the person who is unable to perform any of the skills necessary to feed themselves.

Please keep the following guidelines in mind when someone needs assisting with eating.

- Wash your hands.
- Be aware of food temperatures
- Allow adequate time for eating – Do not rush
- Interact in a pleasant and appropriate manner
- Feed with small bites – a maximum of one-half of the spoon full
- Begin the meal with something the individual likes the most.
- Alternate between solids and liquids unless the persons prefers otherwise
- Do not force the spoon into the mouth.
- Wait a couple of seconds before removing the spoon.
- Don't use the person's teeth and gums to scrape the food off the spoon or scrape food off the person's lips, chin or cheek with the spoon. Use a napkin.
- Don't pinch anyone's nose shut to get them to open their mouth.
- Never feed anyone nor let them feed themselves while they are in restraints.
- Follow any specialized feeding programs, as written.
- Ask for additional training if you are unfamiliar with the feeding program techniques listed for the person.

Positioning While and After Eating

Some individuals may need to be positioned before, while, and after they eat. If so, these individuals will have specific rules that **MUST** be followed. These rules will be found in the individual service plan for each individual.

In general, positioning is needed to:

- Maintain good body alignment.
- Provide comfort.
- Inhibit abnormal reflex patterns.
- Decrease respiratory problems.



Basic Essentials of Positioning:

- Alert individuals with visual or hearing impairments that you will be positioning them
- Make sure the individual is *relaxed*
- Ensure that the chair fits the individual
- Make sure the body is as upright as possible
- Don't let the head tip back
- Make sure the *feet* are supported
- Reposition *immediately*, if the individual moves out of position
- Keep the individual in as close to an *upright* position as possible for an hour after eating.

Risk Factors for Choking

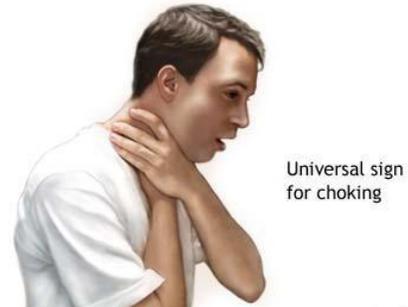
The National Safety Council in 2005 reported that 4,600 people in the United States die annually from choking. A large percentage of these deaths involve persons over 65 years of age. Choking and aspiration are common problems in persons with developmental disabilities.

A number of factors increase an individual's risk of choking, including:

- Neurological and muscular disorders such as cerebral palsy and seizure disorders
- Few or no teeth
- Chewing inadequately

A number of factors increase an individual’s risk of choking, including (continued):

- Eating too rapidly
- Putting too large a portion in one’s mouth
- Talking or being distracted while eating
- Side effects from medications
- Poor posture while eating
- Pica
- Gastroesophageal reflux disease (GERD)
- Difficulty swallowing



High Risk Foods:

In addition to the above risk factors for choking, the most common foods identified as “high risk” for choking include:

- Hotdogs served whole
- Grapes
- Peanut butter
- Peanut butter sandwiches on soft bread
- Dry crumbly foods such as cornbread or rice served without butter, jelly, sauce, etc.
- Dry meats such as ground beef served without sauce, gravy
- Whole, raw vegetables served in large bite sized pieces
- Whole hard fruits like apples or pears
- Candy with large nuts
- Hard nuts

Introduction to Personal Care

The most important aspect of maintaining good health is good *personal hygiene*, also referred to *personal care*. Personal hygiene is keeping the body clean and it helps prevent the spread of germs. For many people, accepting assistance with personal care can be difficult. Even if people have required assistance their whole life long, personal care routines remain very private. People may feel very embarrassed by having someone help them with these most intimate activities even though such assistance is necessary.

Feeling and looking good are important to each person’s emotional and physical well-being. As a DSP, remember that the support you provide in the area of personal care and grooming needs to be completed in a very gentle and respectful way. You are there to assist the person in a caring way, not just complete the task at hand.

When completing personal care routines, always remember to:

- Respect the privacy and dignity of people
- Be sure to keep people safe
- Get to know and respect peoples' personal preferences
- Use a gentle voice
- Get to know the person and recognize what makes them feel comfortable during these routines

Tips on Assisting with Bathing

Bathing means cleaning one's body from head to toe. Providing assistance and support for bathing can be a very sensitive personal care activity for the person supported and the DSP. The DSP needs to know what bathing skills an individual has before beginning to provide assistance and support. It is important that the DSP provide whatever assistance and support is needed to ensure individuals are clean. Remember good personal hygiene is important to promoting good health.

- When assisting a person with bathing, allow the person to do as much as possible during bathing procedures. Check the Individual Service Plan (ISP) to find out how much assistance, prompting and supervision is required. Remember, the person should complete as much of the routine as possible, and the DSP should look for ways to encourage more independence. **Never leave the person unattended in the shower or tub unless it is written that way in the ISP.**
- Always check water temperature
- Check skin for signs of injury or changes in condition
- Always honor personal choice: does the person prefer a bath or a shower, does the person prefer morning or evening showering/bathing, etc. The choice between tub bathing and showering is a matter of personal preference unless it is specified in the ISP or a medical condition exists which dictates which method to use (e.g., open wounds, individual mobility and stability, etc.)
-



- Prepare the area for bathing or showering by making sure the room is comfortable and adjust the temperature if necessary
- Be sure your hands are washed and clean
- Demonstrate and explain correct bathing or showering procedures
- Close windows to prevent drafts
- Close doors and curtains for privacy
- Be prepared with all supplies
- Encourage the person to use the toilet before taking a bath or shower
- Place a mat or small towel on the bathroom floor
- When washing the person, begin with the upper body (face, neck) and then move to lower area (hands, chest, lower body).
- Follow this same “top to bottom” route when drying
- Be sure to remember to check the person for any skin irritations and be sensitive to these while bathing. If you notice any pressure areas, especially if the person is stationary most of the time, be sure to report these. Early warning signs of pressure sores include reddened areas of the person’s skin
- When finished, wash hands and straighten the bath area

Giving a Complete Bed Bath

The following are basic steps/guidelines for giving a complete bed bath:

- Take everything you will need to the bedside before you start the bath (soap, washcloth, wash basin, towels, clean clothing, and bath blanket).
- Explain to the individual what you are going to do.
- Offer the bedpan or urinal.
- Remove the bedspread and regular blanket.
- Leave the individual covered with the top sheet
- Replace the top sheet with the bath blanket without uncovering the individual.
- Undress the individual, keeping him or her covered as much as possible.
- Have, or help, the individual move close to you.
- Use good body mechanics
- Fill the wash basin about 2/3 full of warm water (100°-110°F)
- Wrap the washcloth around your hand
- Wash, rinse, and dry only one part of the body at a time, uncovering only the part of the body that you are washing

- Follow this sequence when washing: around the eyes, rest of face, ears, neck, chest, arms, stomach, legs, back, genital area, buttocks
- Change the water:
 - When it is too soapy, dirty, or cold
 - Before washing the legs
 - Before washing the back
- When washing a limb, place a towel under it
- If you apply skin lotion, make sure it is not cold. (Rub it between your hands to warm it, if necessary)

Giving a Partial Bed Bath

This procedure is identical to that for a complete bed bath except that the following steps are substituted for the sequence of washing and drying body parts:

- Ask the individual to wash the areas that can be reached easily
- Wash your hands and leave the room
- Check back every 5-10 minutes, or when the individual signals you, to see if the individual is finished
- When the individual is finished, change the water and wash your hands again
- Wash the areas the individual could not reach using the same procedure as in a complete bed bath

Health Risks Caused by Poor Bathing Habits:

Poor bathing habits can increase chances of people getting bed sores or some types of infections. Be sure to regularly check the person for skin rashes and infections while bathing. Also, be aware of some common mistakes that are made when bathing others, such as:

- Not drying the body completely after cleaning
- Scrubbing the body too hard or using products that irritate
- Spreading bacteria from one part of the body to another
- Not using moisturizers or other products needed to keep the skin healthy

TOOTH BRUSHING

The following are basic steps/guidelines for assisting people with tooth brushing:

- Wash your hands before and after physically assisting the individual
- Place the head of the toothbrush alongside the teeth with the bristles at 45° angle
- Use a back and forth vibrating motion
- Brush the outer side of each tooth with this technique
- Repeat this technique on the inside surfaces
- For the inside surfaces of the front teeth, tilt the brush vertically and brush up and down using the front part of the brush head
- Brush the tops of the teeth using a back and forth motion
- Brush the tongue and roof of the mouth
- Don't brush too hard
- The best thing to do for bleeding gums is to keep brushing - gently



Toothbrush Care

- Each individual should have his or her own toothbrush
- Toothbrushes should be replaced when they become worn (at least every few months)
- Rinse the toothbrush thoroughly after each use
- Store toothbrushes properly

Flossing

- Cut off an 18 to 24 inch length of floss
- Stretch the floss between the fingers or secure to a floss holder
- Slide the floss between the teeth
- Pull the floss up and down the side surface of the tooth several times
- Repeat this procedure for both sides of each tooth
- When the floss becomes soiled or worn, change to fresh section of floss
- Use thinner floss, if necessary

Denture Care

- Dentures should be removed and cleaned daily, using a toothbrush with a toothpowder or paste
- Avoid extreme water temperatures when cleaning dentures
- Clean dentures over a water-filled sink
- When putting dentures in a denture cup, use lukewarm water and label the cup with the individual's name
- The gums, tongue and roof of the mouth should be brushed gently with a soft toothbrush
- The mouth should be rinsed with warm water
- Encourage individuals to wear his/her dentures (Males should wear their dentures while shaving)

Oral Care

Even individuals who do not have any teeth or dentures need mouth care. This would include at least a daily, gentle brushing and rinsing of the gums, tongue and roof of the mouth.

HAIR GROOMING

Having clean, well-groomed hair is important to everyone! Remember, individuals like different brands of shampoo or conditioner and may have a preferred style. During hair grooming, you may need to keep certain cultural or ethnic considerations in mind. We all like a change every now and then and individuals you help support may also change their minds about how they style their hair. All of these choices should be respected and supported.



- Ask the person if they have a preference about how to style their hair today
- Teach and assist with drying wet hair and applying hair products
- If the hair is long, you may want to divide it into sections before combing or brushing to decrease pulling and tugging on hair
- Teach and assist the individual to comb or brush hair from scalp to ends. Gently brushing from the scalp stimulates circulation. If hair is curly, start at the ends of the hair to assure all tangles are removed before brushing from the scalp to the ends
- Use comb and brush with a gentle touch
- Clean comb and brush regularly
- Encourage the person to look in the mirror when finished styling

Shampooing - How Often?

The general rule is to wash as often as *necessary* to keep the hair *clean*. For some people, washing every 3 or 4 days may be sufficient. Most people require more frequent shampooing.

Caring for African-American Hair or Chemically-Straightened or Curled Hair:

- Do *NOT* wash daily
- After washing and using a moisturizer, chemically-curled hair should be air dried or blown dry. Chemically-straightened hair should be set and curled
- Chemically-curled hair requires a curl activator and moisturized after shampooing and on a daily basis
- The hair may be *covered* during sleep

Haircuts and Styling:

- How an individual's hair is cut or styled should be, as much as possible, the person's *choice*
- Haircuts and hair styling should be done only by *barbers* or *beauticians*

General Guidelines for Shaving

Shaving one's legs, underarms or face is a very personal matter. Cultural differences may be a key to whether an individual shaves or does not shave. For example, in some cultures, women do not shave their legs or underarms. In some cultures, men do not shave their facial hair. It is important to respect these cultural differences.

Shaving tips that can be used for facial, leg or underarm hair

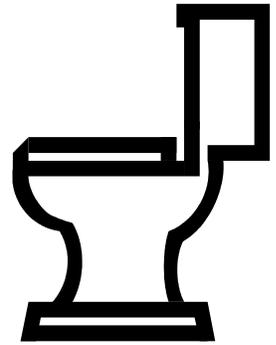
- An electric razor should not be used in the same room where oxygen is used
- Electric razors should not be used around water
- Check all types of razors for chips or rust on the blades
- Always dispose properly of used razor blades
- Use only an individual's personal razor
- Teach and assist the person to check skin for moles, birthmarks or any cuts. If changes in the size, shape or color of a mole or birthmark are noted, the person should be seen by his or her physician
- Supervise the use of razors closely for safe and correct handling before the person shaves independently
- Encourage the person to be as independent as possible
- Teach and assist the individual to rinse the razor often to remove hair and shaving cream so the cutting edge stays clean
- If you are assisting the person with shaving using a non-electric razor, be sure to wear disposable gloves to prevent in the spread of germs
- The area to be shaved should be washed
- In general, shave in the direction the hair grows
- For razor nicks, apply slight pressure with tissue
- Apply aftershave lotion or skin lotion as desired by the individual
- Both electric and safety razors should be cleaned after each use



Assisting with Using the Toilet

In your role as a DSP you may assist people with elimination of their bodily waste. In this role, you will need to understand that safety of the person and preserving their dignity are of utmost importance.

When assisting the person with this bodily function, you should promote independence as much as possible. This allows for greater privacy. However, never leave someone who needs assistance on the toilet outside your range of hearing. If the person should fall or require your help, there would be no way of knowing.



You should become familiar with any adaptive equipment the person you are supporting uses. You should learn about these items before hand and become comfortable with their use.

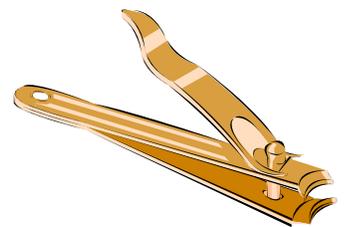
Make sure to follow good hygiene techniques. As always, wear gloves during assistance. Make sure to wash your hands before and after using gloves.

It may also be helpful to have a supply of moist, flushable wipes for use after a bowel movement. Both men and women use these.

When soiling occurs, make sure that the individual is cleaned and clothes are changed as soon as possible. Never feel inside the briefs to check for soiling

Fingernail and Toenail Care

Cleaned and trimmed fingernails and toenails are important for overall health. Germs can collect under the nails. Nails that become too long or are rough and torn can scratch and cut a person's skin and could result in infection. People with diabetes or with thick nails should have their nail care completed by a health care professional. Also, people who like to have nail color applied may need your assistance. As a general rule, fingernails and toenails should be cut about every two weeks.



Nail trimming tips

- Teach and assist the individual how to soak his or her hands or feet in warm water for at least 5 minutes and then to wash hands or feet with soap. Soaking will soften the nails and make them easier to trim.
- Place a towel or paper under fingers or toes when cutting nails
- Use the blunt end of the orange stick to gently push the cuticles back
- File any rough or jagged edges with a nail file or emery board
- Dispose properly of the nail clippings
- Teach and assist the person to clean under the nails; use the pointed end of a wooden orange stick to clean under the nails
- Teach and assist the person to use nail clippers or nail scissors to trim toenails straight across. Fingernails can be trimmed with a slight curve; toenails straight across
- Use a file to shape and smooth the nails
- Never share nail clippers between people to reduce the possibility of transferring diseases
- When caring for a person with diabetes, daily review of the foot is important to check for small cuts and scrapes. People with diabetes are at risk for serious infection without noticing pain

Gait Belts

A gait belt, also referred to as a transfer belt, is a personal adaptive equipment device that when appropriately used enables people in need, the ability to ambulate and/or transfer more easily and safely. Importantly, staff that uses the device properly sustains fewer strain-related injuries. If used appropriately, gait belts are not restrictive devices as they enable people to live up to their physical potential. Failure to employ gait belts on persons, who would otherwise benefit by their use, significantly increases the risk of injury to the individual and the staff who support them.



Gait belts should be considered for all individuals who experience known or suspected musculoskeletal or neuromuscular conditions, and those who are prone to falls or have experienced fall-related injuries secondary to such conditions. Gait belts are prescribed by a physician or a qualified occupational or physical therapist ([59 Ill. Admin Code 120.40](#)).

Although these mobility devices can be helpful in allowing safe mobility or transfer of individuals with unsteady gait, there are times when they should **not** be used.

Website link to Joint Committee on Administrative Rule 59 Ill. Admin Code 120.40:
<http://www.ilga.gov/commission/jcar/admincode/059/059001200A00400R.html>

The following is a partial list of conditions where gait belts should not be used:

- Abdominal surgery, aneurism
- Advanced COPD
- Advanced cardiac disease
- Colostomy
- Fractures, ribs or back
- Pacemaker
- Recent back surgery
- Pain

All staff that support individuals by the use of gait belts must be trained prior to their use. Gait belts may never be used for staff convenience or restrictive purposes. **Gait belts are never used to restrain an individual.** Inappropriate use is considered a violation of one's civil liberties and must be addressed administratively.

Menstrual Care

Menstruation is a normal part of life and the female reproductive cycle. During this time bleeding occurs. Personal hygiene is especially important during menstruation.

To catch the flow of menstrual blood, women use various products. The decision to use tampons or sanitary napkins may rest with the individual, her physician, or the nurse. Be sure to use the products as directed on the box even when flow is light.

Pads: These are used externally. They come in a variety of shapes and thicknesses. Most have adhesive strips to keep them in place inside underpants. Every brand can do the job, but there are a few differences. Some have extra absorbency. Some have side panels to prevent leaking. Don't use a panty liner except on very light days.

Tampons: These are used internally. They are made of absorbent material. The tampon is then compressed in a plastic or cardboard tube which is used to insert the tampon into the vagina.

- ❖ Tampons are encased in two tubes, one smaller than the other. The smaller tube pushes the tampon out. The string is there to pull it out.
- ❖ Avoid deodorized pads or tampons. They are no more effective and they can cause irritation.
- ❖ Tampons/napkins should be changed about every four hours.
- ❖ The least absorbent size of tampon for the amount of flow should be used to avoid getting toxic shock syndrome.
- ❖ Sanitary napkins are easier to use but may cause chapping. They also tend to allow for more odor than tampons. If using sanitary napkins, have the person use the kind with adhesive on the bottom. There are also kinds with wings which also stick to the bottom of underpants, but offer extra protection along the sides.
- ❖ Use the least amount of prompting necessary.
- ❖ Wrap used napkins or tampons in special disposal bag before discarding.

Not changing some products in a timely manner can lead to odor and even deadly infections.

A normal menstrual cycle is about 28 days. In this context “normal” can mean anywhere between 21-35 days. Ovulation generally occurs around the middle of the cycle. Individuals may need extra attention during this time; DSPs should keep in mind:

- Only female staff should assist with this skill.
- If symptoms occur (cramps, etc.), check with the woman’s physician to obtain medications.
- Always obtain permission from the individual and discuss what you are going to do when you do it.
- The flow can last from 3-8 days. It is usually the heaviest on the second and third days.
- Stress and pregnancy can cause skipped cycles.
- Some women have cramps or other problems during or before their periods. They may feel depressed or grouchy. Their breasts may become sore and tender. They may retain water so their ankles and fingers get puffy.
- Douching is not recommended unless a doctor instructs the individual to do so.

- Report any unusual condition. This would include such things as:
 1. Unusually ***heavy*** flow
 2. Unusual ***color or odor***
 3. Presence of large or unusual ***clots***

CLOTHING

Individuals' clothing should be:

- In good repair
- Well-fitting
- Clean
- Age appropriate
- Appropriate for the weather
- Appropriate for the activity planned
- Matching
- As much as possible, the individual's choice



Some content in this section has been adapted from the following: Providing Residential Services in Community Settings: A Training Guide Michigan Department of Human Services, accessed 10/31/11 link: www.michigan.gov/afchfa

Positive Feedback Exercise

Positive feedback is an important part of assisting with activities of daily living. Words of encouragement are important when providing supports. Please list as many ways as you can think of to say "good job". Then compare your list with the one on the next page.

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____

Suggested ways to say "Good Job" are listed below:

1. Excellent!

That's right!	Fabulous!
I'm proud of the way you worked today.	Now you have the hang of it.
You must have been practicing!	Good for you.
Perfect!	Good job, (name of individual)
Nice going.	You figured that out fast.
That's the best ever.	You remembered!
Fine job!	I've never seen anyone do it better.
Good for you!	I couldn't have done it better myself.
I couldn't have done it better myself.	Keep working on it, you're getting better.
That's much better.	Great job!
That's coming along nicely.	Not bad!
You are very good at that.	You make my job fun.
That's good.	You make it look easy.
Now you have it!	Exactly right!
Good work!	Super job!
Wow!	You are learning fast.
You were really working hard today.	You're really improving.
That's the right way to do it!	You did very well today.
That's quite an improvement.	You've got that down pat.
You haven't missed a thing.	Nothing can stop you now!
Tremendous!	That was first class work.
Keep up the good work!	That's much better.
I'm very proud of you.	Cool job!
That kind of work makes me happy.	You haven't missed a thing.
Good going!	That's right!
That's better than ever.	What a good job you did.
You're doing beautifully.	You did great.
You are really learning a lot.	You are so smart.
Way to go!	You're doing great.
Wonderful!	Good job.
Keep on trying.	That's great.
Sensational!	You're really fast today.

It may be necessary to assist individuals with bathing/showering, shaving, hair and nail care and other grooming and daily care activities. The forms on the next few pages can be used as **guidelines** for these activities. While assisting the person, it is important to provide continuous support which fosters greater independence.

OJT Activity #49 Hair Grooming

Attention:

- Allow for personal choice
- Use only personal comb or brush
- Combs and bristles can be sharp
- Encourage independence
- Explain what you are doing while you are doing it

Equipment needed:

Personal comb and/or brush
 Mirror
 Personal hair products

Steps	Partner Check	Instructor Check
Identify the individual who may need assistance with hair grooming.	<input type="checkbox"/>	<input type="checkbox"/>
Ask permission to assist and explain what you will be doing.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist with drying wet hair with dryer and applying gels, hair spray.	<input type="checkbox"/>	<input type="checkbox"/>
Assemble tools to be used (comb, brush, gel, mousse, curling iron, etc.)	<input type="checkbox"/>	<input type="checkbox"/>
Determine hairstyle preference of the individual.	<input type="checkbox"/>	<input type="checkbox"/>
Follow the steps necessary to groom the individual's hair.	<input type="checkbox"/>	<input type="checkbox"/>
Encourage individual to look into mirror when finished styling.	<input type="checkbox"/>	<input type="checkbox"/>
Compliment individual, as appropriate.	<input type="checkbox"/>	<input type="checkbox"/>
Assist individual with returning tools used to proper storage area.	<input type="checkbox"/>	<input type="checkbox"/>

OJT Activity #23 Testing Water Temperature

Part of your job will be to verify that the individuals' water temperature does not exceed 110° or is below 100°.

Attention: Public Health rules indicate that water temperature be no more than 110°.

1. Measure the hot water temperature prior to heavy use, or at least one hour after, so the hot water heater has time to recover and heat to its set temperature.
2. To ensure accuracy in measuring water temperature, follow the instructions for the specific thermometer used by your agency.

Equipment needed:

Bowl or cup

Water testing thermometer

Hot water from the tap

Steps	Partner Check	Instructor Check
Run the hot water for a sufficient amount of time to ensure it is at its hottest temperature.	<input type="checkbox"/>	<input type="checkbox"/>
Fill a bowl or cup with hot water.	<input type="checkbox"/>	<input type="checkbox"/>
Immediately immerse the bulb end of the thermometer completely into the contained water.	<input type="checkbox"/>	<input type="checkbox"/>
Leave the thermometer in the water 30-60 seconds.	<input type="checkbox"/>	<input type="checkbox"/>
Accurately read the thermometer. (Follow the instructions on individual thermometer packages)	<input type="checkbox"/>	<input type="checkbox"/>
Record the temperature in the designated log.	<input type="checkbox"/>	<input type="checkbox"/>
Report temperatures higher than 110 or lower than 100 to the supervisor.	<input type="checkbox"/>	<input type="checkbox"/>

OJT Activity #52 Shaving

Attention: Shaving steps can be used for facial, leg or underarm hair.

- Do not use electric razor in same room where oxygen is used or around water.
- Check all types of razors for chips or rust on blades.
- Discard used razor blades when finished.
- Use only person's personal razor.
- Supervise use of razors closely for safe and correct handling before individual shaves independently.
- Encourage individuals to do as much for themselves as they can.
- Honor cultural choices regarding whether or not to shave.
- Always explain what you will be doing with individual, ask permission and discuss steps as you are doing them.

Equipment needed:

Personal electric or other style razor
 Shaving cream or aftershave lotion
 Personal towel
 Sink
 Mirror

Steps	Partner Check	Instructor Check
Identify appropriate individual.	<input type="checkbox"/>	<input type="checkbox"/>
Gather needed equipment. Use only the individual's personal shaver.	<input type="checkbox"/>	<input type="checkbox"/>
Ask permission and explain what you will be doing with the individual.	<input type="checkbox"/>	<input type="checkbox"/>
Honor cultural choices, if any.	<input type="checkbox"/>	<input type="checkbox"/>
Use disposable gloves.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist individual to check skin for moles, birthmarks, or cuts. Avoid injuring those areas.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist individual to plug in shaver and turn it on (away from water source).	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist individual to use mirror when shaving face, neck or underarms.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist individual to use gentle, even pressure while moving the shaver over skin.	<input type="checkbox"/>	<input type="checkbox"/>

Steps	Partner Check	Instructor Check
Teach or assist individual to use fingers to determine missed hairs.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist individual to turn off shaver, unplug and clean hair from blades.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist individual to apply aftershave or skin lotion, as appropriate.	<input type="checkbox"/>	<input type="checkbox"/>
Compliment individual, as appropriate.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist individual to wash hands after shaving.	<input type="checkbox"/>	<input type="checkbox"/>
Discard gloves.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist individual to appropriately store shaving items.	<input type="checkbox"/>	<input type="checkbox"/>

OJT Activity #26 Oral Hygiene

Attention: Brushing should be done at least twice a day, flossing once a day.

- Check inside of mouth for redness, gum swelling, loose teeth or unusual odor.
- Report any changes in individual's mouth to dentist.
- Disposable gloves and protective eyeglasses are recommended for DSP.
- Encourage individual to do as much as he/she can.
- Review dentist's recommendations for individual to determine any special issues, such as toothpaste or toothbrush type.
- Wash your hands before assisting individual.
- Enable individual to use tooth brushing and flossing aids if the individual does not have good hand or finger control. Adjust procedures as necessary.
- If the individual has braces or bridges, use a floss threader to get floss under the wires.
- If individual has no teeth, gums should still be brushed as recommended by speech therapist or oral hygienist.
- Consult with individual's dentist for special procedures or assistive devices for mouth care.
- Always explain what you will be doing with individual, ask permission, and discuss the steps as you are doing them.

Equipment needed:

Personal toothbrush and toothpaste
 Sink and fresh water
 Personal towel
 Disposable gloves
 Personal dental floss
 Mouthwash (choice of individual)
 Clean glass for rinsing

Steps	Partner Check	Instructor Check
Assemble materials (toothbrush, toothpaste, cup of water, disposable gloves and hand towel).	<input type="checkbox"/>	<input type="checkbox"/>
Greet the individual	<input type="checkbox"/>	<input type="checkbox"/>
Explain to the individual how you will be assisting him/her in brushing their teeth.	<input type="checkbox"/>	<input type="checkbox"/>
Wash your hands and put on disposable gloves.	<input type="checkbox"/>	<input type="checkbox"/>
Rinse the toothbrush and apply toothpaste.	<input type="checkbox"/>	<input type="checkbox"/>

Steps	Partner Check	Instructor Check
Place the head of the toothbrush alongside the teeth at a 45 degree angle.	<input type="checkbox"/>	<input type="checkbox"/>
Move the toothbrush back and forth using a gentle "vibrating" motion.	<input type="checkbox"/>	<input type="checkbox"/>
Brush the outer side of each tooth, both uppers and lowers.	<input type="checkbox"/>	<input type="checkbox"/>
Continue this technique on the inside surfaces of the teeth.	<input type="checkbox"/>	<input type="checkbox"/>
For the inside surfaces of the front teeth, tilt the brush vertically and brush up and down using the front of the brush.	<input type="checkbox"/>	<input type="checkbox"/>
Brush the chewing surfaces using a back and forth motion parallel to the tooth line.	<input type="checkbox"/>	<input type="checkbox"/>
Brush the tongue and the roof of the mouth.	<input type="checkbox"/>	<input type="checkbox"/>
Ask the individual to rinse his/her mouth with water.	<input type="checkbox"/>	<input type="checkbox"/>
Ask the individual to wipe his/her face.	<input type="checkbox"/>	<input type="checkbox"/>
Thank the individual for his/her cooperation.	<input type="checkbox"/>	<input type="checkbox"/>
Remove gloves and wash hands.	<input type="checkbox"/>	<input type="checkbox"/>
Return materials to their proper place.	<input type="checkbox"/>	<input type="checkbox"/>

OJT Activity #53 Teaching Hand Washing

Attention: Killing germs is an important reason to teach frequent hand washing. Proper hand washing kills germs that can spread illness and infections.

Use as little prompting as possible.

Check that hands are washed before and after appropriate activities.

Use the method appropriate for the individual which allows him/her to wash for the recommended time (20 seconds). Examples are singing a particular song, using a clock with second hand, counting, etc.

Always explain what you will be doing with individual, ask permission, and discuss steps as you are doing them.

Equipment needed:

Sink

Soap

Paper towels

Steps	Partner Check	Instructor Check
Choose an appropriate individual.	<input type="checkbox"/>	<input type="checkbox"/>
Ask permission and explain what you will be doing with the individual.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to turn on water to lukewarm temperature.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to push up watch/bracelets so they are as high as possible.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to apply soap to hands and work to a lather.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to wash around and under rings.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to wash and rinse hands for a total of 20 seconds.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist individual to dry hands from the wrist down with a paper towel.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to discard paper towel.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to use a different towel to turn off the water.	<input type="checkbox"/>	<input type="checkbox"/>
Compliment and thank the individual.	<input type="checkbox"/>	<input type="checkbox"/>

OJT Activity #54 Changing Bed Sheets

Attention: A well-made bed offers both comfort and safety. It is an important contribution to the well-being of the individual.

- Making one's own bed helps promote independence.
- Always explain what you will be doing with the individual, seek permission, and explain what is being done while doing it.
- Always hold linen away from your body to reduce contamination.

Equipment needed:

Sheets (top and bottom)
Pillowcase
Blanket
Bedsread

Steps	Partner Check	Instructor Check
Choose an appropriate individual whose bed sheets need to be changed.	<input type="checkbox"/>	<input type="checkbox"/>
Ask permission and explain what you will be doing with the individual.	<input type="checkbox"/>	<input type="checkbox"/>
Use disposable gloves.	<input type="checkbox"/>	<input type="checkbox"/>
If bed is adjustable, adjust height to proper position.	<input type="checkbox"/>	<input type="checkbox"/>
Remove pillowcase; place pillow on chair.	<input type="checkbox"/>	<input type="checkbox"/>
Loosen linen, fold inward, remove from bed, and put in laundry.	<input type="checkbox"/>	<input type="checkbox"/>
Sanitize mattress if it is hospital grade/waterproof.	<input type="checkbox"/>	<input type="checkbox"/>
Take off and discard gloves and wash hands.	<input type="checkbox"/>	<input type="checkbox"/>
Align mattress on bedspring.	<input type="checkbox"/>	<input type="checkbox"/>
Place bottom sheet evenly at foot of mattress.	<input type="checkbox"/>	<input type="checkbox"/>
Tuck in.	<input type="checkbox"/>	<input type="checkbox"/>
Place blanket evenly on bed and tuck in.	<input type="checkbox"/>	<input type="checkbox"/>

Steps	Partner Check	Instructor Check
Place bedspread evenly on bed and tuck in, if appropriate.	<input type="checkbox"/>	<input type="checkbox"/>
Re-adjust height of bed, as needed.	<input type="checkbox"/>	<input type="checkbox"/>
Wash hands.	<input type="checkbox"/>	<input type="checkbox"/>
Compliment and thank the individual.	<input type="checkbox"/>	<input type="checkbox"/>

OJT Activity #25 Assisting an Individual with Bathing

Attention: When assisting with bathing or showering:

- Ensure that the tub/shower has been disinfected before using.
- Check the water temperature using thermometer. It should be no more than 110°.
- Verify that bathroom is warm enough.
- Inspect skin for signs of injury or changes in condition.
- Provide privacy and warmth for the individual.
- Use a clean washcloth. Put in laundry after use.
- Help bathe from top (hair, face) down.
- Encourage the individual to do as much as s/he can for him/herself.
- Be prepared with all supplies.
- Wash your hands before beginning.
- Do not leave an individual with epilepsy alone in the tub.
- Always explain what you will be doing with individual, ask permission and discuss steps as you are doing them.
- Use disposable gloves and change gloves from one bath/shower to the next.
- Disinfect the tub/shower for the next person's use.

Equipment needed:

- Washcloth
- Soap
- Toiletries, as preferred by consumer

Individuals should be allowed to bathe with as much independence as possible. The DSP should ensure that the individual (who needs assistance with bathing) is never left alone during a bath. Privacy can be provided by pulling a shower curtain or turning your back on the individual.

Steps	Partner Check	Instructor Check
Identify an individual who needs to take a tub bath.	<input type="checkbox"/>	<input type="checkbox"/>
Assemble materials.	<input type="checkbox"/>	<input type="checkbox"/>
Greet the individual.	<input type="checkbox"/>	<input type="checkbox"/>
Provide for the individual's privacy.	<input type="checkbox"/>	<input type="checkbox"/>
Explain to the individual how you will be assisting him/her with their bath.	<input type="checkbox"/>	<input type="checkbox"/>
Wash your hands and put on disposable gloves.	<input type="checkbox"/>	<input type="checkbox"/>

Steps	Partner Check	Instructor Check
Fill the bath tub 1/4 to 1/2 full with warm water.	<input type="checkbox"/>	<input type="checkbox"/>
* Ensure that the water is not too hot.	<input type="checkbox"/>	<input type="checkbox"/>
Assist the individual with removing his/her clothes.	<input type="checkbox"/>	<input type="checkbox"/>
Assist the individual into the bath tub.	<input type="checkbox"/>	<input type="checkbox"/>
Wet hair thoroughly.	<input type="checkbox"/>	<input type="checkbox"/>
Apply a small amount of shampoo to his/her hair.	<input type="checkbox"/>	<input type="checkbox"/>
Massage the scalp to create a lather.	<input type="checkbox"/>	<input type="checkbox"/>
Rinse well with a cup or removable shower head.	<input type="checkbox"/>	<input type="checkbox"/>
Assist the individual in holding his/her head backward or forward to prevent shampoo from going into the eyes. (You may also cover eyes with a wash cloth)	<input type="checkbox"/>	<input type="checkbox"/>
Begin washing the individual's body with soap and water. (Pay special attention to areas where two skin surfaces touch)	<input type="checkbox"/>	<input type="checkbox"/>
Rinse thoroughly.	<input type="checkbox"/>	<input type="checkbox"/>
Assist the individual out of the tub.	<input type="checkbox"/>	<input type="checkbox"/>
Assist the individual in drying off, using a patting motion.	<input type="checkbox"/>	<input type="checkbox"/>
Assist the individual in putting on clean clothing and slippers.	<input type="checkbox"/>	<input type="checkbox"/>
Assist the individual in brushing hair.	<input type="checkbox"/>	<input type="checkbox"/>
Thank the individual for his/her cooperation.	<input type="checkbox"/>	<input type="checkbox"/>
Remove gloves and wash your hands.	<input type="checkbox"/>	<input type="checkbox"/>
Assist the individual with returning materials to their proper place.	<input type="checkbox"/>	<input type="checkbox"/>
Sanitize the bath tub for the next individual.	<input type="checkbox"/>	<input type="checkbox"/>

Hot water coming out of the faucet should be between 100 and 100 degrees Fahrenheit. Report the temperatures lower than 100 F and higher than 110 F to the supervisor. Do not expose individuals to water 110 F and above. Temperatures about 110 F can cause scalding and could result in death.

OJT ACTIVITY #50 Cleaning and Trimming Nails

Attention: When assisting with cleaning and trimming nails:

Equipment needed:

- Personal nail clippers or nail scissors
- Personal cuticle stick
- Emery board
- Container for water
- Soap and water
- Personal towel
- Personal emery board or nail file

Steps	Partner Check	Instructor Check
Gather needed equipment.	<input type="checkbox"/>	<input type="checkbox"/>
Choose an appropriate individual.	<input type="checkbox"/>	<input type="checkbox"/>
Ask permission and explain what you will be doing with the individual.	<input type="checkbox"/>	<input type="checkbox"/>
Put on disposable gloves.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to soak hands or feet in warm water for at least 5 minutes.	<input type="checkbox"/>	<input type="checkbox"/>
Wash your hands and put on disposable gloves.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to push nail cuticle back with cuticle stick.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to clean under nails with cuticle stick or nail clipper.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to use nail clippers or nail scissors to trim toenails straight across. Fingernails may be trimmed with a slight curve. Take care not to hurt the individual.	<input type="checkbox"/>	<input type="checkbox"/>
Use emery board or nail file to shape and smooth nails.	<input type="checkbox"/>	<input type="checkbox"/>
Dispose of nail clippings properly.	<input type="checkbox"/>	<input type="checkbox"/>

NOTE: Understand any medical conditions which would directly affect this activity, such as Diabetes.

OJT Activity #55 Shampooing Hair

Attention: When assisting with hair washing:

- Be sure the water temperature is no more than 110°.
- Wash hair in designated area.
- Be sure to wipe up any water that goes on floor.
- Use the least amount of prompting necessary.
- Seek permission and discuss what you are doing as you do it.
- Take care to prevent water from entering individual's ears.
- Choice of shampoo/conditioner is the choice of the individual or his/her doctor.
- Disposable gloves should be worn by the DSP.
- Examine scalp for problems. Inform individual's physician if itching, flaking, head lice, sores or other problems are detected. Follow physician's instructions.
- Shampooing should occur as often as necessary to look good and be odor-free.

Equipment needed:

Shampoo

Conditioner

Towel

Blow dryer or hair dryer

Steps	Partner Check	Instructor Check
Choose an appropriate individual who needs their hair shampooed.	<input type="checkbox"/>	<input type="checkbox"/>
Ask permission and explain what you will be doing with the individual.	<input type="checkbox"/>	<input type="checkbox"/>
Use disposable gloves.	<input type="checkbox"/>	<input type="checkbox"/>
Gather equipment.	<input type="checkbox"/>	<input type="checkbox"/>
Provide for privacy for individual.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to wet hair thoroughly using warm or cool water.	<input type="checkbox"/>	<input type="checkbox"/>
Apply small amount of shampoo to palm of hand and rub hands together.	<input type="checkbox"/>	<input type="checkbox"/>
Apply shampoo to all parts of hair with both hands.	<input type="checkbox"/>	<input type="checkbox"/>

Steps	Partner Check	Instructor Check
Teach or assist the individual to clean the scalp and distribute the suds throughout the hair.	<input type="checkbox"/>	<input type="checkbox"/>
Examine scalp for problems. Inform nurse if itching, flaking, head lice, sores or other problems are detected.	<input type="checkbox"/>	<input type="checkbox"/>
Follow nurse's instructions. Be careful not to get shampoo in the eyes; have individual to close eyes or use a wash cloth.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to rinse hair thoroughly.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to apply conditioner to palm of hand and rub hands together.	<input type="checkbox"/>	<input type="checkbox"/>
Apply conditioner to all parts of hair with both hands.	<input type="checkbox"/>	<input type="checkbox"/>
Leave conditioner on hair for the amount of time recommended on the label.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to rinse hair thoroughly.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to wrap and dry hair with a clean towel.	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to blow dry/set hair or use curling iron if it is the individual's choice.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to style hair in an age-appropriate style per individual's choice.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual in applying gel/mousse, etc. per individual's choice.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to return materials to their proper storage place.	<input type="checkbox"/>	<input type="checkbox"/>

OJT Activity #56 Denture Care

Equipment needed:

Disposable gloves
 Tooth/denture brush
 Denture cleaner
 Denture cup
 Soft brush

Steps	Partner Check	Instructor Check
Choose an appropriate individual who has dentures.	<input type="checkbox"/>	<input type="checkbox"/>
Ask permission and explain what you will be doing with the individual.	<input type="checkbox"/>	<input type="checkbox"/>
Gather individual's equipment.	<input type="checkbox"/>	<input type="checkbox"/>
Use disposable gloves.	<input type="checkbox"/>	<input type="checkbox"/>
Provide for individual's privacy.	<input type="checkbox"/>	<input type="checkbox"/>
Pad sink with washcloths in case dentures are dropped.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to remove top and/or bottom dentures from the mouth.	<input type="checkbox"/>	<input type="checkbox"/>
Loosen upper plate by placing first finger on roof of plate and thumb over outer gum and gently release.	<input type="checkbox"/>	<input type="checkbox"/>
Loosen lower plate by placing finger inside lower plate and thumb on outer gum and gently release.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to put dentures in cup with lukewarm water.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to put denture cleaner on tooth/denture brush.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to clean dentures with tooth/denture brush. Hold the dentures firmly as they are cleaned.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to rinse dentures and storage cup.	<input type="checkbox"/>	<input type="checkbox"/>
Put dentures in empty cup.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to rinse mouth with water and/or mouthwash.	<input type="checkbox"/>	<input type="checkbox"/>

Steps	Partner Check	Instructor Check
Teach or assist the individual to use a soft brush to clean the mouth and tongue while observing the condition of the mouth, gums, and lips.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to apply denture adhesive to the dentures.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to insert the dentures into the mouth, pressing gently, but firmly in place.	<input type="checkbox"/>	<input type="checkbox"/>
Teach or assist the individual to return equipment to proper storage place.	<input type="checkbox"/>	<input type="checkbox"/>
Remove and dispose gloves.	<input type="checkbox"/>	<input type="checkbox"/>
Wash hands.	<input type="checkbox"/>	<input type="checkbox"/>
Thank the individual for their cooperation.	<input type="checkbox"/>	<input type="checkbox"/>



Environmental And Individual Safety



Module 6, Section 6

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Injury Prevention Procedures

Some persons with developmental disabilities are more vulnerable to injuries than people in the general population. When necessary precautions are not taken, it can be devastating to the health and well-being of a person you support, for the home in which he/she lives, or for the agency that provides services. Each year, thousands of accidents occur, some fatal, that could have been prevented by taking specific precautions. It is the responsibility of the DSP to ensure that appropriate precautions are taken based upon the needs of the individual.



More people are injured at home than anywhere else. Most accidents can be prevented though. Taking basic precautions in the home and making sure people are aware of and follow safety procedures can prevent unnecessary risks and injuries.

The most common kinds of household accidents are:

- poisoning, suffocation, or choking from putting foreign items in mouth or nose;
- People falling or objects falling on them
- Misuse or carelessness with tools, knives or chemicals
- Scalds and burns from heat or fire

Why accidents occur?

- People are stressed, hurried, or upset.
- People are distracted, absentminded or negligent.
- People are mentally incapacitated by illness, fatigue, drugs or alcohol, or disability.
- People with mental disabilities are unsupervised
- People are careless or irresponsible.

Preventing Falls

- Make sure carpets and rugs are tacked down and secure.
- Make sure slick floors are dry. Attend quickly to leaks or spills that make floors slippery. Tack down safety mats in areas that are often wet and slippery, such as entry ways, kitchen and bathroom floors. When floors are waxed or mopped, make sure everyone knows.
- Make sure showers and bath tubs have safety mats and/or railings, especially for older adults and people with physical disabilities

- Make sure steps and sidewalks are routinely cleared and salted if you live in a climate where snow and ice are common in winter.
- Make sure you and the people to whom you provide supports use a safe stepladder instead of a chair or stool when getting items from high shelves or cupboards

Preventing Shocks and Electrocutation

- Make sure the people to whom you provide supports are aware of potential dangers in using small and large electrical appliances. For example, they should know not to use radios or hair dryers near water, and not to use electric appliances with wet or damp switches, heating elements, or motors.

Preventing Burns and Scalds

- Make sure heaters and radiators are never close to flammable objects such as draperies or bedclothes. Ensure that the people who live in the home and use space heaters or electric blankets are able to regulate temperatures and turn them off when they leave the room.
- Be certain that the water temperature in the house is at a safe level and that all of the people who live there can mix hot and cold water to the correct temperature. If they are unable to do so, then ensure that the water temperature does not exceed 110 degrees.

Preventing Poisoning or Chemical Accidents

If anyone in the home where you work has specific behavioral characteristics that put them at risk of poisoning or accidental injury, make sure the home has a policy and procedure for keeping harmful chemicals (e.g., cleaning supplies, gasoline) and objects (e.g., knives, baseball bats, ladders) secure. Be certain that you know this procedure.

Preventing Injuries Caused by Tools and Household Items

- Make sure people who use tools for any reason are aware of and follow good safety habits, such as wearing appropriate safety gear and goggles when necessary.
- Make sure tools are put away when not in use. This includes garden tools, mowers, and other items used outside.
- Make sure people who prepare their own food are aware of and follow good safety habits, such as using oven mitts, never leaving ovens or ranges unattended when they are on, keeping flammable items (including clothing) away from the range, and using appropriate cookware.
- Ensure that sharp objects such as knives, scissors, fireplace utensils and other potentially dangerous utensils are stored securely and used safely. If the people you support are considered at risk of hurting themselves or others with these items

they should be kept in a place where they are not readily accessible. However, remember that restricting access to these items should only occur if the individuals are clearly at risk of harm.

Know the Person's Risk Management Plan

Be aware of all habits and potential behaviors of the adults or children in the home that can present dangers such as:

- Self abuse.
- Lighting fires.
- Throwing objects.

Ensure proper supervision is provided based on the needs of the people you support. Do not leave people unsupervised.

Teach Safety By:

- Modeling appropriate and safe behavior
- Using every opportunity to show, tell and demonstrate to everyone in the household why something poses a risk and what they can and should do to prevent the risk.
- Providing positive feedback to people each time you observe them engaging in safe behavior.

A Home Safety Check

Conduct a safety check at the home in which you work. You can do this by conducting an inventory of potential hazards and using the following information as a guide for safety precautions that should be present.

Kitchen

- A smoke alarm with silence button
- A fire extinguisher
- Scatter rugs that have nonslip backings or that are attached with pads or double-faced tape
- Safety latches on cabinets that contain cleaning supplies
- Electrical outlets that are fitted with ground-fault circuit interrupters
- Individual shut-off valves for each gas appliance
- Short, heavy-duty extension cords for appliances
- A range hood or vent kept free of built-up grease
- Radios, televisions and small electric appliances located safely away from the sink
- A list of emergency numbers located prominently near the phone

Living, Dining, and Family Rooms

- A carbon monoxide alarm
- Safety plugs on unused outlets
- Window treatments free of dangling cords
- Extension cords placed safely away from areas where they could be stepped on or tripped over

Baths

- An up-to-date first-aid kit
- Anti-scald shower/tub water controls
- Grab bars within easy reach in each tub and shower stall
- Shatter-resistant faucet parts with no sharp edges
- A night light
- Safety latches on cabinets containing dangerous materials
- An electrical outlet positioned away from water fixtures and fitted with a ground-fault circuit interrupter

Furnace Room

- A smoke alarm.
- A carbon monoxide alarm at least 15 - 20 feet from furnace.
- A fire extinguisher.

Bedrooms

- A smoke alarm in every main hallway and every level of the home
- A carbon monoxide alarm in or near each bedroom
- A night light
- A fire-escape ladder if bedrooms are above main levels
- A fire extinguisher
- A list of emergency numbers posted near any telephones
- A rechargeable flashlight

Adapted from: http://www.firstalert.com/safety_checklist.php

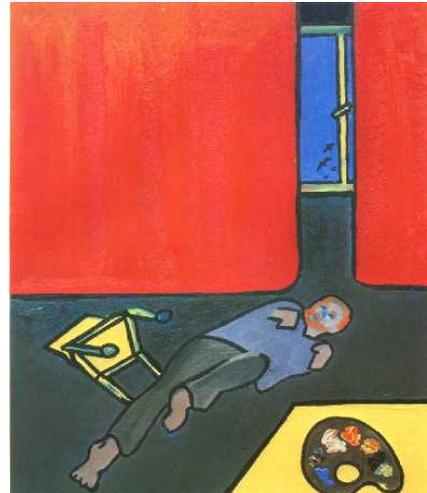
These prevention rules apply to everyone all of the time, however, when preparing a personal, individualized safety plan you should consider the specific habits and characteristics of the people you support as well as the unique physical characteristics of the home where you work.

Safety Considerations for People With Poor Mobility or Epilepsy

The following are tips on how to make home environments safer for people with epilepsy or poor mobility:

Houses

- Carpet the floors in your house or apartment with heavy pile and thick under padding.
- Pad sharp corners of tables and other furniture; look for rounded corners when you shop.
- Put guards around the fireplace or, preferably, close fireplace screens while a fire is burning.
- Don't smoke or light fires when you're by yourself.
- Don't carry hot fireplace ashes or lighted candles through the house.
- Avoid space heaters that can tip over.
- Use curling irons or clothing irons with automatic shut off switches to prevent burns.
- Select chairs with arms to prevent falling.
- Make sure motor-driven equipment, such as a lawn mower, has a "dead man's" handle or switch that will stop the machine if your hand releases normal pressure.



Bathrooms

- Hang bathroom doors so they open outwards instead of inwards (so if someone falls against the door, it can still be opened).
- Put extra padding under carpeting in the bathroom.
- Hang an "Occupied" sign on the outside handle of the bathroom door instead of locking the door.
- Routinely check that the bathroom drain to make sure it works properly before taking a bath or shower.
- If a person falls frequently during seizures, consider using a shower or tub seat with a safety strap.
- Keep water levels in the tub low.
- Consider using a hand held shower nozzle while seated in tub or shower.

- Set water temperature low so that the person will not be scalded if you lose consciousness while hot water is running.
- Avoid using electrical appliances, such as a hair dryer or electric razor, in the bathroom or near water.

Kitchens

- Slide containers of hot food along the counter instead of picking them up, or use a cart when taking hot foods or liquids from one room to another.
- Use plastic dishes and cups with lids (commuter cups) to prevent cuts or burns from spills.
- Use a microwave oven for cooking.
- When you use the stove, try to use the back burners as much as possible.
- Remove burner controls from gas or electric stoves when not in use.
- Use long, heavy duty oven mitts or holders when reaching into a hot oven.
- Wear rubber gloves when handling knives or washing dishes and glassware in the sink.
- Use plastic rather than glass containers as much as possible.

Adapted from: "Home Safety", Epilepsy Foundation
Accessed 11/2/11 www.epilepsyfoundation.org



Safe Food Handling

The 10 Commandments of Safe Food Handling:

As a Food Handler I Will. . .

1. Refrigerate food properly!
2. Cook food or heat process it thoroughly!
3. Not handle food while ill or with infected wounds or cuts that transmit bacteria to foods!
4. Follow strict personal hygiene rules! Wash hands before, during and after handling food!
5. Use extreme care in storing and handling food prepared in advance.
6. Give special attention to preparation of raw ingredients which will be added to food when little or no further cooking will occur.
7. Keep foods at temperatures that are higher or lower than those that permit bacterial growth. Remember above 140 degrees Fahrenheit for hot foods and below 41 degrees Fahrenheit for cold foods.
8. Reheat leftovers quickly to 165 degrees Fahrenheit or higher. **Do NOT use crock pots to reheat foods!**
9. Avoid carrying contamination from raw to cooked and ready-to-serve foods via hands, equipment and utensils!
10. Always clean and sanitize food preparation and serving equipment.

Refrigeration

Proper refrigeration of foods is one of the most important practices in sanitary food handling. To be a safe food handler . . . follow these procedures:

- Keep refrigerator air temperature at 37 degrees Fahrenheit or below
- Keep refrigerator doors and freezer units closed except when in actual use.
- Keep all frozen foods at 0 degrees F or below
- Defrost (thaw) foods at a temperature below 41 degrees Fahrenheit
- Keep all food items stored in refrigerator covered to help prevent food contamination
- Store food in refrigerator loosely stacked so air can circulate freely to insure proper temperature at 41 degrees Fahrenheit or below
- Keep all readily perishable foods refrigerated until ready to use and to avoid excessive growth of bacteria and food spoilage
- Keep milk and milk products covered and refrigerated to avoid spoilage.
- Label and date all foods which are prepared in advance and stored in the refrigerator.

Food Preparation

Keep foods you are preparing safe from germs and bacteria by following these procedures:

- Do not contact exposed ready-to-eat food with bare hands. Use suitable utensils such as deli tissue, spatulas, tongs, or single-use gloves.
- Hold all cooked foods at temperatures of 149 degrees Fahrenheit or higher.
- Thoroughly rinse all fruits and vegetables before cooking or serving. This helps remove contaminants such as dirt, pesticides, insects, etc.
- Reheat leftovers rapidly to 165 degrees Fahrenheit or higher. Rapid reheating inhibits bacterial growth.
- Never dip fingers into food or use stirring spoon to taste. Use a separate spoon and wash it properly before you use it for tasting
- Always marinate food in the refrigerator.

Thawing Potentially Hazardous Foods

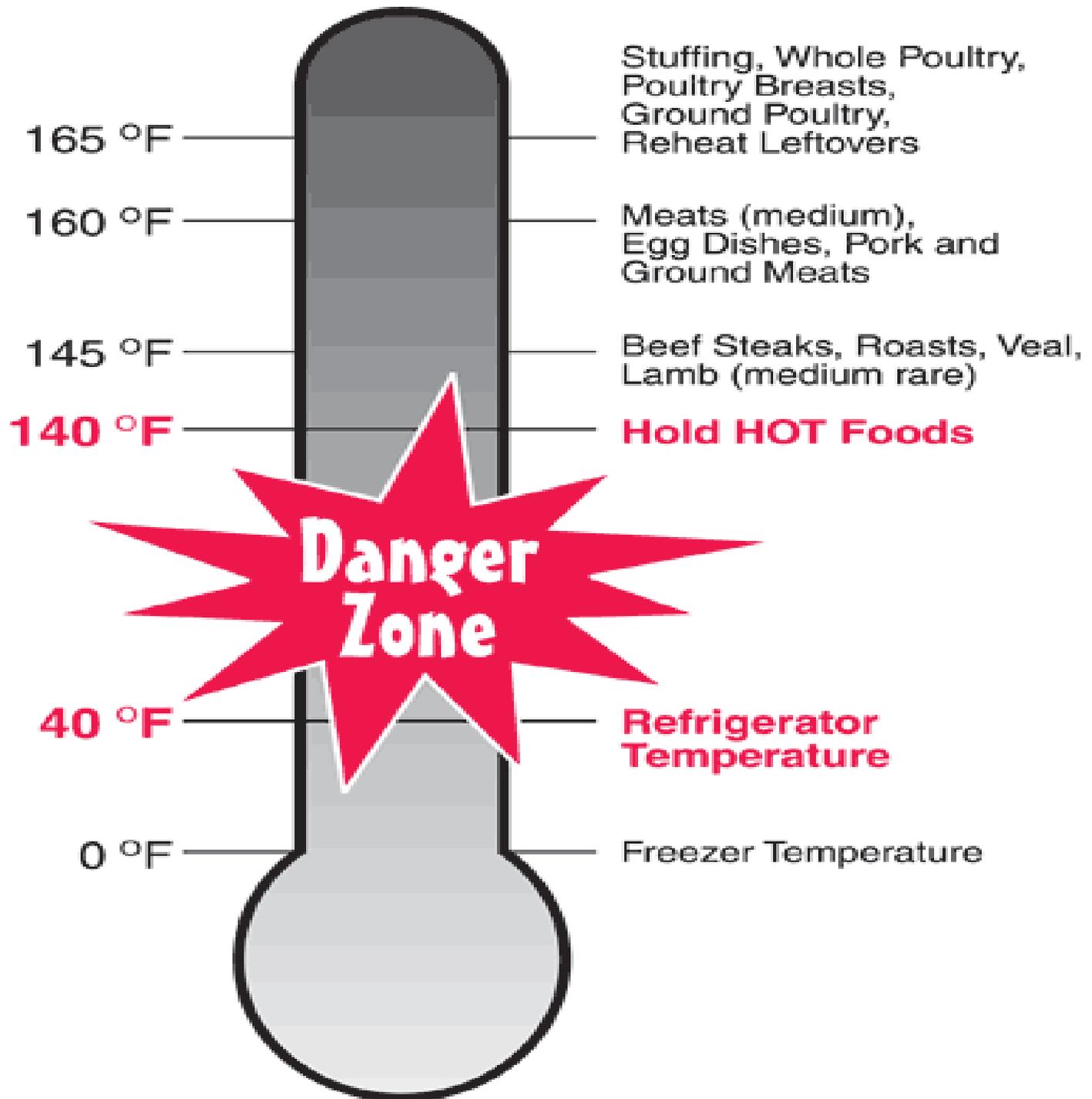
Never defrost food at room temperature. Food must be kept at a safe temperature during thawing. There are three safe ways to defrost food:

- In a refrigerator with food not exceeding 41 degrees Fahrenheit
- In a microwave oven – when food will be cooked immediately afterwards
- Under potable running water at a temperature of 70 degrees Fahrenheit or below for no more than two hours.

Food Storage

Food storage is more than just keeping food. It's keeping food **safe**. To keep food safe, follow these procedures:

- Check food daily and throw away any of questionable quality. **“When in doubt, throw it out,”** also remember “first food in, first food out!”
- Store foods at temperatures that are higher or lower than those that permit bacteria growth - above 140 degrees Fahrenheit for hot foods and below 41 degrees Fahrenheit for cold foods
- Keep all foods covered and safe from contamination
- Store all cleaning, sanitizing, insect and rodent-killing powders and liquids away from foods and food preparation items
- Report all unsafe temperatures or faulty thermometers to your supervisor
- Never use utensils that contain toxic metals or covering acidic foods. Acid can cause the metal to leach out into the liquid and contaminate the food.
- Keep leftovers labeled as to time and date of preparation and rapidly cooled to an internal temperature of 41 degrees Fahrenheit or below. **Improper cooling of potentially hazardous foods is the #1 cause of foodborne illness.**
- Keep all floors and shelving of refrigeration cleaned and sanitized. This will prevent contamination of stored food.



Small Group Activity - (Food Handling)

Your group home has decided to invite several people over for Thanksgiving dinner. You have a large kitchen and dining room so this will work out well. Including individuals, families, friends, and staff, there will be approximately 27 people at this get together. The individuals in your group home have chosen the following foods for the menu:

Turkey
Stuffing
Giblet gravy
Ham
Candied Sweet Potatoes
Fresh Green Beans
Cranberry Sauce
Rice
Hot Dinner Rolls
Butter
Iced Tea

Banana Cream Pie
Pumpkin Pie
Coffee

Six people live in your group home and you will assist three of them in purchasing the foods while the other three will assist in food preparation.

Using the principles of food sanitation and safety, identify important principles in the preparation of this meal. Discuss food purchasing, preparation and storage of leftovers.

Here are the facts which you need to consider in your groups:

You purchase frozen turkeys. Discuss storing and thawing as well as cooking the turkey you purchased.

1. John, who lives in the group home, is assisting with cooking the Thanksgiving dinner. He has cooked about three times the amount of rice needed. Discuss storage of the left over rice.
2. Martin lives in the group home and his mother has insisted on stuffing the turkey the night before. She always does that with her turkeys and bakes them early in the morning. That way, she says, the oven is free for other baking. She just called you and is on her way over to the group home to stuff the turkey. She won't take no for an answer. What would you recommend?
3. Instead of making iced tea as the dinner menu calls for, Bob decided to make

lemonade and he poured it into an unlined decorative copper pitcher rather than the plain glass pitcher which you had asked him to use.

4. The gravy was made two hours ago and left in a covered pot sitting on the kitchen cabinet. Is the gravy safe to serve?
5. Tim's aunt came for dinner and brought macaroni salad. She said that she came directly from her daughter's home where she was for about 3 hours and left the salad in her car feeling that it was cold enough. The high temperature today was 37 degrees Fahrenheit and it was very sunny. Should you serve the macaroni salad? You wonder did it get warmer than 37 degrees Fahrenheit in the car. You hate to hurt her feelings by not serving the salad.
6. Most of your dinner guests ate the pumpkin pie. By the time food was put away, that banana cream pie had been out of the refrigerator for 1½ hours. Do you think it will be safe to eat tomorrow?
7. You just noticed an empty, opened can of green beans in the wastebasket. The can is severely dented and soiled. You asked did someone just open the can and Harry says that he did and added the contents of the can to the fresh green beans because he didn't think there would be enough beans for all of the guests. Are the beans safe to eat?
8. The ham you purchased for the dinner is a canned ham and you bought it in the refrigerated section of the meat counter. The can says "refrigerate" till used. Unbeknownst to you, when Mark was unpacking the groceries, he put the ham on the pantry shelf. You went shopping two days ago. Is this ham going to be safe to use?

Cleaning Products

It is staff's responsibility to keep surfaces clean and germ free. The most effective cleaner for killing germs, including MRSA, is a bleach solution. Agencies can also consider eco-friendly cleaning products such as vinegar, activated charcoal, etc. Visit the website that lists the Sixty Uses of Vinegar at <http://www.i4at.org/lib2/60vine.htm>

Safety Data Sheets

DSPs should understand how to read the labels of cleaning products to determine which ones are dangerous if ingested. The way to find out information about any cleaning product is to look at the Safety Data Sheet (SDS). This is the information from the producer about the ingredients. Get to know where the SDS book is kept in the area where you are working!

Depending on the medical and behavioral considerations of the people you are supporting, **you may need to keep all cleaning products under lock and key.** Some people with developmental disabilities have died because they drank cleaning products.

Poisoning

Accidental poisoning is something we all hope will never happen, but what if it does happen while you are at work? What would you do? Be sure to find out your agency's policy on accidental poisonings. Store cleaning supplies securely and well away from food and food preparation areas.

- Keep all products in original containers.
- Store pesticides, gasoline, turpentine, paint products, car products, and garage products out of reach and out of sight. Lock up these products.
- Keep paint in good condition.
- Always prepare and use products according to label directions.
- Never store food and household cleaners together.
- Never mix different household cleaners together
- Never transfer products like bleach, gasoline, insecticides or other cleaning agents to containers such as a soft drink bottle, cup or bowl.



POISON CONTROL HOTLINE NUMBER
1-800-222-1222

Fires



Fire is one of the leading causes of accidental deaths in the home. Besides practicing basic safety rules, you may also be called upon to act in the event of a fire. You should review your agency policies on fire drills and evacuations, including the maximum evacuation time, frequency of drills, times of day for drills, special procedures for blocked exits, individuals with special needs (wheelchair, autism, blindness, etc.). Fire prevention is everyone's responsibility. If you see any practices or situations that reduce fire protection for individuals or employees, report those problems immediately so they can be corrected.

When an alarm sounds for a fire drill or a real fire, follow the instructions provided by your agency. After a fire or evacuation drill, everyone's response to the fire drill must be reviewed and evaluated so improvements can be made in future drills or in the case of an actual fire.

Remember to RACEE

If you smell smoke or discover a fire at your site, you should do the following in the order outlined:

- **R**emove/**R**escue the resident and anyone else in immediate danger.
- **A**lert the fire department by calling **911** (or local emergency number) from a phone out of harms way.
- **C**ontain the fire by closing the doors between you and the fire.
- **E**xtinguish the fire by using the proper type of fire extinguisher when appropriate or the fire is small and easy to contain.
- **E**vacuate (leave) the building immediately.

In the Event of Fire:

Using A Fire Extinguisher

To understand how employees are to react to fire, your agency should explain in advance, its policy regarding when employees should attempt to put out fires by using fire extinguishers and when fire extinguishing should be left to the firefighters. If your agency has a policy that says it is appropriate to try to put out certain types and sizes of fires using a fire extinguisher, DSPs should follow the agency's policy unless unsafe to do. If your agency does not allow it, employees should move directly to taking Evacuation steps.

Source: Illinois Department of Human Services, Bureau of Training and Development

Fire Evacuation Considerations

- ✦ Always crawl or stoop low in leaving a smoky environment to stay below the heat and toxic gases.
- ✦ Keep doors and windows closed.
- ✦ When evacuating non-ambulatory persons, make sure their head is as low as possible.
- ✦ Smoke follows the path of least resistance. Know your building and predict where and how smoke will travel. Use this information in your evacuation plan.
- ✦ NEVER re-enter a burning building once you and others have made it outside.
- ✦ If trapped in a room, seal the doors and vents to prevent smoke from entering.
- ✦ If trapped in a room, hang a bed sheet or blanket from the window. This is the universal sign to request help.

The Role of the DSP in Responding to Emergencies

In order to effectively handle emergencies, you will need to be prepared and informed. You may want to consider these steps:

Learn about the types of hazards that may affect your community (blizzards, tornadoes, floods, and so on). You can get more information at your local emergency management office. <http://www.state.il.us/iema/>

Find out what emergency plans are in place at your agency. Look over whether the plans meet your specific needs and the needs of the individuals you support.

Identify what the plan is for notifying people when a disaster may be on its way or is actually occurring.

Consider how a disaster might affect your daily routines and those of the people you support. Make a list of the specific needs before, during and after a disaster.

Become Familiar with Your Agency Emergency Plans!

Don't wait for an emergency to happen to become familiar with these. Read them now so you are prepared to handle emergencies.

The National Organization on Disability has developed this checklist to create a 'go kit' containing most essential items to take with you if you must leave immediately. You can find this list at www.nod.org/emergency

Also, be sure that you have plans for your children, pets or others at home if an emergency occurs while you are at work. The people you support may be at risk if you leave them unattended and this may be considered neglect.

Some types of emergencies that you may face as DSP include natural disasters such as tornadoes or flooding.

Tornadoes

Tornadoes are violent storms with whirling winds up to 300 miles per hour. Following are some facts about tornadoes:

They may strike quickly, without warning

The average **forward** speed of a tornado is 30 MPH, but may vary from stationary to 70 MPH. In Illinois tornado season is March through June with the deadliest tornadoes occurring in March, April and May. Tornadoes are most likely to occur between 3 p.m. and 9 p.m.

Illinois ranks 6th in the nation for number of “killer” tornadoes and has an average of 27 tornadoes per year.

A **tornado watch** means conditions are favorable for tornadoes. Go to or stay in a safe area and listen for sirens, news reports on local television and radio stations, and keep the phone lines clear for emergency calls.

A **tornado warning** means a tornado has been spotted. Seek shelter immediately!

Thunderstorms often precede a tornado. Thunderstorms can have straight-line winds which may exceed 100 miles per hour. During a tornado or thunderstorm you should move into a building, preferable in the basement or lowest level or an interior room away from windows. Close the windows and stay away from doors. If you are outside during a tornado and are unable to find a sturdy building, seek shelter in a low lying ditch that is unlikely to flood. Do not stay in or near water.



If you are under a tornado WARNING, seek shelter immediately!

If you are in:	Then:
A structure (e.g. residence, small building, school, nursing home, hospital, factory, shopping center, high-rise building)	Go to a pre-designated shelter area such as a safe room, basement, storm cellar, or the lowest building level. If there is no basement, go to the center of an interior room on the lowest level (closet, interior hallway) away from corners, windows, doors, and outside walls. Put as many walls as possible between you and the outside. Get under a sturdy table and use your arms to protect your head and neck. Do not open windows.
A vehicle, trailer, or mobile home	Get out immediately and go to the lowest floor of a sturdy, nearby building or a storm shelter. Mobile homes, even if tied down, offer little protection from tornadoes.
The outside with no shelter	<p>Lie flat in a nearby ditch or depression and cover your head with your hands. Be aware of the potential for flooding.</p> <p>Do not get under an overpass or bridge. You are safer in a low, flat location.</p> <p>Never try to outrun a tornado in urban or congested areas in a car or truck. Instead, leave the vehicle immediately for safe shelter.</p> <p>Watch out for flying debris. Flying debris from tornadoes causes most fatalities and injuries.</p>

http://www.fema.gov/hazard/tornado/to_during.shtm

Lightning

Lightening is the second most common weather condition that KILLS (floods are first). It is important to plan in advance your evacuation and safety measures. When you first see lightning or hear thunder, activate your emergency plan. Lightning often precedes rain, so don't wait for the rain to begin before suspending activities.

If outdoors, avoid water, high ground, open spaces and all metal objects. Unsafe places include underneath canopies, small picnic or rain shelters, or near trees. Where possible, find shelter in a substantial building or a fully enclosed metal vehicle such as a car, truck or van with the windows completely shut.

If lightning is striking nearby when you are outside, you should:

- ***Crouch down.*** Put feet together, place hands over ears to minimize hearing damage from thunder.
- ***Avoid proximity.*** Stay a minimum of 15 feet away from other people.

All outdoor activities should be suspended for 30 minutes after the last observed lightning or thunder.

If indoors, avoid water, stay away from doors and windows, do not use the telephone, take off head sets. Turn off, unplug, and stay away from appliances, computers, power tools, and TV sets. Lightning may strike exterior electric and phone lines sending electrical charge to inside equipment.

Flooding

Be aware of flood hazards. Flooding is the weather condition that KILLS the most. Floods can roll boulders, tear out trees, destroy buildings and bridges, and scour out new channels. Flood waters can reach heights of 10 to 20 feet and often carry a deadly cargo of debris. Flood-producing rains can also trigger catastrophic debris slides.

Regardless of how a flood or flash flood occurs, the rule for being safe is simple: **head for higher ground and stay away from flood waters.** Even a shallow depth of fast-moving flood water produces more force than most people imagine. The most dangerous thing you can do is to try walking, swimming, or driving through flood waters. Two feet of water will carry away most automobiles.

Preparation for Survival

Know you agency's disaster preparation policies!

Gather these things in a safe place off site to use in an emergency:

- Battery powered radio, flashlight and plenty of extra batteries
- First aid kit and book
- Adjustable wrench for turning off gas and water
- Bottled water (1 gallon per person)
- Non-electric can opener
- Extra set of keys
- Current Disaster Plan with information about relocation, poison control, physician names and phone numbers. All emergency numbers should be posted by the phone—large enough for everyone to read.

This information must be available for each individual:

- List of current medications and prescribing physician
- A supply of currently prescribed medications
- Emergency information for each individual (date of birth, insurance/Medicaid number & card, food sensitivities, nearest relatives, guardians, or friends phone number)
- Signed consent for treatment form

NOTE: All emergency numbers should be posted by the phone and be large enough for everyone to read easily.

Medication Safety: Storage and Summer Use

Some medications can become less effective when exposed to direct sunlight, heat, cold or moisture. Be especially careful during summer months to store medications properly.

General Storage Guidelines:

- Store medications that do not need refrigeration at room temperature below 86 degrees Fahrenheit
- Avoid storing medication in moist, humid areas
- Keep medication away from direct sunlight
- Store medications in their original containers
- Discard expired medications according to your agency policy

When in Doubt Throw it Out

- Medication may lose its potency because of improper storage or transport
- Medication should not be given when any of the following are observed:
 - A change in appearance or odor
 - A change in consistency (i.e. tablets that crumble easily or capsules that are stuck together or crack)
 - Liquid medications that become cloudy or thick or change from their initial appearance or consistency

Medications, Activities and the Sun

Some medications can cause sensitivity to sunlight called **photosensitivity** which can result in:

- A rash-like condition
- Severe burns and skin cell damage
- Sunlight intolerance
- Eye pain

Every medication should be evaluated for possible sunlight intolerance.



Prolonged exposure to the sun should be avoided by individuals with known sensitivity to the sun. Protective clothes, hats, sunglasses and sunscreen should be used when outside. When photosensitivity is suspected, discuss a possible medication change with the doctor.

Commonly Prescribed Medications that can Cause Sun Sensitivity

(This is not an exhaustive list)

Benadryl

Elavil

Tegretol

Bactrim

Cipro

Haldol

Dilantin

Ibuprophen

Glucotrol

Capoten

Lasix

Claritin

Remember. . .

During hot weather increased fluid intake may be needed. Sweating can cause some medications to become more concentrated in the body and become "toxic".

EpiPens

Allergies are common phenomena that impact millions of Americans. Allergic reactions may be caused by many factors including environmental contaminants such as pollen, animal dander and dust mites or by specific foods, insect bites or medications. Most people with allergies experience minimal to moderate symptoms. However, some people are highly allergic to allergens that are difficult to avoid and may be life-threatening. In such cases, individuals must be followed closely by medical professionals who are familiar with these conditions. In most cases, certain medications will be prescribed for use in the event of a possible life-threatening exposure.



Injectable epinephrine, in a delivery system known as an “EpiPen” or epinephrine auto-injector”, is commonly prescribed to people with known serious and unavoidable allergic reactions. It is a first aid measure that can save a person’s life if given promptly when a person experiences a severe allergic reaction known as anaphylactic shock; also known as anaphylaxis. The EpiPen is a single dose closed system which, when engaged, delivers epinephrine as a first aid measure. For more information on the use of an EpiPen, go to www.epipen.com .

Before using, DSPs must be trained in the proper use of EpiPens.

Seasonal Safety

Summer Issues

Prevention tips to beat the heat:

Drink more of fluids regardless of your activity level. Do not wait until you're thirsty to drink. Make an extra effort to drink a minimum of six to eight 8 ounce glasses of cool fluids daily. During heavy exercise in a hot environment, drink two to four glasses of cool fluids each hour. Parents should be sure young children get sufficient fluids. If on a special fluid-restricted diet or taking diuretics, ask the physician about fluid intake during hot weather.



Avoid liquids that contain caffeine, alcohol or large amounts of sugar – these can cause one to lose more body fluid. Also, avoid very cold drinks because they can cause stomach cramps.

Take cool showers, baths or sponge baths. These can reduce body temperatures. In addition, wet clothing has a cooling effect.

Protect your body. Wear lightweight, light-colored, loose-fitting clothing. When spending time outdoors, avoid direct sunlight, wear a hat and use sunscreen with a sun protection factor (SPF) **greater than 15** to protect against sunburn.

Never leave anyone, including pets, alone in a closed, parked vehicle. The air temperature inside a car rises rapidly during hot weather and can lead to brain damage or death.

Stay indoors and, if at all possible, stay in an air-conditioned place. If your home does not have air conditioning, go to a public place that does have air conditioning.

Seek out the nearest facility that is air conditioned, such as a cooling shelter, a senior citizen center, a church, a mall, the local YMCA or other center designated by your community. Even a few hours spent in air conditioning can help your body stay cooler when you go back into the heat. Fans alone will not effectively cool an overheated person when air temperatures are above 90 degrees Fahrenheit.

Heat Exhaustion occurs when excessive perspiration leads to extreme loss of fluids and salt (electrolytes). **Symptoms** include dizziness, nausea, light-headedness, severe headache, cool clammy skin, heavy perspiration, shallow breathing, muscle tremors or

cramping. **Prevention:** drink extra liquids (no caffeine or alcohol), schedule strenuous activity during morning or evening hours, take frequent water breaks, and wear lightweight loose fitting clothing.

Heatstroke is caused by overexposure to direct sunlight. **Symptoms** include headache, red dry face, skin hot to the touch, body temperature dramatically elevated, strong pulse, loss of consciousness, seizures or irregular heartbeat. **Treatment:** place person in semi-sitting position in shady area or indoors, loosen tight clothing, flood the head and body with cold water or ice. Do not put anything in the mouth. Seek medical attention.

Heat cramps are muscle pains or spasms. Basically in the abdomen, arms or legs that affect people who sweat a lot during strenuous activity that depletes the body of salt and moisture. **Treatment:** stop all activity and sit quietly in a cool place, drink clear juice or sports beverage, do not return to strenuous activity for a few hours. Seek medical attention if cramps do not subside in one hour.

Excessive sun exposure can increase the risk of skin cancer. **Protection:** seek shade, cover up, wear a hat, sunglasses and rub on sunscreen. **Treatment:** Follow first aid procedures for 1st, 2nd, or 3rd degree burns.

Tornados are violent storms with whirling winds up to 300 miles per hour. For a **watch**, listen to local radio and TV stations and keep telephone lines clear for emergency calls. Report any funnel shaped clouds to the police. For a **warning**, take shelter immediately.

Protect yourself from being struck by falling objects, injured by flying debris or being blown away. The best shelter is underground. If at home, go to the basement or a corner of your home and take cover under a sturdy table. Do not stay in trailer or mobile home. If you are in open country, lie flat in the nearest depression and cover your head with your arms.

Floods can produce raging waters in just a few minutes. They can occur in very small streams, creeks, etc. **Protection** includes getting to higher ground, staying out of flooded areas, and abandoning stalled vehicles in flooded areas if you can do so safely. Try to take a flashlight with you to attract help.

Winter Issues

Preparing for severe weather. Emergency supplies include: portable radios, flashlights, extra, fresh batteries, supplies of food that can be prepared without a stove, candles and matches, extra clothing, fire extinguishers, an ample supply of prescription medicines.



Winter driving: Equip your car with blankets, extra outer clothes, fresh batteries, flashlight, battery powered radio, sand and traction mats or old rugs, shovel, windshield scraper.

Hypothermia is a drop in body temperature to 95° Fahrenheit or less. It can be fatal if not detected promptly and treated properly. **Symptoms** include an attitude of not caring, forgetfulness, drowsiness, slurred speech, a change in appearance (such as puffy face), weak pulse, slow heartbeat, very slow shallow breathing, coma or death-like appearance. Other symptoms may include shivering, stumbling or falling, stiff muscles, respiratory arrest. People who are more **susceptible** include those with pre-existing and current health conditions, medications and intoxicants and compromised acute or chronic central nervous system impairments, and wetness. **Treatment:** Take the person's temperature. If a person's temperature is 95° Fahrenheit or below, call 911 or take the person to the hospital. If the person is alert, give small quantities of warm food or drink. Do not give alcoholic beverages.

Frostbite most often occurs to face, ears, wrists, hands and feet. Frostbitten skin is whitish and stiff and the area is painful. **Treatment** includes gradually warming the affected area, wrapping it in blankets, etc., or placing frostbitten hands under armpits. Seek medical attention immediately.



Transportation

Another role you may have with individuals is transportation.

You will need to do/know the things described in the following pages every time you drive an individual.

Review you agency's transportation policies regarding the following:

- ✓ Safe use of wheelchair lift (including inspection/maintenance).
- ✓ Proper wheelchair tie down procedures.
- ✓ Proper use of seatbelts
- ✓ Defensive driving techniques.
- ✓ Inspection of vehicles before using. (Gas level, oil, interior cleanliness, exterior cleanliness, damages, light & blinker functioning, first aid kit, etc.)
- ✓ Trip log.

- ✓ Counting individuals before leaving and after you get there.
- ✓ Information which should be carried regarding individuals being transported.
- ✓ Agency policy on smoking in vehicle.
- ✓ Handling medical emergencies while traveling.
- ✓ Assisting individuals with special needs. (Vision/hearing impaired, confusion, refusal to cooperate, autism, difficulty getting into and out of vehicle, balance problems, etc.)
- ✓ How to transport assistive devices (wheelchairs, talkers, walkers, etc.)
- ✓ What to do and not to do if there is an accident.
- ✓ What to do and not to do if there is a vehicle breakdown.
- ✓ Procedures for adverse weather. (flooding, tornado, torrential downpour, slippery roads, unplowed snow on roads, blowing snow, etc.)
- ✓ Vehicle inspection and log after trip is over.

Moving People in Wheelchairs Safely

Wheelchair use presents special issues which must be addressed. There is a right way and a wrong way to transport people who need assistance using wheelchairs. Please keep the following guidelines in mind when you assist individuals in wheelchairs.

Review you agency's moving people safely policies!

- ✓ Always **ask** the individual if he/she wants assistance.
- ✓ Encourage the individual to **self-transport** as much as possible.
- ✓ Make sure the individual's **hips** are all the way back in the wheelchair.
- ✓ Fasten **seatbelt. It's the law!**
- ✓ Verify that **footrests** are in place and the individual's feet are properly on them.
- ✓ Make sure **brakes** are locked before helping a person into or out of a wheelchair.
- ✓ Grasp both push handles on the chair firmly.
- ✓ Start and stop **slowly**; take corners slowly, and maintain a steady pace while moving. Avoid jostling the person or throwing him/her off balance.

- ✓ Be alert for **changes in surface levels** (door jams/elevator floor, etc.) Hitting a half-inch rise at standard wheelchair speed can bend the front casters and pitch to person forward.
- ✓ Don't **open doors** by pushing with the front of the wheelchair. This can damage the footrests, the person's feet or the door. Stop the wheelchair, open the door by hand, and bring the wheelchair through. If the door does not stay open on its own, hold it with one hand or your backside. Do not let the door bang the side of the wheelchair.
- ✓ Be sure the person's weight is **pushing back toward you** on inclines and ramps. Going uphill means pushing the person. To go downhill, turn the chair around and walk backwards. The person's weight will always be pushing back toward you.
- ✓ Be alert for anything that can **trap front casters** or cause the chair to tilt, such as holes, cracks, stones, sand or soft shoulders.
- ✓ To maneuver **up curbs**: stop at the curb, raise the front casters by pressing the foot lever, roll the front casters onto the sidewalk and roll the large wheels over the curb by lifting slightly on the push handles as you push forward.
- ✓ To maneuver **down curbs**: face backwards with the large wheels coming first. Maintain some upward pressure on the push handles as you pull the wheelchair toward you.

Protect Your Back

Lifting

- Most back injuries are the result of improper lifting. Before lifting anything, think about the lift. One of the most important things you need to remember is proper planning. Ask yourself, can I lift this safely? Do I need help? Plan every step before you do it physically.
- Get a wide base of support. Your feet should be about shoulder width.
- Bend at your knees, keeping your back straight
- Turn your body, don't twist it. Move your body as a single unit. Make turns with your feet, not your waist.
- Tighten your abdominal muscles to support your back when you lift.
- Lift with your legs. Let your powerful leg muscles do the lifting, not your weaker back muscles.
- Keep the load close to your body. The closer it is to your body, the less force it exerts on your back.



Reaching

- Reach only as high as your shoulders.
- Use a stool or stepladder if needed.
- Test the weight of the load by pushing up on a corner before lifting. If it is too heavy, get help.

Bending

- When bending down to reach or lift, move your whole body to protect your back.
- Bend your knees and hips, not your back.
- Kneel down on one knee, if necessary.
- Get as close to the object as you can so you won't have to reach with your arms.

Pushing

- Pulling large objects can be as hard on your back as lifting. Instead, push.
- Stay close to the load without leaning forward.
- Tighten your stomach muscles as you push.
- Push with both arms keeping your elbows bent.

Turning

For some tasks you may be tempted to twist your body. Instead:

- Get close to the object. You may need to kneel down on one knee.
- Position yourself so you're stable.
- Use your arms and legs to do the work...not just your back.

Posture While Standing

When you perform a task that requires prolonged standing, you may slouch and forget to maintain the natural curves of your back. Bad posture can cause muscle tension, stiffness, fatigue, backache, and neck ache. It also contributes to degeneration of disks and ligaments.

To maintain good posture:

- Stand close to the individual so you don't have to lean forward.
- Bend with your knees and maintain your back's natural curve.

Prevention

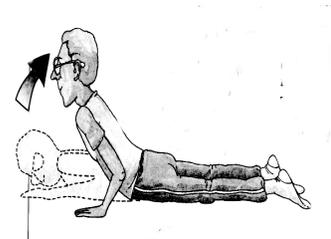
If you find that you do experience back pain, you may want to do some exercises to strengthen your back.

Back Exercises

Press Up

Purpose: To increase flexibility of spine.

1. Lie on stomach and place hands on floor at sides of shoulders, elbows bent.
2. Keeping elbows bent, slowly push upper body off floor. Keep hips on floor. Relax. Repeat 10 times, lifting higher each time.



Standing Back Bend

Purpose: To increase flexibility of spine.

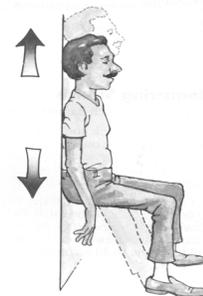
1. Stand.
2. Press palms against lower back.
3. Gently arch back.



Wall Slide

Purpose: To strengthen back, hip, and leg muscles.

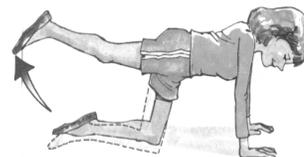
1. Stand with back against the wall and feet shoulder width apart. Find your position of comfort.
2. Slide down the wall. When hips and knees are bent to 80-90 degree angle, hold for a count of 5 and slowly slide back up. Repeat 5 times. Work up to 3 minute holds.



Arm and Leg Reach

Purpose: To strengthen muscles of back, buttocks and legs.

1. Start on hands and knees. Find your position of comfort.
2. Extend one arm straight out in front of you and hold it parallel to floor for a count of 5.
3. Then extend one leg straight out behind you and hold it parallel to the floor for a count of 5.
4. Don't let back, head, or stomach sag and try not to arch back. Return to starting position. Repeat 5 times, then switch arms and legs.



More Exercises

Chin Tuck- Purpose: To stretch chest, neck, and shoulder muscles.



Sit or stand upright.

Without lifting chin, glide head straight back. You know you're doing this right if it gives you the feeling of a double chin.

Hold for 20 counts and repeat 5-10 times.

Range of Motion - Purpose: To stretch and relax neck muscles.

Sit or stand upright.

Tilt head slowly toward one shoulder.

Relax and let gravity pull head down to stretch neck.

Hold for 10 counts, rest briefly, then switch sides.

Repeat 5-10 times on each side.



OJT Practice Activity #58 - Bed to Wheelchair Transfer



Attention: When transferring an individual from bed to wheelchair, have the individual help by pushing with arms and extending legs.



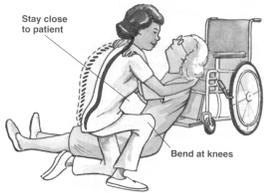
1. If possible, take advantage of aids like mechanical lifts to safely move individuals.
2. Use a transfer belt to help you move an individual safely and securely when doing a wheelchair transfer. Place hands on individual’s waist or transfer belt to prevent twisting and provide support.
3. If possible and necessary, teach individuals to assist moving themselves in bed and to give assistance during transfers

Equipment needed:

Bed/Wheelchair

Steps	Partner Check	Instructor Check
DSP appropriately identifies the individual.	<input type="checkbox"/>	<input type="checkbox"/>
DSP asked permission and explained what was going to be done.	<input type="checkbox"/>	<input type="checkbox"/>
DSP used transfer belt/mechanical lift properly.	<input type="checkbox"/>	<input type="checkbox"/>
DSP locked the wheelchair properly.	<input type="checkbox"/>	<input type="checkbox"/>
DSP removed wheelchair armrest nearest the bed.	<input type="checkbox"/>	<input type="checkbox"/>
DSP supported individual's knees between their legs.	<input type="checkbox"/>	<input type="checkbox"/>
DSP moved the individual correctly.	<input type="checkbox"/>	<input type="checkbox"/>
DSP lowered individual into wheelchair by bending knees.	<input type="checkbox"/>	<input type="checkbox"/>
DSP had the individual hold him/her at the waist.	<input type="checkbox"/>	<input type="checkbox"/>

PRACTICE EXERCISE - Wheelchair to Toilet Transfer



Attention: A wheelchair to toilet transfer presents special problems because there is little room to maneuver in most bathrooms. The possibility of falling is increased.

Equipment needed:

- Chair (representing toilet)
- Wheelchair

Steps	Partner Check	Instructor Check
DSP appropriately identified individual.	<input type="checkbox"/>	<input type="checkbox"/>
DSP asked permission & explained what was to be done.	<input type="checkbox"/>	<input type="checkbox"/>
DSP washed his/her hands.	<input type="checkbox"/>	<input type="checkbox"/>
DSP positioned individual's stronger leg closest to toilet.	<input type="checkbox"/>	<input type="checkbox"/>
DSP locked the wheelchair.	<input type="checkbox"/>	<input type="checkbox"/>
DSP correctly had the individual use the grab bar and wheelchair arm for support.	<input type="checkbox"/>	<input type="checkbox"/>
DSP bent knees correctly.	<input type="checkbox"/>	<input type="checkbox"/>
DSP obtained additional help, if needed.	<input type="checkbox"/>	<input type="checkbox"/>
DSP washed his/her hands.	<input type="checkbox"/>	<input type="checkbox"/>

PRACTICE EXERCISE - Wheelchair to Tub Transfer



Attention: Since your ability to maneuver may be hampered by working within a small space, do what you can to break up the steps and to enlist the individual’s help. If the patient is fairly strong, one person can handle this move by grasping safety railings and taking some weight onto their arms.



Equipment needed:

- Wheelchair
- Tub

Steps	Partner Check	Instructor Check
DSP appropriately identifies the individual.	<input type="checkbox"/>	<input type="checkbox"/>
DSP asked permission and explained what was going to be done.	<input type="checkbox"/>	<input type="checkbox"/>
DSP washed his/her hands.	<input type="checkbox"/>	<input type="checkbox"/>
DSP filled the tub with water not hotter than 110 degrees Fahrenheit.	<input type="checkbox"/>	<input type="checkbox"/>
DSP put the transfer belt on the individual, if needed.	<input type="checkbox"/>	<input type="checkbox"/>
DSP positioned the individual's legs directly underneath the wheelchair and gave support as needed.	<input type="checkbox"/>	<input type="checkbox"/>
DSP had the individual sit on the edge of the tub or transfer seat.	<input type="checkbox"/>	<input type="checkbox"/>
DSP moved the wheelchair out of the way.	<input type="checkbox"/>	<input type="checkbox"/>
DSP correctly helped the individual put his/her legs into the tub.	<input type="checkbox"/>	<input type="checkbox"/>
DSP let the water out and assisted with drying and putting clothes on, as needed.	<input type="checkbox"/>	<input type="checkbox"/>
DSP correctly used transfer belt, as needed, to lift individual out of the tub and into the wheelchair.	<input type="checkbox"/>	<input type="checkbox"/>