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](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 themselves; 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 the 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 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

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

### Sensory and Symptoms

<table>
<thead>
<tr>
<th>Sensory</th>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attention, Behavior And Social</td>
<td>Jumps from one activity to another frequently and it interferes with play</td>
</tr>
<tr>
<td></td>
<td>Has difficulty paying attention</td>
</tr>
<tr>
<td></td>
<td>Is overly affectionate with others</td>
</tr>
<tr>
<td></td>
<td>Seems anxious</td>
</tr>
<tr>
<td></td>
<td>Is accident prone</td>
</tr>
<tr>
<td></td>
<td>Has difficulty making friends, does not express emotions</td>
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</table>
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](http://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 of 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 wheelchair. 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 wheelchair.

**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 McDonald's 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/


Illinois 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/

DHS 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.theautismprogram.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:

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

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

Blood borne 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 Disabilities 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 contacts of a group of muscles caused by an attack on the nerve cells in the brain. Symptoms include uncontrolable 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 activity that takes place when a person is under the age of consent, physically or mentally unable to defend his or herself, or unable to understand and give informed consent regarding sexual activities.

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.