



## **MODULE 1**



# **INTRODUCTION TO THE WORLD OF THE QUALIFIED INTELLECTUAL DISABILITIES PROFESSIONAL (QIDP)**

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# Some People

*Some people come into our lives and quickly go. Some people move our souls to dance. They awaken us to new understanding with the passing whisper of their wisdom. Some people make the sky more beautiful to gaze upon. They stay in our lives for awhile and leave footprints on our hearts and we are never, ever the same.*

*Source: Unknown*

# Introduction to Becoming a Qualified Intellectual Disabilities Professional

## Ice Breaker Activity

Spend 5 minutes talking to your partner, and answering these questions . . . then switch roles.

- ❖ Where are you from?
- ❖ Where did you grow up?
- ❖ Why did you choose to participate in this training?
- ❖ How many brothers/sisters do you have?
- ❖ Do you have any pets?
- ❖ Are you a person with a lot of friends, or just a few really close friends?
- ❖ What is one big change that has occurred in your life in the past year?
- ❖ What do you love about your job or life?
- ❖ What is your biggest worry about this training?
- ❖ What is your biggest goal to get out of this training?
- ❖ What is the one thing you would like to change about where you work?
- ❖ How would your best friend describe you?
- ❖ How would your parents describe you?
- ❖ If you had three wishes, what would they be?



Modified from the Council on Quality Leadership (CQL)

## **IT ALL BEGINS WITH ATTITUDE!**

*Your attitude is the basis for everything you do and say. It determines how you are going to react in every situation. It reflects your personality. It also has an influence on the success or failure of the team, the staff and the individual receiving services. As an employee of your agency, your attitude also reflects the way people view your agency. How do you want people to view you and your agency?*

*"The longer I live, the more I realize the impact of attitude on life. Attitude, to me, is more important than facts. It is more important than the past, than education, than money, than circumstances, than failures, than successes, than what other people think or say or do. It is more important than appearance, giftedness, or skill.*



*It will make or break a company, a church, a home. The remarkable thing is we have a choice every day regarding the attitude we will embrace for that day. We cannot change our past; we cannot change the fact that people will act in certain ways. We cannot change the inevitable. The only thing that we can do is play on the one string we have, and that is our attitude. I am convinced that life is 10% what happens to me and 90% how I react to it. And, so it is with you. We are in charge of our attitudes."*

-- Charles Swindoll



## Why do we need Qualified Intellectual Disabilities Professional (QIDPs)?

In the early '70s, one of the most important court decisions regarding individual rights was the Wyatt vs. Stickney case. This class action suit, which involved state-operated facilities in Alabama, resulted in a finding that the constitutional rights of the residents with intellectual disabilities were being violated. One of the 49 principles established in this decision was the definition for a Qualified Mental Retardation Professional (QMRP).

In February 1, 2010, the Division of Developmental Disabilities replaced the use of "QMRP" (Qualified Mental Retardation Professional) with "QSP" (Qualified Support Professional).

Effective 1/1/2012, Public Act 097-0227, required all state agencies to replace the term "mental retardation" with "intellectual disability" or "intellectually disabled" in all rules, policies and procedures. This change required the Department of Human Services to now refer to QMRP or QSPs as "Qualified Intellectual Disabilities Professional" or QIDPs. However, in the federal language, they are still known as QMRP until replacement language is adopted by that entity.

In the role as a QIDP you are responsible for taking into consideration the needs, wants and desires of each individual as you develop, monitor, and advocate for appropriate individualized habilitation plans. These plans are important tools for assisting individuals with developmental disabilities in reaching and maintaining their maximum potential. You are also responsible for ensuring the rights of the individuals receiving services are not being violated.

**<http://www.adap.net/Wyatt/landmark.pdf>**

**<http://www.mh.alabama.gov/Downloads/UT/WyattBrochure.pdf>**

## Rosa's Law

**Legislation known as "Rosa's Law"** was signed by President Obama on October 5, 2010. It changes the terms "mental retardation" and "mentally retarded" to "intellectual disability" and "intellectually disabled" in various federal laws. It will make federal language consistent with that used by the U.S. Centers for Disease Control, the World Health Organization and the President's Committee on Individuals with Intellectual Disabilities.

"Stay tuned" for information that may be forthcoming on document revisions, policy changes, and how QIDPs are referred to in federal documents as a result of Rosa's Law.



President Barack Obama hugs nine-year-old Rosa Marcellino, from Edgewater, Md., after he signed the Twenty-First Century Communications and Video Accessibility Act of 2010, in the East Room of the White House in Washington. Rosa's Law is named after Marcellino who has Down syndrome.  
Source: Chicago Tribune.com

In addition to the changes made for persons with intellectual disability, the following events affected people with a disability:

## MENTAL HEALTH LAW FACTS

- Wyatt v. Stickney sets minimum standards of care for people with mental disabilities, safeguards human rights in Alabama psychiatric and mental retardation institutions, and mandates community care for residents.
- The Fair Housing Amendments Act of 1988 makes it illegal to deny access to housing based on a disability.
- Oxford House v. Babylon, establishes that a group of people with disabilities living together is a “family” for zoning purposes and cannot be excluded from a neighborhood of single-family homes (1993).
- Olmstead v. L.C. preserves the rights of people with disabilities to receive services in the least restrictive setting consistent with their need (1999).
- Congress mandates preadmission screening for nursing home applicants, annual reviews of residents to prevent “warehousing,” and ensure active treatment for residents (1987).
- Mills v. Board of Education establishes access to appropriate education through the public schools for children with disabilities (1972). The Act is now called the Individuals with Disabilities Education Act (IDEA).
- The Americans with Disabilities Act prohibits discrimination against people with physical or mental disabilities in employment, public services and all aspects of public life (1990).
- Wyatt v. Hardin establishes procedures to be followed before an institutional resident may be sterilized (1974) and sets standards governing the use of electroshock in Alabama institutions (1975, revised in 1992).



*Information taken from [www.bazelon.org](http://www.bazelon.org)*

## Agency QIDP Job Description

(Insert and discuss your agency’s QIDP job description here.)

## Agency Mission Statement

Identify the values and principles we have discussed in our agency’s mission statement.

Be sure to know and understand this agency’s mission statement.

(Insert your agency’s mission statement)

**How does your role as a QIDP contribute to your agency achieving its mission?**

## Values and Principles

The following is a list of values and principles that will be common themes in your role as a QIDP. They will also be used throughout the training modules.

❖ Active treatment	❖ People’s positive outcomes
❖ Advocacy	❖ People first language
❖ Choice and preference	❖ Quality enhancement
❖ Communication and active listening	❖ Respect and dignity
❖ Confidentiality	❖ Rights and responsibilities
❖ Documentation	❖ Self-advocacy and empowerment
❖ Involvement and participation	❖ Customer satisfaction
❖ Normalization	❖ Appreciation and diversity
❖ Self-Directed Support	❖ Person-Centered Planning

## Roles and Responsibilities of a QIDP

**Activity:** With the assistance of your trainer, check off the responsibilities you have as a QIDP. If you check no, list the person who is responsible for that task.

Roles & Responsibilities	Yes	No	If no, who?
Assure rules and regulations are being followed			
Manages financial matters			
Trains staff			
Facilitates the ISP planning process			
Coordinates the planning process			
Completes the review process			
Writes goals & objectives			
Participates in and scheduling daily activities			
Counsels individuals, guardians, and direct staff			
Leads or chairs meetings			
Acts as a community liaison			
Facilitates estate planning & wills			
Monitors the plan			
Writes & develops plans			
Develops a quality enhancement process			
Intervenes in crises			
Participates in the development of behavior intervention plans			
Assures medical needs are met			
Supervises and leads team meetings			
Assures rights & responsibilities are known and met			
Assures due process of law is followed if individuals' rights need to be restricted			
Keeps records			
Assures quality of life, health and safety are met			
Participates in and coordinates transition planning			
Shares responsibility for direct service work			
Effectively communicates with all staff and the people they serve			
Understands Active Treatment			
Models agency's values and principles			
Assists individuals to become self-advocates			
Understands appropriate rules (115, 116, etc.)			

## CONFIDENTIALITY

A word of caution: It is **VERY** important that you do not share personal information about the persons you are supporting with anyone except those who have reason to know. Health Insurance Portability and Accountability Act or HIPAA laws require this. You will learn more about HIPAA in another module. Treat the persons you support with the same respect you would treat friends or loved ones. You wouldn't spread stories about your mom or dad who had an illness, would you? Would you want others to gossip about you?

If it is necessary for you to talk about persons you support, be sure that a "Consent to Release Information" form is signed by that person or the guardian. Ask your supervisor for a copy of your agency's consent to release information form and add it to your notebook for future use in situations such as this.

## DEVELOPMENTAL DISABILITY DEFINITIONS

*NOTE: Mental retardation is still a medical term used in the Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> Edition. Otherwise staff should be using the term Intellectual Disability. The DSM-IV manual is published by the American Psychiatric Association and covers all mental health disorders for both children and adults.*

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

### **A – Mental Retardation**

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.



### **B – Related Condition**

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

- 1) It is attributable to-  
Cerebral palsy or epilepsy; or any other condition, other than mental illness, found to be closely related to intellectual disability because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of persons with an intellectual disability, and requires treatment or services similar to those required for these persons.
- 2) It is manifested before the individual reaches age 22.

- 3) It is likely to continue indefinitely.
- 4) 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 will interfere with daily functions.

**You may notice that some persons may have a diagnosis of cerebral palsy, epilepsy, or autism and not be considered to be developmentally disabled. That's because some individuals with a diagnosis with cerebral palsy, epilepsy, or autism are not considered to have a developmental disability because they do not have functional limitations in three or more major life activities.**

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. The term developmental delay refers to children between the ages of 3 and 9 years. You can read more on this topic at:

**<http://www.med.umich.edu/1Libr/yourchild/devmile.htm>**

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

A child 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.

**Children from birth to age 9** are considered to have a developmental disability without demonstrating substantial functional limitations in at least 3 major life activities, if they have **an** Intellectual Disability.

## 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 developmentally 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:

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

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

### Mild

People are classified as having a mild intellectual disability if their I.Q. scores range from about 50 to about 70, have substantial difficulties in at least two areas of adaptive behavior and those difficulties are first evidenced in a developmental period before adulthood. Females are less likely than males to be identified with mild intellectual disabilities. Children are identified as having a 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 verb ideas.
- ❖ 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. (Diagnostic & Statistical Manual, 2004)

**Moderate**

People are classified as having a moderate intellectual disability if they have an I.Q. score range of about 35 to about 55 and have substantial adaptive behavior difficulties in several areas. Most persons who have moderate intellectual disability are first diagnosed with this classification in the preschool years. People with a 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 are identified as having severe intellectual disability if they have IQ scores ranging from about 20 to about 40 and 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 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

People with a profound intellectual disability are classified as having IQ scores between 0 and about 25. Skills vary from the 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 a spoon and fork, but often spill food.
- ❖ Can put on a skirt or pants, but need 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.
- ❖ Understand simple verbal communications.
- ❖ Participate 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.**

## **What is Adaptive Behavior?**

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

- 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, including 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 necessarily be able to tell time)
- ❖ I need 2 coins that match this picture to buy a soda.  
(doesn't need to necessarily be able to count money/make 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 necessarily be able to count)

## WHY DO SOME PEOPLE HAVE AN INTELLECTUAL DISABILITY?

**Some causes of intellectual disabilities are:**

### **Difficulties before birth**

Lack of adequate prenatal care

### **Difficulties during pregnancy**

Diseases: measles, syphilis, HIV, etc.

Alcohol/drug use/smoking by mothers or fathers (fetal alcohol syndrome/cocaine addicted babies, etc.)

### **At birth challenges/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 HELP PREVENT INTELLECTUAL DISABILITIES

- ❖ 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.

## **THE MAJOR TYPES OF DEVELOPMENTAL DISABILITIES**

### **WHAT IS CEREBRAL PALSY (CP)?**

Cerebral Palsy (CP) is a condition, usually from birth, which causes difficulties with movement, delayed motor development, lack of coordination, and sometimes intellectual disabilities.

#### **Physical Characteristics of Some People with Cerebral Palsy:**

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 (CP)?**

The cause of the majority of CP cases is uncertain. It is believed that 40% to 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, CP can result from other causes including 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 intellectually disabled, 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. <http://www.ucp.org/>

## 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 be 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, and temperatures 90° or higher can trigger seizures in some people.

Source: Eastern Paralyzed Veterans Association.

<http://www.naec-epilepsy.org/>

**You may notice that some persons with a diagnosis of cerebral palsy, epilepsy, or autism are not considered to be developmentally disabled. That's because they do not have functional limitations in three or more major life activities.**

**ACTIVITY:**

**Directions: Read over these scenarios. 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, he cannot work a regular job.

**Q: Does Tom have a developmental disability? Why or why not?**

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

**Q: Does Ted have a developmental disability? Why or why not?**

**Q: What might Ted ask us for help with?**

## WHAT ARE AUTISM SPECTRUM DISORDERS?

Autism spectrum disorders (ASDs) are a group of developmental disabilities that can cause significant social, communication and behavioral challenges. People with ASDs handle information in their brain differently than other people.

ASDs are "spectrum disorders." That means ASDs affect each person in different ways, and can range from very mild to severe. People with ASDs share some similar symptoms, such as difficulties with social interaction, but there are differences in when the symptoms start, how severe they are, and the exact nature of the symptoms. Data indicate an increasing incidence of autism diagnosis in children due to the change in diagnosis.

(<http://www.sciencedaily.com/releases/2008/04/080408112107.htm>)

Autism can cause challenges with effective communication such as:

- Responding to others
- Unusual behavior
- Verbal and nonverbal communication skills
- Poor social skills which hinder the development of social relationships
- Responses to things which stimulate the senses.

### The categories in the autism spectrum include:

#### Autistic Disorder

**Autistic Disorder** (also called "classic" autism.)

This is what most people think of when hearing the word "autism." People with autistic disorder usually have significant language delays, social and communication challenges, and unusual behaviors and interests. Many people with autistic disorder also have intellectual disability. <http://www.cdc.gov/ncbddd/autism/facts.html>

#### Asperger's Disorder

Asperger's Disorder is a milder variant of Autistic Disorder. In Asperger's Disorder, affected individuals are characterized by social isolation and eccentric behavior in childhood. There are impairments in two-sided social interaction and non-verbal communication. Though grammatically correct, their speech may sound peculiar due to abnormalities of inflection and a repetitive pattern. Clumsiness may be prominent both in their articulation and gross motor behavior. They usually have a circumscribed area of interest which usually leaves no space for more age appropriate, common interests. The name "Asperger" comes from Hans Asperger, an Austrian physician who first described the syndrome in 1944. <http://www.aspergers.com/>

## **Childhood Disintegrative Disorder**

Childhood disintegrative disorder, also known as Heller's syndrome, is a condition in which children develop normally until ages 2 to 4, but then demonstrate a severe loss of social, communication and other skills.

Childhood disintegrative disorder is very much like autism. Both are among the group of disorders known as pervasive developmental disorders, or autism spectrum disorders. And both involve normal development followed by significant loss of language, social, play and motor skills. However, childhood disintegrative disorder typically occurs later than autism and involves a more dramatic loss of skills. In addition, childhood disintegrative disorder is far less common than autism.

**<http://www.mayoclinic.com/health/childhood-disintegrative-disorder/DS00801>**

## **Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism)**

The diagnostic category of pervasive developmental disorders (PDD) refers to a group of disorders characterized by delays in the development of socialization and communication skills. Parents may note symptoms as early as infancy, although the typical age of onset is before 3 years of age. Symptoms may include difficulty using and understanding language; difficulty relating to people, objects, and events; unusual play with toys and other objects; difficulty with changes in routine or familiar surroundings, and repetitive body movements or behavior patterns.

**<http://www.ninds.nih.gov/disorders/pdd/pdd.htm>**

## **Rett Syndrome**

Rett syndrome is a unique developmental disorder that is first recognized in infancy and seen almost always in girls, but can be rarely seen in boys. It is caused by mutations on the X chromosome on a gene called *MECP2*. There are more than 200 different mutations found on the *MECP2* gene. Most of these mutations are found in eight different "hot spots." This disorder strikes all racial and ethnic groups, and occurs worldwide in 1 of every 10,000 to 23,000 female births. It is *not* a degenerative disorder. Rett syndrome causes difficulties in brain function that are responsible for cognitive, sensory, emotional, motor and autonomic function. These can include learning, speech, sensory sensations, mood, movement, breathing, cardiac function, and even chewing, swallowing, and digestion.

**<http://www.rettsyndrome.org/about-rett-syndrome.html>**

## Life Stressors and Mental Health

An individual with a developmental disability experiences life stressors. As a QIDP, you need to be aware of these since they represent risk factors to be considered when developing plans/programs. Consider why life stressors that affect all of us have the potential for a more devastating effect on a person with a developmental disability. Individuals with developmental disabilities frequently have poor coping skills which increase their risk of developing problems. Additionally, many people with DD have spent most or part of their lives in institutional type settings, and thus have become dependent on others for decision-making. This can be stressful for them when they are suddenly asked to make choices and advocate for themselves in the person-centered world.

Other life stressors that could be risk factors include:

- Lack of control over their life
- Loss of a loved one
- Change in health status
- Birth of sibling, being surpassed by younger siblings
- Change in environment (residence, work)
- Onset of puberty
- Lack of assertiveness
- Negative environmental conditions (noise, temperature, crowding)
- Lack of communication skills
- Repeated failures or fear of failure
- Overprotection
- Being pushed toward over achievement
- Menopause
- Mental illnesses

## **What is Mental Illness**

### **Are intellectual disability and mental illness the same?**

No, a developmental disability is TOTALLY different from mental illness. Mental illness is not the same as intellectual disability.

Mental illness is a disorder that causes abnormal behavior and mood difficulties. It affects a person's emotions.

When a behavior or emotion falls outside the "normal" range the person may:

Be happy one minute and sad the next.

Have outbursts of anger or crying.

Need to do things over and over in order to feel good.

Have hallucinations or delusions.

Withdraw from contact with others.

React with great fear after being comfortable with a situation before.

### **How are Mental Illnesses Diagnosed in People with Intellectual Disabilities?**

A bio-psychosocial assessment enables us to evaluate physical, neurological and psychological aspects, combined with interview and observation, as well as assessment of influences from the environment. Classification of mental illness is made according to the categories established in the Diagnostic and Statistical Manual of Mental Disorders (DSM IV).

Additionally, there are standardized screening tools available that can predict the existence of psychiatric diagnoses in persons who have intellectual disabilities.

### **What is the Frequency?**

Estimates of the frequency of dual diagnoses vary widely from 20% - 35% of people with intellectual disabilities having the co-existence of a psychiatric disorder, as compared to 16% - 20% in the general population.

### **What Types of Mental Illnesses are Found in Persons Who Have Mental Retardation?**

The types of psychiatric disorders found are the same as those found in the general population. However, these individual's life circumstances or levels of intellectual functioning may alter the appearance of the symptoms. Depression, anxiety, personality disorders and psychoses are all types of psychiatric challenges that have been diagnosed in persons who have mental retardation. Further, persons who have a dual diagnosis can be found at all levels of mental retardation (mild, moderate, severe and profound).

## What is a Dual Diagnosis?

A person with a dual diagnosis has both a developmental disability and a mental illness.

A “Double Jeopardy” effect on an individual occurs when two disabilities, a developmental and mental health issue, are present at the same time. This can have a profound effect on the individual’s life.

The result of this combination of disorders is often a **diagnostic overshadowing**, meaning that mental health problems are ignored because symptoms are judged to be part of the disability. Since this individual has both issues, it becomes difficult to determine which of the person’s behaviors are due to a mental illness and what is due to the nature of the developmental disability.

### Facts about People who are Dually Diagnosed

When intellectual disabilities and mental illness co-exist, a person is said to have a dual diagnosis.



The service plans of individuals who have dual diagnosis must address both issues. Treatment of the mental illness is directed by a psychiatrist or other mental health professional working in conjunction with a Board Certified Behavior Analyst. Persons who are dually diagnosed should have a formal behavior treatment program. Persons who receive psychotropic medications should be evaluated by a psychiatrist and receive a professional treatment plan. You, as a QIDP, must coordinate both approaches.

Many issues must be considered to distinguish between mental illness and behavioral issues. Often an individual responds atypically to illnesses making diagnosis and treatment very difficult. It is important to document the signs and symptoms that may indicate mental illness.

### Is this a new Phenomenon?

The identification of psychiatric disorders in persons with intellectual disabilities is not a new phenomenon, but has received much more attention in recent years. The process of deinstitutionalization has highlighted the visibility of dual diagnosis. During the era of institutionalization, these persons were kept in the back wards of residential institutions without appropriate care and treatment. Research outcomes have demonstrated that persons with dual diagnoses respond favorably to a combination of medication management and behavior treatment. Persons who receive evidence-based behavioral treatment have shown improvement in symptoms and in some cases have been able to reduce their medications

**Throughout this training, you will be tracking a woman named Rachel. She is an individual you help support. You are responsible for providing the best services possible to aid Rachel in developing the skills necessary to become independent.**

## Scenario One

**Directions:** Read over the following scenario. As you do so, think back to our earlier discussion of your responsibilities and the list of values and principles. Use what you know to respond to the discussion questions.



Rachel is a 34 year old, single female with a diagnosis of moderate intellectually disability, a severe blood disorder (must not have iron in her diet), and an eating disorder. She is talkative and relates more to staff than her peers.

Rachel has independent self care skills, takes medications for her blood disorder and she lives in a 16 bed ICF/CILA. She also attends a day training program six hours a day (½ day work ½ day DT). Her long range goal is an apartment with a husband. Her male interests change from week to week. Rachel loves race cars and her idol is Kyle Busch.

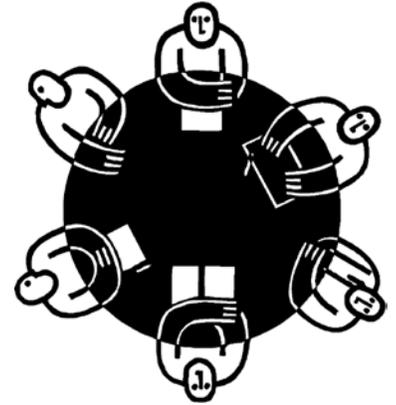
She is theatrical when upset or excited. She has strong family ties. Her family lives close by and she is very concerned about pleasing her parents. Her parents want to be kept informed about everything. She is an only child and her parents are legal guardians.

Direct service staff say it is difficult to keep Rachel focused on any activity due to her “constant talking.” Therefore, they are asking for a restrictive program of time out. You have some questions as to whether or not time out is a good idea. Her goals (check writing, developing shopping lists, and street crossing) are interrupted by her inability to focus. Her parents are not opposed to time out as they make her sit in a corner when at home.

She likes to go out, but only with staff. Rachel also passes gas which prompts angry responses from her peers and staff and causes them to separate from her. She has lived in this location for five years.

## Scenario One Discussion Questions

1. What are three or four issues you need to address as a QIDP?
2. On Rachel's shopping list, she has chosen raisins, which are high in iron. How will you balance Rachel's right to have choices with her need for a restrictive diet?
3. How would you help Rachel choose additional leisure activities?
4. Rachel seems to want her own home and a husband. Are you sure that is what she really wants? What techniques would you use to clarify what Rachel really wants?
5. Staff has asked for a restrictive program to help Rachel control her "constant talking." What are the pros and cons for this type of program?



## Questions as Rachel's QIDP

**Directions:** Use the space below to make a list of questions that come to your mind regarding Rachel that you would want to explore as a QIDP.

## A DAY IN THE LIFE OF THE OTHER GUY

As the overhead light comes on, I hear the voice of someone saying, "Time to get up, sweetie-pie." I don't recognize the voice. Must be a new worker. Before I can scarcely open my eyes, a chill comes over me as the blankets on my bed are pulled down to reveal my uncovered legs. My nightgown has shifted up during the night and my "everything" is showing. "Time to get out of bed, honey. Let's go, let's go."



By now, I have been pulled into a sitting position and my worker is reminding me that we have to hurry and get ready for breakfast. Before I know it, I have been lifted into my wheelchair, and am on my way to the bathroom. I am placed on the toilet and left to go to the bathroom with the door standing wide open. Brrrr.... I'm cold. I let out a shriek!

I wait and wait. No one comes to assist me. I finally hear the voice of my worker. (Wish she would tell me her name). "Ready to get into the tub?" I prefer to take a shower, but she doesn't have my communication board so I can't tell her that. I am soon sitting in a tub of lukewarm water. Brrrr.... I'm cold. I let out another shriek!

While sitting in the tub, another worker comes into the bathroom to talk to my worker. They are making plans to go to the movies Friday night. My worker tells the other worker that I was stubborn about getting up this morning. She tells her that I wasn't very cooperative about taking a bath. She says I yelled and made a lot of noise.

The other worker leaves, and my worker tells me that we don't have time to shampoo my hair today. It will have to wait until tomorrow. Doesn't she know how important it is to have my hair look nice EVERY DAY?

After my bath, it is time to get dressed. My worker has chosen my outfit for the day – a pair of jeans with a broken zipper and an old tee shirt. She tells me that the tee shirt will cover up the broken zipper. She runs a brush through my hair, but says there is no time to fix it before breakfast. I try to tell her that I want to wear make-up today, but she doesn't listen. "Come on honey, we've got to get going if you want to eat breakfast today."

It's off to the kitchen where my breakfast is sitting on the table. The eggs and toast are cold, and my milk is warm. Grape jelly is already spread on my toast. I hate grape jelly. I don't want to eat it. I shake my head "no." My worker says that I better shape up or I won't get to eat anything before I go to work. She pushes my plate closer to me, but has not given me my adaptive silverware so that I can feed myself. "Boy, she's stubborn," she announces to the others in the kitchen. After 10 minutes my worker tells me it's time to leave for work.

It's back to my room to get my coat. There's no time to brush my teeth and wash the milk off my face. She doesn't ask if I need to use the bathroom before leaving for work. My communication board is lying on my dresser, and the worker grabs it and sticks it into my bag. (Wish she would tell me her name). "Let's go honey, the bus is waiting on you."

*Sue Blakestead*

*Director of Resource Services*

*American Institute of Mental Retardation*



## MODULE 2



# EFFECTIVE LEADERSHIP

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*I can be my own person.  
I am a strong person  
I have had to fight for my independence.  
I'm very stubborn.  
I don't want help.  
I fight for what I really believe in.  
I've never given up on what I want and  
need.*

*Source: Paige Doyle, Self-Advocate*



## Background Reading

### Learning to Lead

*Learning to Lead: An Action Guide for Success* by Elwood N. Chapman and Patricia Heim

### Team Building

*Team Building: An Exercise in Leadership* by Robert B. Maddux

Chapters 6, 15, & 18 of *Developing Staff Competencies for Supporting People with Developmental Disabilities* by James F. Gardner and Michael S. Chapman

*Facilitation Skills for Team Leaders* by Charles L. Martin and Donald Hackett

*Developing Positive Assertiveness: Practical Techniques for Personal Success* by Sam R. Lloyd

*Managing Disagreement Constructively: Conflict Management in Organizations* by Herbert S. Kindler

## On Leadership

Leadership is an invisible strand as mysterious as it is powerful. It pulls and it bonds. It is a catalyst that creates unity out of disorder. Yet, it defies definition. No combination of talents can guarantee it. No process of training can create it where the spark does not exist.

The qualities of leadership are universal; they are found in the poor and the rich, the humble and the proud, the common man, and the brilliant thinker, they are qualities that suggest paradox rather than pattern. But wherever they are found, leadership makes things happen.

The most precious and intangible quality of leadership is trust - the confidence that the one who leads will act in the best interest of those who follow - the assurance that he will serve the group without sacrificing the rights of the individual.

Leadership's imperative is a "sense of rightness" -- knowing when to advance and when to pause, when to criticize and when to praise, how to encourage others to excel. From the leader's reserves of energy and optimism, his followers draw strength. In his determination and self-confidence, they find inspiration. In its highest sense, leadership is integrity. This command by conscience asserts itself more by commitment and example than by directive. Integrity recognizes external obligations, but it heeds the quiet voice within, rather than the clamor without.

*--International Business Machines, 1974*

## Opportunities for Effective Communication

As a liaison, you will have numerous opportunities for communicating and linking with others. Look over the following chart and add other opportunities for communication. Indicate the potential problems that may prevent effective communication. As you read in this module, identify ways of avoiding or minimizing potential barriers to effective communication and how they are overcome or resolved.



The *American Heritage Dictionary* defines liaison as:

1. a. Communication between different groups or units of an organization.  
b. A channel or means of communication.
2. A close relationship or link

### Opportunities for Effective Communication (cont.)

Who	When	Potential Barriers	Solutions
<b>Individual</b>	<ul style="list-style-type: none"> <li>❖ daily living</li> <li>❖ self-assessment</li> <li>❖ meetings</li> <li>❖ counseling</li> <li>❖ opportunities for choice/preference</li> <li>❖</li> <li>❖</li> <li>❖</li> <li>❖</li> </ul>	<ul style="list-style-type: none"> <li>❖</li> <li>❖</li> <li>❖</li> <li>❖</li> <li>❖</li> </ul>	
<b>Families</b>	<ul style="list-style-type: none"> <li>❖ visits</li> <li>❖ meetings</li> <li>❖ problems</li> <li>❖ medication approval</li> <li>❖ transitions</li> <li>❖ placements</li> <li>❖</li> <li>❖</li> <li>❖</li> </ul>	<ul style="list-style-type: none"> <li>❖</li> <li>❖</li> <li>❖</li> <li>❖</li> <li>❖</li> <li>❖</li> <li>❖</li> </ul>	

Who	When	Potential Barriers	Solutions
<b>Surveyors</b>	❖  ❖  ❖  ❖  ❖	❖  ❖  ❖  ❖  ❖	



## NON-VERBAL COMMUNICATION

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

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

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

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

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

Sometimes this skill is not developed during developmental learning stages. For example, a person with autism or autism spectrum disorder may never learn to use or understand non-verbal cues. Create a communication dictionary for all persons who are non-verbal or who need communication support.

### Listening Effectively

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

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

## Communication Functions

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

**Create a chart like this for each of the individuals on your caseload who are non-verbal or need communication supports.**

## Coaching/Training Tips

- ❖ Use common terms rather than long or unusual words.
- ❖ Avoid using jargon or technical terminology.
- ❖ Avoid emotional words or phrases.
- ❖ Combine communication with the previous knowledge and experience of trainees.
- ❖ Encourage trainees to think through the new job for themselves.
- ❖ Ask questions to check the understanding of the trainee.
- ❖ Avoid using yes or no questions.
- ❖ Use indirect/open-ended questions to allow trainees to discover for themselves some of the reasons and some details.
- ❖ Note all training points in advance of the training session.
- ❖ Arrange the points in a logical order.
- ❖ Gather all training material in advance of the training session.
- ❖ Allow adequate time for the training session.
- ❖ Attempt to minimize distractions.
- ❖ Explain why this is important.
- ❖ Explain how it fits into the larger picture.
- ❖ Break up what you are teaching into small, digestible chunks.
- ❖ Assess the trainee's power of recall and aptitude periodically.
- ❖ Provide opportunities for practice.
- ❖ Offer incentives for learning the task.
- ❖ Emphasize what the trainee does right, not what is done wrong.



- ❖ Offer a reward for learning the task.
- ❖ Follow-up after the trainee has been doing the task for a while.
- ❖ Show enthusiasm when you are coaching.
- ❖ Get the learner to participate.
- ❖ Make proper use of the equipment and material for demonstration and practice.
- ❖ Ensure that the trainee's final performance produces the desired outcome.

## Coaching Strategies

A QIDP wears many hats throughout the work day. They may also carry a coach's whistle.



### Strategies for Providing Leadership & Coaching Include...

#### 1. Investing Attention in Employees

- ❖ Recognize employee's accomplishments and contributions.
- ❖ Be accessible.
- ❖ Communicate with employees on a regular basis.
- ❖ Provide special recognition awards/privileges.
- ❖ Provide opportunity for involvement in some aspect of the organizational structure of the agency or facility to impact the management operation of the organization.

#### 2. Facilitating Learning

- ❖ Facilitating learning means teaching; coaching and supporting employees to not only learn how to perform, but also why they need to perform in a prescribed way.
- ❖ Give information so the employee knows the importance of why s/he must do what s/he is being asked to do.
- ❖ Everyone you supervise will make mistakes. The goal is to help the person learn from them.
- ❖ Identify specific skill areas for improvement as well as strengths.
- ❖ Make sure the employee has the tools needed to do what is expected.

## Strategies for Providing Leadership & Coaching (continued)

### 3. Acknowledging and Building Upon the Strengths of Employees . . .

- ❖ Listen to the opinions and suggestions of employees, ask for input and give feedback so the person knows s/he has been heard.
- ❖ Consistently provide positive, constructive feedback.
- ❖ Acknowledge success.
- ❖ Emphasize strengths.

### 4. Practicing What You Preach

- ❖ Do what you say you will do and doing what you tell others to do.
- ❖ Be accountable for what you say and do.
- ❖ Acknowledge failures and successes.
- ❖ Admit mistakes and learn from them.

### 5. Concentrating on Solutions, Rather Than Problems...

- ❖ Determine what the problem is in order to quickly move on to find a solution.
- ❖ Avoiding focusing on assessing blame.
- ❖ Refocusing the team by putting energy into identifying strengths and solutions.

### 6. Communicating Effectively

- ❖ Listen carefully.
- ❖ Prevent misunderstanding by paraphrasing and verifying.
- ❖ Pay attention to nonverbal communication.
- ❖ Use language to foster communication not argument.
- ❖ Be sensitive to the emotional content of language.
- ❖ Be aware of jargon.

### 7. Using Feedback Effectively

- ❖ Be proactive.
- ❖ Be specific.
- ❖ Separate what the person did and needs to do differently from its emotional effect on you.
- ❖ Offer feedback on behavior or conditions that the listener is able to change.
- ❖ Feedback should be offered as soon as possible after the incident.
- ❖ Check for clarity.

## Scenario Two

***Directions:*** Read over the following scenario. Please think of Rachel as someone who is supported in your agency. As you do so, think back to what you learned in this module. Use what you know to respond to the discussion questions that follow.

A special team meeting is being held with the Inter-Disciplinary Team (IDT) due to problems Rachel is having on her job site. Rachel received a warning notice from work saying she may lose her paying job due to lack of attention. Her work supervisor indicated that Rachel talks incessantly while at work, resulting in a poor production level. Her talking is also distracting her fellow workers.

Direct support staff report that she has been observed talking excessively to male co-workers, requiring extra time from them to redirect her.

On the days that these behaviors occur, staff removes her from production role and puts her on alternative work activities.

Her parents have noticed that her recent paychecks are less than usual and have called to investigate. They do not understand the problem, because at home they have her sit in the corner a while and that usually takes care of the problem. Service providers are recommending time out to deal with Rachel's disruptive behavior.

However, in view of best practice, you as her QIDP have some real concerns with the use of time out.

## Scenario Two Discussion Questions



1. What are three or four issues that you need to address as a QIDP?
2. How will you clarify the goal of the meeting? (What do you think Rachel wants out of the meeting?)
3. How will you convey the intended message to participants?
4. What information does the IDT need?
5. Are there past records you should review? If so, which ones?

6. What feedback/information would you like from each of the IDT members?
7. How will you encourage all members of the IDT to share their thoughts?
8. Is there a behavior intervention issue?
9. What strategies could you utilize to facilitate problem solving so that solutions are not limited to *time out*?
10. How can you address actions already taken by staff?
11. What will you do if members of the IDT do not agree?
12. What is the best way to implement the decisions from the IDT meeting?
13. How will you evaluate the success of the implementation plan?



## Questions as Rachel's QIDP

***Directions:*** Use the space below to make a list of questions that come to your mind regarding Rachel that you would want to explore as her QIDP.

## Scenario Three

**Directions:** Read over the following scenario. Please think of Rachel as someone who is supported in your agency. As you do so, think back to what you learned in this module. Use what you know to respond to the discussion questions that follow.

You have arranged an IDT meeting to address concerns related to Rachel's eating disorder.

The dietician asserts that Rachel must eat a specific and restricted diet which she has prepared based on a physician's order. Rachel's mother stated to you earlier that she does not want her daughter to be deprived of normal choices and ranges of experiences in her diet.

The direct support staff argues that the proposed diet restrictions are not going to work because she is getting snacks at the workshop during the day. The workshop staff states that the problem is a result of what she eats while on weekend home visits, not what she gets at the workshop.



## Scenario Three Discussion Questions

1. What are three or four issues that you need to address as a QIDP?



2. How will you clarify the goal of the meeting? (What do you think Rachel wants out of the meeting?)
3. How can you support Rachel's choices and still stay within the parameters of her medical condition?
4. What information does the IDT need?
5. Are there past records you should review? If so, which ones?

6. What feedback/information would you like from each of the IDT members (including Rachel, family members, staff, etc.)?
  
7. What are the risks and benefits of ignoring the eating disorder?
  
8. How will you facilitate the establishment of a consensus?
  
9. What is the best way to implement the decisions from the IDT meeting?
  
10. How will you ensure that everyone follows the plan as it is written?
  
11. How will you evaluate the success of the implementation plan?



## Questions as Rachel's QIDP

***Directions:*** Use the space below to make a list of questions that come to your mind regarding Rachel that you would want to explore as her QIDP.

## Say What?

**Directions:** Read each of the following statements by emphasizing the bolded word. Pay attention as to how the meaning changes with each statement.

1. **I** didn't say you were stupid.
2. I **didn't** say you were stupid.
3. I didn't **say** you were stupid.
4. I didn't say **you** were stupid.
5. I didn't say you **were** stupid.
6. I didn't say you were **stupid**.



## Remember

I may not  
remember what you say to me.

I may not  
remember what you did to me.

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

Maya Angelou

## Don't Dictate...Facilitate: How to Gain Consensus Without Being a Tyrant

by Diane DiResta, for *Winning Team*

Do discussions you're leading shut down when you're hoping they will open up? Is one person always dominating meetings? Do team members not in agreement sabotage your efforts? Chances are you're contributing to the meltdown. Here are a few reasons why team members crash and burn in team meetings.

**The team leader talks too much.** Lecturing leads to some of the lowest levels of learning and retention. People can easily tune out. According to adult learning research, adults want a sense of control. When the leader does most of the reporting or speaking, the team does not feel involved and will not buy into new ideas so readily. Sell, don't tell.

**Team members don't listen.** Even if the team leader is listening, others may not be. Is the role of the leader to facilitate the discussion so that others can be heard? Members may talk over one another, take credit for someone else's idea, or discredit a person's suggestions. These behaviors demonstrate a failure to listen. When people aren't heard, they don't feel respected. Without respect, the members won't support each other.

**One member dominates.** This can happen when the team leader gives one person the floor. More often, it's a result of a strong personality with unmet needs. He or she can intimidate others. The challenge for the team leader is to meet the needs of the dominating person while encouraging others to contribute.

A facilitator orchestrates but does not take center stage. The focus is on the team. This requires a change of mindset. Many leaders fall back on lecturing, telling, and instructing instead of coordinating and facilitating. It's easier to do what's familiar. And some leaders believe to facilitate is to give up control.

Why facilitate? Team members feel heard and respected. This increases morale. More ideas are captured for greater innovation and productivity. Mistakes, glitches and weak strategies are identified, reducing costly errors. Leaders earn support and commitment when the team "owns" the idea. Finally, work is more fun when everybody feels important.

Good facilitators do the following:

**Speak less and listen more.** Be clear about your objective. If your objective is to get ideas from the group or to gain support for a new initiative, state the purpose, ask questions, and listen. To facilitate a meeting effectively, speak 20% of the time and listen 80% of the time.

**Keep the discussion on track.** Your job is to make sure that the major points are covered through discussion. A good facilitator preplans the time for each agenda item but is flexible enough to depart from the agenda. The challenge is to know when to rein in the discussion without turning people off. Facilitation is like fishing with a net. You let out the net far enough to catch the fish—the fish swim into the net.



## **MODULE 3**



## **ASSESSING AND ENHANCING QUALITY OUTCOMES**

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*“Do you see my behavior,  
Or, do you see my story?”*

*Source: a Self-advocate.*

## Background Reading

*Developing Staff Competencies for Supporting People with Developmental Disabilities: An Orientation Handbook* by James F. Gardner and Michael S. Chapman. Chapter 19.

*Creating Individual Supports for People with Developmental Disabilities: A Mandate for Change at Many Levels* by Valerie J. Bradley, John W. Ashbaugh, and Bruce C. Blaney. Chapter 26.

*Challenges for a Service System in Transition: Ensuring Quality Community Experiences for Persons with Developmental Disabilities* by Mary F. Hayden and Brian H. Aberly. Chapter 9.

*Outcome Management: Achieving Outcomes for People with Disabilities* by Art Dykstra, Jr.



## Habilitation vs. Rehabilitation

Programs for individuals with a developmental disability need to focus both on habilitation and rehabilitation.

First, QIDPs need to know the difference between habilitation and rehabilitation.

Habilitation--The process of supplying a person with the means to develop maximum independence in activities of daily living through training or treatment.

Rehabilitation--The restoration of an individual or a part to normal or near normal function after a disabling disease, injury, addiction, or incarceration.

Anderson, K., Anderson, L., & Ganze, W. (Ed.). (1994). Mosby's medical dictionary (4<sup>th</sup> ed.). St. Louis: Mosby.

## Changing Philosophies in Service and Program Planning

The change in emphasis from the "traditional" method to person-centered supports is a movement away from "fixing" a person towards maximizing a person's quality of life.

The traditional method is characterized by a focus on:

- ❖ identifying deficits
- ❖ planning interventions to remove deficits

The person-centered method is characterized by a focus on the individual's:

- ❖ desired lifestyle outcomes (hopes, dreams, etc.)
- ❖ abilities
- ❖ preferences/choices
- ❖ current circumstances

Examples of person-centered supports include:

- People living in homes they choose for themselves.
- People living with people they choose to live with.
- People choosing their leisure-time activities while they are at home just like everyone else.
- Support staff and others respecting the person's home just as they do the homes of other people they might visit. For example, they knock before entering the home, or the person's room, and they ask people before using their things, like phones or television.
- People are employed, or are engaged in daily activities that they enjoy and that help them develop and maintain relationships they feel are important.

## Interviewing: Knowing the People You Support

It is important to know the people you support, including their desires in life. You learn about someone in many ways. Some ways are informal, such as visiting with the person. Some ways are more formal; an interview is a formal way to gather information from an individual at a particular time and place in his or her life. Knowing this information from an individual will help to better individualize services and supports, and guide person centered plans. You may also want to interview family, friends, and caregivers to help create a balanced picture of a person's values and desires.

Before interviewing someone, first determine the purpose of the interview and the process and questions that you will use. Questions you consider should fall in line with quality of life factors common to each of us. For example, does the person:

- ❖ Feel safe
- ❖ Feel respected
- ❖ Choose where and with whom the person lives
- ❖ Understand and exercise the citizen rights that are important to them
- ❖ Experience freedom from abuse and neglect
- ❖ Have the best possible health
- ❖ Have enough friends
- ❖ Choose where to work and the type of work
- ❖ Set personal goals
- ❖ Have a religious and spiritual life
- ❖ Have the ability to respond to emergencies
- ❖ Take a vacation
- ❖ Manage and save money
- ❖ Enjoy a hobby or other leisure interest
- ❖ Pursue other interests

After you have decided the process and line of questioning, whether it is based upon an accreditation agency's standards or some other format, it is important to recognize what is discovered as being important to the person today may not be as important in the future. People often change their minds over time as a result of new and different experiences and understandings. For instance, a person might indicate a desire to live in an apartment with a number of other people, but later realize that having only one housemate would allow for more privacy.

It is important for QIDPs to be in tune to very subtle as well as major behavioral forms of communication by clarifying your understanding of what the person is telling you. Ensure open lines of two-way communication. Reading and reviewing the person's case history and other documents ahead of the discussion may assist you in understanding the person. However, the information you gather directly from the individual and the support person is the most important and relevant at the time.

## Individual Life Quality Outcomes

This section can be used as a guide to help you increase the level of excellence of your services and supports. It can be used as a tool to strengthen your relationships with the people you serve and in promoting activities which will enhance the quality of their lives.

Continual assessment and reassessment of service quality are essential to assuring, as best you can, the individual qualities of life and to advancing the overall level of service quality. Quality improvement is a process which requires continuous attention to the services that are provided and the individual's satisfaction with those services.

The following is a list of 24 service quality outcomes.

### CHOICE

1. Individuals identify their needs, wants, likes and dislikes.
2. Individuals make major life decisions.
3. Individuals make decisions regarding everyday matters.
4. Individuals have a major role in choosing the providers of their services and supports.
5. Individuals' services and supports change as wants, needs and preferences change.

### RELATIONSHIPS

6. Individuals have friends and caring relationships (this could include romantic).
7. Individuals build community supports which may include family, friends, service providers/professionals and other community members.

### LIFESTYLE

8. Individuals are part of the mainstream of community life and live, work and play in integrated environments.
9. Individuals' lifestyles reflect their cultural preferences.
10. Individuals are independent and productive.
11. Individuals have stable living arrangements.
12. Individuals are comfortable where they live.

## HEALTH AND WELL-BEING

13. Individuals are safe.
14. Individuals have the best possible health.
15. Individuals know what to do in the event of threats to health, safety and well-being.
16. Individuals have access to needed health care.

## RIGHTS

17. Individuals exercise rights and responsibilities.
18. Individuals are free from abuse, neglect and exploitation.
19. Individuals are treated with dignity and respect.
20. Individuals receive appropriate generic services and supports.
21. Individuals have advocates and/or access to advocacy services.

## SATISFACTION

22. Individuals achieve personal goals.
23. Individuals are satisfied with services and supports.
24. Individuals are satisfied with their lives.

## SUGGESTIONS FOR SERVICE QUALITY ENHANCEMENT

The following provides information and suggestions for service quality enhancement and self-assessment for each of these 24 outcomes:

### CHOICE

1. Individuals identify their needs, wants, likes and dislikes.

### About this Outcome

This outcome recognizes that all people have individual needs, wants, likes and dislikes and can express them in some way (with words, gestures or behaviors) so that the people around them are aware of and understand their preferences and respond to them. Their ISP and services and supports are centered on the individual and take into account their needs and preferences. There are many ways to find out about someone's preferences. Some of the information comes from asking the person, family member, friends and people who work with the individual about the things he or she likes to do and can do well. It is also important to find out what prevents the person from doing the things he or she likes to do. Additional supports (such as interpreter services or communication devices) may be necessary help overcome communication barriers. If people can't talk for

themselves with or without supports, it's important to spend time with them and to observe how they react to different situations in order to understand their preferences.

### **Examples of Opportunities for Service Quality Enhancement**

This outcome is accomplished when the wants, needs, likes and dislikes of individuals are known (or there is an active plan to identify those preferences) through:

- talking with or spending time with each person served and talking to others who know him or her well;
- providing additional supports as necessary to assist each person to communicate his or her preferences;
- including each person or people who know him or her best in planning for services and supports; and,
- knowing the goals in each person's ISP.
- Individual preferences are reflected in each person's daily life activities.

#### **CHOICE**

#### **2. Individuals make major life decisions.**

### **About this Outcome**

This outcome is about individuals exercising control over major life decisions. To make sure that people with developmental disabilities have opportunities for decision-making, individuals (and where appropriate, their parents, legal guardian, or conservator) should participate in decisions affecting their own lives, including, but not limited to, where and with whom they live, their relationships with people in their community, the way in which they spend their time (including education, employment, leisure), and the pursuit of their own personal future. In addition, they should have the opportunity to actively participate in the development of their Individual Service Plan (ISP) including the planning for and selection of services and supports. Other ways to support people in developing this important skill include providing: (1) options to choose from; (2) understandable information about each option; and (3) opportunities to directly experience each option. Agencies should respect the choices made by individuals, or where appropriate, their parents, legal guardians, or conservator.

### **Examples of Opportunities for Service Quality Enhancement**

#### **Support the individuals in making major decisions, including:**

- where to live and with whom;
- what kind of a job, education and/or training they have; and,
- how to budget their money.

**When individuals need training and support in making major life decisions or have difficulty communicating those decisions:**

- Provide each person with understandable information about the choices he or she has (e.g., videotapes/dvds, talking with peers);
- Provide each person with opportunities to learn about the options (job tryouts, field trips);
- Provide each person with opportunities to make major life decisions (e.g. where to live, which job); and,
- Make sure you know someone in each person's life who knows him or her well enough to speak for him or her when major life decisions must be made, if necessary.

**CHOICE**

**3. Individuals make decisions about everyday matters.**

**About this Outcome**

This outcome is about individuals (and where appropriate, their parents, legal guardian or conservator) making everyday decisions about things like what to wear, what and when to eat, and how to spend free time. People should be provided with opportunities to exercise decision-making skills in all aspects of day-to-day living, including daily living routines, choice of everyday companions, leisure and social activities. People are supported in developing this important skill when given: (1) options to choose from; (2) understandable information about each option; and, (3) opportunities to directly experience each option. Agencies should respect the choices made by individuals, or where appropriate, their parents, legal guardians, or conservator.

**Examples of Opportunities for Service Quality Enhancement**

**Support each person served in making everyday decisions, including:**

- when to get up
- when to go to bed
- what to wear
- when to take care of personal hygiene
- what to eat
- what to do in free time
- who to spend time with
- how to use spending money; and
- whether or not to exercise.

**When individuals need training and support in making everyday decisions or have difficulty communicating those decisions:**

- Provide each person with opportunities to make choices each day. (e.g., a jacket or sweater, cold or hot cereal, going to the movie or shopping at the mall);
- Provide each person with understandable information about everyday choices (e.g., dvds to watch, talking with peers);
- Provide each person with opportunities to learn about the options (e.g., eating a new food, learning a new game); and,
- Be sure you know someone in each person's life who knows him or her well enough to speak for him or her when everyday decisions must be made.

**CHOICE**

**4. Individuals have a major role in choosing the providers of their services and supports.**

**About this Outcome**

This outcome emphasizes that individuals should have a leadership role in choosing the providers of services and supports. When making choices between service providers, we usually think about when services and supports are available, who delivers them, how well they are provided, how well they will meet our needs and the cost of the service. In choosing service providers, consider the individual's (or parent, conservator, or guardian where appropriate) choice in the selection process. Other factors to be considered include: service quality; success in achieving individual goals; natural community, home and work settings; and, the costs of services and supports of the same quality. Services and supports should not be continued unless the individual is satisfied.

**Examples of Opportunities for Service Quality Enhancement**

**When supporting persons served in having a major role in choosing the providers of their services and supports:**

- Support each person in learning about his or her service options; and,
- Make available understandable information about services to any individuals, family members, or others involved in a service selection.

**CHOICE****5. Individual's services and supports change as wants, needs and preferences change.****About this Outcome**

As people grow and change, their needs and preferences may change, including personal and service relationships. They may develop new friendships, change jobs, learn a new hobby or participate in different social activities based on changing interests, age or health conditions. In order to reflect those natural changes, services and supports should be flexible and available to meet an individual's needs throughout his or her lifetime. Changes in services and supports should occur based on the needs or preferences of the individual. However, there are times when things happen that may be beyond the individual's control (e.g., a staff member leaves, an agency closes). In those instances, attention should be given to preparing the individual for change and providing service options from which to choose.

**Examples of Opportunities for Service Quality Enhancement**

Try to ensure that services and supports change in response to the individual's changing needs and preferences.

**When a person wants or needs a change in services and supports, support him or her by:**

- adapting services and supports to the individual's changing needs and preferences;
- providing information about alternative service options from which to choose; and,
- assisting the person to prepare for and make the change (e.g., finding a new job, learning a new hobby, participating in new social activities).

**RELATIONSHIPS****6. Individuals have friends and caring relationships.****About this Outcome**

This outcome is about individuals choosing and developing friendships and intimate relationships. These relationships are based on shared interests, compatibility, shared work environments or mutual economic interests. Relationships are developed through opportunities to socialize with family members, neighbors, coworkers and fellow community members. Support may be needed to achieve this outcome, ranging from transportation, family counseling, or sexuality training.

### **Examples of Opportunities for Service Quality Enhancement**

#### **Help the people you serve develop friendships and caring relationships by helping them to have:**

- regular contact with friends and family (e.g., providing privacy for telephone calls, helping with transportation for visits);
- opportunities to develop friendships with whomever they choose (encouraging a variety of activities to meet people);
- a choice of whom they spend their time with;
- a place to spend time with their friends at home or elsewhere (and privacy if desired); and,
- supports and services which facilitate the development of friendships (e.g., transportation, scheduling activities) and/or caring relationships (e.g., information and training for adults regarding dating, sexuality, responsible intimacy, marriage).

### **RELATIONSHIPS**

#### **7. Individuals build community supports which may include family, friends, service providers/professionals and other community members.**

#### **About this Outcome**

Everyone has a group of individuals that they count on for friendship, advice and social contact. We all have the experience of developing different types of these supportive relationships at work, at home and in the community. While people with developmental disabilities typically have supports which include family members and service providers/professionals, they often need some help in developing (e.g., getting to places where people participate in social activities) and keeping supportive relationships (help in setting up a phone contact or activity) with friends and other community members. One of the aims of this outcome is to provide opportunities for people with and without disabilities to participate in life activities together. These relationships are to be respected and fostered and regional centers may assist individuals and their families in identifying and building circles of support within their community.

#### **Examples of Opportunities for Service Quality Enhancement:**

#### **Assist people in building community supports with family members, friends or community members by:**

- helping with making arrangements or providing transportation as needed;
- facilitating involvement in a variety of community activities;
- helping him or her have a formal or informal support group of nonpaid community members (e.g., friends, neighbors, co-workers, etc.); or,
- providing assistance to develop a support group if needed and wanted.

**LIFESTYLE****8. Individuals are part of the mainstream of community life and live, work and play in integrated environments.****About this Outcome**

This outcome is about involvement and participation of people with developmental disabilities in the community. People should be provided with opportunities to be integrated into the life of their community in the areas of work, education, recreation, social activities, and community service. People should have the choice to live and participate in the community in the same ways as their neighbors, friends and fellow community members (of the same age). In order to assist the individual to achieve this outcome, services and supports should be provided to the maximum extent possible in natural home, community, work and recreational settings.

**Examples of Opportunities for Service Quality Enhancement:**

**Provide supports that will help individuals be involved in the life of his or her community such as:**

- having access to understandable information about everyday community activities (e.g., newspaper, television);
- having opportunities to choose and participate in everyday community activities (e.g., shopping, banking, eating, learning, meeting friends) with other community members on a regular basis;
- having opportunities to work in typical community jobs with other community members;
- having supports and services which enable them to participate (e.g., job training, transportation, mobility training) in everyday community activities and work with other community members on a regular basis.

**LIFESTYLE****9. Individuals' lifestyles reflect their cultural preferences.****About this Outcome**

This outcome focuses on the differences in language, religion, country of origin, ethnicity and race that affect our individual lifestyles. Recognize this diversity when it states that the assessment process (which assists in the development of the ISP) shall reflect awareness of, and sensitivity to, the lifestyle and cultural background of the person and the family. When cultural preferences are indicated, they should be reflected in individualized services and supports.

### **Examples of Opportunities for Service Quality Enhancement:**

#### **Support individuals in having a lifestyle that reflects their cultural preferences, by providing them with:**

- opportunities to communicate with others who understand their culture;
- opportunities to practice religious, cultural or ethnic traditions and holidays;
- understandable information about services and supports with help from an interpreter if needed,
- supports and services which reflect language, cultural and ethnic preferences, holidays, music, clothing, special foods).

#### **LIFESTYLE**

#### **10. Individuals are independent and productive.**

#### **About this Outcome**

Independence (e.g., doing things for yourself) and productivity (e.g., social, cultural, spiritual, or fiscal contribution to family, community or society) are often referred to as outcomes. For example, understand the importance of achieving independent, productive, and normal lives. This outcome focuses on whether people have the necessary training and/or supports (e.g., adaptive or assistive technology, direct support person) that will enable them to be as independent and productive as possible. Services and supports should be individualized to the person's age, degree of disability and physical health to assist the person in achieving their maximum potential.

#### **Examples of Opportunities for Service Quality Enhancement**

#### **For persons served to achieve independence and productivity, provide access to:**

- adaptive technology, assistive devices (e.g., wheelchair, environmental controls), personal support as needed;
- a method of communication (e.g., speech synthesizer, computer, adapted telephone);
- the opportunity to complete the activities of everyday life (e.g., eating, dressing, personal care, exercise, getting around, social and recreational activities) with as little support as is needed;
- the opportunity to be productive (e.g., paid work, volunteer work) with as little support as is needed; and,
- the opportunity to learn skills (e.g., personal care, getting around, job training) which leads to greater independence and productivity.

**LIFESTYLE****11. Individuals have stable living arrangements.****About this Outcome**

This outcome is about a person's living arrangement. Services and supports for people with developmental disabilities should: (1) promote a stable and healthy living environment for each individual; (2) be available for people based on their needs and choices, regardless of their age or degree of disability. When a change in living arrangement is needed or cannot be avoided, careful planning needs to occur to ensure the best possible transition to the individual's new living arrangement.

**Examples of Opportunities for Service Quality Enhancement****Provide an environment in which each person:**

- experiences a sense of security
- has emergency and crisis intervention services as needed.

**LIFESTYLE****12. Individuals are comfortable where they live.****About this Outcome**

In addition to typical appearances of comfort, the special needs of the individual and their privacy must be considered. People should have things of their own that are personal and private. Comfort means different things to different people. Consideration should be given to personal needs and preferences in décor, room arrangement and use of living space.

**Examples of Opportunities for Service Quality Enhancement:****Provide an environment for persons served that is comfortable and includes:**

- access to living space (e.g., kitchen, living room, yard) as desired;
- his or her own bedroom or one that is shared with someone that he or she chooses;
- privacy (e.g., curtains & shades, for personal care, visiting with friends and relatives);
- a secure place to keep personal effects (e.g., mementos, pictures) and records;
- a key to his or her home;
- personal things around that express his or her individuality;
- furniture and décor that suits his or her taste and activity to the extent possible;
- the special equipment (e.g., wheelchair modifications, sheepskin wraps for arms and legs, etc.) it takes to get around a home.

**HEALTH and WELL-BEING**  
**13. Individuals are safe.**

**About this Outcome**

Recognize the value of safety by stressing that people have a right to be free from harm and to live in a healthy environment. Individuals have a right to be free from hazardous procedures. The individual's safety has to be a prime concern for service providers, and for those involved in relationships with the individual. However, a concern for safety has to be balanced with sensitivity to the individual's right to make decisions and to try new experiences. This balance is achieved when appropriate services and supports are in place that provide opportunity and practice for people to learn safety skills, but do not expose the person to danger or harm. If the individual cannot provide for his/her own safety, the necessary services and supports should be planned to meet this objective.

**Examples of Opportunities for Service Quality Enhancement**

**In order to assure that each person served has a feeling of safety and security, provide:**

- opportunities and practice for learning safety skills as needed that do not expose him or her to danger or harm;
- training on fire extinguishers and smoke alarms;
- special furniture and equipment as needed;
- site safety practices inside and outside; and,
- training on staying safe in the community and among strangers.
- a safe work or training environment (e.g., equipment, safety skill development).

**HEALTH and WELL-BEING**  
**14. Individuals have the best possible health.**

**About this Outcome**

In addition to shelter and comfort, health is considered to be a valued outcome. Recognize this by identifying an individual's right to receive prompt medical care and treatment and promoting a healthy living environment. Health includes general physical, mental and dental well-being. As with other outcomes, individuals should receive information and training in methods to increase or maintain their own health (e.g., being responsible for their own medication, eating nutritious meals, etc.) and be provided with opportunities to demonstrate their skills in these areas. If people cannot take the full responsibility for their own health, services and supports must be planned to meet this objective.

## Examples of Opportunities for Service Quality Enhancement:

### Provide information, training and services that promote individuals achieving the best possible health by supporting him or her to:

- ❖ eat a healthy diet on a regular basis;
- ❖ get regular exercise;
- ❖ take prescribed medicine for special health conditions that they have;
- ❖ monitor special health conditions and follow any prescribed medical regimens;
- ❖ maintain a safe weight range for their height;
- ❖ complete personal care (e.g., bathing, dental hygiene) on a regular basis;
- ❖ practice safe sex;
- ❖ do not use to excess addictive substances (e.g., alcohol, tobacco, drugs);
- ❖ do not place themselves in dangerous or high-risk situations; and
- ❖ access supportive counseling, when desired.

## HEALTH and WELL-BEING

### 15. Individuals know what to do in the event of threats to health, safety and well-being.

#### About this Outcome

This outcome focuses on the responsibility of individuals for their own well-being and includes such things as environmental risks (e.g., earthquakes, tornados), physical risks (e.g., falling, burns, being in an unsafe area), and financial risks (e.g., running out of spending money before the end of the month). Everyone encounters a variety of possible dangers and risks in the course of everyday living, and needs the knowledge and skills necessary to respond appropriately to those situations. The opportunity for prompt medical care and treatment can be increased when individuals recognize and report problems associated with their health, safety and well-being. This includes, among other things, identifying the source of the threat, whether or not help is needed and, if needed, who can help. When individuals cannot identify or report threats to their health, safety and well-being, services and supports should be planned to meet this objective (e.g., individualized training, education and/or advocacy).

Emergency back-up plans should also be in place as needed.

### **Examples of Opportunities for Service Quality Enhancement**

**In the event of threats to individuals' health, safety and well-being, they should:**

- recognize the source of the possible danger or risk (e.g., health, environment, person);
- know what to do to end a possible danger or risk or take the appropriate precautions (e.g., call for help, go to the doctor) to prevent one;
- know where to report possible danger or risk (e.g., service providers, family, 911);
- know how to seek help (e.g., hospital, police, counselor); and have support from others in dealing with possible dangers or risk.
- receive training and support in how to identify the source of threats to health, safety and well-being;
- have training and support in seeking help.

#### **HEALTH and WELL-BEING**

#### **16. Individuals have access to needed health care.**

#### **About this Outcome**

Access to health care is essential for maintaining good health and receiving prompt medical care and treatment. Access means that: (1) health care professionals are available for specific health conditions and/or to monitor ongoing health; (2) health care is provided in a way which is accessible to people with developmental disabilities (e.g., supports, interpreters); and, (3) transportation to the site of the health care is available as needed. In general, health care professionals include: physicians; dentists; mental health practitioners; and others recognized as health care professionals, such as physical therapists, dietitians, speech therapists, etc.

#### **Examples of Opportunities for Service Quality Enhancement:**

**Ensure that each person has access to health care professionals and services including:**

- a physician who knows them and is familiar with and able to work with people with a developmental disability;
- physician/dentist/other health professionals for routine health care needs;
- a dentist who knows them;
- emergency medical services as needed;

- mental health services as needed;
- other recognized health care professionals as needed;
- supports to assist in understanding and making health care decisions, including medical advocate if a sexual assault occurs.

## **RIGHTS**

### **17. Individuals exercise rights and responsibilities.**

#### **About this Outcome**

People with developmental disabilities have the same legal rights guaranteed to all other individuals by the Constitution and laws of the United States and the State of Illinois. In addition, people with developmental disabilities have a right to: treatment and habilitation; dignity, privacy, and humane care; prompt medical care and treatment; religious freedom; social interaction; physical exercise; and, freedom from harm and hazardous procedures. Also, people have the right to make choices in their own lives, such as: where to live; who to live with; who to have relationships with; education and employment; leisure; and, planning for the future. Rights fall into several categories, such as personal (e.g., privacy rights), educational (e.g., a free and appropriate education), citizen (e.g., voting), and access (e.g., public transportation). Along with all of these rights are responsibilities, such as respecting the privacy rights of others, being an informed voter, etc. In addition, training, opportunities and supports to exercise rights are important aspects of achieving this outcome.

#### **Examples of Opportunities for Service Quality Enhancement**

#### **In order to support individuals in the exercise of their rights and responsibilities, ensure that they:**

- know their rights and responsibilities;
- have frequent opportunities to use them (e.g., freedom of choice, vote);
- have training and support on rights and responsibilities as needed (e.g., not breaking the laws of the community, state and nation);
- know how to make a complaint (e.g., grievance procedures, fair hearings, ombudsperson, etc.); and,
- have someone to assist them (e.g., guardian, conservator, advocate) if they do not know or understand their rights and responsibilities or how to make a complaint.

**RIGHTS****18. Individuals are free from abuse, neglect and exploitation.****About this Outcome**

Abuse, neglect and exploitation are each forms of mistreatment which may affect the person physically (bodily harm), emotionally (mental health status) or financially (theft or loss of funds). One of the basic rights of people with developmental disabilities is a right to be free from harm, including unnecessary physical restraint, isolation, excessive medication, abuse(mental or sexual), or neglect. These rights extend to the person's living, working and community environments. Training and support in self-advocacy (as needed) are important aspects of this outcome.

**Examples of Opportunities for Service Quality Enhancement**

**In order to keep people free from abuse, neglect and exploitation, ensure that they have:**

- a healthy, physical appearance (appear to be free from physical, nutritional or mental abuse);
- no symptoms of abuse, neglect, exploitation or over-medication;
- a bank account or safe place to keep their money and access to it as desired;
- training and support about how to prevent and report (as needed) abuse, neglect, or exploitation;
- a way to communicate that they feel safe from harm or that they have been abused, neglected, or exploited to someone in their life who can recognize harm from abuse, neglect, or exploitation and takes immediate and appropriate action; and,
- a family member, friend, and/or service coordinator who has frequent contact and can identify and report problems.

**RIGHTS****19. Individuals are treated with dignity and respect.****About this Outcome**

This outcome incorporates a basic right. Dignity and humane care is a basic right of people with developmental disabilities. In practice, dignity and respect are measured by looking at how individuals are treated by others, including those who provide services and supports. These rights extend to the person's living, working and community environments.

### **Examples of Opportunities for Service Quality Enhancement**

- Positive interactions with people.
- Ensure if any staff has generally positive interactions with the individuals.
- Think of individuals as people with unique gifts and talents.
- Promote individuals being treated with dignity and respect by others (friends, relatives, coworkers, other service providers).

#### **RIGHTS**

**20. Individuals receive appropriate generic services and supports.**

#### **About this Outcome**

This outcome focuses on the services and supports a person receives from publicly-funded agencies having a legal obligation to serve the general public. These are known as generic services and they are typically available to people whether they have a disability or not (for example, community colleges, public parks, libraries, senior centers). Generic services also include public benefits, such as Social Security which are available to people with disabilities.

This outcome looks at the degree to which individuals receive information about generic services, whether the services are provided when requested, and advocacy efforts needed when services are not provided.

### **Examples of Opportunities for Service Quality Enhancement**

#### **Assist individuals in accessing and receiving generic services and supports they qualify for, including:**

- Social Security, Medicare/Medicaid, and other benefits; public elementary and secondary education;
- adult learning programs such as adult education or a community college;
- local community resources (e.g., public parks, library, senior center, transportation services);
- state and federally-funded services (e.g., mental health, rehabilitation,
- employment training,
- community agencies which support victims of violence.

#### **Assure individuals have training and advocacy to assist them in utilizing generic services as needed.**

**RIGHTS****21. Individuals have advocates and/or access to advocacy services.****About this Outcome**

This outcome is available to any individual or family member. This outcome is especially important for people who lack close family and friends and/or have difficulty expressing themselves or need support in understanding their rights and how to exercise them. Advocate for the civil, legal, and service rights of persons with developmental disabilities. Also provide information about federal, state and local generic services as well as advocacy for those services on behalf of individuals.

**Examples of Opportunities for Service Quality Enhancement**

**Ensure that individuals have advocates and/or access to advocacy services, including:**

- a family member, friend, and/or service coordinator who will advocate for them when they cannot or do not advocate for themselves;
- understandable information about advocacy services
- training and support in self-advocacy, as needed and desired; and,
- persons to accompany and/or represent them in ISP meetings or other important discussions or activities.
- a medical and/or legal advocate who will advocate for the person if an act of sexual or domestic violence occurs.

**SATISFACTION****22. Individuals achieve personal goals.****About this Outcome**

Everyone has dreams and desires about things that they need or want to achieve in their life. When an individual decides what they want to achieve, they set a personal goal. Personal goals range from every day activities (e.g., getting regular exercise, learning to use the bus) to major goals (changing jobs, going back to school, moving into a different living arrangement). Individuals either achieve their goals or are taking steps to achieve them and are satisfied with their progress.

## Examples of Opportunities for Service Quality Enhancement

### Providing support to people in achieving his or her goals, for example:

Around the home (e.g., using the microwave, recording a favorite T.V. show), in self care (e.g., using a toothbrush, taking a shower); self improvement (e.g., exercise, weight control); saving for something (e.g., clothes, furniture, outing); learning new skills at work (e.g., shelving products as a stock clerk, raking leaves on a landscape crew); finding or changing a job; getting more involved in local community activities; or, making a new friend.

### When individuals achieve personal goals they typically:

- feel good about what they have accomplished or their progress toward their goal;
- express pride in their achievement.

## **SATISFACTION**

### **23. Individuals are satisfied with services and supports.**

### About this Outcome

Service satisfaction is an important outcome. No service or support specified in the ISP and provided by any agency or individual shall continue unless the individual (or where appropriate, his or her parents, legal guardian, or conservator) is satisfied and reasonable progress has been made towards meeting objectives.

### Examples of Opportunities for Service Quality Enhancement:

**Work to assure satisfaction with services and supports by asking each individual and his or her family members, as appropriate, what they believe is working well and what things could be better. When someone expresses dissatisfaction, strive to improve the situation and ask what changes he/she would like to have happen.**

### Individuals who are satisfied with services and supports, typically:

- express their satisfaction when asked;
- want to continue with their current services and supports and/or their service provider;
- show their satisfaction in some way when they cannot communicate it;
- have a personal advocate who expresses satisfaction if they cannot express or show it themselves.

**SATISFACTION****24. Individuals are satisfied with their lives.****About this Outcome**

For many of us the question that means the most in terms of life quality is: Are we satisfied with our lives? A person's satisfaction with their life reflects a general sense of well-being involving a range of life experiences in the areas of choice and decision-making, relationships, participation in the life of their community, health and safety, and home, work and leisure. This outcome is about individual perception of personal life quality.

**Examples of Opportunities for Service Quality Enhancement:**

**Support each person served in achieving life satisfaction by asking him or her or his or her family members, as appropriate, about life satisfaction and what could make things better and working with them to increase their satisfaction with their lives.**

**Individuals who are satisfied with their lives, typically:**

- express their satisfaction when asked;
- express a positive outlook on life;
- show their satisfaction in other ways when they cannot communicate it;
- have a personal advocate who expresses satisfaction if they cannot express or show it; and,
- seek to maintain what they have.

As the individuals you serve have greater opportunities to make choices, exercise their rights and make decisions about their everyday lives, they will be better able to express their satisfaction with service quality and with their lives and to work in partnership with you in designing quality services.

Source: Excerpts taken from *Looking at Service Quality Handbook for Providers of Services and Supports* California Department of Developmental Services

[www.dds.ca.gov/Publications/docs/LookingServiceQuality.pdf](http://www.dds.ca.gov/Publications/docs/LookingServiceQuality.pdf)

## The Choice Making Process

### Assessing Interests and Preferences to Promote Choice Making

Promoting active choice making is a primary way to address self-determination for people with severe disabilities. Making a choice involves the identification and communication of a preference. For people with severe disabilities, there are multiple barriers to making choices. Because many people have such a limited number of opportunities, they do not know how to make choices. Therefore, they need specific and direct instruction in this skill. Other people with severe disabilities do not express their preferences through conventional means and the use of alternative means to assess personal preferences must be explored.

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

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

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

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

## Assessing Behavior

### Positive Behavior Supports

At its most basic level, all behavior is communication. This is particularly true for people who do not express themselves by talking or have limited communication skills. Behavior is what we do to get what we want or to get away from something we don't want. People with intellectual disabilities don't engage in 'behaviors' because they have a disability, they engage in behaviors that have worked for them to get what they want. However, understanding what a person is trying to communicate through behavior may not always be easy.

People don't "have" behaviors; rather, they use their actions for specific reasons. They are actually communicating how they feel or what they want. According to the **Basic Principles of Learning:**

- ❖ All behavior occurs for a reason
- ❖ Both good and bad behaviors continue to occur because they work
- ❖ Both good and bad behaviors stop occurring because they no longer work

**Positive behavior support** is a way to help people get what they want or get away from something they don't want in a way that's safe for them and others around them.

For the support plan to be effective, we must first 'listen' to the behavior and try to figure out what the person is trying to tell us. Perhaps it may be as simple as sitting next to a different person in the workplace. Perhaps the plan may include giving them something they like when they engage in a particular behavior. **However, Positive Behavior Supports never use 'aversives' or things people don't like or things that give them pain.**

### What is 'behavior?'

A behavior is anything a person does that is observable and measurable. In other words, a behavior can be seen and counted.

When identifying a behavior, use specific words to indicate exactly what the person is doing. This allows all staff members to have a clear understanding if you use behavioral terms.

For example, the statement "John has several seizures a day" does not indicate how serious the problem is. A clearer statement would be "John had 3 tonic clonic seizures yesterday."

## Steps to Building a Behavior Treatment Program

1. Choose a philosophy upon which to base your program.
2. Define the challenging behavior(s) you want to decrease.
3. Begin baseline data collection on challenging behavior with an ABC sheet.
4. Conduct functional assessment interviews.
5. Complete reinforce assessments.
6. Analyze data and interviews to determine function(s) baseline of each behavior.
7. Define the behavior you want to increase-which may be a replacement behavior.
8. Write the behavior plan to include both definitions and environmental conditions.
9. Submit the plan to the HRC if it contains any elements of restrictions.
10. Plans with restrictive measures also require guardian's approval and signature.
11. Create a final data sheet.
12. Train staff and family-all who work with the individual.
13. Assign responsibilities for data sheets and generating the reports.
14. Monitor the implementation of the plan through direct observation and review data.
15. Do random monitoring as well as scheduled.
16. Re-evaluate the plan's effectiveness and revise as needed.

## Functional Analysis

A functional analysis consists of at least two measures. The interview is one measure of function. Data are usually the second measure. A good analysis of behavior can help increase your understanding of what the person is trying to tell you. A written functional assessment studies the person's environment and the behavior of the person. The assessment may look at activity patterns, people in the environment, support staff and the physical environment to determine why the problem behaviors occur.

In other words, the functional analysis should attempt to identify what function or purpose the behavior serves for the person. We might ask questions such as:

- ❖ Does it get them something they want?
- ❖ Does it help them get away from something they don't want?
- ❖ Is it the only way they know to express themselves?
- ❖ Are they experiencing pain or discomfort?

If we can identify the function of the behavior, we are better able to determine what **replacement behavior** can be taught.

**Everyone who interacts with the person served in any significant way should receive training in the plan.**

## ABCs

A functional analysis is sometimes referred to an ABC chart. ABC stands for:

**A**ntecedent

**B**ehavior

**C**onsequence

- A** stands for *antecedents* – the events that have led up to the behavior's occurrence. They are important because each behavior has a cause; it is an attempt to communicate a message. Without charting this important information these events may go unnoticed.
- B** stands for *behavior*- the specific behavior you are trying to increase or decrease.
- C** stands for *consequences* – what happens after the behavior occurs. The consequence influences whether the behavior will be repeated.

An ABC is part of a functional analysis because it records the conditions before the event occurred and what happened after the challenging behavior.

### An example of ABC is:

- **Antecedent: Staff person starts the teeth brushing**
- **Behavior: Individual hits the staff person**
- **Consequences: Staff person stops the teeth brushing**

The ABC chart can help in the study of behaviors and their antecedents and consequences. This chart can also help to make decisions based on the data. Following the analysis, the staff are better able to design strategies that help the individual to communicate needs and/ or desires in more appropriate ways. Also, strategies can be designed to give the individual more control over their environment.

## Data Collection

In order to analyze a person's behavior in detail, it is necessary to collect information or data. The data give a precise report about the behavior and can be used in the development of a behavior plan. It is important to gather data before a behavior plan is implemented. These data are called "baseline" data.

Data collection and analysis are used to determine if the plan is achieving the desired results. Many times progress is made one tiny step at a time. Tracking behavior is a very

significant part of a positive behavior support plan. Many times people confuse a positive reinforcement plan with a positive behavior support plan. There is no real plan in place if there is no tracking to monitor progress, and using observations to modify the plan if necessary.

Sometimes the reason that a certain behavior began is not the same reason it continues. For example, George began banging his head because he had a headache, but the behavior **maintained** because of associated attention he received.

It's important to remember that any behavior can become a habit and eventually a chronic behavior. Generally, the longer a behavior is in place, the longer it will take to change.

## Discovering Reinforcers

Positive and personal reinforcers include actions, consequences, or rewards that can cause an increase in desired behavior. Activities or incentives can be used, for example, to promote lifestyle changes such as increased exercise in free-time activities; healthy snacks, etc. When choosing personal reinforcers, it is important to:

- Get to know the person well
- Ask the person to help choose the type of reinforcers he would like to earn
- Observe what the person enjoys doing
- Ask others that know the person well
- Give a choice of items or activities

A reinforcer is any stimulus or event that when it follows a behavior, increases the probability that the behavior will occur again.

Remember...

- No single item or event is reinforcing to everyone
- The strength of an item to serve as a reinforcer can vary with time and circumstances

### Types of Reinforcers:

**Primary** (substances that sustain life - food, water)

**Secondary/Social** (conditioned reinforcers that are generalized from primary reinforcers - money, social interactions, tokens, etc.)

When using praise as a secondary reinforcer, praise the person **immediately** after the desired behavior occurs.

With **Effective Praise**, you offer the praise:

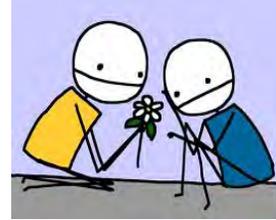
- Immediately
- Frequently
- Enthusiastically
- With eye contact
- Using a variety of statements

Why use Praise and Positive Feedback as Positive Reinforcers?

- Praise and feedback are always available and cost nothing
- It is normal for people to receive praise and feedback
- People rarely get tired of being praised
- Praise and feedback can be provided without disrupting ongoing activities

## Tips on How to Facilitate Desired Behavior

- Always pay attention to new or infrequent behaviors, if you would like to see them occur again.
- Attend to inappropriate behavior as little as possible. If you do need to intervene, do not spend a lot of time discussing the incident, especially at the time it occurs. At a later time, you can simply identify the behavior and explain why it is inappropriate.
- If another person is providing attention for an inappropriate behavior, move that person without drawing more attention to the behavior.
- Let people do as much as they can on their own.
- Realize that shaping and refining behavior takes time and that some individuals progress very slowly - one step at a time. Also remember to give positive feedback after accomplishing each step.
- Promote age appropriate behavior. Encourage people to engage in activities and dress in ways typical for their age group.
- Always state your verbal instructions in a positive way instead of a negative way.
- Make sure your verbal instructions and statements are as clear as possible.
- Give the reason why you want the person to engage in the requested behavior.
- State the positive consequences of behaviors whenever possible.
- Be an appropriate role model.
- Be "proactive", not "reactive". Do not wait for something to happen; try to anticipate it.
- Avoid forcing your personal values on others and moralizing about their behavior.
- Show others that you mean what you say. Don't make promises unless you will be able to keep them.
- Don't issue threats to get people to comply.
- Don't assume anything. Diagnostic labels and past performance often cause people to assume incorrectly. Speak to the person even if you're not sure whether the person understands.
- Never speak about the person with a disability as if the person wasn't present. It isn't polite, nor is it supportive.



## Understanding Risk

The "Dignity of Risk" has been discussed since the 1960s. Dignity of Risk reflects a commitment to each person's right to control his or her destiny and fully experience life, both the good and the bad. Although Dignity of Risk is frequently debated, it is less often practiced. So what's the problem?

Our concern about risk stems our uncertainty and confusion about responsibility. First, we are unsure of our responsibility for keeping a person "safe from harm" in balance with respect for the person's right to make choices that may be bad for them or to refuse treatment. Second, we have little experience defining the person's responsibility (and ability) to acknowledge the potential consequences associated with typical risks encountered in life.

Safety is not an absence of risk. Instead, safety is matching the level of risk to personal well being. The service provider's challenge is to manage risk, not avoid it.

While we cannot guarantee people safety from harm, we can diligently assess individual variables related to risk within the service process. This "risk" assessment is individualized. Risk cannot be evaluated in the absence of knowledge about the person. The degree of risk is determined by weighing the dangers in the environment, individual skills, experiences, and supports. Skills, experience and supports can lessen the amount of risk present in a given situation. Beyond the accepted minimum safety standards, no guidelines can ensure unquestionable safety. A reasonable precaution for one person is an outrageous intrusion for another.

Each person's support needs for any new situation or experience must be defined through the service process. If the person needs little or no support, consider the activity routine. For example, even though driving a car poses risks, these risks are considered reasonable for a person who has the needed skills, experience and supports. Risk increases when skill, experience and support are limited. The following guidelines enable us to manage risk and identify supports for people:

**Give people permission to try.** Take action and enable the person to experience new situations. Many discussions about risk get mired in the hypothetical particulars of a specific event or activity that have not yet taken place. Don't let this happen. Act by learning about the person and then assisting the person to gain experience and skill under the safest conditions.

**Assess the true cost of failure.** All risky situations are not equal. Some consequences are minor and inconvenient; others are dramatic and permanent.

**Minimize risk through dialogue.** Don't assume that people understand the skills and experiences required for different situations. Discuss requirements and outcomes with people and develop a shared understanding.

**Plan for "what if" situations.** Anticipate and plan for mistakes or failure. Practice contingencies. This prevents minor failures from becoming major disasters.

**Give people the opportunity to learn from small mistakes.** No person should be placed in the position of making major risky decisions, without the benefit of previous experience and practice.

**Support the person.** When risk increases, so does the need for support. The service provider's responsibility is to individually assess risks and take reasonable precautions to prevent foreseeable dangers. This is different from protecting people from all potential consequences. Learning includes action, and all action carries risk. Avoiding all risk prevents people from learning and from leading a life that is full and rich.

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## Dignity of Risk

### What if...

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



*Changing Expectations/Planning for the Future: A Parent Advocacy Manual*,  
by Dorothy Sauber, Association for Retarded Citizens of Minnesota, Minneapolis, MN.

## Know the Person's Risk Management Plan

Be aware of all habits and potential behaviors of the adults or children in the home that can present dangers such as:

- Self abuse
- Pica behavior
- Lighting fires
- History of aggressive/abusive behaviors

Develop a Risk Management Plan to assure there is proper supervision based on the needs of the individuals.

Knowing the risk management plan for potential behaviors would entail some form of a functional assessment to help understand the individual's behaviors. These behaviors may be to escape, avoid, or to obtain something, most behavior intervention plans stem from the knowledge of why an individual misbehaves and should be based on a functional assessment. Understanding the function of problem behaviors should help formulate plans to minimize risk of harm. Example: If a person has a history of elopement to get attention or to escape, alarms may be needed on the doors or windows.

Risk management also involves medical and mental health risks. For example, Bowel Movement Tracking should be done for all clients with a diagnosis, history, or risk of constipation.

Risk assessment tools are used as a resource for planning purposes to ensure the health and safety of people supported as well as a tool to encourage individual choice and actions and to minimize occurrence of serious incidents.

### **Some general areas of potential risk that may be considered include:**

- Community safety
- Health/Medical
- Sexuality/relationships
- Abuse
- Financial exploitation
- Pica
- Home environment
- Fire safety
- Personal care/daily living,
- Mental health,
- Police involvement
- Informed consent
- Support services

**Some specific issues that may be included in your agency's risk assessment/management plan may include:**

- Compromised communication skills
- History of pregnancy or parenthood
- Substance abuse
- Risky sexual behaviors
- Refusal of services
- History of sexually aggressive behavior
- Stealing
- Destruction of property
- Predatory behavior
- Self injury
- Pica
- Multiple visits to emergency room
- Significant change in health or mental status
- mobility impairment
- Swallowing difficulty
- History of choking or aspiration
- History of suicidal ideation or suicidal gestures

## Quality Assurance



Agency QIDP quality enhancement activities associated with Quality Assurance (QA) focus on compliance with established processes and procedures. Many aspects of the QA activities focus on compliance with standards and regulations. The focus of many of the facility's management goals and objectives is on maintaining an acceptable level of compliance with State and Federal standards and regulations that apply to the facility. The outcome of both internal and external review mechanisms is often the impetus for establishing a new QA activity or the development of a new management goal or objective.

A major portion of the QA activities at \_\_\_\_\_ revolve around the use of standard forms used regularly to validate compliance with a variety of State and Federal regulations. The frequency of use of each document is determined by the nature of the issue being addressed. Some forms are reviewed on a regular basis by management staff. In other cases, the data from the forms are used to prepare reports which are then reviewed by management staff. If there is evidence of a need to improve compliance with a particular procedure or standard, the data may be incorporated into a management goal or objective. It would then be included in the annual Program Evaluation report or in the DD Division Quality Indicators.

## Quality Enhancement



Quality Enhancement activities go beyond the point of minimum compliance (Quality Assurance) and focus on the realization, attainment or achievement of personal outcome measures as defined by the individuals who live at \_\_\_\_\_. Individuals who live at \_\_\_\_\_, their family members and guardians have ample opportunity to provide input into the establishment of the goals and objectives. While several facility management goals and objectives focus on personal outcomes for people, it should be noted that the management goals and objectives are established by facility staff. The true measure of quality for each individual is based upon the \_\_\_\_\_'s ability to provide services and supports in a manner which will help each person achieve the personal outcomes as he or she has defined them.

## Least Restrictive Environment

The Fourteenth Amendment to the Constitution declares:

“All persons born or naturalized in the United States, and subject to the jurisdiction thereof, are citizens of the United States and of the State wherein they reside. No State shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any State deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws.”

The IDT is responsible for determining if the individual is appropriate for a less restrictive environment. If this is determined to be so, documentation must be included in the individual’s plan identifying a time frame for transition. The individual’s QIDP or QMHP are responsible for monitoring the individual’s transitional plan supervision and supports.

If a determination is made that an individual is appropriate for intermittent supervision and supports, the PAS agency in conjunction with the provider agency must submit a completed CILA rate determination to the Department for development of a rate to support the intermittent supervision and supports.

### Underlying Assumptions

- The use of restrictive practices is a major event in the lives of all concerned and should be employed only when positive supports are ineffective.
- Regular evaluation of the plan must take place. That can only be done accurately with the use of effective data collection techniques.
- Restrictions are presumptively viewed as temporary and must be coupled with training in the acquisition of positive behavioral skills.

**Restrictive Interventions which must be reviewed** (a descriptive, rather than exhaustive, list)

All interventions with restrictive components, such as:

Limitations on access:

- To personal possessions (money, mail, clothing, cigarettes);
- To personal or public space (locked areas, off limits areas);
- To food or drink;
- To activities;
- To friends, family, children, significant others, etc.;
- To community services;

### Limitation on movement

- Bed rails;
- Mitts;
- Belts;
- Therapeutic holds;
- Bed or door alarms
- Escorts;
- Braces, helmets, splints for behavior control;
- Mechanical restraints.

### Medication

- Psychoactive drugs and medications used for behavior control

## **How to survive an HRC submission**

- Know the history behind the issues under consideration.
- Know what has been tried before and what happened.
- Be sure you understand what is maintaining the behavior (Attention, escape, etc)
- Submit data, preferably in graph form.
- Use the best available techniques. If the issue is important enough to restrict a fellow human being, we should at least carry out our interventions according to best practices.

### **The submission should include following:**

- Functional Assessment of the target behavior for which the restrictive behavior is designed.
- Documentation that indicates the risks of the target behavior versus the risk of the proposed restrictive intervention.
- Efforts to replace the target behavior.
- Documentation that the behavioral support plan is reviewed regularly by the person's support team.
- Definition of the targeted behavior or behaviors.
- Informed consent from the individual or the individual's legal representative.

## Scenario Four

Rachel is now living in a home with three other women. This home is a Community Integrated Living Arrangement (CILA) and is owned by the agency providing the services and supports to Rachel. There is currently 24-hour supervision of this home.

Rachel wishes to become more independent in getting around the neighborhood/community. She loves to shop and go to the mall and prefers in many instances to do things alone. She has experience living in a large residential environment with many people and has always been part of a supervised group when she has used community resources. Since she moved to this new home six months ago, she has enjoyed exploring her neighborhood and mall.

She has informed you that she wants to take the bus to the mall by herself. You are concerned that Rachel would be at risk if she did this without prior experience, support, and training. Rather than denying this request (not valuing her request) you can use this desire to facilitate choice making.



### Scenario Four Questions

1. What are some questions you might ask Rachel to help her understand the health, safety, and financial parameters of this request? **Note:** Walking Rachel through this task analysis will help her identify where she needs support and/or training. These questions are not meant to dissuade her from the outcome she desires. Instead it creates a base of information staff can use to negotiate a realistic option/choice with Rachel.

- ❖ *Do you know where the bus stop is?*

- ❖

- ❖

- ❖

- ❖

- ❖

2. Consider your answers to the previous question. List below a range of choices you and Rachel would have to decide on.

- ❖ *I could ride the bus with you and do my own shopping while you do yours.*

- ❖

- ❖

- ❖

- ❖

3. How does this negotiated option show you value her choice?

4. What opportunities for training and support does this choice offer Rachel?

❖ *Telling time*

❖

❖

❖

❖

❖

***Directions:*** Set aside some time during your next work day to complete this OJT Activity from the Direct Support Person curriculum; Appendix 3. Follow the steps listed below and document your experience for review during your next class.

**OJT Activity #43:**

Opportunities for Choice

**Approximate Time to Complete:**

1-2 hours

**Recommended Number of Practice Opportunities:**

1-2 practice sessions

**Interventional Competencies Addressed:**

- ❖ Communicates effectively in verbal and written form.
- ❖ Intervenes or identifies advocacy issues.
- ❖ Offers opportunities for choice.
- ❖ Educates individuals in choice making and their potential outcomes.
- ❖ Assists in individual self-advocacy efforts.
- ❖ Creates opportunities for the individual to speak on his/her own behalf in a variety of situations.
- ❖ Is respectful.
- ❖ Actively engages in a non-directive manner with individuals.
- ❖ Establishes rapport.
- ❖ Supports choice.
- ❖ Listens to the individual.
- ❖ Facilitates choice in the person's life by assisting in identifying positives and negatives.

**On the Job Training Activity Steps:**

1. Identify an individual to assist you in the choice process.
2. Identify an opportunity for choice.
3. Assist the individual in developing a range of choices.
4. Identify the health, safety, financial parameters and risk associated with the choice.
5. Offer the individual the opportunity to make a choice.
6. Show the individual that you value his choice.
7. Educate and negotiate with the individual when choices are outside the parameters.
8. Document the choice experience.

## Principles of Adult Learning

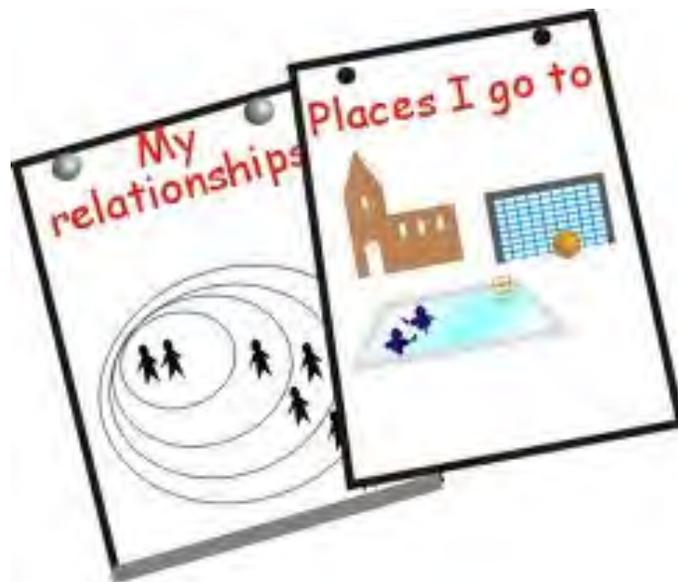
The principles of adult learning and the coaching and training tips that follow may assist you in teaching individuals the choice process:



- ❖ Adult learners must be active participants in the learning process.
- ❖ Learner motivation is enhanced by experiences of success (e.g., repetition with reinforcement).
- ❖ Learning is dramatically increased when multiple senses are involved (e.g., hearing, saying, touching, doing, etc.).
- ❖ Generalization of learning is enhanced when practiced in varied contexts.
- ❖ Individual, cultural, and sub-cultural styles of learning exist that need to be reflected in designing learning experiences for staff.
- ❖ Staff will bring self-concepts to the training situation that will affect their learning.
- ❖ Staff may tend to be motivated to learn when they feel accepted and affirmed by the trainer/supervisor.
- ❖ Learning is enhanced when staff can associate new knowledge with previous knowledge.
- ❖ Staff members are more motivated when they understand the purpose and importance of new learning.
- ❖ Learning is directly influenced by the physical and social environment.



## MODULE 4



## THE PLANNING LOOP

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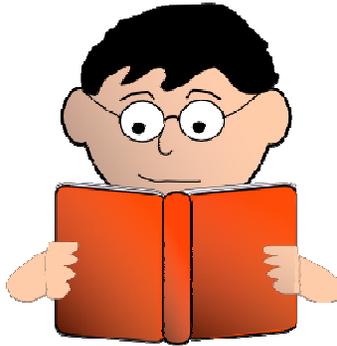
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*What will you do today to make  
someone's dream come true?*

*Source: New Visions: The Power of Dreams*

## Background Reading



*Developing Staff Competencies for Individuals with Developmental Disabilities* by James F. Gardner & Michael S. Chapman. Chapters 5, 6, 7, 8, 9, 10, 11, 12, & 13

*Reach for the Dream! Developing Individual Service Plans for Persons with Disabilities* by Dale DiLeo.

*It's My Choice...* by William T. Allen

*It's Never Too Early, It's Never Too Late: A Booklet about Personal Futures Planning* by Beth Mount and Kay Zwernik

*Making Futures Happen: A Manual for Facilitators of Personal Futures Planning* by Beth Mount and Kay Zwernik

*A New Way of Thinking* by the Minnesota Governor's Planning Council on Developmental Disabilities.

*A Handbook For Scenario-Based Active Treatment*, edited by Richard R. Saunders, Jim Rast, and Muriel Saunders.

## **Interdisciplinary Process**

### **Rule 115, Section 115.230 Interdisciplinary Process**

- ❖ Rule: 115.230 e)4)A)
  - A physical and dental examination, both within the past 12 months, which shall include a medical history.
  
- ❖ Rule: 115.230 e)5)C)
  - An annual psychiatric examination for individuals with a mental illness.
  
- ❖ Rule: 115.230 n)
  - The Community Support Team (CST) shall review the services plan as a part of the interdisciplinary process at least annually for individuals with developmental disabilities and semi-annually for individuals with mental illness and shall note progress or regression which might require plan amendment or modification.

**Agencies licensed to operate CILAs must comprehensively address the needs of individuals through an interdisciplinary process.**

**What we mean by the interdisciplinary process is that the following people need to be involved:**

- ❖ The individual and/or his or her legal guardian, or both.
  
- ❖ Members of the individual's family unless the individual is not legally disabled and does not desire the involvement of the family or the family refuses to participate.
  
- ❖ Significant others chosen by the individual.
  
- ❖ The QIDP or the QMHP.

Other members of the CST, which may include people who provide habilitation, treatment or training; and professionals who assess the individual's strengths and needs, level of functioning, presenting problems and disabilities, service needs and who assist in the design and evaluation of the individual's service plan.

Through the interdisciplinary process, the IDT is responsible for preparing, revising, documenting and implementing a **single individual integrated services plan** for each individual.

### **Initial Assessments**

The agency shall assure that each individual receives an initial assessment and reassessments that shall be documented in the individual's record and the results explained to the individual and guardian.

The assessments shall determine the individual's strengths and needs, level of functioning, the presenting problems and disabilities, diagnosis and the services the individual needs. Assessments shall be performed by employees trained in the use of the assessment instruments.

Through the selection of the assessment instruments and the interpretation of results, all assessments shall be sensitive to the individual's:

- Racial, ethnic and cultural background;
- Chronological and developmental age;
- Visual and auditory impairments;
- Language preferences; and
- Degree of disability.

### **Initial assessment for individuals with a mental disability should include:**

- **A physical and dental examination**, both within the past 12 months, which shall include a medical history;
- Previous and current adherence to medication regime and the **level of ability to self-administer medications** or participate in a self-administration of medication training program;
- A **psycho-social assessment** including legal status, personal and family history, a history of mental disability and related services, evaluation of possible substance abuse, history of trauma and resource availability such as income entitlements, health care benefits, subsidized housing and social services;

- An assessment with **form IL 462-1215, "Specific Level of Functioning Assessment and Physical Health Inventory," (SLOF)** for individuals with a mental illness and with the **Inventory for Client and Agency Planning (ICAP)** (Riverside Publishing Co., 425 Spring Lake Drive, Itasca IL 60143 (1986)) or the Scales of Independent Behavior-Revised (SIB-R) (Riverside Publishing Co., 425 Spring Lake Drive, Itasca IL 60143 (1996) ) for individuals with a developmental disability;
- An **educational and/or vocational assessment** including level of education or specialized training, previous or current employment, and acquired vocational skills, activities or interests;
- A **psychological and/or a psychiatric assessment**; both must be conducted for individuals with both a mental illness and a developmental disability;
- A **communication screening** in vision, hearing, speech, language and sign language; and
- **Others as required** by the individual's disability such as physical therapy, occupational therapy and activity therapy

**Within 30 days after the individual's entry into the CILA program, a service plan must be developed.**

### **Annual Reassessments**

Annual reassessments for individuals with a mental disability shall include:

- A physical and dental examination including a review of medications.
- The Strauss-Carpenter Level of Function (SLOF) for individuals with a mental illness or Inventory for Client and Agency Planning (ICAP) or Self-Injurious Behavior (SIB) for individuals with a developmental disability.
- An annual psychiatric examination for individuals with a mental illness.
- Other initially-assessed areas, as necessary.

### **At least monthly...**

The QIDP and QMHP must review the services plan and document that:

- Services are being implemented as identified in the service plan developed by the interdisciplinary team.
- Services identified in the service plan are being implemented and continue to meet the individual's needs or need modification to better suit the person's needs.
- Actions are recommended and implemented when needed.

## Individuals' Thoughts on the IDT Process

Individuals with developmental disabilities have been the focus of countless staffings. We can learn from their experiences, if we are willing to listen. A consumer group from Macon Resources offers the following tips for you to consider when supporting them in interdisciplinary team meetings (IDT). This is not an exhaustive list, but a sample of the input that is available to staff if we ask and listen. The most important thing to remember is that the meetings belong to the persons and their families. Their input regarding the staffing process is as varied as the persons themselves.



## Approaches to Interdisciplinary Team Planning

The traditional approach to team planning focuses on the individual who is involved in a day or residential program. The interdisciplinary team develops goals and objectives that are based on the services provided by the day or residential program, and the team consists of employees of the program. The goals and objectives reflect the services available within the program. This type of interdisciplinary team process takes a narrow approach to planning for the person with a developmental disability and is considered inappropriate by today's standards.

A second, more contemporary planning approach is where the agency responsible for service coordination arranges for the completion of comprehensive evaluations. These evaluations are performed by the staff of the residential or day program or by professionals outside the program. The results of the assessments are shared by the team members. The focus of the team meeting is to determine what services in the community can help the person to reach his or her goals. Decisions as to the long-range goals are based on the person's needs without regard to availability of services. If the needed services are not available in the particular day or residential program, they often can be obtained elsewhere in the community.



A third approach, called Personal Futures Planning, team membership is expanded to include friends, relatives, neighbors, and even local business representatives. The purpose of personal futures planning is to provide an opportunity for the individual with a developmental disability to express personal interests and desires. Professionals, family members, friends, and community representatives all commit to assist the individual in achieving his or her stated goals. Unlike the first two approaches, goals and objectives stated during personal futures planning include issues related to community participation. The individual states that the goals that he or she wishes to achieve in the community and actively solicits the help of the team in pursuing them. Should the goals not be reached, the individual and team members critically review their roles in not fulfilling their obligations.

### **Preparation**

Nearly all of the individuals surveyed indicated that it is very helpful when someone takes the time to meet with them before the formal staffing and discuss the purpose and details of the staffing. A mutual review of the individual's progress and satisfaction during the previous time period should be a topic of discussion, as well as, plans, desires, etc. for the future. If a person knows ahead of time to think about what they would like to learn/do, he/she is less likely to feel 'put on the spot.' It is helpful to go over the results of assessments and get the person's opinion of their assessed needs and strengths. This preparation meeting can also alert the staff member to any topics that the person may find embarrassing or difficult to discuss. This is also an excellent time to select/confirm the best location and the desired/necessary participants.



### **Location**

Individuals vary a lot in their preferred location for their staffing. Some individuals we spoke with expressed a strong preference for their home setting; some preferred to meet at the facility; some expressed a strong preference not to have providers in their homes. (One person said, "Then I'd have to clean for a week!"); and, some individuals had no preference of location. The individual and family should be consulted in planning the time and location for the staffing. Their preferences should be given strong consideration.

### **Participants**

Many individuals expressed how helpful it is to have a 'friend' at their staffing. A friend meant someone they could talk with about serious stuff; someone who listens and knows them well; someone who would help them remember what they wanted to discuss at the staffing; and, someone who would help them feel less alone and more capable. This 'friend' is often a staff member the individual is close



with or a friend of the family. The critical thing is that the person is given the opportunity to invite the important people in their life that they wish to be present.

## **Communication**

As we all know, communication is crucial in our relationships with other people. Individuals with developmental disabilities and/or mental illness are the subject of most communications which occurs during the IDT process. Those of us in the “helping profession” need to remember the person as we are doing our high-tech planning and review processes. It is easy for an individual to feel threatened or outnumbered. Persons we spoke with wanted their input taken seriously and wanted to be believed when they spoke . . . they wanted to be spoken to, not spoken about. As professionals, we need to be aware of our professional lingo and attempt to speak in everyday language. The big words and multitude of acronyms that we use can be like listening to someone speaking in a foreign language.

### **What’s in a name?**

A small number of people were bothered by the names “staffing” and “IDT.” Some of the terms that providers use with ease can cause some persons to feel threatened. These persons stated they preferred that we called the IDT staffing a “meeting” or a “get together.”

Shared by: Shirley Pacey  
Director of Blue Tower Training  
Macon Resources, Inc.



## Active Treatment

### What is Active Treatment?

Simply put...**Active TREATMENT** means **ALWAYS TEACHING**

Jayma Tucker, Division of Developmental Disabilities, Bureau of Quality Review



picture graphics source: [www.dshs.wa.gov/](http://www.dshs.wa.gov/)

We often hear the term "active treatment" used to describe something that staff are doing at a given time. Example: "I was in the living room doing active treatment." This is not an accurate use of the term. Active treatment is a PROCESS. It's not just "keeping people busy." If you perform your job duties well, active treatment will be the RESULT of your interactions with people. The test of whether or not what you are doing is really "active treatment" is found in the answer to these questions:

- Did the person served LEARN something as the result of your interactions that will allow him/her to function more INDEPENDENTLY?
- Did the person served INCREASE his/her SKILLS as the result of the services you provided?
- Did the activities and services you provided help PREVENT the LOSS of skills the person already had?

### How can service providers maximize the success of active treatment efforts?

- Know each person's goals and objectives and consistently implement formal and informal training.
- Look for opportunities to practice skills throughout the day.
- Encourage each person to do as much for themselves as possible.
- Talk to and listen to people you support.
- "Teach" rather than "do".

- Get people actively involved in the routine of their home (doing chores, making choices, etc.)
- Be a good role model.
- Our first responsibility is to protect from harm.
- Remember, we are teachers, not caretakers.
- Focus on abilities, not disabilities.
- RESPECT ourselves, each other, and the people we serve.
- Don't take it personally/Break the chain.
- The best prompts are nonverbal and subtle.
- Remember to reinforce desired/positive behavior.
- Direct care staff makes it happen.
- Watch body language (open hands, don't cross arms, etc.).
- The best training environments are natural.
- Power struggles mean everyone loses.
- Fade in and fade out prompts.
- Self-esteem and independence go hand in hand.
- Keep your interactions positive and encouraging.
- Provide options and choices for everyone.

## **Tips for Making Your Interactions More Therapeutic (Maximizing Opportunities for Active Treatment to Occur)**

- Think of yourself as a "teacher." Look at every interaction with people as an opportunity to TEACH something.
- Involve all members of the group in your activities by increasing verbal and physical interactions. Regularly invite people into the group if they are not involved.
- Do things WITH persons, not FOR them. (One noted teacher/author on this subject jokes that staff fingerprints should never be found within areas where persons served receive quality services. That's because persons served are performing all the tasks, not staff, even if persons served are doing it with hand-over-hand guidance.)
- If persons served are resistive to hand-over-hand guidance, try hand-on-hand activity with the hand of the person served on top of the staff person's.
- Consider all the things that must be done for the person served. Find ways to get them more involved, even if initially it is only a small part of the task.



Active Treatment isn't just "table top" activities or implementing formal programs. Involve persons in routine household duties such as cleaning, organizing, storing, etc.

## The Importance of Leisure

Leisure involves choices about free time. Many people discover interests by experiencing a variety of experiences and choosing those that they most enjoy. Staff can help people to experience a variety of leisure activities and assist each with participating in those that are preferred.

Leisure time is important because it balances work and learning. Leisure time, or free time, is a perfect time to help people make choices that are important to them – choices that are personal and individualized. Choices are important because they let us know how people want to spend their free time.

Many people with developmental disabilities have a great deal of free time because employment opportunities are limited. Effective use of free time can help with:

- ❖ Reducing inappropriate social behaviors
- ❖ Teaching social and communication skills
- ❖ Promoting physical health

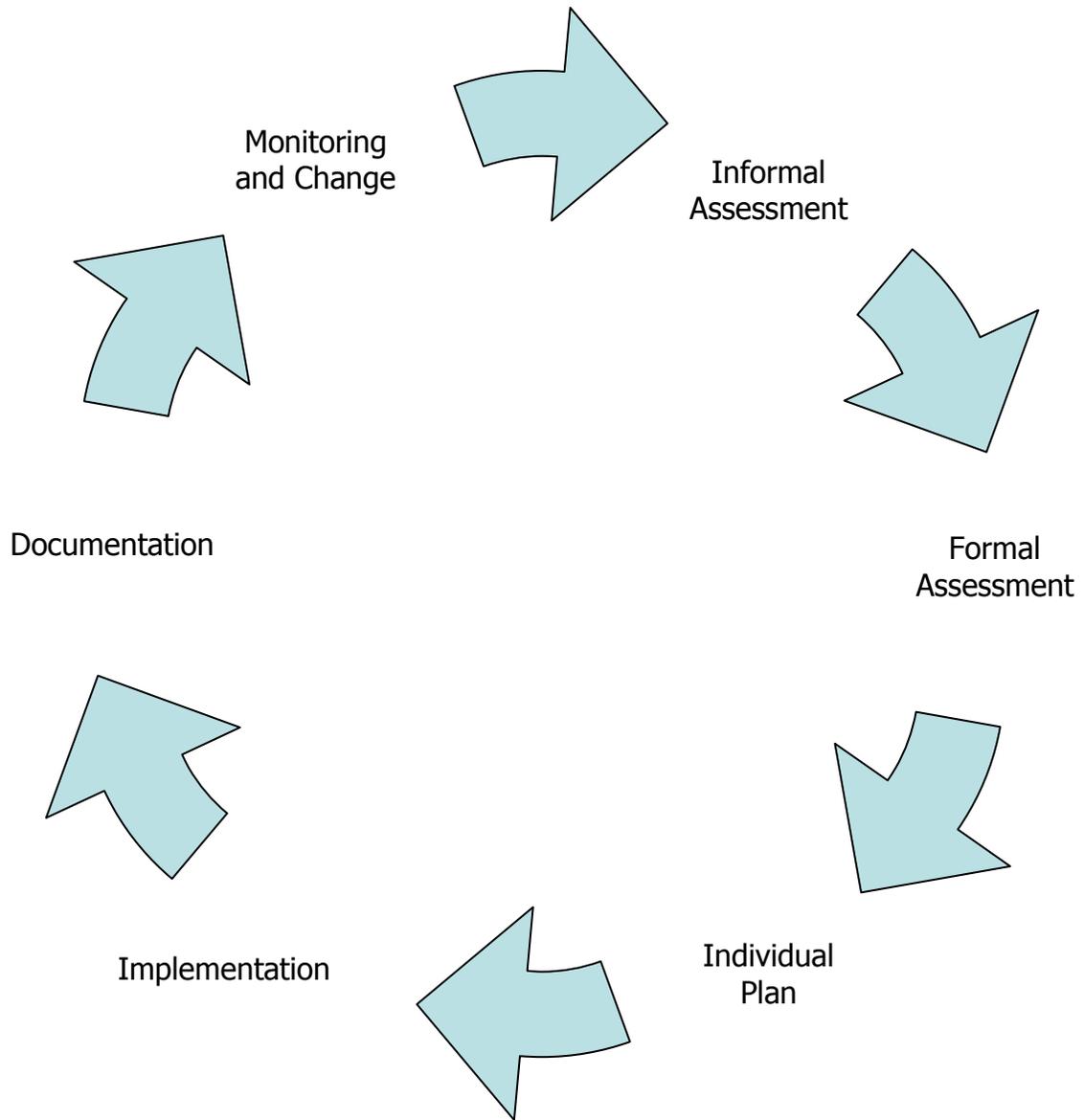
## Characteristics of Appropriate Leisure Programs

Appropriate leisure programs should:

- ❖ Be consistent with the principle of normalization
- ❖ Take place in the community (when appropriate)
- ❖ Be based on personal preference
- ❖ Be integrated

Activity and Treatment Ideas for Recreation Therapy can be found at:  
[www.recreationtherapy.com](http://www.recreationtherapy.com)

## The Active Planning Loop



The basic components of the Active Planning Loop are:

- ❖ Assessment
- ❖ Individual Plan
- ❖ Implementation
- ❖ Documentation
- ❖ Monitoring and change

## Writing Goals and Objectives

Goals are used as a departure point from which the more specific and complete behavioral objective can be developed.

A goal is a statement which includes a group of related behaviors in a given area; such as: skills of independent living; or; vocational; or social/recreational; etc.

### Goals

The goal statement defines the direction of a person's program. It indicates what the person will accomplish in a specific length of time. The goal is based on the person's needs, and should be written without regard to the availability of services. The goal statement is an expectation of what the person will accomplish. Goals are written in a positive manner, stating what the person will do.

#### Four basic steps to include when planning goals are:

1. At every step of the planning, keep the desires, interests, and needs of the person served in mind;
2. Think about who shall be responsible for monitoring the goal achievement;
3. Determine what steps will be needed to achieve the goal, see if they can be established in a logical chronology;
4. Set a deadline—choose a date when everyone agrees the goal can reasonably be attained.

## Behavioral Objectives

A behavioral objective is an attempt to define clearly the successful completion of behavioral change. Objectives are **measurable** intermediate steps between the person's present level of performance and the desired level as stated in the goal.

#### Qualities of well written Behavioral Objectives are that they be:

- Sequential
- Relate directly to a goal
- Are measurable
- Behavior to be modified to clearly observable
- Are singularly stated (no compound objectives)

When writing a behavioral objective it should be **one sentence** which is **composed of the following five elements in this order:**

- Conditions
- Person
- Behavior
- Performance
- Timeline

- **Conditions** – describes the things that have happened or are required to happen during the program or things the person will be given to carry out the program. **Example: “When handed his checkbook . . .”**
- **Person** – Use the individual’s name, not nickname, not “he” “she” or “you”
- **Behavior-** Specify one behavior that the individual will perform in measurable and observable terms. The behavior should be **overt** (sensed through one of the senses and able to be measured), not **covert**. Look at some differences between these terms:

#### **COVERT**

Distinguish  
Conclude  
Concentrate  
Think  
Recognize  
Be aware  
Infer

#### **OVERT**

Draw  
Fill in  
Underline  
Repeat out loud  
Point to  
Walk  
Count out loud

**Performance** – Describes the degree to which the person will perform the task satisfactorily. This may be done by various methodologies:

- ❖ How many—i.e., the number of responses; ex.: “will walk a straight line 15 times”
- ❖ How long—i.e., time-related—for what length of time; ex. “will package plastic soap dishes into the box for 20 consecutive minutes”
- ❖ How often--# of responses that are time-related; ex.: “will make his bed four out of seven times in one week”
- ❖ How well—to what degree or at what level of accuracy; ex. “write down the sums of addition problems with 80% correct score or higher.”

## **Timeline**

The timeline is the date by which the performance criteria should be achieved. The timeline date must always include month, date and year.

## OBJECTIVES WORKSHEET

**Practice I: Underline the condition statement in each of the objectives below:**

1. When shown a red colored card and asked "What color is this?", John will state out loud "red" nine times out of ten by May 14, 2012.
2. Given a bolt-grid and ten bolts of various sizes, Mary will place all ten bolts onto the corresponding bolt on the bolt grid nine times out of ten by June 4, 2011.
3. After using his toothbrush, Randy will place the toothbrush in the holder two out of three times by February 28, 2011.
4. Before leaving the classroom, William will put on his coat nine days out of ten by March 30, 2010.

**Practice II: In the spaces below, add condition statements to the beginning of each of the sentences below:**

1. \_\_\_\_\_  
**Thomas will tie his shoes nine times out of ten by September 30, 2010**
  
2. \_\_\_\_\_  
**Terry will place the fork to the left of the dinner plate four out of five times by May 6, 2011.**
  
3. \_\_\_\_\_  
**Ellen will write her name cursively on the endorsement section of her paycheck for the next five pay periods, by August 1, 2012.**
  
4. \_\_\_\_\_  
**Jan will select the sugar substitute packet for her cereal for ten consecutive breakfasts by October 31, 2012.**

**Practice III: Listed below are some statements which contain either overt or covert behavior. Place a C for Covert in the blanks before those statements expressing covert behavior and an O for Overt in the blanks for those statements expressing overt behavior.**

- \_\_\_\_\_ Mary will walk. . . . .
- \_\_\_\_\_ John will catch a ball .....
- \_\_\_\_\_ Henry will remember. . . . .
- \_\_\_\_\_ Sarah will pick up . . . . .
- \_\_\_\_\_ William will indicate. . . . .
- \_\_\_\_\_ Harriet will be able to . . . . .
- \_\_\_\_\_ Jim will learn to . . . . .
- \_\_\_\_\_ Fred will make the sign. . . . .
- \_\_\_\_\_ Summer will understand. . . . .

**Practice IV: Listed below are some statements that are objectives. Look at the objectives and circle whether the objective has overt or covert behavior. If you believe the behavior is covert, in the blank provided, write down how would you re-word the objective to make it overt.**

1. Given five coins of which one is a dime and the instruction, "point to the dime", Rosemary will point to the dime nine times out of ten by June 1, 2012.  
 COVERT                      OVERT                      Reworded?  
 \_\_\_\_\_
  
2. After using the restroom, Sam will wash his hands with soap and water nine times out of ten by May 15, 2012.  
 COVERT                      OVERT                      Reworded?  
 \_\_\_\_\_
  
3. When at meals, Jerry will learn to lift his spoon from the plate to his mouth for ten consecutive meals by December 15, 2011.  
 COVERT                      OVERT                      Reworded?  
 \_\_\_\_\_
  
4. When presented with a picture of a dog and asked "What is this?", Jerry will be able to sign "dog" nine times out of ten by January 1, 2012.  
 COVERT                      OVERT                      Reworded?  
 \_\_\_\_\_

**Practice V: In the objectives written below, the performance criteria for each has been omitted. In parentheses next to the blank will be indicated the type of performance criteria you should insert on the blank provided.**

1. Given the verbal prompt, "It is time to eat," Rachel will walk to the dining room (How Often) \_\_\_\_\_ by January 1, 2012.
2. Given a drill and drill bit, Harry will insert the bit into the drill chuck (How Well) \_\_\_\_\_ by August 1, 2011.
3. Upon sitting at her work station, Marion will assemble battery packages (How Long) \_\_\_\_\_ by November 30, 2011.
4. Given fifteen double digit subtraction problems, Jason will write the answers (how well and how many) \_\_\_\_\_ by September 30, 2012.

Source: Chuck Padgett, Kreider Services

## Task Analysis

### What is a Task Analysis?

Task analysis is a process by which a task is broken down into its component parts. Everyone uses a task analysis at some point, even if it is unconsciously. How else would anyone learn to complete processes? Like the old saying goes, “You have to walk before you can run”. We may forget that certain tasks are really complex and need to be broken down into steps because, after a time, they become like second nature. With people who have special needs, it is necessary to break each task down into small manageable steps.



Sometimes a task an individual is learning is too complicated for the person to learn all at once (e.g., brushing your teeth). Therefore, we break the task down into *teachable steps*:

- ❖ Determine what task you want the person to perform.
- ❖ Figure out what steps will be required to complete the task (and figure out how small to make each step based on the strengths of the learner).
- ❖ Teach the person one step until mastery is displayed (mastery must be defined in the individual’s plan).

This allows the learner to develop multi-step, complex skills that would otherwise be difficult to acquire. Identifying the step-by-step sequence does this. This requires a task analysis.

You should note that much of our own learning is done in steps. Many of the things we learn, remember, and do are done in this process.

You are going to get practice in doing just this in the next exercise.

## Task Analysis Activity

**Your instructor will guide you through the next activity. After completion, please consider the following questions:**

1. What happens when each staff does a task differently when helping a person with a developmental disability learn to do a task?
2. Why is it important to do a program plan the way it is written?
3. What should staff do if the program plan doesn't seem to be working?



Also consider. . .

- Is there more than one way to do the same thing?
- What happens if each of you does a task differently with an individual?
- Why is it important to implement an individual's training plan the way it is written?

## TECHNIQUES FOR TEACHING SKILLS

The task analysis exercise you just did demonstrates a very important step in teaching a new skill. However, many times, a person you support may not be able to learn all of the steps at one time. Teaching techniques sometimes used are:

### Shaping

**Shaping** is a way of adding behaviors to a person's repertoire. Shaping is used when the target behavior does not yet exist. Following are some different types of shaping.

These are:

—**Forward chaining** is a procedure that teaches a task from start to finish. It involves teaching people one step at a time, working forward step by step to accomplish a simple task.

—**Backward chaining** involves teaching the last step first.

### Fading

**Fading** involves reducing the amount of information given in order to decrease dependence.

**Remember, as staff members you are always teaching, whether it is by active involvement with the individual or by modeling appropriate behavior with staff and/or individuals.** (Dale DiLeo, *Enhancing the Lives of Adults with Disabilities.*)

## Teaching Strategies

Active teaching should support each person to reach their maximum potential, encouraging as much independence as possible. The teaching strategy would encourage the individual to perform a skill independently. However, prompts or cues may be necessary for the person to complete the task. The cues or prompts follow a continuum from least to most involved.

The cue or prompt level may be one of the following:

- ❖ Natural
- ❖ Gestural
- ❖ Verbal
- ❖ Modeling
- ❖ Physical

**Natural**— The natural cue is also called the independent level. The cue actually comes from the environment. The person does the skill or task without prompting from staff.

**Gestural**— The gestural cue is performed if performing the natural cue is not possible. Example: A person may not initiate picking up an object, but if the support staff points to the object to be picked up and the person picks up the object, that person did the task at the gestural prompt level.

**Verbal**— The verbal cue is performed when a support staff member asks the person to perform a task and the person does it.

**Modeling**— This is completed by the support staff. Member will perform (model) the desired behavior. The staff member would then put the object back and if the person performed the requested task, the person would have completed the task at the modeling level.

**Physical**— If the task cannot be completed at any of the other levels, then the physical task will need to be used. This is completed by having a staff provide *brief* hand-over-hand assistance in order for the person to complete the task. This should never be forceful in nature. If the person resists, the staff person may try putting the person's hand *over* theirs.

## What Is Person-Centered Planning?

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

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

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



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

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

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

### Guidelines

These Person Centered Planning (PCP) process guidelines are intended to assist the individual (i.e., the person receiving the services), his/her family members and friends, service coordinators/case managers, and state and local service providers who participate in life planning. The purpose of this document is to guide the team in making the choices and developing strategies that comprise the support plan based on the individual's desired lifestyle rather than the traditional remediation and deficit approach.

## Important Concepts of Person Centered Planning

- ❖ The person centered planning process requires a shift in traditional thinking, actions, and way of doing business or individual directs the services and supports.
- ❖ The individual is the central driving force in determining his or her future vision, goals, supports and services.
- ❖ The planning process requires family members, friends, and professionals to:
  - listen to the individual;
  - attend to the details;
  - be open and sensitive to situations that can be difficult and confusing;
  - encourage dreams and desires of the individual and to contribute to those dreams and desires; and
  - identify and support what really matters to the person.
- ❖ The person centered planning process is a core component of quality service delivery.
- ❖ Person centered planning replaces the deficit-based assessment that traditionally has driven the Individual Service Plan.
- ❖ Person centered planning should not be viewed as an "add-on" to the current planning process.



### I. Definition of Person Centered Planning

Person centered planning is a process whereby persons with disabilities, with the support of families, direct the planning and allocation of resources to meet their own life vision and goals. This planning process:

- is based on a person's preferences, dreams, and needs;
- understands how a person makes decisions;
- understands how a person is and can be productive;
- discovers what the person loves and dislikes;
- encourages and supports long-term hopes and dreams;
- is supported by a short-term support plan that is based on reasonable costs given the person's support needs;
- includes the individual's responsibilities;
- includes a range of supports including funded, community and natural supports; and
- should be conducted based upon the needs of the individual, but at least annually.

## II. Terminology

1. **Discovery process:** the process of identifying the strengths, preferences, and desires of an individual. It is an information gathering process that provides the foundation for developing/updating an individualized support plan. This occurs on an ongoing basis.
2. **Facilitator:** the person who leads the team through the person centered planning process, which includes developing an individualized support plan. The facilitator is anyone chosen by the individual. The facilitator gets people to share ideas and efficiently leads them through the process. He or she involves the individual and assures understanding of the discussion. The facilitator must be a good listener, check understanding regularly, observe themes, and guard against immediate or old solutions. He or she prepares for the meeting(s), maintains focus and redirects concerns unrelated to the plan development.
3. **Individual:** a person with a disability seeking or receiving services.
4. **Informed Choice:** the ability to make a voluntary decision based upon options presented to the individual. The individual will engage in a variety of experiences to identify preferences and choice.
5. **LAR (legally authorized representative):** is a person authorized by law to act on behalf of an individual and who may include a parent or guardian of a child, or a guardian of an adult.
6. **Natural Supports:** supports that occur naturally within the individual's environment. These are not paid supports, but are supports typically available to all community members. Natural supports should be developed, utilized and enhanced whenever possible. Purchased services should supplement, not supplant, the natural supports. Some examples of natural supports are the family members, church, neighbors, co-workers, and friends.
7. **Open-ended questions:** questions that do not suggest an answer, e.g. not simply yes/no or multiple choice questions.
8. **Service Coordinator/ Case Manager:** an individual who provides assistance to the individual in identifying and accessing medical, social, residential, employment, educational, behavior, and other appropriate services that will help an individual achieve a quality of life and community participation acceptable to the individual (and LAR on the individual's behalf) as follows:
  - a. crisis prevention and management-locating and coordinating services and supports to prevent or manage a crisis;
  - b. monitoring-ensuring that the individual receives needed services; evaluating the effectiveness, relevancy, and adequacy of services; and determining if identified outcomes are meeting the individual's needs and desires as indicated by the individual (and LAR on the individual's behalf).

- c. assessment-identifying the nature of the presenting problem and the service and support needs of the individual; and
  - d. service planning and coordination-identifying, arranging, advocating, collaborating with other agencies, and linking for the delivery of outcome focused services and supports that address the individual's needs and desires as indicated by the individual (and the LAR on the individual's behalf).
9. **Support Team:** the team established by the individual that typically includes his/her legally authorized representative (if applicable), close family members/advocates, the case manager, providers, and others identified by the individual as being important in his/her life.

### III. Guiding Principles for Person Centered Planning

Person centered planning is based on a variety of approaches or "tools" to organize and guide community change and life planning with people with disabilities, their families and friends. All approaches or "tools" have distinct practices, but share common beliefs. Person centered planning process is based on a framework that describes five essential accomplishments: **1) community presence, 2) community participation, 3) choice, 4) respect, and 5) competence.**

1. Individual differences and differences in family dynamics and composition are respected and accepted.
2. Person centered planning requires that it is the individual who defines what is meaningful in his/her life and what really matters most to him/her.
3. All individuals have the opportunity to make informed choices and need to exercise control of their lives. Sometimes in order to do this effectively they must be supported by others and have a variety of experiences, either in their natural environment or from within the system.
4. Person centered planning should not be viewed as an "add-on" to the current planning process, but a central starting point for planning.
5. Individuals must have choice among flexible, dependable services that meet their immediate needs and support their goals and aspirations for a lifestyle that affords personal control, informed decisions, dignity and respect.



6. Person centered planning process builds on an individual's strengths, gifts, skills, talents, and contributions.
7. Person centered planning processes encourage the "building of community" around individuals. They help develop supports to facilitate relationships with people within the individual's community.
8. Individuals should fully and actively participate in making the decisions that affect their lives.
9. Solutions to obstacles and issues that emerge during the person centered planning process are negotiated to ensure that resulting activities are consistent with the individual's preferences and goals.
10. The individual partners with the support team to explore creative options to meet the preferences and goals expressed by the individual.
11. Resources to support the individual are based on identified needs that the individual may have and are available in the community and/or in an agency. Natural resources presently available in the community are used first, then the agency resources. In instances where generic resources may not exist, they may need to be developed within the community.
12. All strategies and resources used must support the desired outcomes and identified needs of the individual. Strategies are developed to increase the likelihood that individuals will increase control over their lives, participate in community life and develop relationships.
13. Person centered planning is a dynamic, rather than a static process. The individualized support plan is revised as new opportunities and obstacles arise or when significant changes occur in the individual's life.
14. A person's cultural background is acknowledged and valued in the planning and decision-making process.

## IV. The Differences between Person Centered Planning and Traditional Planning

Person centered planning is an interactive planning process which brings together the people who live with the concerns and issues daily and who are committed to learning together to respond to the situation. Specifically, the differences are:

<b>Traditional Planning</b>	<b>Person Centered Planning</b>
A team of service providers meets annually with the individual and/or family members to develop a plan for services	A support team made up of the individual, legally authorized representative, family members, service providers and other community members meet as frequently as needed to develop and implement a future vision and goals for the individual. The team will meet based upon the needs of the individual, but at least annually.
Relies on standardized and non-standardized tests and assessments.	Spends time getting to know and discovering the person.
Begins with an assessment process that highlights deficits. Looks at the person in need of services and who has to get "ready" for community life.	A support team gathers, organizes, and manages assessment information into a personal profile and future vision and goals using highly visual and graphic maps.
The individual and family members are invited to participate in the development of the individual service plan.	The support team assists the individual in a respectful and competent manner to actively lead and/or participate in the meeting.
Establishes goals that are already part of existing programs. The plan is designed to fit the person into a particular program, even if that program is not exactly what the person needs.	The individual, family members, friends, and general community members define the personal profile and future vision and look to service providers for supports. Programs are developed around the needs of the individual.
Relies primarily or solely on professional judgment and decision-making.	Depends on people, families, friends, and direct service providers to build good descriptions.
An individual service plan is mandated to guide the services.	A future vision and action plan guide the activities and drive the Individualized Support Plan content.
Implementation of the plan is ensured through provisions of professional services.	Implementation of the plan depends upon the commitment and partnership of the team and their connections with the individual.

## V. Tips to Implement Person Centered Planning

### A. Discovering the Person

1. ***Listen, acknowledge, and discover the personal goals, preferences, choices, and abilities of the individual directing the plan:***



- a. A person centered planning process occurs only when the individual is present.
- b. Prior to the planning meeting, the facilitator goes over the issues to be discussed with the individual or family/primary caregiver. They identify those issues that will be discussed in a larger group (public issues) and those that are to be discussed more privately (private issues).
- c. The facilitator asks open-ended questions to elicit information from the individual or family/primary caregiver in order to discover the preferences, choices, goals and abilities of the individual.
- d. The discovery process may or may not occur in a planning meeting with a large group of people. It can occur separately with the individual, family/primary caregiver and those that know him/her well.
- e. The discovery process solicits information based on the individual's strengths, capacities, gifts, skills, talents, and contributions.
- f. All the information collected from team members (within or outside of the person directed planning meeting) during the discovery process must be confirmed with the individual to ensure accuracy before documenting it.
- g. The individual's goals and preferences are constantly evolving; therefore, person centered planning is ongoing and not a one time/annual planning process. Question-asking, listening and discovering the preferences of the individual is on-going.
- h. Every effort must be made to ensure that the individual is fully informed to make responsible choices based upon options presented.

**2. *Documentation of the information gathered during a person centered planning process is important***

- a. All information should be written in a respectful manner. Information is to be communicated to the individual in a way that she or he understands.
- b. Document all the information gathered from the individual /family to ensure that it is available to all pertinent staff and/or providers (new and old). This helps reduce or eliminate the need to ask the same questions repeatedly by new staff to the individual or family members.
- c. All the information must be documented in the plan without changing the meaning that the individual/family attributes to it.
- d. The documentation should cover the individual's daily routines and desired goals. It should be descriptive, but concise, painting a picture of the individual. This picture should lead to the development of a meaningful day and activities for the individual. For example, identifying that the individual works 25 hours a week as a stocker for the hardware store, volunteers 5 hours a week at the senior center and works out at the community recreational center.
- e. The person centered planning process must include information relevant to any issues concerning the individual's health and safety. Supports to maintain the individual's health and safety should be developed within the context of his or her preferred lifestyle so that it does not conflict with his/her preferences. Describing issues functionally provides a better picture of the individual's need for support. For example, when documenting a behavior such as verbal or physical aggression, a description of how it manifests and the situations in which it occurs must be included. Merely stating that the individual is verbally or physically aggressive may not provide sufficient information to determine the supports the individual may need. Example: Tom often grasps his hands and breathes heavily prior to becoming physically aggressive by hitting or pushing people near him.

**3. *The individual determines who is involved in the planning process:***

- a. The individual chooses the members of the person centered planning team. The team may include the individual's legally authorized representative, close family members/advocates, the case manager, providers, and others identified by the individual as being important in his/her life.
- b. The team members must respect, trust, and support the individual.
- c. If bringing together a team for the planning process is difficult, then developing one should become a priority. However, the planning process can be initiated while the team is being developed.
- d. The team members meet in a comfortable location, as defined by the individual. This may help the individual feel relaxed and open enough to share things that are important to him/her with the rest of the team.

4. ***Identify the existing supports (natural or paid), both used and unused, that are consistent with the individual achieving identified goals***

- a. In most situations family members, friends, and the individual have the most knowledge about the preferences, capacities, and gifts of their children, friends, and themselves respectively. However, professionals usually have knowledge of resources available in order to provide appropriate supports and services for the individual. All members should play an active and collaborative role in order for the planning process to be effective.
- b. The individual, families and professionals recognize and document in the individualized support plan the existing supports in the individual's life.
- c. Previously unexplored natural supports in the community are discovered during the process.
- d. Identified supports match the preferences of the individual.
- e. The planning process considers the supports that the individual may require for issues that may not be directly related to the outcome but influence the strategies and actions that are developed to achieve the outcome. For example, counseling for anger or stress management.



5. ***Other professionals not originally included by the individual in their planning teams are identified as consultants, when needed.***

- a. All professional consultations, such as with a nurse or psychologist, occur in the presence, or with the permission, of the individual/LAR and are conducted in a manner respectful to the individual.
- b. The support team (i.e., individual, family and professionals) and other professional consultants are encouraged to have a trusting and collaborative relationship.

6. ***Issues of safety, health, rights, and freedom from abuse, neglect and exploitation are dealt with in the person directed plan***

The planning process includes a discussion of individualized health and safety issues in the context of the life desired by the individual. The process maintains a balance between rights (choice/control), responsibilities and risks (health/safety) experienced by all citizens.

## **B. Individualized Support Plan**

1. ***To identify additional natural supports and negotiate needed service system supports***
  - a. Both natural and system supports are negotiated to develop the best possible support plan to achieve what is important to the individual.
  - b. The individual determines his/her own supports by participating in selecting, evaluating, and when necessary, changing his/her activities and support staff.
  - c. The support team members identify opportunities and activities to connect the individual to the community.
2. ***Implementation of the support strategies becomes the responsibility of the planning participants***
  - a. The individualized support plan includes i) outcomes, strategies and activities, ii) person/s responsible for the completion of the activity or strategy, and iii) the date by which it is to be completed. Including specific names of people responsible and timeframes facilitates the monitoring process.
  - b. The goals and aspirations are prioritized by the individual.
  - c. The most important goals and aspirations are addressed first.
  - d. A support plan is more easily implemented if the team works on a few goals and aspirations at a time.
  - e. The individual is supported to develop community connections.
  - f. Preferences should not be considered to be the same as services and supports. Services and supports are used to facilitate the acquisition of the individual's preferences. For example, the individual may express a preference to work in a bank. However, he or she may require the support of a job coach to achieve the desired goal. The support of a job coach is not the expressed preference of the individual in this case. The job coach is the support needed to achieve a goal based on the expressed preference.
  - g. In a case where there is a disagreement between the individual and their LAR, every effort should be made to negotiate and clarify conflicting issues. The facilitator must keep the individual's preferences and desires the main focus of the planning process and resolve the LAR's concerns to come up with the best compromise between the two.
  - h. There must be a partnership between all the team members to implement the individualized support plan. No single team member should be responsible for its implementation.

3. ***When people choose outcomes that conflict with state/programmatic standards, the following strategies should be considered to meet people's needs***
- Identify goals/needs that can be achieved within the existing standards, rules and regulations, while problem solving on how to accomplish the ones that are more difficult to achieve.
  - Explore resources in other systems and programs serving people with disabilities and services available to all citizens, whether or not they have a disability, in the community to fulfill these needs.
  - Use the existing system to its fullest potential and negotiate to create the best possible arrangement for the individual.

Discover why a particular choice or the refusal of an alternative presented in place of the original choice is important to the individual.

## VI. The Role of the Facilitator

One of the key elements of the person centered planning process is a good facilitator. Good facilitators do not just run meetings. They must get to know and understand the individual and significant others in that person's life. A skilled facilitator is one who clearly understands the change process and the corresponding values. Skillful facilitators have the ability to listen, concentrate, take directions from the individual, and be inquisitive to constantly search for capacities and areas for exploration.



A number of people can serve as a facilitator during the person centered planning process. No one person is excluded from being a facilitator and no person is assumed to serve as the facilitator. However, whoever serves as the facilitator must understand the role and ensure completion of the components.

## VII. Monitoring the Quality of the Person Centered Planning Process

The quality of a person centered planning process is defined by the individual and is reflected in more personal outcomes being achieved. There will be a multi-level monitoring process to ensure the quality of person centered plans. The indicators of successful implementation of a person centered planning process are:

- Evidence that the individual determines his/her preferences during the person centered planning process with the support of family/LAR, friends, and staff if necessary.
- Evidence that the individual chose whether or not other persons should be involved and identified the people to be included in the person centered planning process.

3. Evidence that the individual chose the time and location of the person centered planning session.
4. Evidence that the individual chose his/her outcomes and support staff whenever possible.
5. Evidence that the individual's preferences and outcomes were seriously considered and in situations where it was difficult to implement his/her preferences and outcomes, the team arrived at a compromise acceptable to all.
6. Evidence that case managers/service coordinators ensure that support plans remain current at all times and are monitored on an ongoing basis for their effectiveness in achieving the outcomes identified by the individual with the support of his/her family/LAR. This is a critical element since an individual's goals and preferences are constantly evolving. It is important to keep asking questions, listening and discovering the preferences of the individual.
7. Quality improvement plans actively seek feedback from the individuals and families receiving services and supports regarding the opportunities they have to express needs and preferences and the ability to make choices.

### ***The Person Centered Planning Process Happens When . . .***

people work together to solve the challenges that arise when individuals live and work where and how they choose and strive to reach their dreams and goals.



## Person Centered Planning Helps/Hinders

<b>COMMENTS THAT PROMOTE PERSON CENTERED PLANNING</b>	<b>COMMENTS THAT INHIBIT PERSON CENTERED PLANNING</b>
I'll help you find out.	I don't know what you would do here. You might want to call...(i.e., someone other than me).
You can help just like everyone else.	We can't fit that into your schedule.
Let's talk about what other tasks you might like to do.	We can't do that because the state doesn't give us money to do that.
You can volunteer in my Sunday School room, my area, etc.	The rules don't allow that.
You can try that and see if you like it.	I really want to but our schedule just doesn't allow me the time.
Tell me more about what you like about that.	There's a program like that for people with disabilities.
What do you want to discuss at your meeting?	You need this.
What do you need to be able to do that?	This would be much better for you because...
Do you need someone to help you?	I don't think you would want to do that.
Let me make sure that I understand what you are saying.	I know that you expressed you wanted to do this at your last meeting (6 months ago) and we are working on this.
I'm listening.	Yes, I'm listening but...
I'll be there!	You are on the list and by next year you should be able to start interviewing for a different job.
I think you're a neat person!	My Life, My Dream by: Grossi, McCarty, Holtz and Todd

## **SOCIAL HISTORY**

**An important part of developing a person centered plan is to understand the social history of the individual. Below is a sample social history of Sue.**

Sue is a single, never married, white, 37 year old female. She is the fifth of six children born to \_\_\_\_\_ and \_\_\_\_\_. Her father is deceased as of 11/89 and mother resides in a nursing home in southern Illinois. There is sporadic contact with one brother and mother, no contact with remaining family.

Sue attended and graduated from High School in 1983. No other education history is known. She currently works part time at a fast food restaurant and does some volunteer work at a local elementary school. She used to do housework and cleaned in a laundromat.

Sue is overweight, has high blood pressure and is allergic to antibiotics. She has difficulty with speech articulation which makes communication difficult. She is able to read and write simple phrases.

Sue lives with her boyfriend in a house they own together and they split expenses. Sue has no guardian or representative payee. She receives benefits from Social Security and has Medicaid insurance.

## **PERSONAL SKETCH**

Sue is a short, stocky woman with a smile that makes her eyes crinkle up at the corners and that causes those around her to smile back. She is "thirtyish," with thick, brown, wavy hair that is always shining and in place. Sue is working hard to lose weight and get her blood pressure down so her doctor will stop "yelling" at her.

Sue is a dreamer, always has been. There was a time many years ago when it seemed unlikely that any of her dreams would ever be more than that--dreams. Sue is not only a dreamer, she is a doer, against the odds she carries her positive attitude and persistence to make her dreams reality.

Sue was the fifth of six children born to parents with developmental disabilities in rural \_\_\_\_\_ County in 196-. Her mother was barely 14 years old when she ran away to Mississippi to marry Sue's father. Within seven years she had borne six children while little more than a child herself. Life was difficult for this family. Both parents were overwhelmed and poorly equipped to handle the needs of six children. Sue was so emotionally and culturally deprived that at the age of 5 ½ she had yet to speak her first words. In desperation, the family turned to the Department of Children and Family Services and the Department of Public Aid

for help. Sue's parents agreed to what they thought was a temporary placement of all of their children at \_\_\_\_\_ State School. Instead, all of the children were placed in foster homes while awaiting placement. Eventually, Sue and two of her siblings were placed at \_\_\_\_\_ School, the other three siblings whereabouts were unknown to Sue and her parents.

In 1968, Sue's parents moved to \_\_\_\_\_ in hopes of starting a new life. Sue's father got steady work as a farm hand and he and his wife rented a three room house on the southwest side of town. The home had no indoor plumbing. Drinking water came from a rain barrel that collected water which ran off the roof of the house. Sue's parents were distraught at the loss of their family and angry with the court system that they believed had deceived them. They sought the assistance of the Legal Aid Society and discovered that they could get Sue released from \_\_\_\_\_ State School. They did this as soon as they were able to make arrangements. Sue was reluctantly released from the state school in 1969. The staff felt that Sue had been making significant progress.

Sue was immediately linked to P\_\_\_\_\_ School, which was not a public school but an agency that provided services to people with disabilities that were not, at the time, served by public schools. Eventually, she was linked to S\_\_\_\_\_ School which is a public school and at the time provided services to "E.M.H. and T.M.H" students. The environmental deprivation in Sue's home was so severe that one of the teachers at S\_\_\_\_\_ School offered to take Sue into her home in order to give her the attention she needed and craved. Sue's parents agreed because above all else, they loved their daughter and wanted to best for her.

Sue's dreams began. Graduation from S\_\_\_\_\_ School approached and Sue had decided she wanted her own apartment. Sue's friend, the teacher from S\_\_\_\_\_ School, helped her find an affordable, safe apartment and set her up there. PRC (used to be P School) assisted Sue with her shopping, medical appointments and managing her money.

Sue kept dreaming, she wanted more. She wanted a job and she got one at the Steak and Shake. She loved earning her own money. Sue lived across the street from a laundromat so she approached the owner about keeping the machines clean and the floor swept, he hired her. Soon her reputation as a housekeeper earned her several regular housekeeping jobs. Sue also found time to give of herself in volunteer work at MRI (what used to be PRC). Sue did pet therapy once a week for individuals in training and the staff. Everyone looked forward to the day that Sue brought her contagious smile and some fuzzy little animal to love on.

Sue's dreams continued. Sue dreamed of finding someone to love and share her life with. She met Mr. Right when they shared a bus seat on an outing to St. Louis organized by MRI. Six years later the two of them were sure they had found the love of their life and Sue's dreams grew. They wanted a real home of their own. With support and assistance from MRI and his family, they found and purchased a bungalow in a quiet neighborhood. The white sided house was lovingly decorated and maintained right down to the "Welcome" mat on the

front porch. They each put up half of the earnest money, they are both listed on the title to the house and they split the household bills and mortgage payment.

The dreams continued. Now Sue had her home and life mate and she would like to get married. There were concerns about losing benefits if they married and how the bills would be covered if something happened to her. While MRI would help Sue and her boyfriend to work through this, which Sue appreciated, she also dreamed of being independent. She had succeeded, after years of training, to manage her own money. She had a checking and savings account which she managed independently; however she required assistance in filing her income taxes and completing Public Aid forms.

Through the years Sue had always had the dream of finding her other siblings and reuniting them with her mother. Sue feared time was running out as her mother was ill and in a nursing home in southern Illinois. In part, due to Sue's trying to find a way to do it, a teacher from S\_\_\_\_\_ School heard the story and something clicked in her memory from when she worked in southern Illinois. Following through on the hunch proved correct. Sue had found her lost siblings and was able to get them together with their mother. What a joyous success for Sue. For those of us who are lucky enough to know Sue, she has a wonderful gift of sharing her joy in a way that enables you to feel her joy in your heart.

Currently, Sue's dream of being married to the love of her life has come to an end. Her boyfriend passed away, suddenly and unexpectedly. Just as those who know Sue and shared her joy, we share her grief. Sue is working hard to stay on track and get on with her life. Her many friends and the family of her boyfriend do all they can to help. Again it seems we who "work with" Sue gain and learn so much more from her than we give. She can sign/say, "I still cry sometimes." Then the smile appears that let's you know she misses him terribly and yet is so very thankful she had him in her life.

Sue's dreams now are focused on keeping the home she shared with her boyfriend. She works part-time and continues at S\_\_\_\_\_ School as a teacher's aide. She continues to work on controlling her weight and blood pressure. She would like to save money to make some improvements on the house. Sue is staying involved in life by volunteering and doing things with friends.

## Scenario Five

**Directions:** You have been getting to know Rachel in each of the previous modules. However, it might be helpful to get some insight from her peers, support staff, family, and Rachel herself. The following pages provide you some additional information from their points of view. Use what they say to complete the person centered planning tool included in this module. A person centered planning tool is meant to emphasize the positive qualities of the individual. Pay particular attention to those questions/issues that are raised.



### Peers' Point of View

I go with Rachel on outings with staff. She doesn't talk to anyone but staff. She always wants to go to the mall. When we watch TV, she wants to watch race cars all the time. I don't like to sit next to her because she stinks up the room and laughs too much.

. . . . .

Rachel sits next to me at work and never stops talking about boys and race cars. Anytime I try to talk to staff, Rachel always starts talking and staff can't hear me. When we are supposed to be working, she is talking and doing other stuff so I can't get my job done. At lunch she steals my food and laughs when she stinks up the place. She is always bothering my boyfriend and never listens to me.

## Family's Point of View

**Family Background:** Rachel's mother was forty-three when Rachel was born. Rachel lived at home until she was 29. She is an only child. Both of her parents are alive, although her mother has diabetes and now is on dialysis due to renal dysfunction. This is the reason that she was placed outside of the home. Her parents are her guardians.

She has an aunt in Texas who has minimal involvement due to the distance, although she was involved in her early years. She still corresponds with Rachel.

**Father:** Rachel was a sickly child and had numerous hospitalizations. We kept her at home and had special tutors on occasion. She did not have a formal education due to her health. She was the center of our lives.

Mother spoiled and smothered her. She did not allow Rachel to learn or gain more independence. She just kept her at home. When Mother's health started deteriorating, I felt we couldn't keep her at home. I used to enjoy shopping with Rachel, but I can't handle both of them now. We just want her to be in a place where she is cared for, happy, and where someone will train her to be more independent and control her when she gets upset.

We are making arrangements for her aunt to be her guardian if something should happen to us.

**Mother:** I had Rachel late. In fact, I never thought I would have a child. She's been the light of my life, my baby. She was so sick as a child. When she was healthy she helped around the house a little. I just never felt she could handle school and the other children making fun of her. She acts up sometimes, but she's not a bad child. She needs some reminders when she gets upset. She would never hurt me though--she has never hurt anyone.

Rachel likes to talk a lot. She talks a lot when she is nervous or not feeling well.

## Support Staff Point of View

- Rachel's always on the phone.
- She answers the phone but doesn't pass along the messages.
- Her talking interrupts her work.
- Co-workers complain "she's gross."
- She has a new habit--picking her nose.
- Rachel likes getting a paycheck.
- Rachel is not a good listener.
- She offends people on the bus.
- She stays up late watching car races and then doesn't want to get up in the morning.
- She responds well one-on-one with favored staff.
- She has adjusted well to her diet at home.
- However, she makes inappropriate choices from vending machines at the workshop.
- Rachel eats what she wants on home visits.
- She works well with the floor supervisor at work.
- At breaks times, she is engaging in inappropriate sexual activity.
- Parent's are sending care packages with inappropriate food choices.
- Rachel has a chance at supportive employment if she pays attention.
- She has a male friend who is riding a bike, so Rachel is interested in learning to ride a bike.
- Staff now ride the bus to the mall with Rachel. But, she shops independently.
- Rachel is beginning to invite male friends to her home for supervised interaction.
- Staff have expressed a desire for Rachel to remain abstinent to prevent pregnancy and venereal disease.
- Workshop staff has expressed a desire for a time-out program when she is not paying attention.
- One staff member recommended moving Rachel so that the kitchen doesn't have to be locked to keep her from stealing the food in her CILA home.

## **Rachel's Point of View**

People just don't listen to what I have to say. Everybody treats me like a child. I'm not. I'm a grown woman. I want to meet some new guys and marry like Mom did.

I also want to do real work for real money. There's nothing wrong with me. Why do I have to be with these people.

I don't want to work on these old goals. I want to learn to write so I can write to the bus driver.

## Person Centered Planning Tool For Rachel

**Directions:** Complete this person centered planning tool using all of the information we have learned about Rachel from the past five scenarios.

### About Rachel

Support people in Rachel’s life . . . . .

*Include family, friends, acquaintances, community members, direct support persons, QIDP & other paid staff.*

Some great things about Rachel . . . . .

Some things Rachel needs help with . . . . .

What does Rachel like to do?

*Include: leisure activities, spiritual issues, cultural issues, community activities, work & household activities.*

What does Rachel wish she could do?

*Do not censor the list. Include everything she would like to do.*

What makes Rachel happy?

What makes Rachel sad?

Rachel's current job . . . . .

*Include: job duties, hours, pay, support needed, benefits, coworker relationships & flexibility.*

The job Rachel would most like to have . . . . .

Rachel's current residential situation. . . . .

*Include: neighborhood, location, roommates, privacy, transportation issues & supports needed.*

Where does Rachel want to live?

Rachel's dreams for the future . . . . .

*Do not censor the list.*

Rachel's medical condition. . . . .

*Include diagnosis, medications, therapies, diet & supports needed.*

**How Can We Best Support Rachel:**

In completing the things she needs help with?

In achieving the things she wants to do?

In finding/maintaining a job she is happy with?

In finding/maintaining a residence she is happy with?

In achieving her goals for the future?

To ensure the stability of her medical needs?

### **How Can We Make Sure This Works?**

Who is responsible for implementing this plan?

How will they ensure the continued success of this plan?

## Person Centered Planning Application Exercise #1

**Directions:** Work with one individual with an up-coming staffing or IDT meeting. Assist them in completing the first part of this person centered planning tool. Use this tool as a way of helping the individual communicate their wants and needs at the meeting. The second and third parts of this person centered planning tool will be completed with the help of all persons present at the meeting.

Remember to model the principles of confidentiality at all times. Your actions can influence how others react to confidentiality issues. Share it with your trainer when you are done.



# About \_\_\_\_\_

Support people in \_\_\_\_\_'s life . . . . .

*Include family, friends, acquaintances, community members, direct support persons, QIDP & other paid staff.*

Some great things about \_\_\_\_\_ . . . . .

Some things \_\_\_\_\_ needs help with . . . . .



What does \_\_\_\_\_ like to do?

*Include: leisure activities, spiritual issues, cultural issues, community activities, work & household activities.*

What does \_\_\_\_\_ wish he/she could do?

*Do not censor the list. Include everything he/she would like to do.*

What makes \_\_\_\_\_ happy?

What makes \_\_\_\_\_ sad?

\_\_\_\_\_’s current job . . . . .

*Include: job duties, hours, pay, support needed, benefits, coworker relationships & flexibility.*

The job \_\_\_\_\_ would most like to have . . . . .

\_\_\_\_\_’s current residential situation. . . . .

*Include: neighborhood, location, roommates, privacy, transportation issues & supports needed.*

Where does \_\_\_\_\_ want to live?

\_\_\_\_\_’s dreams for the future . . . . .

*Do not censor the list.*

\_\_\_\_\_’s medical condition. . . . .

*Include diagnosis, medications, therapies, diet & supports needed.*

**How can we best support \_\_\_\_\_:**

In completing the things he/she needs help with?

In achieving the things he/she wants to do?

In finding/maintaining a job he/she is happy with?

In finding/maintaining a residence he/she is happy with?

In achieving his/her goals for the future?

To ensure the stability of his/her medical needs?

## How can we make sure this works?

Who is responsible for implementing this plan?

How will they ensure the continued success of this plan?



## SECTIONS OF THE SERVICE PLAN

Most service plans contain the following information:

**Personal Description-** This section describes the person. It goes beyond the old way of describing a person ( i.e., 25-yr. old black male with down syndrome).

**Medical/Dental/Nutritional-** This section contains a summary of significant medical issues. This includes any medication the person takes and the reasons. There may be nutritional information mentioned here, as well.

**Background/Historical-** This is a summary of significant events that have happened in the individual's life. These events may be a clue as to what shaped who the person is today.

**Social Relationships-** Here is where details of the person's social life are outlined. Important people are mentioned, as well as, all types of relationships (e.g., family, friends, work, staff members). Some of these relationships may be positive and others not. Sometimes we draw maps to show how these people are related. These show graphically, the connections between people. This area would indicate whether the person prefers to be with people or by himself/herself.

**Goals/Objectives-** This section identifies the areas targeted for development. The information for this section is gathered through interviews, assessments, and on-going interactions with the person. Goals can be from any area, but they need to be important to the person, not necessarily the staff providing input into the plan. We must set goals in various areas to obtain funding. This includes economic self-sufficiency, daily living skills, and community integration. We look at what the person wants to learn and prioritize short and long term goals based on the person's preferences.

**Interests and Activities-** This is where we learn what interests the person outside of work and home responsibilities. Leisure activities, hobbies, sports, or just about any other interest can be listed in this section.

**Personal Values-** This section makes a statement about what is important to the person. This is useful to know because often times we are motivated by what we value the most.

**Personality, Feelings, & Emotions-** We need to know these things about the person in order to develop a supportive environment. Therefore, getting to know the person is essential.

**Sources of Comfort and Discomfort-** This section will outline what things provide comfort as well as, discomfort to the person. You may want to remember that we can never know everything about a person. So, this section may have information only known to the staff who wrote it. Further, as people grow and change, this area of the plan may have to undergo change. Again, you will learn much about the person as you interact with him/her.

**Assessments-** The results of assessments or tests may be included here. For example, PT/OT, IQ, speech and language, etc.

**Strengths and Needs-** Here we learn about the abilities as well as areas which require support.

**Vocation-** This section will describe the kinds of work the individual likes to do or would like to do.

**Education-** A summary of the person's educational background as well educational goals.

**Financial -** This area discusses financial information about the person including sources of income and needs for the future.

**Communication Style-** The best way to communicate with the person would be spelled out here. People can and do communicate in a variety of ways and it is important for you to understand how to communicate with each person you will be working with.

**Learning Style-** How the person learns is outlined. This includes strategies you can use to work most effectively given the person's specific situation.

**Personal Rights-** In this area, we would learn which rights are most important to the person. Also, what if any rights restrictions might be in place and details of the situation.

**Recent Life Changes-** Anything that has recently occurred in a person's life which may have an effect on his/her day-to-day functioning should be noted here. This is another area that would be updated continually.

**Vision for the Future-** Just as we have dreams and hopes for the future, so do people we support in our programs. You need to get to know the person. This will assist you in identifying his/her hopes and dreams. Then you can assist the person in realizing them.

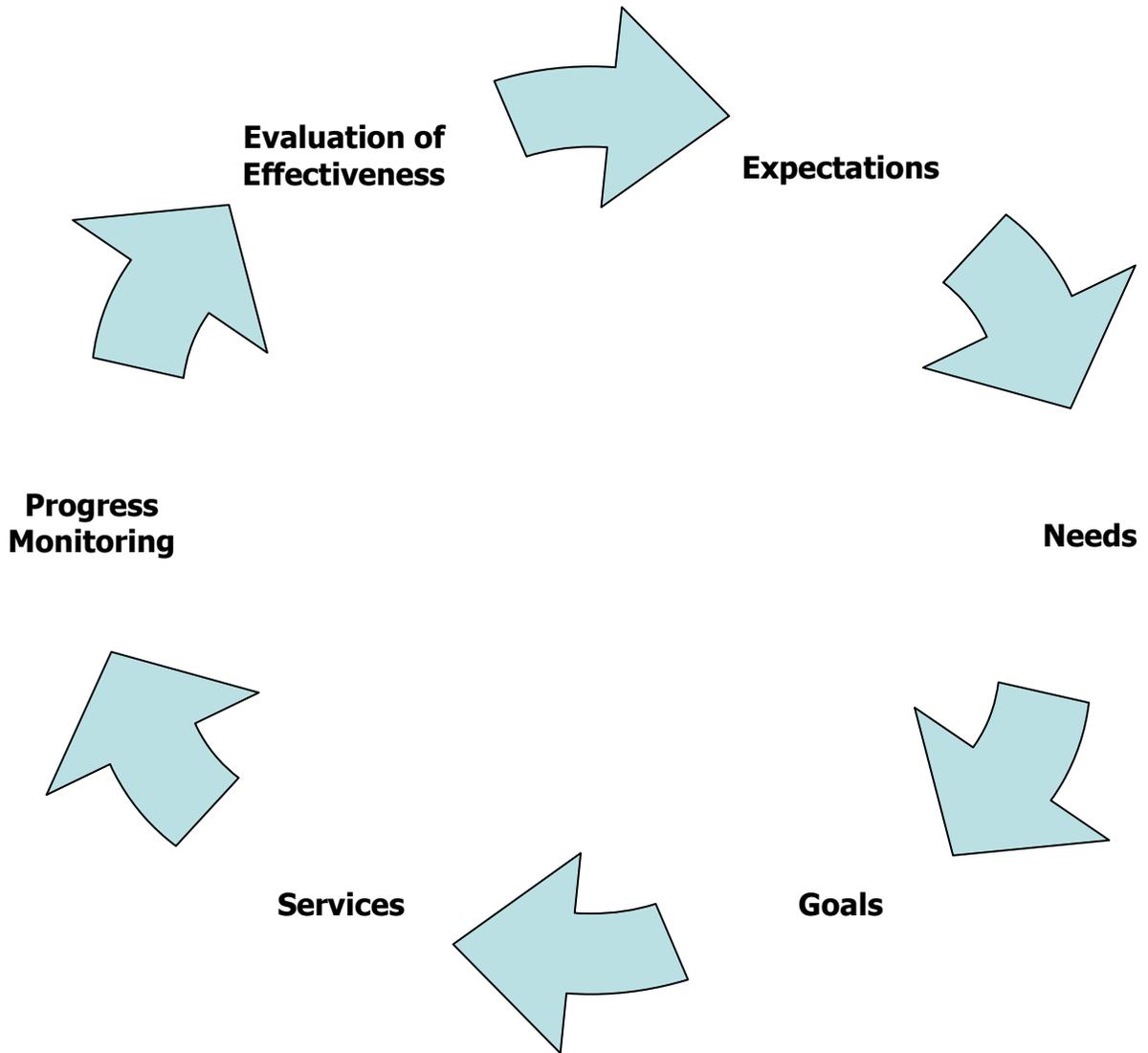
**Each Individual Habilitation Plan is tailored to the individual. Therefore, not all service plans contain all of these components. Some plans may have additional information not listed here.**

Additional Information: Service Plans are developed and signed by the individual or guardian, the QIDP, and all service providers. Service Plans explain significant changes in services or providers and indicate that the individual, family members and Service Facilitator participated in the decision process regarding these changes.

Service Plans contain formal (e.g., ICAP) and informal assessment information, including an indication that individual preferences were considered.

Service Plans contain at least one measurable goal. Service Plans contain an explanation of instructional methods for assisting the individual in moving toward accomplishment of his/her goal(s) and a way to monitor the individual's progress in achieving the goal. It also contains the name(s) or role(s) of the person(s) responsible for assisting the individual in achieving the goal.

# GOALS/SERVICES PLANNING MODEL



## What is a Rights Restriction?

**“Restriction”** means anything that limits or prevents an individual from freely exercising his/her rights and privileges.

Something is usually considered restrictive if it impedes the enjoyment of general liberties that are available to all citizens.

**With any program that causes a restriction of rights, it is implied that:**

- The restriction is **temporary**
- The restriction is defined with **specific criteria** (under exactly what circumstances will it be used)
- The program is **paired with learning/training components** to assist the person in the eventual removal of the restriction
- The restriction is **removed** upon reaching clearly defined objectives
- **Reviewed** regularly by HRC

## Rights of Individuals

The **US Constitution** guarantees these rights to each citizen, **regardless of ability:**

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

## **Rights of people receiving supports in the Illinois DD Support System include:**

- Right to services in the least restrictive environment
- Right to normalized living conditions
- Right to dignity and respect
- Right to freedom from discomfort and deprivation
- Right to appropriate clinical, medical and therapeutic services
- Right to religious worship
- Right to physical exercise
- Right to manage personal funds
- Right to adequate nutrition
- Freedom from involuntary servitude
- Freedom from unnecessary medication and mechanical, chemical, or physical restraints

### **With any program that causes a restriction of rights, it is implied that:**

- The restriction is **temporary**;
- The restriction is defined with **specific criteria** (under exactly what circumstances will it be used);
- The program is **paired with learning/training components** to assist the person in the eventual removal of the restriction;
- The restriction is **removed** upon reaching clearly defined objectives;
- **Reviewed** regularly by the Human Rights Committee.

**Some examples of rights restrictions include:**

- Locks on refrigerators
- Locked kitchen
- Areas off limits in home
- Loss of activity due to behavior
- Limiting who the person may socialize with
- No food/drink in room
- Restitution
- Limiting use of phone
- Making someone go to bed at a certain time
- Alarms on doors
- Limiting opportunity to learn
- Limiting access to personal property

## PEOPLE FIRST LANGUAGE

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

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

- ❖ Staff
- ❖ Media
- ❖ Family members
- ❖ Politicians
- ❖ People with disabilities



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

1. **Do not focus on a disability** unless it is crucial to a situation. Avoid tear-jerking human interest stories about incurable diseases, congenital impairments, or severe injury. Focus instead on issues that affect the quality of life for those same individuals, 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 a 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 disability, or people who are deaf.*"

5. **Put people first**, not their disability. Say, "*woman with arthritis, children who are deaf or people with disabilities.*" This puts the focus on the individuals, not the particular functional limitation. Do not say "crippled," "deformed," "suffers from," "victim of," "the retarded," "infirm," "the developmentally disabled," "the autistic," "the mentally ill," etc. This is NEVER acceptable under any circumstances.
6. **Emphasize abilities**, not limitations. For example: *Uses a wheelchair/braces, walks with crutches*, rather than confined to a wheelchair, wheelchair-bound or is crippled. Similarly, do not use emotional descriptors such as unfortunate, pitiful, and so forth. Disability groups also strongly object to using euphemisms to describe disabilities. Some advocates, who have a visual impairment, dislike partially sighted because it implies avoiding acceptance of blindness. Terms such as handicapped, mentally different, physically inconvenienced, and physically challenged are considered condescending. They reinforce the idea that disabilities cannot be dealt with upfront.
7. **Do not imply disease** when discussing disabilities that result from a prior disease episode. People who had polio and experience after effects years later have a *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 disease associated with a disability is acceptable only with chronic diseases, such as arthritis, Parkinson's disease, or multiple sclerosis. People with disabilities should **never** be referred to as patients or cases unless their relationship with their doctor is under discussion.
8. **Promote that people with disabilities are active** participants of society. We know that persons with disabilities interacting with non-disabled people in social and work environments helps break down barriers and open lines of communication.



## **MODULE 5**



## **RECORD KEEPING**

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*“People with intellectual disabilities  
are not broken;  
they do not need to be fixed.”*

*“Nothing about me without me.”*

These maxims were copied from a list of 144 posted at **Universal LifeStyles, L.L.C.** at <http://www.universallifestyles.com/maxims.html>

## Importance of Record Keeping

Record keeping is done:

- ❖ to provide an historical view of the individual.
- ❖ to ensure consistency and continuity of care/service.
- ❖ as a planning tool.
- ❖ to provide a credible record of service.
- ❖ as a form of communication among those working with an individual.
- ❖ to link team members.
- ❖ to set baselines and develop indicators.
- ❖ to obtain funding for services.
- ❖ to provide accountability.
- ❖ to document compliance that complies with regulations.
- ❖ to evaluate organizational effectiveness.
- ❖ to document expenditures.



## TYPES OF RECORDS

QIDPs are involved in maintaining many different types of records that include:



### Individual Habilitation Plan (IHP)

#### Also Known As:

- ▶ Individual Program Plan (IPP)
- ▶ Individual Treatment Plan (ITP)
- ▶ Individual Service Plan (ISP).

#### Purpose

1. Ensures compliance with standards and rules established by various licensing, certifying, and accrediting bodies.
2. Utilized to establish reimbursement rates based upon the services and supports required by the individual.
3. Documents the personal goals of the individual and the training and services needed to support the person in attaining those goals.
4. Records the results of assessments & reassessments.
5. Creates a snapshot of the person's current status in relation to progress made toward achieving goals and objectives.
6. Records the Interdisciplinary Team's deliberations and decisions about the appropriateness of the plan, as well, as recommended revisions and/or additions.

#### Contents:

The IHP must be:

- ▶ data-based;
- ▶ goal-directed;
- ▶ self-correcting;
- ▶ monitored;
- ▶ reviewed by the QIDP on a schedule established by the agency/center; and/or
- ▶ reviewed by the IDT on an annual basis.

## Responsibility

The QIDP must ensure the team gathers information and develops, reviews, and updates the IHP.

## Individual Family Service Plan (IFSP)\*

### Purpose

- ▶ Used as a planning and billing document for children from birth to age three.
- ▶ Meets the requirements of 99.452, State Board of Education and DHS.

### Responsibility

QIDP must ensure team gathers information and develops, reviews, and updates IFSP.

## Individual Education Plan (IEP)

### Purpose

- ▶ Used as a planning document for school age children through age 21.
- ▶ Meets the requirements of PL 94-142.
- ▶ Similar in purpose to that of the IHP.



### Responsibility

The school in conjunction with the QIDP must ensure team gathers information and develops, reviews, and updates IEP.

## Progress Notes

### Purpose

- ▶ Share information
- ▶ Provide sequential perspective
- ▶ Useful in establishing trends or patterns
- ▶ Documents procedures or events that have occurred
- ▶ Can reference other forms or treatment plans

## Contents

- ▶ Date
- ▶ Time
- ▶ Duration
- ▶ Location
- ▶ Individuals involved
- ▶ Description of situation
- ▶ Signature of staff
- ▶ Position of staff

## Responsibility

- ▶ Staff member involved must complete.
- ▶ Case manager/QIDP is responsible for seeing that progress notes are recorded, filed and followed up on.



## Periodic Summary Reports

### Monthly Report

#### Purpose

- ▶ Comply with Centers for Medicare and Medicaid Services
- ▶ Comply with Rule 132 if a Medicaid facility  
<http://www.dhs.state.il.us/page.aspx?item=32626>
- ▶ Communication tools
- ▶ Reflection of active treatment/needs
- ▶ Provides a view of the individual as a dynamic, changing human being

#### Contents

- ▶ Period to be covered
- ▶ Change in status (e.g., health, mental, employment, etc.)
- ▶ Progress towards goals
- ▶ Family involvement
- ▶ Reference to updated assessments/evaluations
- ▶ Focus of upcoming treatment
- ▶ Current diagnosis

#### Responsibility

- ▶ QIDP must assure monthly review is completed, make sure it is recorded, and filed.

## Legal Documents

### Types

- ❖ Documentation of individual's review of human rights
- ❖ Guardianship
- ❖ Birth Certificate
- ❖ Restraint orders
- ❖ Do Not Resuscitate
- ❖ Releases of information
- ❖ Receipt of personal property
- ❖ Consent and authorization for—
  - treatment
  - special behavior programs
  - medications
  - emergency treatment
  - living will
  - advance directives
  - release of information
  - marriage/divorce
- ❖ Restriction of rights
- ❖ Change in legal status
- ❖ Social security card application
- ❖ Incident reports
- ❖ Power of Attorney
- ❖ Information about funeral arrangements, burial/cremation, etc. ????
- ❖ Voter registration



### Responsibility

QIDP must ensure all are present.

## Informed Consent and Confidentiality

Confidentiality is an important component of a person's plan. Conversations should be kept confined to the meeting room and care must be taken to assure topics are not discussed in hallways, parking lots, etc. Likewise, after the meeting, care must be taken that papers containing identifiable information are not left lying about.

When discussing an individual served during the meeting, some organizations use initials, identification numbers, etc. to keep complete anonymity even from the committee members. It is agreed that if discussion includes someone who is not receiving services at the agency, the person's identity must be kept confidential.

With the enactment of the Health Insurance Portability and Accountability Act (HIPAA) staff must be diligent in assuring that their practices remain in accordance with state HIPAA regulations. Again, the intent of this statute is to assure that an individual's personal information is not shared without permission. A central aspect of the Privacy Rule is the principle of "**minimum necessary**" use and disclosure. A covered entity must make reasonable efforts to use, disclose, and request only the minimum amount of protected health information needed to accomplish the intended purpose of the use, disclosure, or request.

When records are shared, or information requested, **informed consent** must be obtained. According to the Mental Health & Developmental Disabilities Confidentiality Act, the consent should be in writing and contain the following elements . . .

- The person or agency to which disclosure is to be made
- The purpose for which disclosure is to be made
- The nature of the information to be disclosed

- The right to inspect and copy the information to be disclosed
- The consequences of a refusal to consent, if any
- The calendar date on which the consent expires
- The right to revoke the consent at any time

**All consents should be written in plain language that is easy for the individual served to understand. The use of pictures may be necessary.**

## **RECORD RETENTION**

As a general rule, the records in individuals' closed files should be retained for seven years. Records may be paper, film, disk, or other physical type or form; and the method of recording may be manual, mechanical, photographic, electronic, or any other combination of these or other technologies. **Records may be stored in inactive or closed files per agency policies.**

Other agency records may not require a seven year retention period. However, all the different types of records pertaining to individuals should be retained. **For advice on record destruction, agencies should contact their agency's legal counsel.**

## Sections of Individual Files

Each organization has a different format for organizing its individual files. Common sections include:

- ▶ Individual profile
- ▶ Evaluations/assessments
- ▶ Diagnostic results
- ▶ Physician Consultations
- ▶ Current therapy and progress
- ▶ Legal information
- ▶ Program data
- ▶ Employment
- ▶ Historical information
- ▶ Correspondence



## Record Keeping Tips & Rules

### Records are considered legal documents. Therefore:

- ▶ Never use "white out".
- ▶ Sign your name the same way each time, using your legal signature.
- ▶ Include your title and the date with your signature.
- ▶ Draw a single line through all unused space.
- ▶ Fill out all lines.
- ▶ Use blue or black ink (see your organization's requirements).
- ▶ Write legibly.
- ▶ Report objectively (keep feelings out).
- ▶ Ask yourself, "Would I like this printed on the front page of the paper if this were me?"
- ▶ Put information in chronological order.
- ▶ Use proper names.
- ▶ Protect confidentiality of individuals. (Do not release information except to individuals who have a signed release of information and a legitimate need to know.)
- ▶ Draw a single line through errors; initial; then write corrections (if applicable).
- ▶ Record individual's preferences.
- ▶ Follow your organization's guidelines when referring to other staff or individuals in documentation.



## DOCUMENTATION GUIDELINES



The following tips can help you document important information so that it will be accurate and meaningful to those who may need it now, or later. Do not sign a document that has inaccurate information.

- If two people witnessed an incident, each person should make separate reports or entries. You should never document for another person or from another person's perspective.
- Always include the date (day, month, and year) on all documents.
- Always include the time of day on all documents using a.m. or p.m. for all times.
- Be careful about using abbreviations or acronyms that some people may not understand.
- Ensure the privacy of people on all documents. When referring to another person in an individual's document you may want to describe the relationship to the person (e.g., coworker, roommate, another staff person, cousin, sister) and the person's initials.
- Always use your signature.

### **Completing Documentation in a Timely Manner**

It is important to document events as soon as possible after things happen so you can remember all the details of what occurred. Your recollection of the events that happened will not be as clear and accurate if you wait even a day or two after the occurrence. This

also results in poor communication with co-workers, family members or guardians, and the people you support.

If there is no documentation about a situation, other people providing supports may not have all the necessary information needed to make the best decisions when handling the situation afterwards.

If you forget to document something on the day it happened, it is important to begin your documentation with a statement that indicates your entry was made some time after the event occurred; for example, "late entry."

### **The Benefits of Good Documentation.**

Keep in mind that the report you are writing may later be read by people who do not know the persons involved. They should be able to easily understand the situation despite the fact that they do not know the people involved.

### **EXAMPLES OF OBJECTIVE DOCUMENTATION:**

- He was crying and his hands were visibly trembling afterwards.
- She stated that she didn't know what to do.
- I have never encountered a similar situation while working with this individual.

### **EXAMPLES OF SUBJECTIVE DOCUMENTATION:**

- He was so upset afterwards.
- She didn't know what to do.
- Something funny was going on.

### **Always include the four W's:**

**NOTE: The examples used here are for reporting suspected abuse, neglect and exploitation.**

- Who - This includes everyone involved.
- What - Start at the beginning and explain step by step until the end of the incident.
- When - Note the exact time, day/month/year and hour including a.m. or p.m.
- Where - The exact location, address, inside or outside, what room.

**WHO?**

- Who is the suspected perpetrator?
- Who is the suspected victim of abuse, neglect, or exploitation?
- Who are the individuals that witnessed the incident?
- Who else may have been involved in the incident?



**WHAT?**

Document what happened step by step. Start at the beginning of the incident and include all details until the end of the incident. Report only the facts and write an objective description of your observations in your report. Do not write your feelings, opinions, and attitudes. Also do not make judgments about the situation.



Here is an example:

'This morning, I heard a sound from the back bedroom. I went to the back room and knocked on the door. The staff person said, "We are OK, don't worry." I asked if I could come in. The staff person said, "yes." I opened the door and saw Amy sitting on the floor on the right side of her bed. Amy was holding her wrist and crying. I asked Amy if she was OK. Amy stated, "My wrist hurts." I then examined Amy's wrist. There were no visible signs of injury. Two hours later, I examined Amy's wrist and there was visible bruising about 2 inches in diameter.'

- Report only the facts and objective descriptions of your observations in your report.
- Do not write feelings, opinion, attitudes or judgments. Include any other important statements and details, such as your relationship to the victim.

**WHEN?**

Note the exact time of the incident, including the month, day, year, and time of day with a.m. or p.m. noted.



December 9, 2010. At 9:00AM this morning, I heard a sound from the back bedroom. I went to the back bedroom room and knocked on the door. The staff person said, "We are OK, don't worry." I asked if I could come in. The staff person said, "yes." I opened the door and saw Amy sitting on the floor on the right side of her bed. Amy was crying and

holding her wrist. I asked Amy if she was OK. Amy stated, "My wrist hurts." I then examined Amy's wrist. There were no visible signs of injury. Two hours later, I examined Amy's wrist and there was visible bruising about 2 inches in diameter."

## WHERE?

- Note where the incident occurred.
- Outside or inside.
- The address of the place of the incident.
- The exact room the incident took place.
- The exact place in the room where the incident took place.

**WHERE?**

- Back bedroom
- Inside
- 555 North Prairie Street, Springfield, Illinois
- Amy's bedroom
- On the right side of the bed.

Depending on the situation, agency procedures, and local and state laws, you may need to document in any numbers of locations. Here are some of the possibilities:

- The staff log.
- The file of the individual who receives supports.
- An official internal reporting form.
- An external reporting form.
- You may also be required to provide verbal reports or faxed or e-mailed copies of reports to certain external agencies or people. It is important for you to be familiar with the right place to document and report these types of incidents.

## Other Important Considerations:

- Any statement that individuals have made should be included in the report. You should use quotation marks around any relevant statement.
- Your relationship to the potential victim. For example, that you are a QIDP and have known the victim for X number of years.

- Any relevant personal characteristics of the victim such as communication and mobility skills.

## **Why Document?**

- Having the information written down in a clear format will allow many people to receive the needed information.
- Documenting an incident helps to identify repeated incidents, which may show a pattern of abuse, neglect or exploitation.
- It may help identify unrecognized needs of an individual.
- It provides fact-based evidence that the proper procedure was followed in regards to suspected maltreatment.
- It is likely that your agency requires documentation of suspected maltreatment.
- Documentation preserves information against later changes in recollections and influences upon memory and narration.
- It provides notice to those who need to know about the situation.

## **How to Document**

- Make sure handwriting can be clearly read.
- Do not sign a document that another person has written.
- If two individuals have witnessed the incident, each should make their own entries, from their perspective.
- Always include the date (day, month, and year).
- Always include the time of day, including a.m. or p.m.
- Ensure the privacy of people in documents. Refer to them in relation to the person such as, coworker, roommate and then use initials to identify them.

## **Record Keeping Application Exercise**

1. Use the background information at the end of the module to complete the following forms:
  - 
  - 
  - 
  - 
  - 
  - 
  - 
  - 
  - 
  - 
  -
2. File each of these forms in a file folder using your agency's table of contents.
3. Review all of the forms that were provided to you pertaining to Rachel.
4. Circle all areas where information is missing or recorded incorrectly.
5. Complete all of the required paperwork to reflect that you overheard Rachel telling her roommate that she had been slapped by her supervisor at DT.

## **Background Information**

**Name:** Rachel Lynn O'Brien

**Address:** Adams Resource Center  
4321 North Washington Street  
Chatham, IL 62629

**Phone Number:** 217/555-5494

**Birth date:** 12/20/60

**Age:** 50

**Birthplace:** Kansas, IL

**Sex:** Female

**Religion:** Jewish

**Race:** Caucasian

**Education:** Home tutoring

**Citizenship:** U.S.

**Admission Date:** 05/28/93

**Marital Status:** Single

**Guardianship Status:** Incompetent



**Type of Guardianship:** Plenary of Person & Estate

**Legal Guardians:** Shamis and Nancy O'Brien

**Address:** 267 Beachfront Lane  
Tinley Park, IL 60477

**Phone:** 708/555-4945

**Emergency Phone #:** 847/555-5944

**Social Security #:** 329-40-8803

**Medicare #:** 222-15-3437C3

**Public Aid #:** ???

**Type of Communication:** Verbal; English primary language

**Employer/Training Name & Address & Phone:**

- Hickory High School, 345 Creativity Dr., Wheaton, IL (708)454-0777
- Rainbows Enrichment Center, 765 Inspirational Lane, Carol Stream, IL (708) 563-4040

## **Release of Information**

There are times when you might be asked to release confidential information on behalf of an individual. In order for anyone to release this information, the individual must sign a release of information form. If the individual has a legal guardian, then the legal guardian would sign the release of information form.

Please insert and review your agency's Release of Information Form



## **MODULE 6**



**At work,  
it's what people  
CAN do that  
matters.**

# **COMMUNITY RELATIONS AND RESOURCES**

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## *DREAMS*

*D is for DETERMINATION-Stick with the person you support, and with their dreams.*

*R is for RELATIONSHIPS-Build relationships based on trust*

*E is for ENERGY-It takes a lot of time and energy to make dreams come true*

*A is for ATTITUDE-Always try to have a positive attitude and don't put people's dreams down*

*M is for MILESTONES-Celebrate the "little goals" you meet on the way to the BIG one*

*S is for SOURCES-check out money, transportation, and other help you'll need*

*Amy Walker, Illinois Voices Systems Change Activist*



## **Background Reading**

*Challenges for a Service System in Transition*, by Mary F. Hayden and Brian H. Abery. Chapter 5.

*Developing Staff Competencies for Supporting People with Developmental Disabilities*, James F. Gardner and Michael S. Chapman. Chapter 6.

## Your Role as a Liaison



The *American Heritage Dictionary* defines liaison as:

1. a. Communication between different groups or units of an organization.  
b. A channel or means of communication.
2. A close relationship or link

In your role as a QIDP, you will be involved in communicating with a variety of groups and individuals who offer various types of assistance. You will be responsible for linking the individuals you support to the resources you have identified. The resources may include any of the following:

- ❖ Transition planning
- ❖ Technical assistance
- ❖ Program planning
- ❖ Residential services
- ❖ Day training services
- ❖ Medical assistance

## Community Resources, Supports & Technical Assistance

<b>Type of Assistance</b>	<b>Where to Look</b>
Assistive Technology	<ul style="list-style-type: none"> <li>* Illinois Assistive Technology Project</li> <li>* Centers for Independent Living</li> <li>* Assistive Tech Unit at University of Chicago UIC</li> </ul>
Banking	<ul style="list-style-type: none"> <li>* Local Banks</li> <li>* Savings Institutions</li> <li>* Credit Unions</li> <li>* Family Support units</li> <li>*</li> </ul>
Behavior/Emotional Support	<ul style="list-style-type: none"> <li>* Psychologists or In-house consultants</li> <li>* Local mental health associations</li> <li>* State Operated Developmental Centers (SODC)</li> <li>* Developmental Disabilities Network Facilitators</li> <li>* Family physicians</li> <li>* Community hospitals</li> <li>* Medical schools</li> <li>* Developmental Disabilities Family Clinics UIC</li> <li>* CART/SST committees</li> </ul>
Communication	<ul style="list-style-type: none"> <li>* Office of Rehabilitation Services</li> <li>* Illinois Assistive Technology Project</li> <li>* Local Colleges</li> <li>* Independent living centers</li> <li>* Assistive Technology Unit UIC</li> <li>* University Centers for Excellence in DD (UCEDD)</li> </ul>

<b>Type of Assistance</b>	<b>Where to Look</b>
Disability specific	Local chapters of: * United Cerebral Palsy * Epilepsy Foundation * American Lung Association * American Heart Association * Easter Seals Foundation * Muscular Dystrophy * Autism Association * The Arc * Association for Down Syndrome * *
Educational	* Local school districts * Centers for independent living * Community Colleges * Day training programs * Project READ * Institute on Disability & Human Development UIC
Employment	* Vocational training programs * Division of Rehabilitation Services * Want ads * Local businesses * State employment agencies Disability Business & Technology Assistance Ctr UIC
Financial	* Housing and Urban Development * Supplemental Security Income * Food Stamps/Medicaid * Local charities * Local Family Community Resource Center

<b>Type of Assistance</b>	<b>Where to Look</b>
Housing	<ul style="list-style-type: none"> <li>* Illinois Assistive Technology Project</li> <li>* Centers for independent living</li> <li>* Local/federal housing authorities</li> <li>* Office of Rehabilitation Services</li> <li>* Home of Your Own</li> <li>* Illinois Department of Human Services</li> <li>* Assistive Technology Unit UIC</li> <li>*</li> <li>*</li> <li>*</li> </ul>
Legal	<ul style="list-style-type: none"> <li>* Guardianship</li> <li>* Legal Aid Society</li> <li>* Equip for Equality</li> <li>*</li> <li>*</li> </ul>
Medical/Dietary	<ul style="list-style-type: none"> <li>* Personal physician</li> <li>* Agency staff</li> <li>* Local health offices</li> <li>* Medical schools</li> <li>* Local hospitals</li> <li>* National Ctr. on Physical Activity and Disability UIC</li> <li>* Home health care agencies</li> </ul>
Mental Health	<ul style="list-style-type: none"> <li>* Local mental health associations</li> <li>* Self-help groups</li> <li>* General Relief Opportunities for Work (GROW)</li> <li>* Community hospitals</li> <li>*</li> <li>*</li> <li>*</li> </ul>

<b>Type of Assistance</b>	<b>Where to Look</b>
Personal Relationships	<ul style="list-style-type: none"> <li>* Religious organizations</li> <li>* Self-help groups</li> <li>* Big Brother/Big Sister</li> <li>* Senior Center</li> <li>*</li> <li>*</li> </ul>
Recreation	<ul style="list-style-type: none"> <li>* Local park district</li> <li>* Recreation Dept. of Colleges and Universities</li> <li>* YWCA/YMCA</li> <li>* National Ctr. on Physical Activity and Disability UIC</li> <li>*</li> <li>*</li> <li>*</li> </ul>
Religion	<ul style="list-style-type: none"> <li>* Local religious institutions</li> <li>* Interfaith associations</li> <li>*</li> <li>*</li> <li>*</li> </ul>
Intimacy/Sexuality	<ul style="list-style-type: none"> <li>* Institute on Disability &amp; Human Development UIC</li> <li>* Consultants (e.g., Oreida Horne-Anderson)</li> <li>* Local law enforcement agencies</li> <li>* Safety Awareness &amp; Family Education</li> <li>* Family planning office</li> <li>* Planned Parenthood</li> <li>* Local Health Department</li> <li>* Rape Crisis Center</li> <li>* Domestic Violence Program</li> <li>*</li> </ul>
Transportation	<ul style="list-style-type: none"> <li>* Family Community Resource Center</li> <li>* Senior citizen</li> <li>* Mass transit systems</li> <li>* Taxi Services</li> <li>*</li> <li>*</li> <li>*</li> </ul>

## Financial Matters

Each organization has its own way of handling individuals' financial matters. Review your organization's policies & procedures on each of the issues listed below. Use the space provided to outline your responsibility for each.

### Estate Planning

- 
- 
- 
- 
- 

### Insurance Benefits

- 
- 
- 
- 
- 

### Budgeting of an Individual's Money

- 
- 
- 
- 
- 

For home-based services, working with families to determine which services to pay for with their monthly allotment, and also possibly working with families to apply for, and utilize, one-time funding.

## Legal Matters

A variety of legal issues can and will impact the work you do to support individuals with developmental disabilities. Some of the specific issues you may encounter include:

- ❖ Guardianship
- ❖ Power of Attorney
- ❖ Grievance Procedures
- ❖ Rights Violation (including abuse & neglect)
- ❖ Legal/Criminal Matters
- ❖
- ❖



Review your agency's policies and procedures on these matters with your instructor.

## **WHAT IS A GUARDIAN?**

A guardian is a person, institution or agency appointed by the Probate Court to manage the affairs of another, called the ward.

## **WHO MAY HAVE A GUARDIAN APPOINTED TO MANAGE HIS/HER AFFAIRS?**

The law presumes that an adult eighteen years of age or older is capable of handling his/her own affairs. A guardian may be appointed to serve as a substitute decision-maker if a person is disabled because of:

- ❖ mental deterioration
- ❖ physical incapacity
- ❖ mental illness
- ❖ developmental disability.

The disability must prevent the person from making or communicating responsible decisions about his/her personal affairs. A guardian may also be appointed if, because of "gambling, idleness, debauchery, or excessive use of intoxicants or drugs," a person spends or wastes his/her estate so as to expose himself/herself or his/her family to want or suffering. In either case, guardianship may be necessary to protect the person and to promote the interests of others, such as service providers or creditors.

It is especially important to note that the parent of a child with a disability does not automatically become the child's guardian when the child turns 18 simply because the child has a disability. Guardianship must be appointed. Some parents/families are surprised to learn this when their child turns 18.

## WHAT ARE THE STEPS IN THE GUARDIANSHIP PROCESS?

### Preliminary Steps

Before starting a court proceeding, one must obtain a report certifying that the person has a disability and needs a guardian. A pre-printed form for the report can usually be obtained from the Probate Clerk of the court where the guardianship proceeding would take place. This is the court in the county where the person with disabilities resides. If the court does not have a pre-printed form, an attorney should be consulted. The report should be completed and signed by a licensed physician and any other professionals who are familiar with the person with disabilities. One or more of the persons who sign the report may be needed later to testify in court. It is important that the report contain all of the information required by paragraph 11a-9 of the Probate Act:

- ❖ description of the nature and type of the respondent's disability, and an assessment of how the disability impacts on the ability of the respondent to make decisions or to function independently.
- ❖ analysis and results of evaluations of the respondent's mental and physical condition and, where appropriate, educational condition, adaptive behavior and social skills, which have been performed within 3 months of the date of the filing of the petition.
- ❖ opinion as to whether guardianship is needed, and the reasons therefore.
- ❖ recommendation as to the most suitable living arrangement and, where appropriate, treatment or habilitation plan for the respondent and the reasons therefore.
- ❖ signatures of all persons who performed the evaluations upon which the report is based, one of whom shall be a licensed physician and a statement of the certification, license, or other credentials that qualify the evaluators who prepared the report.

The more detailed the report, the more likely it will contain all of the information legally required for the court's decision. Since many Illinois physicians are unfamiliar with limited guardianship, it is important for the petitioner or his/her attorney to fully explore the potential for limited guardianship in each case regardless of the initial recommendation of the physician. Total (plenary) guardianship should only be used when the person with disabilities is so incapacitated that he/she truly cannot make any decisions himself/herself.

The report should accurately reflect the skills and abilities of the person as well as deficits and problems. It is up to the petitioner to assure that this is done; it may be necessary to have other professionals contribute to the report if the physician is not familiar with all aspects of the person's life, or if the nature of the disability is outside the physician's area of expertise.

## **Attorney Representation and Other Protections**

Although an individual seeking guardianship for another may do so without the use of an attorney, the advice of legal counsel may be beneficial. The involvement of an attorney can be helpful where the alleged person with disabilities objects to guardianship or where complicated personal or financial issues are presented to the court. When a person opts to petition for guardianship without representation by legal counsel, a regional Office of State Guardian attorney or a legal assistance agency may be consulted, in order to learn about specific practices or requirements in a particular court. In addition, the clerk of the court should be consulted to obtain copies of local court forms, and to learn about the scheduling of guardianship cases.

A person facing guardianship adjudication has the right to a court appointed attorney and a trial by a jury of six persons. An individual facing guardianship adjudication also has the right to request an independent medical evaluation, which must be paid from the funds of the alleged person with disabilities.

## **Can Guardianship Be Used In Case Of An Emergency?**

Yes, when the court determines that emergency protection is warranted, a temporary guardian may be appointed. If there is an emergency situation requiring a guardian to be appointed before the hearing on the guardianship petition can be completed, one can ask the court to appoint a temporary guardian until the hearing.

## **How Does One Assess That a Person May Be In Need Of Guardianship?**

The fact that a person has a mental disability does not automatically dictate a need for guardianship. The test for determining the need for guardianship focuses on the ability of the person to make decisions and to properly communicate decisions once made. Making incorrect or ill-advised decisions on a periodic basis is not the test. Rather, it is an inability to engage in the decision-making in the first place which is important. A practical set of questions that may be addressed are as follows:

- Does the person understand that a particular decision needs to be made?
- Does the person understand the options available in any decision?

- Does the person understand the consequences of each option?
- Is the person able to properly inform appropriate parties once the decision has been made?

The inability to make sound decisions about where to live, where to work, how and when to seek medical care or other professional services, how to properly care for dependents, and how to purchase items like food and clothing is indication that a person may be in need of some guardianship services.

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

## Crisis Intervention

A crisis can be defined as many different things. Each crisis will require a different type of response. The effectiveness of your response will be dependent on your knowledge of the individual and an assessment of the current situation. If an individual is having severe behavior issues, there are resources in the community to help you guide an individual through their behavior crisis. These resources include:

- ❖ Psychologists
- ❖ Psychiatrists
- ❖ Mental Health Center
- ❖ Hospitals
- ❖ State-Operated Developmental Centers
- ❖ Clinical & Administrative Review Team (CART)\*
- ❖ Support Services Team (SST)\*\*
- ❖ Legal Services



\*CART is comprised of individuals from state and community agencies. They are available to assist you with the service needs of individuals in a behavior crisis. After reviewing the background information on an individual, including all of the interventions you have currently tried, they will provide you with additional options to present to the individual's interdisciplinary team.

\*\*The SST will implement delivery of interdisciplinary crisis response services to individuals served by the Division who are in need of immediate intervention due to acute behavioral or medical issues. These services will allow individuals to receive intensive supports, in cooperation with their service provider, to reduce the need for displacement from their current home.

<http://www.dhs.state.il.us/page.aspx?item=50861>

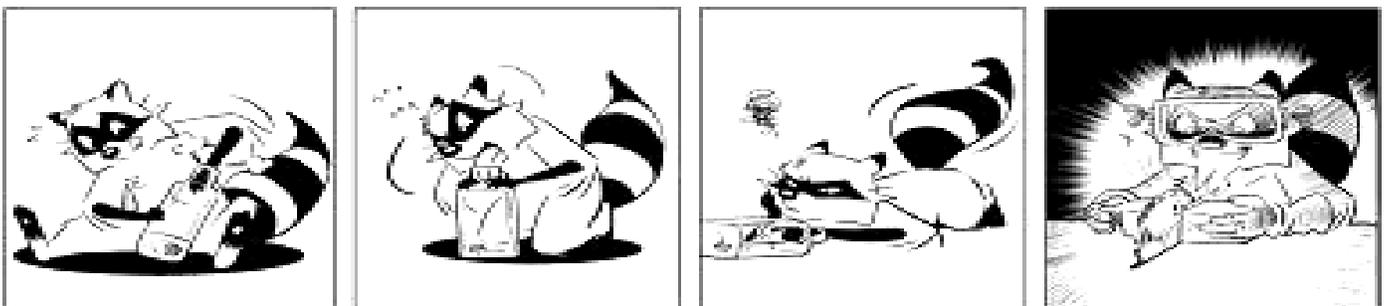
**Who gets contacted in your agency when a crisis occurs?**

## PROBLEM SOLVING MODEL

Review the following problem-solving model. It is a good tool to help you look for resources that match the interests, gifts, and talents of self-advocates. It can also be used to identify barriers to community inclusion and to develop a plan for minimizing these barriers.

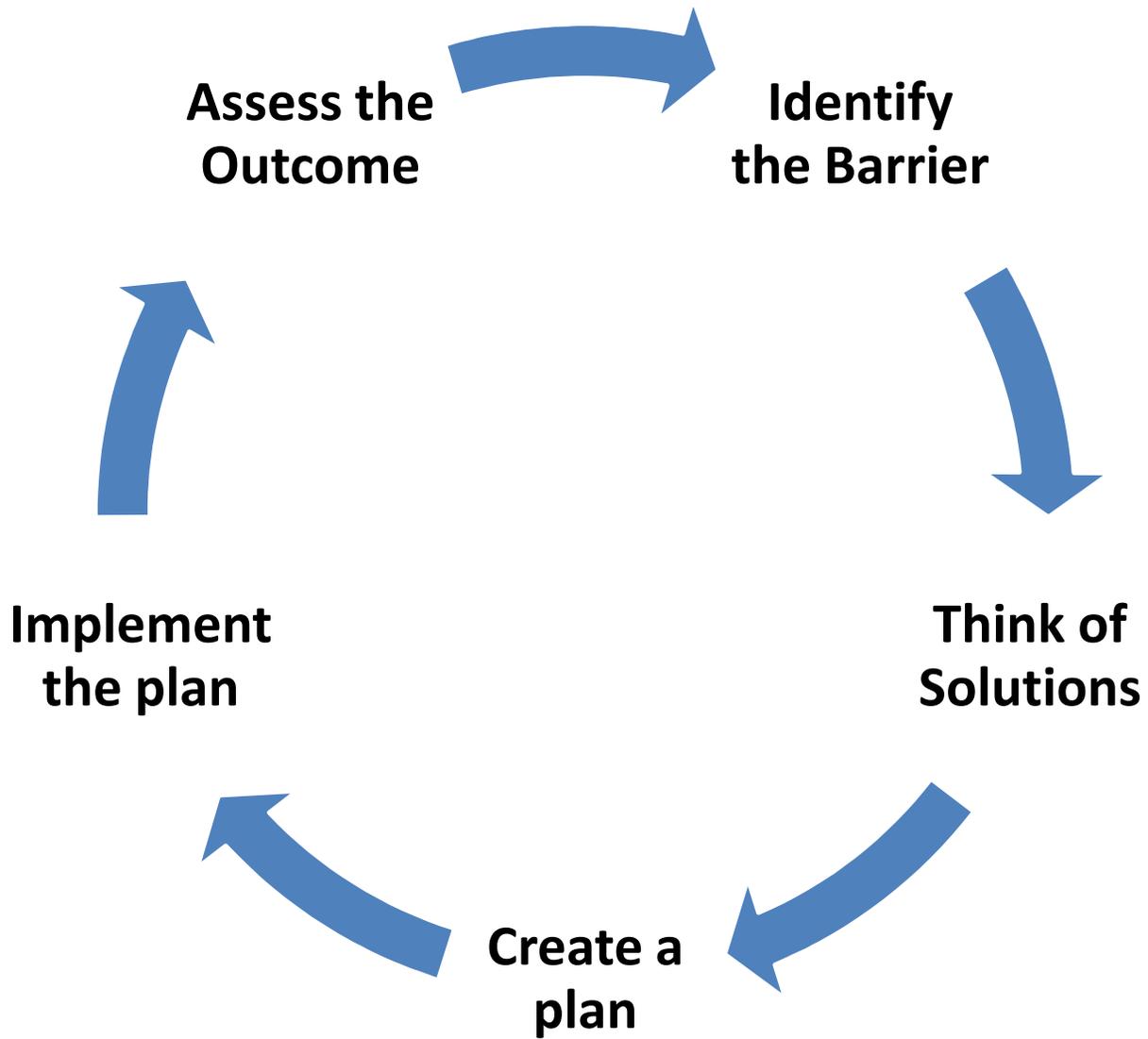
- ❖ **Identify the gifts, talents and dreams of the self-advocate.** Be specific.
- ❖ **Identify the barrier(s).** Write down what you see as the barrier(s). Be specific.
- ❖ **Think of solutions.** List all the possibilities that could/would solve the identified barrier(s).
- ❖ **Evaluate the options:** Look at all the options and start evaluating the ones that would be the most practical for removing the barrier(s). Then prioritize the solutions. Eliminate the ones that are not possible and review the final 2 or 3 solutions on the list. Discuss these as a group and then chose one possible solution to begin.
- ❖ **Create a plan.** Review the group's chosen solution and then develop a plan or a way to remove the barrier. Figure out who will do what and when and in what order to solve the problem. This is called an Action Plan.
- ❖ **Implement the Plan.** This is the action part of the process. Follow the steps you have outlined in your action plan and try to remove the barrier. Ask yourself if the barrier has been removed. If your answer is "yes," then you are done. If it is "no," then take a look at what happened when you implemented your action plan.
- ❖ **Assess the outcome.** Did the Action Plan work? Why or why not? What about the quality of the outcomes? Is the self-advocate satisfied with the outcome? Unhappy? Excited? What would have to change to remove the barrier? Do another solution from the list need to be selected to try to remove the barrier?
- ❖ **Modify the Plan as needed.** Finally, change your Action Plan as needed to get closer to a solution. You may need to go back to the evaluating step, review another potential solution, and work your way through removing the barrier until an outcome is reached that satisfies the self-advocate and the support people.

Submitted by Krescene Beck, Blue Tower Training



Scandal and Woo Sewie sindhaasambodh.com, by Pinner and Oliver Maxwell

## PROBLEM SOLVING METHOD



## **Activity – Finding Solutions to Supporting Self-advocates in Achieving their Dreams**

**Directions: Read over these scenarios. Using the problem solving model as a guide, work as a group on coming up with solutions for supporting self-advocates in achieving their dreams:**

Tom is a 38 year old man with black hair and blue eyes. He comes from a large family and has 4 brothers and 3 sisters. He enjoys being around animals and has had several pets growing up. Tom's IQ is over 70. Tom has a diagnosis of Epilepsy and has seizures twice a day. When he has seizures, he blacks out for about 5-10 minutes and doesn't remember anything that happened and is forgetful for a while. Tom dreams of living in an apartment and working at a job where he can be with animals. How can Tom be supported in his dreams?

Sarah works at a developmental training program. She enjoys working there, and the staff all appreciate her sense of humor and that she lights up the building when she arrives in the morning. Sarah has a visual impairment and uses a wheelchair. She has worked on a variety of contracts but her dream is to work out in the community with a small group that goes out daily to clean offices. How can Sarah's dream of working in the community be supported?

Rich is a lively 8 year old boy with freckles and short blond hair. Rich has been diagnosed with Autism Spectrum Disorder. Rich's likes include water, swimming, play-doh, Legos, and art; he does not like sudden changes in his schedule, loud noises, trucks, or touching coins. Rich prefers to wear shorts with elastic at the waist and short sleeve shirts without collars or buttons. Rich lives in an area that receives a lot of snow during the winter, yet he does not want to miss any school due to the weather. How can Rich be supported in regards to his likes and his dislikes?

Angela is a shy woman who enjoys watching television, listening to her CD's, and bowling. She dreams of having a boyfriend and going horseback riding. Angela recently moved into a group home after living with her family. Her family is very supportive and enjoys having contact with her. English is Angela's second language; her family speaks Spanish. None of the other people living in the group home speak Spanish and only two staff members speak Spanish. How can Angela's dreams of settling into her new home and doing the things that she wants be honored?

1. What did you notice about the descriptions of the four people?
2. Describe the roadblocks/barriers to inclusion.
3. What supports do you recommend for Tom, Sarah, Rich, and Angela that could help them achieve their goals?

## **INCLUSION**

### **Community Inclusion is a success when people:**

- Have relationship with people who are not paid to spend time with them.
- Have opportunities to experience a variety of social roles that include friendships, contributing to the community and gaining new skills.
- Have opportunities and resources to do and accomplish things that are important to them.
- Experience a sense of belonging.



### **Benefits of Inclusion to the Individual:**

Some of the benefits of inclusion to the person are:

- Improved feelings of well-being and self-esteem.
- Access to resources and activities not available in the group home.
- Expanded "horizons"/life experiences. Participating in activities in different types of settings.
- Participation – engaging with others; being known.
- Feeling the excitement of being part of a community group
- Opportunities to make new friends and develop new and varied relationships.
- Incentive to learn appropriate social behavior.

### **Benefits of Inclusion to the Community:**

- More diversity in personal relationships.
- The cost of supporting people decreases when persons served do not have to rely on paid professionals. This can affect tax dollars needed to provide supports.
- People with disabilities can pay taxes if they have a job.
- People with disabilities can share their gifts and talents with the community.



## How Staff Can Support Inclusion:

Staff can support inclusion by:

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



- Making sure the person has the training and skills necessary to become independent. For instance, training the person how to use the bus can pay off in a lifetime of inclusion and freedom from relying on staff for every transportation need.
- Being prepared to advocate for and educate others about the benefits of inclusion.
- Understanding when to get involved and when to stay out of the person's relationships. Instead of sheltering people from potential dangers by isolating them, support staff should help the person manage risks in real and sometimes complex situations.
- Teaching daily living, vocational, and educational skills in natural settings in a functional and empowering way.
- Networking to find contacts and allies in the community who may have information about social or vocational opportunities.
- Developing strategies to minimize a person's risks and barriers and help the person understand the importance of making good choices that will reduce such risk.
- Pairing a person's interests, talents and dreams to a community person, group or activity.

### **How can you as a QIDP, work with DSP staff to help support inclusion?**

### **Training to develop the person's skills to prepare them for inclusion includes:**

- Determining their strengths and interests. Helping them with their vision for a desirable future. Then moving to select the most important skills to learn to achieve these dreams.
- Incorporating skills training into real life events. Training should never be done as a prerequisite to real life.
- Finding places where people can fit in as they are and where other community members take a direct role in skill development and support.
- Providing enough support so that the person has a chance to succeed. Competence comes from trying and often failing and trying again. But plan for mistakes that will be made. The person should just keep going. It's part of learning.
- Providing daily opportunities to communicate with others and make choices.



## **The Five Dimensions of the Principle of Normalization**

Evaluations that measure service quality in terms of the agency's adherence to the principle of normalization and service quality in terms of the agency's implementation of normalization contain numerous items and groupings. Most of the major items can be included under five groupings:

### **Community Presence**

This means that both the programs and the people themselves must be situated in the community. Community presence can be considered as physical integration. Services and activities should be provided in local neighborhoods and communities. Isolation should be avoided. Programs and services for people with developmental disabilities can be located in rural, suburban, and urban settings. Proximity is one measure of community presence.

## Community Participation

This is the measure of the extent to which people are socially integrated into the community. This includes both impersonal and personal interactions. The impersonal interactions take place, for example while purchasing an item at the neighborhood "Dollar Store," while ordering a meal in a restaurant, and during work or work training. Impersonal



interactions require mutual respect and esteem. Public attitudes and the behavior and appearance of people with developmental disabilities should be positive.

## Skill Enhancement

This principle implies that people should perform according to the expectations of the culture for a particular age range. In some limited and exceptional instances where an individual may fail to grow and to adapt, the culture's value system supports the idea of individual growth and adaptation throughout the life cycle. A developmental growth orientation should be present in residential, vocational, and recreational programs. Realistic, yet firm, expectations should be set for people with developmental disabilities.

## Image Enhancement

This principle is the consideration that the public perception of human services programs is as important as what the programs accomplish. Agency staff members have a particular responsibility to act as role models for people with developmental disabilities. For some people, you may be one of several role models or even their only one. You have a very powerful influence on the self-image of those people. You also have a major responsibility for how they are



perceived. By acting in a conscientious and prudent manner, you encourage similar behavior in others.

Improvement of their self-image and personal appearance and the development of skills and behaviors in these individuals contribute to a more positive public perception.

### **Autonomy & Empowerment**

The final and most important component of normalization is autonomy and empowerment. In one sense, these issues are related to legal rights. People of all ages have basic rights. Due process, equal protection of the law, freedom from abuse, and the right to medical treatment are rights accorded all people regardless of age. Other rights are acquired gradually with age. The law often sets forth specific ages at which adolescents can gain specific rights. The legal age of maturity generally corresponds to the time period when people attain greater autonomy.

## THE PRINCIPLE OF NORMALIZATION

Self-advocates hate the term “retarded” and dislike the term *mental retardation*. The term has many negative implications. The primary assumption is that a person with “mental retardation” cannot perform certain tasks or accomplish personal goals. Yet many people with developmental disabilities live independently in the community. They are moving from activity centers to supervised employment settings, participating in community recreational activities and attending classes in community colleges.



The normalization principle has helped to focus attention on what people with developmental disabilities can achieve. Various writers in the United States and Europe have provided definitions of the normalization principle.

Sensitivity to the normalization principle is important because it can:

- prevent devaluation of people
- decrease discrimination against people that occurs simply because they have developmental disabilities
- help you make decisions
- assist you in deciding what services to provide and how they should be provided.
- help people with developmental disabilities make decisions about their own lives.

Normalization is . . . the utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible.” Wolf Wolfensberger (1972)

The normalization principle is particularly helpful in thwarting the first and second steps in the self-fulfilling prophecy. The portrayal of people with developmental disabilities as unique individuals who have strengths and capabilities decreases prejudiced beliefs. Expectations are changed. For example, an agency may provide an excellent work training program that leads to supervised employment. The goal of placing people in work situations is compromised, however, if any of the following situations occur:

- The trainees arrive at the program and depart on a yellow special education bus.
- The trainees carry Super Heroes lunch boxes.
- The trainees are underpaid.

If you were a potential employer visiting the work training program, what would you conclude from these three examples? Would you view the trainees as potential employees? Would the program send you a message of low expectations? What conclusions would you make about expanding employment opportunities for people with developmental disabilities?



*Attitude is a little  
thing that makes a  
big difference  
—Winston Churchill*

## KEY PRINCIPLES TO COMMUNITY-BASED INTEGRATION

There are several key components to organizing Community-Based Integration (CBI) for people with disabilities. These are listed and then explained further in the text.

❖ **The instruction is individualized and focused on those specific skills needed and wanted by the person for a desired life.**

Individual instruction means that there is not some set, pre-defined curriculum that a person must master in some particular order in order to graduate or move on to the next level of training or community integration. Rather, it is a mixture of instruction, environmental modifications, support-building, and other approaches that help the individual succeed in settings where he or she wishes to be.

❖ **The instruction is provided in a variety of actual settings where individuals want to be competent or will need to utilize life skills.**

If a person wants to be able to shop for groceries, an approach likely will combine some direct instruction in a grocery store that the person will use. It might include working out an arrangement with the store manager so that the person can have an account. It might also include setting up something with a neighbor or family member to help with getting to and from the store. The community provides lots of potential settings where competencies can be explored based on interests.



❖ **Instruction focused on participation in functional activities rather than just performing an isolated skill.**

An example of a useful skill in community living is to be able to purchase a needed item at a store. Rather than task-analyzing the entire process or shopping and settling on one skill to learn, such as money management and counting change, it is better to actually perform the entire sequence of skills within the shopping activity as a whole. Shopping could include choosing a store, trying things out, selecting an article and paying for it.

❖ **Varied instruction combined with supports natural to a setting are used to help individuals generalize skills.**

The best way to reduce trainer dependency is to be sure the community setting provides all needed cues. Instruction should include planning to fade from prompts that are not a part of the natural environment and direct the individual to the setting's natural cues. Fading is an active process and does not mean arbitrarily reducing the trainer's presence. It includes active monitoring of performance and support needs.

❖ **Instruction takes place at the time of day at which the task is usually performed.**

If an individual wants to learn or prepare lunch, return a book to the library, or make a bank deposit, instruction should occur at the natural time that event would typically occur.

❖ **Whenever possible, instruction comes from the natural environment from those with the skills and experience who are in the setting where the skills will be utilized.**

One typical failing in many community-based instructional programs is the attempt of one or two professional staff – teachers, teacher's aides, day program or group home staff – to provide all or most instruction on community skills. It is better to recruit people from the community who are willing to offer assistance and training in identified skills and tasks. So, once you have a good understanding of each individual's learning priorities and life goals, invest some time to inventory the capacities and resources of the person's community. This process is sometimes called a "capacity inventory" or "asset mapping."



Source: Community-Based Instruction, Dale DiLeo, 2005.

## Functional Life Domains in the Community

The following lists a number of life domains that could be a part of a learning curriculum for Community Based Integration.

### Transportation and Community Mobility

- Crossing street intersections
- Knowing traffic signals, stop signs
- Identifying curb cuts and accessible entrances
- Riding on city buses – identifying the needed route
- Paying for public transportation
- Learning a walking route
- Knowledge of pedestrian safety
- Using public restrooms
- Knowing a community and selecting a destination
- Responding to problems (getting lost; late bus)



### Shopping

- Evaluating grocery items for freshness and nutritional value
- Staying within a budget
- Shopping from a prepared list
- Choosing items or personal items to size and need
- Trying on items to see if they fit
- Using a wallet
- Getting and returning a shopping cart
- Waiting in line
- Using words or pictures to select items for purchase

## Meals

- Planning simple weekly nutrition meals
- Using kitchen utensils and equipment
- Cooking safety
- Following a recipe
- Using good table manners
- Setting the table for daily meals
- Storing leftovers and un-used ingredients to avoid spoilage
- Cleaning the kitchen after meal prep



## Dining Out

- Asking for a menu
- Viewing a posted menu
- Demonstrating appropriate dining behavior in a restaurant
- Responding to restaurant staff (e.g. "what kind of potato would you like?")
- Selecting items within a budget
- Asking for the check
- Paying for the check
- Know when/if to tip and how much

## Home Management

- Keeping the household clean
- Using a washer and dryer
- Yard care
- Handling garbage and waste
- Simple home repair (changing light bulbs, etc.)
- Leisure activities in home (TV; VCR; DVD)
- Using home appliances – washer, dryer, dishwasher

## **Money**

- Ways to save money
- Using an ATM machine
- Maintaining a savings or checking account

## **Using Banking Services**

- Completing a money order
- Reading a pay stub
- Paying monthly expenses
- Purchase using cash
- Paying with a check
- Paying with an ATM card
- Comparison shopping

## **Personal Hygiene**

- Standards of appearance in various community settings
- Self-care, bathing and hygiene
- Care and cleaning of clothing

## **Safety and Health**

- Emergencies – dialing 911; injury; crime
- Recognizing dangerous situations
- Recognizing people to ask for immediate help (clerks, bus drivers, etc.)
- Caring for minor illness and simple injuries
- Knowing when to seek medical attention

## **Communication**

- Standards of communication with friends, family, school and work
- How to use email
- Telephone use
- How to mail a letter

## Recreation and Leisure

- Going to a movie,
- Joining a club
- Taking a community class
- Going to a concert
- Making new friends
- Using the library
- Joining a sports team



## Employment

- Completing a job application
- Developing a resume
- Interviewing for a job
- Getting along at work
- Maintaining employment and how to change jobs

## Sexuality and Relationships

- How to have respectful relationships
- How anger and dishonesty impact relationships
- Understanding the difference between gender and sexual orientation
- Knowing how to prevent pregnancy
- Knowing how to prevent sexually-transmitted diseases
- Knowing how to make good decision regarding sexual relationships
- Managing conflict
- How to be a good neighbor
- What is appropriate to share and what is not
- Gift giving and receiving
- Sending thank-you notes
- Sending holiday and birthday/anniversary greetings



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Pittsburg, PA

## Values Influencing Quality of Life

Following is the result of the study that asked students at the University of California at Los Angeles to identify the values that contributed to the quality of life. The values are listed in order of importance, as rated by respondents.

- ❖ Love
- ❖ Self-respect
- ❖ Peace of mind
- ❖ Sex
- ❖ Challenge
- ❖ Social Acceptance
- ❖ Accomplishment
- ❖ Individuality
- ❖ Involvement
- ❖ Well-being (economic, health)
- ❖ Change
- ❖ Power (control)
- ❖ Privacy

The next set of values represents the consensus of a group study of the American Academy of Arts and Sciences. They are listed in order of importance as rated by respondents.

- ❖ Privacy
- ❖ Equality
- ❖ Personal integrity
- ❖ Freedom
- ❖ Law and order
- ❖ Pleasantness of environment
- ❖ Social adjustment
- ❖ Efficiency and effectiveness of organizations
- ❖ Rationality
- ❖ Education
- ❖ Ability and talent

**What are the dreams of the people you support?**

## Sexuality and Education

According to the World Health Organization, "Sexuality is an integral part of the personality of everyone: man, woman and child; it is a basic need and aspect of being human that cannot be separated from other aspects life." (World Health Organization, 1975)

While not all individuals choose to be sexually active, all individuals are sexual beings. Expressions of sexuality include, but are not limited to, socialization, activities of friendship, boundaries in relationships, body awareness, human connectedness, genital interactions, assertiveness, self image, self-care, decision making, and personal code of ethics.

### **Why is age appropriate, meaningful sexuality education important for children, youth and adults with intellectual disabilities?**

- Sexuality education should include not only facts about sex and biology, but must also teach people to manage and enjoy relationships, make responsible choices and distinguish right from wrong.
- Sexuality education helps people with an intellectual disability recognize if someone is trying to take advantage of them so they can recognize inappropriate sexual advances early on, better protect themselves from exploitation and/or be able to report incidents of suspected sexual abuse.
- Education also helps people with disabilities avoid making social mistakes that might make them look foolish or might be mistaken for criminal activity.
- Information about sexuality also increases a person's awareness of the possible consequences of sexual activity, such as the risk of pregnancy or of acquiring a sexually transmitted disease.

Sexuality education teaches people how to protect themselves from some of the unintended outcomes of sexual activity.

learning



working



# Becoming Independent



creating

## Scenario Six



Rachel has continued to have changes in her life since you met her in the first module. She has recently moved into an apartment. Your role as a QMRP is to take these life changes into consideration as you design and provide supports for her.

1. Identify the services/entitlements she is eligible for now that she has moved to her own apartment.
2. Complete all relevant forms.
3. Indicate what you would do with each of the forms.
4. List the supporting documentation you would need to include with each one.
5. Indicate what you will do if she does not have one of these forms.
6. What entitlements did she lose when she moved into her own apartment?
7. What will you do if any of her applications are denied?
8. What unanswered questions from Module 5 should be addressed here?

## Background Information

**Name:** Rachel Lynn O'Brien

**Address:** Adams Resource Center  
4321 North Washington Street  
Chatham, IL 62629



**Phone Number:** 217/555-5494

**Birth date:** 12/20/60

**Age:** 50

**Birthplace:** Kansas, IL

**Sex:** Female

**Religion:** Jewish

**Race:** Caucasian

**Education:** Home tutoring

**Citizenship:** U.S.

**Admission Date:** 05/28/93

**Marital Status:** Single

**Guardianship Status:** Incompetent

**Type of Guardianship:** Plenary of Person & Estate

**Legal Guardians:** Shamis and Nancy O'Brien

**Address:** 267 Beachfront Lane  
Tinley Park, IL 60477

**Phone:** 708/555-4945

**Emergency Phone #:** 847/555-5944

**Social Security #:** 329-40-8803

**Medicare #:** 222-15-3437C3

**Public Aid #:** ???

**Type of Communication:** Verbal; English primary language

**Employer/Training Name & Address & Phone:**

- Hickory High School, 345 Creativity Dr., Wheaton, IL (708)454-0777
- Rainbows Enrichment Center, 765 Inspirational Lane, Carol Stream, IL (708) 563-4040

## THE DIFFERENCES ARE OBVIOUS

We like things

They fixate on objects

We try to make friends

They display attention-seeking behaviors

We reach for the stars

They expect the impossible

We take a break

They go "off task"

We have hobbies

They self-stim

We persevere

They perseverate

We insist

They tantrum

We have talents

They have splinter skills

We are spontaneous

They exhibit impulsivity

We like people

They develop dependencies

We change our minds

They have short attention spans

We stand up for ourselves

They are non-compliant

We assess

They consume



# **MODULE 7**



## **ENVIRONMENTAL, HEALTH & SAFETY**

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*Be the change you would like to see in the world.*

*Source: Mahatma Gandhi*

*To keep a lamp burning, we have to keep putting oil in it.*

*Source: Mother Teresa*



## **Background Reading**

*Developing Staff Competencies for Supporting People with Developmental Disabilities,*  
by James F. Gardner. Chapter16

## A Quality Home

There are many things that make up a quality home. As a group, discuss the different characteristics of a quality home. You can use the space below to record your own thoughts and those of the group.



## Accommodations

A quality home must be environmentally safe and appropriate to the needs of the individual. Due to the varying abilities of the individuals we serve, it may be necessary to make accommodations. Discuss, with your group, the types of accommodations that some individuals may require:

What may be safe for one individual, may not be safe for another. Environmental accommodations may be needed to make a living situation appropriate. List what accommodations might include:

- ❖
- ❖
- ❖
- ❖
- ❖
- ❖
- ❖
- ❖
- ❖
- ❖

## Roles and Responsibilities

Every organization has its own process for repair and maintenance of their facilities. Spend some time reviewing your organization's policies & procedures concerning this issue.

Whether you are visiting a home or potential home or working on projects that affect homes for people with developmental disabilities, you must continue to ask yourselves:

- Is the living area safe & sanitary?
- Is it appropriate for the occupant?
- What is my responsibility in assuring that this individual lives in a quality home?



## Visual/Mental Checks

Not all accommodations are needed for all individuals. However, when visiting a home, we should do a mental/visual check to make sure it meets the needs of the individual.

You need to be conscious of the environment where individuals with developmental disabilities live and are supported. This requires frequent visual/mental checks; for this, active observation is the key.

You should always do a visual/mental check when you are in an individual's home. This involves using your senses, including common sense!

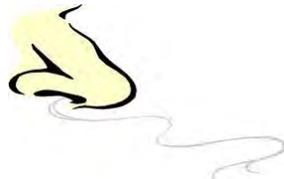
- Sight



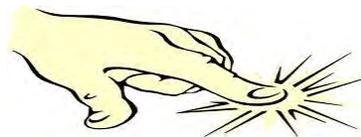
- Sound



- Smell



- Touch



## Universal Sign for Emergency

For individuals who are deaf-blind, receipt of an emergency message often involves diverse communication needs. Communication with individuals who are deaf-blind can range from sign language near the person's face to sign language in the palm to words written on the palm with a finger.

**The universal symbol for an emergency is a tactile symbol "X," "drawn" on the back of a person who is deaf-blind by an individual who is alerting him or her.**

This symbol is understood to mean that an emergency has occurred and that it is imperative for the individual receiving the message to follow directions and not ask questions.



## Safety Checklist

**Directions:** Use the following checklist as you are making a visual/mental check when you visit individuals' homes. It focuses on a number of potential hazards that we need to be aware of.

Place Y next to the question if the answer is yes and a N next to the question if the answer is no. Those questions answered no will require your attention or the attention of a professional. This section will deal with some of these potential hazards. Let us look first at fire as a potential hazard.

## Fire Safety

- \_\_\_\_\_ Is there a means to exit?
- \_\_\_\_\_ Is the means of exit suitable for this individual?
- \_\_\_\_\_ Is there an escape plan suitable for the individual?
- \_\_\_\_\_ Does the individual know the escape plan?
- \_\_\_\_\_ Is there an alternate escape route?
- \_\_\_\_\_ Are there working smoke detectors?
- \_\_\_\_\_ Are they in appropriate locations?
- \_\_\_\_\_ Are there fire extinguishers?
- \_\_\_\_\_ Does someone know how to use the fire extinguishers?
- \_\_\_\_\_ Are flammables and combustibles stored in appropriate locations?
- \_\_\_\_\_ Is the individual a smoker?



## Physical Hazards

- \_\_\_\_\_ Are there good housekeeping practices?
- \_\_\_\_\_ Are stairs free of obstacles?
- \_\_\_\_\_ Are the floors dry?
- \_\_\_\_\_ Are carpeting and rugs secure?



## Chemical Hazards

- \_\_\_\_\_ Is the living area free from carbon monoxide?
- \_\_\_\_\_ Is the area free from radon?
- \_\_\_\_\_ Are cleaning compounds, pesticides and other chemicals properly stored?

## Electrical Shock

\_\_\_\_\_ Is the living area free from potential electrical shocks ( e.g. frayed cords, overloaded outlets, water near electrical equipment, etc.)?



## Food Service Sanitation Hazards

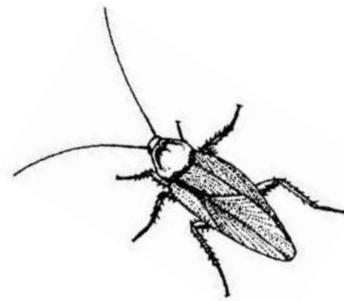
\_\_\_\_\_ Are individuals using proper personal hygiene?

\_\_\_\_\_ Are foods stored at safe temperatures?

\_\_\_\_\_ Are foods properly protected?

## Pest Control Hazards

\_\_\_\_\_ Is the living area free from evidence of roaches, rodents, flies, fleas, etc.?



## Water Supply & Sewage Disposal

\_\_\_\_\_ Is the water free from contamination?

\_\_\_\_\_ Does water drain freely from sinks, tubs, showers, stools, etc.?

\_\_\_\_\_ Is the septic system working?

\_\_\_\_\_ Is the living area free from the presence or smell of sewage?



## Preventing Burns and Scalds

- Make sure heaters and radiators are never too close to flammable objects such as draperies or bedclothes. Ensure that the people who live in the home and use space heaters or electric blankets are able to regulate temperatures and turn them off when they leave the room.
- Be certain that the water temperature in the house is at a safe level and that all of the people who live there can mix hot and cold water to the correct temperature. If they are unable to do so, then ensure that the water temperature does not exceed 110 degrees.

## Material Safety Data Sheets

A material safety data sheet (MSDS) is a form containing data regarding the properties of a particular substance. It is intended to provide workers and emergency personnel with procedures for handling or working with substances in a safe manner and includes information such as physical data (**melting point**, boiling point, flash point, etc.), toxicity, health effects, first aid, reactivity, storage, disposal, protective equipment, and spill-handling procedures, chemical compounds, and chemical mixtures. MSDS information may include instructions for the safe use and potential hazards associated with a particular material or product.

The Occupational Safety and Health Administration (OSHA) requires that material safety data sheet (**MSDS**) "**shall be maintained and kept in a readily accessible area**". That means that MSDSs for the hazardous substances should be available to all staff. Any MSDS sheets that you receive with shipments or that you receive separately should be placed in your MSDS binder or file.

Before you work with products or chemicals, you should familiarize yourself with their potential for flammability, corrosiveness, and toxicity, as well as storage and handling information. Also, it is vital that you are able to refer to that MSDS immediately in the event of an emergency such as a spill, fire, or physical contact with the chemical. So, the next time you receive an MSDS, remember that it provides important and necessary health and safety information.

### Free MSDS can be found at:

<http://www.msds.com/>



## Hazardous Household Products

Many of the products we use for housework, gardening, home improvement, or car maintenance contain hazardous materials that endanger our health as well as pollute the environment. The average house has an estimated three to 10 gallons of hazardous products. Collectively, these materials can contaminate our drinking water if they are not stored carefully and disposed of properly. In addition to poisoning our water, inappropriate use and disposal of hazardous household products can cause injuries, poisoning and air pollution.



### What Makes A Household Product Hazardous?

Household products are hazardous if they are:

- **Ignitable** - capable of burning or causing a fire
- **Corrosive** - capable of eating away materials and destroying living tissue when contact occurs
- **Explosive and/or Reactive** - can cause an explosion or release poisonous fumes when exposed to air, water or other chemicals
- **Toxic** - poisonous, either immediately (acutely toxic) or over a long period of time (chronically toxic)
- **Radioactive** - can damage and destroy cells and chromosomal material (known to cause cancer, mutations and fetal harm)

### How Do You Know If A Product is Hazardous?

The Federal Hazardous Substances Act of 1960 established labeling requirements for consumer products containing hazardous substances. If a product has a hazardous substance, the front label must include a warning and a description of the hazard.



### *Levels of hazards are identified this way:*

**DANGER** - substances which are extremely flammable, corrosive or highly toxic.

**POISON** - substances which are highly toxic.

**WARNING, or CAUTION** - substances which are moderately or slightly toxic.

## As a consumer you should make it a habit to read hazardous product labels.

These labels must include the following information:

- Brand Name
- Common and/or Chemical Name (Example: sodium hypochlorite or bleach)
- Amount of Contents (example: 16 oz.)
- Signal Word - Danger, Poison, Warning or Caution
- Instructions for Safe Handling and Use (example: recommended amount to use)
- Name and Address of Manufacturer, Distributor, Packer or Seller
- Description of Hazard and Precautions (example: Irritant to skin and eyes, harmful if swallowed)
- First Aid Instructions, when necessary or appropriate (example: If swallowed, feed milk).

### Pesticides Are Different

Regulations concerning pesticides are different. On pesticides, the word "warning" means that the product is moderately toxic. This means that one teaspoon to one ounce can kill an average adult. The word "caution" means that the product is slightly toxic. It would take over one ounce to kill an average adult.



### What Don't the Labels Tell?

There is no standardized list of chemical names. Many chemicals have numerous trade and/or scientific names. This makes it hard for you to compare products. Antidotes listed on the label may be incomplete, out-of-date, or even dangerously wrong.

Also, many labels do not tell you how to dispose of a product safely. The use of the term "non-toxic" is for advertising only. It has no regulatory definition by the federal government.

## Selection, Use and Storage Of Hazardous Household Products

Select the right product . . .

When you go shopping for products, your selection can be your first step toward minimizing danger. Follow these guidelines:

- Read the label. Make sure you want the product. Are the ingredients safe to use in and around your home?



- Make sure the product will do the job you need to have done.
- Buy the least hazardous product for the job. Let the signal words (Poison, Danger, Warning, Caution) be your guide.
- Check the label to see if a product has several uses. Then you can avoid buying a different product for each job.
- Avoid aerosol products. Aerosol products may contain hazardous or toxic propellants, and the fine mist that they produce may be more easily inhaled. Pressurized cans cause problems or explode when they are crushed, punctured or burned.
- Make sure you know how to properly dispose of the container.

Remember, the word "non-toxic" is for advertising only. It does not mean the product meets any federal regulations for non-toxicity.

### *Use it safely . . .*

It may be impossible to totally eliminate hazardous products in your home. The following guidelines will help you when using hazardous products to keep your home and environment safe.

- Read the directions on the label and follow them. Twice as much doesn't mean twice the results.
- Use the product only for the tasks listed on the label.
- Wear protective equipment recommended by the manufacturer.
- Handle the product carefully to avoid spills and splashing. Close the lid as soon as the product is used. This will control vapors and reduce chances of spills. Secure lids tightly.
- Use products in well-ventilated areas to avoid inhaling fumes. Work outdoors if possible. When working indoors, open windows. Use a fan to circulate the air toward the outside. Take plenty of fresh-air breaks. If you feel dizzy, headachy or nauseous take a break and go outside.
- Do not eat, drink or smoke while using hazardous products. Traces of hazardous chemicals can be carried from hand to mouth. Smoking can start a fire if the product is flammable.
- Do not mix products unless directions indicate that you can safely do so. This can cause explosive or poisonous chemical reactions. Even different brands of the same product may contain incompatible ingredients.



- Use it all up.
- If pregnant, avoid toxic chemical exposure as much as possible. Many toxic products have not been tested for their effect on unborn infants.
- Avoid wearing soft contact lenses when working with solvents and pesticides. They can absorb vapors and hold the chemical near your eyes.
- Carefully and tightly seal products when you have finished. Escaping fumes can be harmful and spills can occur.
- Most important of all: Use common sense.
- Store it safely in your home . . .
- Follow label directions for proper storage conditions.
- Leave the product in its original container with original label attached.
- Never store hazardous products in food or beverage containers.
- Make sure lids and caps are tightly sealed.
- Store hazardous products on high shelves or in locked cabinets out of reach of children and animals.
- Store incompatibles separately.
- Keep flammables away from corrosives.
- Store volatile products—those that warn of vapors and fumes in a well-ventilated area, out of reach of children and pets.
- Keep containers dry to prevent corrosion.
- Store rags used with flammable products (furniture stripper, paint remover, etc.) in a sealed marked container.
- Keep flammable products away from heat, sparks or sources of anything that could ignite them.
- Know where flammable materials in your home are located and know how to extinguish them.

## Poisoning

Accidental poisoning can be reduced by keeping all medicines, including nonprescription drugs, and other poisonous substances away from regular food and drink. Never store poisonous materials in unmarked or easily confused containers. But what if it does happen while you are at work? What would you do? Be sure to find out your agency's policy on accidental poisonings. Store cleaning supplies securely and well away from food and food preparation areas. Keep all products in original containers. Make sure you have a list of antidotes for various poisons.

## Poison Help Hotline 1-800-222-1222



### In Summary

An astounding array of hazardous products can be found in and around our homes. They are in common, everyday household products as well as in pesticides. While we cannot eliminate all contact with toxic materials we can minimize the contact.

Make informed decisions about the selection, use and storage of hazardous products. Remember hazardous products may be: flammable, explosive/reactive, corrosive/caustic, toxic/poisonous or reactive.

Learn to read the labels. Look for the signal words. **POISON** means highly toxic. **DANGER** means extremely flammable or corrosive or highly toxic. **WARNING** or **CAUTION** means less toxic.

Lastly, use common sense when using and storing hazardous products to decrease the potential health hazards and pollution.

## Food Safety Guidelines

The law requires that if you prepare and/or serve food as part of your job that you be trained and use proper care.

Careful shopping can help you avoid purchasing foods that are unsafe; or could become unsafe:

- Shop for shelf-stable items first (shelf-stable refers to unopened canned, bottled, or packaged food products that can be stored at room temperature before opening; the contents may require refrigeration after opening).
- Add the frozen and refrigerated foods to your cart last, especially during the summer months.
- Check "sell by" and "use by" dates on dairy products, eggs, cereals, canned foods and other goods. Select only the freshest products.
- Check packaging dates and "use by" dates on fresh meats, poultry and seafood. Do not purchase if they are outdated.
- Do not use damaged, swollen, rusted, or deeply dented cans. Check that packaged and boxed foods are properly sealed.
- Avoid unpasteurized juice (unless prepared at home with washed produce).
- Choose shelf-stable salsa rather than salsas found in the refrigerator section of the grocery store.
- Avoid unpasteurized milk, yogurt, cheese, and other unpasteurized milk products.
- Do not use foods with any mold present. Throw away the entire food packages or containers with any mold present, including yogurt, cheese, cottage cheese, fruits (especially berries), vegetables, jelly, bread, cereal and pastry products.
- Avoid unrefrigerated, cream and custard-filled pastry products such as fresh bakery items such as cream-filled doughnuts, cream pies, crème puffs, etc. Commercial, shelf-stable items are allowed.
- Avoid foods from "reach in" or "scoop" bulk food containers if it will not be cooked prior to consumption.
- Do not use cracked eggs.
- Place meat, poultry and fish in plastic bags. Ask to have these items placed in separate bags from the fresh produce and ready-to-eat foods when at the checkout stand.

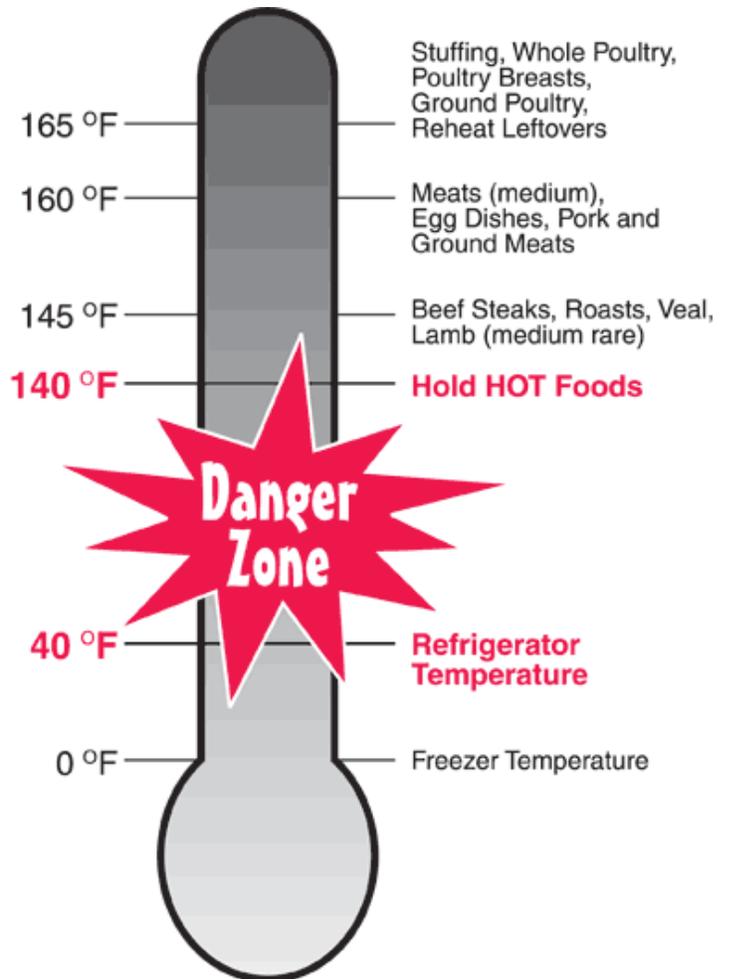


- Wash the tops of canned goods before opening. Clean the can opener after each use.

## Cooking and Food Temperature

### Cooks Foods Adequately:

- Insert the meat thermometer into the middle of the thickest part of the food to test for doneness. The entire part of the stem, from the dimple to the tip, must be inserted into the food. For thin foods, insert the thermometer sideways. (Also, follow the manufacturer's instructions.)
- Test a thermometer's accuracy by putting it in boiling water. It should read 212° F.
- A refrigerator thermometer should be placed on a shelf toward the back of the refrigerator. It should read 40° F.
- Cook meat until it is no longer pink and the juices run clear. These are signs that the meat may be cooked to a high enough temperature. However, the only way to be sure that the meat has been cooked to the proper temperature is to use a food thermometer (See Table 1 on the next page).
- Thoroughly heat hot dogs until steaming (165° F) before eating.
- Do not eat raw or lightly cooked eggs or soft boiled eggs
- Do not eat uncooked foods containing raw or undercooked eggs, such as raw cookie dough, cake batter or salad dressings containing raw or coddled eggs.
- Hold food at safe temperatures: hot food above 140° F.



## Microwave Cooking

- Microwave cooking can leave cold spots in food where bacteria can survive. Rotate the dish a quarter turn once or twice during cooking if there is no turntable in the appliance.
- When heating leftovers, use a lid or vented plastic wrap to cover them. Stir several times during reheating. When the food is heated thoroughly (to a minimum of 165 o F) cover and let sit for 2 minutes before serving.
- Use caution when removing hot liquids from the microwave. According to General Electric, microwaved water and other liquids do not always bubble when they reach the boiling point. They can actually get superheated and not bubble at all. The superheated liquid will bubble up out of the cup (much like a carbonated liquid that has been shaken) when it is moved or when something like a spoon or tea bag is put into it. To prevent this from happening, do not heat any liquid more than two minutes per cup. After heating, let the cup stand in the microwave for thirty seconds before moving it or adding anything into it.

## Adaptive Equipment

In some cases, meal intake and nutritional status can be improved through the use of adaptive feeding equipment (cups, utensils, and plates) that has been modified to allow for continued independent eating. An occupational therapist can decide which residents can benefit from adaptive feeding equipment. Once an order is written for adaptive equipment, it is the responsibility of the dietary department to assure that clean, sanitized equipment are placed on the resident's meal tray at each meal. Nursing staff must assure the equipment is returned to the kitchen after each meal for sanitizing.

### Why use adaptive feeding equipment?

- To allow independent feeding as long as possible.
- To assure maximum comfort and dignity during meals.
- To maximize intake for residents who have trouble feeding themselves.

### Types of equipment commonly used

- Scoop plate
- Plate guard or lipped plate (used in cases of weakness or poor hand coordination)
- Mugs with handles (used with tremors or weakness)

- Nose cut-out cup (used in patients with limited range-of-motion)
- Spout cup (used if resident needs to suck rather than drink, spills frequently, or has poor lip control)
- Cup with base and lid (used for a resident that has frequent spills, poor lip control, tremors, instability)
- Rocker knife (cuts by rocking rather than sawing). (Used for those with CVA (Cerebral Vascular Accident), those with use of only one hand, poor coordination, tremors).
- Weighted utensils (used for Parkinson's and other conditions resulting in tremors).
- Utensils with built-up handles (used for those with weak grip, arthritic hands, tremors)
- Non-slip handles (used for those with decreased fingertip sensation, poor grip)  
Angled utensils (used for those with poor range of motion, or who are unable to get utensil to mouth).

## Nutritional Assessment

Nutritional assessments are done upon admission to residential facilities and updated after 30 days, then annually or as needed. They are completed by a professional, certified nutritionist. This assessment will guide you in meal planning, preparation and serving.



Documentation is kept in the individual's clinical file that should include:

- an analysis of a person's nutritional condition which takes into account: general physical condition, age, lab results, medications, eating habits, and food preferences.
- recommendations on how the person can maintain a healthy diet and improve eating habits.
- recommendations to staff with ideas for nutritional goals.

## What is Involved in Serving Foods to People with Special Needs?

### Before the meal begins

- Make sure tables, chairs and wheelchair trays are clean
- Have person use the washroom to use toilet and/or wash hands
- Have adaptive equipment on hand and clean.

### Serving the person

- Wash your hands
- Ensure that the food to be served adheres to the person's dietary requirement.
- Observe and provide assistance as needed

### Allow for as much independence as possible. Let the person decide:

- How the food is seasoned
- What to eat first etc.

### Alternate liquids and solids

### Don't rush the person

**Be aware of:**

- food temperature
- size of bites
- the person's likes and dislikes

**Abnormal eating movements with specific persons require specific feeding techniques**

- Jaw thrust
- Tongue thrust
- Tonic bite
- Tongue retraction
- Sucking problems
- Swallowing problems
- Nasal regurgitation

**Devices used in eating or food preparation:**

- Oversized handles on utensils
- Dycem mats to prevent plates from slipping
- Curved ridges on plate rims
- Jar/bottle openers
- Picture recipes
- Switch adapted appliances
- Double handled cups

**Maintaining good body positioning:**

- Provides comfort
- Inhibits abnormal reflex patterns
- Decreases respiratory problems

**Make sure individual:**

- is relaxed
- fits the chair
- Sits upright as possible
- Head is not tipped back
- Feet are on floor or foot rest
- Does not slide or slouch down during the meal
- Stays as close to upright as possible for an hour after the meal

**Meal time as social time:**

- Communicate: make small talk and talk about the meal
- Set a pleasant mood

## Obesity

*Obesity is growing faster than any previous public health issue our nation has faced.* The prevalence of overweight people has increased 50% since 1960. 31.3 percent of U.S. adults are obese. Illinois's obesity rate is slightly higher, coming in at 31.5%. A recent analysis of National Core Indicators data of the Body Mass Index (BMI) of people receiving DD services in Illinois indicates that the DD population's obesity rates mirror those of the general population.

As people with developmental disabilities have more choices, they need more information to make informed decisions concerning food choices and activity levels. QIDPs should:

- Promote increased participation in physical activities and promote exercise programs, including those with limited mobility.
- Ensure increased focus and monitoring by the person and his/her interdisciplinary team on healthy eating habits. The monitoring and supports can include:
  - ❖ visits with the person's doctor and/or a registered dietician to plan a safe and healthy diet and exercise program.
  - ❖ helping people choose foods and drinks with less calories (i.e. a salad with low calorie dressing instead of French fries); caffeine/sugar free drinks, etc.

Sources: <http://www.cdc.gov/obesity/index.html>, accessed Oct. 25, 2009; National Core Indicators

## Personal Hygiene

Food borne illness is a disease that is carried or transmitted to people by food. Bacteria are the cause of food borne illness. Food borne illness is occurring with increasing frequency among the general population. A food borne illness is any illness caused by eating a food that is contaminated with a bacteria, virus, mold or parasite. Examples of organisms that can cause a food borne illness are E. coli, Salmonella, and Listeria. Sources of food borne illness or "food poisoning" may be the food handler, the environment (such as a contaminated work surface) or the food itself.

### **Wash hands**

Everyone preparing food should wash their hands before handling food and after handling raw meat. Ensure that soap and paper towels are always available. Follow good hand washing procedures.



### ***Do not Cross-Contaminate***

- Use a clean knife for cutting different foods (for example, use different knives for cutting meat, produce and bread).
- During food preparation, do not taste the food with the same utensil used for stirring.
- In the refrigerator, store raw meat separately from ready-to-eat foods.
- When grilling, always use a clean plate for the cooked meat.

### **Tools for Food Safety**

- Food and refrigerator thermometers
- Hand soap
- Clean towels (cloth or paper)
- Bleach solution\* (for washing countertops, cutting boards and other items)

\*Dilute Bleach Solution: Mix 1/3 cup unscented household bleach with 3 1/3 cups of water (This will make a total of 3 2/3 cups of bleach solution.)

## Fire Hazards

### Fire and Evacuation Drill Statutory Requirements

**ICFDD** disaster preparedness, fire and evacuation drill requirements include the following:

- **Fire drills shall be held at least quarterly** for each shift of facility personnel. Disaster drills for other than fire shall be held **twice annually** for each shift of facility personnel. Drills shall be held under varied conditions. . .
- Fire drills shall include simulation of evacuation of residents to safe areas during at least **one drill each year on each shift**.
- Each agency shall establish and implement policies and procedures in a written plan to provide for the health, safety, welfare and comfort of all residents when the heat index/apparent temperature, as established by the National Oceanic and Atmospheric Administration, inside the residents' living, dining activities, or sleeping areas of the facility exceeds a heat index/apparent temperature of 80 degrees F.

**Source: JCAR Administrative Code, Title 77, Chapter I, Section 350.690 a) through j)**

### **CILA fire and evacuation drill requirements include the following:**

- Each living arrangement shall have a smoke detection system which complies with the Smoke Detector Act [425 ILCS 65].
- Every Illinois home is required to have at least one carbon monoxide alarm in an operating condition within 15 feet of every room used for sleeping purposes.
- There shall be documentation that living arrangements are inspected quarterly by the licensed CILA agency to insure safety, basic comfort and compliance with this Part.
- The agency shall develop, implement and maintain a disaster preparedness plan which shall be reviewed annually, revised as necessary and ensure that records and reports of fire and disaster training are maintained.
- **Evacuation drills are conducted at a frequency determined by the agency to be appropriate based on the needs and abilities of individuals served by the particular living arrangement but no less than on each shift annually.**

- Special provisions shall be made for those individuals who cannot evacuate the building without assistance, including those with physical disabilities and individuals who are deaf and/or blind.
- Evacuation drills shall include actual evacuation of individuals to safe areas.
- At least one approved fire extinguisher shall be available in the residence, inspected annually and recharged when necessary
- First aid kits shall be available and monitored regularly by the agency.

**Source: JCAR Administrative Code, Title 59, Chapter I, Section 115.300 and Environmental Management of Living Arrangements, a) through e) and rules of the Office of the State Fire Marshal at 41 Ill. Adm. Code 100 and any local fire codes that are more stringent than the NFPA as enforced by local authorities or the Office of the State Fire Marshal.**

## **Carbon Monoxide Detectors**

Carbon monoxide detectors are true life savers. Carbon monoxide (CO) is:

- a colorless, odorless, and tasteless gas or liquid
- It results from incomplete oxidation of carbon in combustion.
- It burns with a violet flame.
- It is slightly soluble in water
- It is soluble in alcohol and benzene.

For more information on Illinois State Law and Carbon Monoxide detectors go to:  
**<http://www.idph.state.il.us/public/hb/hbcarbon.htm>**

## Other CILA Statutory Requirements of Safety and Basic Comfort

**CILAS are also required to provide persons served with the following:**

- **Bathrooms:** At least one bathroom shall be provided for each four individuals.
- **Bedrooms:** Each single individual bedroom shall have at least 75 square feet of net floor area, not including space for closets, bathroom and clearly definable entryway areas. Each multiple bedroom shall accommodate no more than two individuals and each bedroom for two individuals shall have at least 55 square feet of net floor area.
- A fire-graded mattress and box springs that is suitable to the size of the individual, if beds are provided by the agency.
- At least one outside window

Source: JCAR Administrative Code, Title 59, Chapter I, Section 115.300 Environmental Management of Living Arrangements, a) through e),

## Day Training

**Day training facilities'** fire and evacuation drill requirements (in part) are as follows:

- Buildings used by the provider for the program shall conform with Chapters 28, 29 and 31 (specifically Section 31-1.1 through 31-1.6 of Chapter 31) of the NFPA 101, Life Safety Code (National Fire Protection Association, 1988)
- The provider shall develop, implement and maintain a disaster preparedness plan which shall be reviewed annually, revised as necessary and ensure that . . .
- A record of actions taken to correct noted deficiencies in disaster drills or inspections is maintained.
- Evacuation drills are conducted at a frequency determined by the provider based on the needs and abilities of the individuals served.
- Evacuation drills occur at least annually.
- Special provisions are made for those individuals who cannot evacuate the building without assistance, including those with physical disabilities and individuals who are deaf and/or blind.

Source: P JCAR Administrative Code, Title 59, Chapter I, Section 119.255 a) through e)

## **DHS Surveyors' Recommendations on Fire Drills**

You are required by law and Rule(s) to practice fire drills at your agency. When conducting drills, remember:

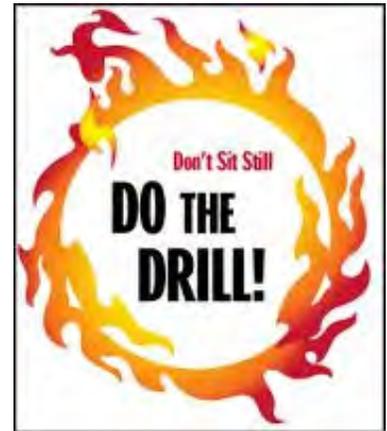
- During a drill, practice what is written in the evacuation procedures. If they don't result in a successful outcome, evaluate the reasons and amend the procedures.
- Record actual time of day the drill began, the length of time it took to clear the site, and the time it took for all individuals to reach the agreed upon meeting place.
- Be sure to document what was done to correct a problem, not just identify the problem in the follow up documentation.
- If multiple individuals at the site need physical assistance, how and/or in what order are staff to assist.
- When planning drills, not only should they be timed during different shifts, but also during various activities.
- If your agency changes a procedure in writing in order to correct a problem, you are responsible for implementing that change.
- You may want to incorporate rule language when writing policies and procedures.
- Whenever possible, teach individuals to use safety devices (drop down ladders, fire extinguishers, etc.) **IN CASE STAFF ARE UNABLE TO ASSIST THEM DURING AN EMERGENCY.**

### **Documentation of a disaster drill should include:**

- What time of the day the drill occurred. Be sure and put PM or AM- and the specific time. Be precise about the shift.
- What activity was occurring at the time of the drill.
- How long it took to evacuate.
- Listing of who was present by name (staff and individuals).
- Citation of problems.
- Defining resolutions to problems.
- Weather conditions
- Exits purposely

## Fire Drills

When an alarm sounds for a fire drill or a real fire, follow the instructions provided by your agency. After a fire drill or an evacuation drill, everyone's response to the fire drill is reviewed and evaluated so improvements can be made in future drills or in the case of an actual fire.



- Review agency policy and procedure on disaster drills to ensure compliance with rule requirements and agency philosophy.
- Write a drill schedule for the entire year, including the dates each type of drill should be run and on what shift it should occur.
- Ensure staff is following the drill schedule by checking documentation the following day.
- Follow up on any problems that may have occurred during the drill. Then check the documentation next month to see if they reoccur.
- If your system is hard wired to an alarm company, check with them for any reception problems.
- Run a surprise drill by not telling any staff or residents. If there are problems during this drill, it may be an indication that staff is not properly implementing fire & disaster drills.

**REMEMBER – DO THE DRILL NO MATTER WHAT!**

**A good (free) video** entitled *Get Out Alive* can be viewed at this site: [www.firstalert.eu/create-a-safer-home/get-out-alive-video](http://www.firstalert.eu/create-a-safer-home/get-out-alive-video)

This video dramatically illustrates the hazards associated with fire. As you watch it, think about those you support and the potential for fire in their homes.

## Home Accident Statistics

According to the 2009 edition of Injury Facts (Copyright 2009, National Safety Council), an estimated 74,000 or 62% of all unintentional-injury deaths occurred in the home and community. Another 20,600,000 people suffered non-fatal disabling injuries. About 1 out of 15 people experienced an unintentional injury in the home and community and about 1 out of 4,100 people died from such an injury.

The five leading causes of unintentional-injury deaths in home and community are:

- Poisoning
- Falls
- Drowning
- Choking
- Fires/flames

25% of emergency room visits could be avoided if people knew basic first aid and CPR.

### Other Safety concerns:

#### Radon

Radon is a colorless, odorless, tasteless, and chemically inert radioactive gas. The Surgeon General estimates that 21,000 lives are lost each year to radon-induced lung cancer. Radon can be found in all 50 states. Unless you test for it, there is no way of telling how much is present. For more information on how to test your home, contact the National Radon Hotline at 800-SOS-RADON (800-767-7236).

#### Lead Poisoning

Today there are still about 38 million homes that contain some lead paint—about 40% of all US housing. Leaded gasoline emissions that were deposited over the years in the soil near highways and busy roads continue to contaminate many yards. And thousands of old lead pipes that continue to serve as water service lines in many older US cities also continue to leach lead into drinking water. Also, many imported items such as toys have leaded paint. The good news is that lead poisoning is preventable. Families need to be informed about the various sources of lead and need to be vigilant in preventing exposure.

## **Sun Safety**

With one in five Americans developing skin cancer, childhood education about sun safety is a vital step toward reducing risk and improving public health. Overexposure to the sun's ultraviolet (UV) rays seriously threatens human health. Besides the immediate effect of sunburn, over time excess UV radiation can cause skin cancer, eye damage, immune system suppression, and premature aging. About 23 percent of lifetime sun exposure occurs before the age of 18. Learning about sun safety and dangers of sunbeds is the key to reducing the risk of future health problems.

## **Protecting Ourselves from Slips, Trips and Falls**

In 2007, more than 21,700 Americans died as a result of falls and more than 7.9 million were injured by a fall including over 1.8 million older adults who had a fall-related injury that resulted in an emergency room visit. Falls are the leading cause of injury-related deaths among older adults 73 and older and the second leading cause of death from ages 60-72. The links below can help you protect yourself and your loved ones from falls.

To prevent falls:

- Stay fit and flexible. Maintain your physical strength to improve your balance to prevent falling
- Remove tripping hazards from indoor and outdoor spaces
- Secure electrical cords and scatter rugs
- Check for slippery substances on walkways and stairs
- Make sure walkways are well lit and clutter-free

## Electrical Hazards

### Electrical Hazards Safety Suggestions:

- ❖ Have a licensed electrician install a safety switch inside the house to replace your external fuse box.
- ❖ Frayed, worn, or damaged cords and extension cords should not be repaired with tape—throw them out.
- ❖ Always turn an appliance off before unplugging it.
- ❖ When unplugging an appliance, make sure to hold the plug and not the cord.
- ❖ Turn small appliances off when not in use.
- ❖ Make sure outdoor appliances don't come into contact with pools or puddles of water.
- ❖ When using electricity in wet areas, always wear rubber sole shoes.
- ❖ Never touch appliances or switches with wet hands.
- ❖ Never fold or crumple an electric blanket.
- ❖ Call a licensed electrician for any repairs needed to switches, power points, or light fittings.
- ❖ Send faulty appliances to be repaired or throw them out. Don't attempt to repair them yourself unless you are qualified.
- ❖ Use plug-in covers to prevent children from poking objects into power points.
- ❖ Make sure to unplug electrical appliances after using them.



## Know the Person's Risk Management Plan

Be aware of all habits and potential behaviors of the adults or children in the home that can present dangers such as:

- Self abuse
- Pica behavior
- Lighting fires
- History of aggressive/abusive behaviors

Develop a Risk Management Plan to assure there is proper supervision based on the needs of the individuals.

Knowing the risk management plan for potential behaviors would entail some form of a functional assessment to help understand the individual's behaviors. These behaviors maybe to escape, avoid, or to obtain something, most behavior intervention plans stem from the knowledge of why an individual misbehaves and should be based on a functional assessment.

These behaviors may be to:

- ❖ Escape
- ❖ Avoid
- ❖ Obtain something

Most behavior intervention plans stem from the knowledge of why an individual misbehaves and should be based on a functional assessment.

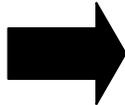
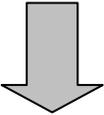
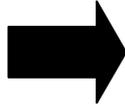
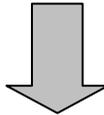
Risk assessment tools are used as a resource for planning purposes to ensure the health and safety of people supported as well as a tool to encourage individual choice and actions and to minimize occurrences of serious incidents.

Some general areas of potential risk that may be considered include:

- ❖ Community safety
- ❖ Health/Medical
- ❖ Sexuality/Relationships
- ❖ Abuse

- ❖ Financial exploitation
- ❖ Behaviors
- ❖ Home environment
- ❖ Fire safety
- ❖ Personal care/Daily living
- ❖ Mental health
- ❖ Police involvement
- ❖ Informed consent
- ❖ Support services
- ❖ Other

**The information on the following page will help them stay safe.**

<b>Responding to Risk</b>			
<p>Is the problem real or immediate?</p>	<p>YES </p> <p>NO </p>	<p>Remove the individual(s) &amp; notify the appropriate authorities. Know &amp; follow your organization's policy &amp; procedures.</p>	
	<p>Is there a potential risk?</p>	<p>YES </p> <p>NO </p>	<p>Report the problem and follow your organization's guidelines to see that the problem is corrected.</p>
		<p>Continue to monitor the home to make sure environmental health and safety problems do not develop.</p>	

## Disaster Preparedness Rules

<b>TOPIC</b>	<b>CILA (Rule 115)</b>	<b>DT (Rule 119)</b>	<b>ICFDD (Rule 350,370)</b>
<b>Fire Extinguishers</b>	At least one at each site which staff can locate and use. Inspected annually.	Same as Rule 115	All personnel must be properly instructed in its use. Practice during drills.
<b>Diagram of Evacuation Route</b>	Same as Rule 119.	Special provisions for individuals who cannot evacuate without assistance.	Must be posted and made familiar to all personnel employed.
<b>Severe Weather</b>	Plan reviewed annually and revised as necessary. Staff knows how to react. Drills no less than annually on each shift.	Same as Rule 115.	Written plan developed. Drills held twice annually for each shift. Written evaluation of effectiveness.
<b>Fire Drills</b>	Plan reviewed annually and revised as necessary. Staff now how to react. Drills no less than annually on each shift. Drills (incl. actual evac) no less than annually on each shift. Plan of correction for inefficiency or problems.	Same as Rule 115.	Held at least quarterly on all shifts. Written evaluation of effectiveness.
<b>Disaster Requiring Relocation</b>	Disaster drills should include actual evacuation of individuals to safe areas.	Same as Rule 115	Written plan for bedrooms below 55 degrees or over 80 degrees. Actual evacuation to safe areas at least once a year.
<b>Training</b>	Retain records and reports, including plan of correction. Staff and volunteers trained. Safety, fire, and disaster procedures.	Keep records of fire and disaster training. Safety, fire and disaster procedures. Must have CPR, Heimlich, and First Aid Training.	N/A
<b>Emergency Phone numbers</b>	Readily Available	Readily Available	N/A
<b>Smoke Detectors</b>	Must comply with Smoke Detector Act (425 ILCS 65)	N/A	N/A
<b>Mattresses &amp; Box Springs</b>	Should be fire grade.	N/A	N/A
<b>First Aid Kits</b>	Available and monitored regularly	First Aid kit should be equivalent to the American Red Cross First Aid Kit	N/A
<b>Buildings</b>	Same as Rule 119	Conform with NFPA, Life Safety Code	Conform with NFPA, Life Safety Code
<b>Disaster Plan</b>	Must be reviewed annually	Same as Rule 115	Must evaluate for effectiveness.

On the following pages are five application exercises that will help you apply the information we have discussed in this module:

## Application Exercise One

Jack Paulis, FSIQ 40, has spent the majority of his 54 years in state facilities and a community ICFDD. He has uncontrolled seizures, is non-verbal, has an unsteady gait and becomes combative when upset. His medications include Risperdal, Tegretol. He also takes Inderal for blood pressure.

Consider the needs of this individual and describe the type of accommodations that should be present to make the environment safe and appropriate.



*Choose a spokesperson from your group to present your case.*

## Application Exercise Two

Wilma Miller is 55, FSIQ 55, requires daily breathing treatments and uses an inhaler due to chronic upper respiratory problems, chronic bronchitis and lung congestion. She weighs 95 pounds, is non-ambulatory, has cerebral palsy, contractures, and is paralyzed from the waist down. She uses a communication board to communicate.

Consider the needs of this individual and describe the type of accommodations that should be present to make it safe and appropriate.



*Choose a spokesperson from your group to present your case.*

## Application Exercise Three

Jeremy Johnson, 35, is 5'8" and weighs 310 pounds. His FSIQ is 40. Jeremy is insulin dependent due to diabetes, has congestive heart failure, varicose veins and uses a diuretic. He uses a wheel chair at all times but is very slow.

Consider the needs of this individual and describe the type of accommodations that should be present to make it safe and appropriate.



*Choose a spokesperson from your group to present your case.*

## Application Exercise Four

Robin Harris is 22, FSIQ 65, and communicates by sign language because of deafness. She also has a secondary diagnosis of schizophrenia which is treated with Seroquel.

Consider the needs of this individual and describe the type of accommodations that should be present to make it safe and appropriate.



*Choose a spokesperson from your group to present your case.*

## Application Exercise Five

Jeff Knox is 34 and has a FSIQ of 10. He is non-verbal and dependent on others for adaptive activities of daily living. He frequently walks away. He does not take any medications.

Consider the needs of this individual and describe the type of accommodations that should be present to make it safe and appropriate.



*Choose a spokesperson from your group to present your case.*



## **MODULE 8**



## **MEDICAL ISSUES**

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*IT'S ABOUT WHAT'S  
IMPORTANT TO THEM, NOT  
WHAT'S IMPORTANT FOR  
THEM.*

*Source: Nancy Thaler*

## Introduction

The medical status of an individual can dramatically impact his/her quality of life. As a QIDP, you are responsible for coordinating and/or providing supports to enhance an individual's capacity for health and safety. Where necessary, you will need to develop supports to fill gaps for an individual who cannot manage each of these independently.

First and foremost in evaluating health services is to know the individual. A basic physical assessment needs to be done to provide a baseline. This establishes what is normal for the individual. Variations above or below the baseline range are indicators of potential problems or emergencies which require interventions. Inform appropriate staff, family, administrators, etc. Make sure the information is passed on to those that have a need to know.

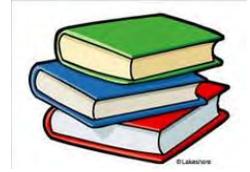
Although 98.6 degrees is the average body temperature, your personal baseline temperature may be lower or higher. Know normal ranges for temperature, blood pressure, pulse rate, bowel movement patterns, etc.

Even changes in behavior can often be indicators of health issues. If a person who is usually active is now very quiet or if a person who is usually cooperative and compliant becomes aggressive or self-abusive, changes in health status may be the underlying cause of these behavior changes.

The remainder of this module will focus on a variety of aspects related to health and safety. In each case, always ask yourself, "How can I relate this to an individual?" You may want to keep Rachel in mind.

## Background Reading

*Developing Staff Competencies For Supporting People With Developmental Disabilities: An Orientation Handbook*, By James Gardner. Chapter 17



*Developing Staff Competencies For Supporting People With Developmental Disabilities: An Orientation Handbook*, By James Gardner. Chapter 14

*Developing Staff Competencies For Supporting People With Developmental Disabilities: An Orientation Handbook*, By James Gardner. Chapter 12

In your position as a QIDP you will be coordinating individuals' access to medical consultations and medical services. Agencies' policies and affiliations with medical professionals differ and may be based on location or personal preference; i.e., small towns may have only one doctor; some individuals may have their own private medical professionals that they use for consultations, etc.

## Medical Consultation

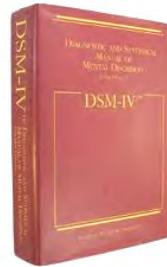
**Directions:** List below the professionals you can consult on health related issues and services.



- ❖
- ❖
- ❖
- ❖
- ❖
- ❖
- ❖
- ❖
- ❖
- ❖

## Medical References/Resources

- ❖ DSM-IV
- ❖ Physicians Desk Reference
- ❖ Nursing and Health Services Procedure Manual
- ❖ Agency specific policies and procedures
- ❖ Nurse Drug Guide (various publishers)
- ❖
- ❖



Many times a disease or medical condition affects the person’s temperature, plus, respiration, and/or blood pressure. An individual may also lose or gain weight or fail to grow normally. Even if you are not required to measure these, this information is available in an individual’s record and you will need to understand what it means.

## Basic Physical Assessment

List the individuals in your organization who are responsible for completing basic physical assessments.

- ❖
- ❖
- ❖
- ❖
- ❖

## COMPONENTS OF A BASIC PHYSICAL ASSESSMENT

The following components are included in a basic physical assessment. It is important temperature, pulse, respiration and blood pressure be taken occasionally when an individual is in his or her usual state of health. This data will assist in establishing a baseline. Otherwise, there are no data for comparison when the person is ill.

### Temperature:

Temperature is the degree of heat maintained by the body.

<b>Normal Body Temperature (Averages)</b>	
Oral	98.6° F
Axillary	97.6° F



Temperatures varying from 97 degrees to 99 degrees F are considered normal and compatible with health.

#### Factors causing an increase in heat production and a rise in temperature are:

- ❖ Exercise- muscles working increase heat production and cause feelings of warmth throughout the body.
- ❖ Shivering- another form of muscular activity.
- ❖ Ingestion of food- increasing fuel supply increases amount of heat.

- ❖ Strong emotions- excitement, anxiety, nervousness and similar emotions cause increased activity of secretory glands to increase heat production in body.
- ❖ Increased temperatures of environment- high room temperature or hot bath may increase temperature.
- ❖ Brief exposure to cold- stimulates body to increased heat production.
- ❖ Very high external temperature- may upset balance of heat regulation and produce high body temperature, as in sunstroke.
- ❖ Illness - an increased metabolic rate, used to fight infection, may cause an increase in body temperature.

**Factors causing a decreased heat production and a lower temperature are:**

- ❖ Illness - muscular activity curtailed and less heat is produced.
- ❖ Fasting - inadequate supply of food or fuel leads to decreased heat production.
- ❖ Lowered vitality- in conditions of illness or injury in which body resistance is lowered, body functions are slowed and muscular activity diminishes so heat production is decreased.
- ❖ Prolonged exposure to cold - reduces body temperatures
- ❖ Sleep - when body is less active, less heat is produced and body temperature is lowered.
- ❖ Depression - of the nervous system, mental depression, unconsciousness, use of narcotic drugs, all act to lessen activity and thus decrease heat production.

## Fever

**Fever is the elevation of body heat above normal.  
Technical name – pyrexia.**

**Cause of fever:** disturbance in heat-regulating mechanism.

### **Symptoms of fever:**

- ❖ Flushed face with dry skin and hot.
- ❖ Eyes bright and anxious in expression.
- ❖ Rapid, shallow breathing and increased pulse rate.
- ❖ Unusual thirst, loss of appetite, headache and complaints of nausea.

### **In extreme temperature:**

- ❖ Urine scant and concentrated
- ❖ Diarrhea
- ❖ Constipation
- ❖ Delirium

### **Nursing care of people with fever:**

- ❖ Depends on disease causing the fever.
- ❖ Specific orders of doctor.
- ❖ Accurate taking and recording of temperature at regular intervals.
- ❖ Cool water sponging.
- ❖ Dry bed linens.
- ❖ Force fluids.
- ❖ Proper diet.
- ❖ Good oral hygiene.

Note: Fever is one of the body's defense mechanisms to fight illness. Consult medical personnel before using medication to control fever.

## Thermometer

**A thermometer is an instrument used to measure the temperature of the body.**

### Digital Pacifier Thermometer

With the digital pacifier thermometer you can easily get a reading within 90 seconds. This thermometer resembles a regular pacifier. When the thermometer reaches the maximum temperature it beeps.

### No-touch thermometer

A no-touch thermometer allows you to get a temperature reading without having direct contact with the skin. You press a button on the thermometer, which releases two safe LED lights approximately three centimeters from the forehead. Within seconds the temperature appears on the display screen.

### Tympanic Thermometer

Another popular thermometer is the tympanic or ear thermometer. This thermometer provides accurate readings when it is aligned in the ear canal.

## Pulse

**Pulse is the rhythmic expansion of an artery produced by increased volume of blood forced into it by contraction of left ventricle at each heartbeat.**

### Locations for taking pulse:

- ❖ Radial artery - thumb side of wrist (usually used).
- ❖ Temporal artery - just above and to the outer side of eye orbit.
- ❖ Carotid artery - either side of neck directly in front of ear lobe.
- ❖ Femoral artery - in the groin.

Do not use your thumb when taking pulses; your thumb has a pulse of its own.

### Factors causing variation in pulse rate:

- ❖ Age.
- ❖ Gender (females faster pulse than males).
- ❖ Physique - short and heavy people more rapid pulse than thin person.
- ❖ Exercise - increased muscular activity causes temporary increase.
- ❖ Food - slight increase for a few hours.
- ❖ Posture - increased when standing, lowered when sitting or reclining.
- ❖ Mental or emotional disturbance - temporarily increases pulse rate.
- ❖ Increased body temperature - pulse usually elevated 10 beats per each degree of elevated temperature.
- ❖ Disease condition - heart, thyroid disturbance, infections are examples.

- ❖ Drugs - stimulant drugs increase pulse rate; depressant drugs decrease pulse rate.
- ❖ Blood pressure - when blood pressure is low, pulse rate increases in attempt to increase flow of blood and therefore increase blood pressure; in high blood pressure, pulse is decreased.

**Characteristics of pulse:**

- ❖ Rate - number of detectable pulsations per minute.
- ❖ Rhythm
  - Regular - beats are of uniform force and separated by equal intervals of time.
  - Irregular or intermittent - beat missed at regular or irregular intervals.
- ❖ Volume - full or large volume of blood in circulatory system is constant. Small, feeble, weak, thready, or flickering - volume decreased (example - hemorrhage).
- ❖ Pounding - pulse is large or full and rapid in rate.

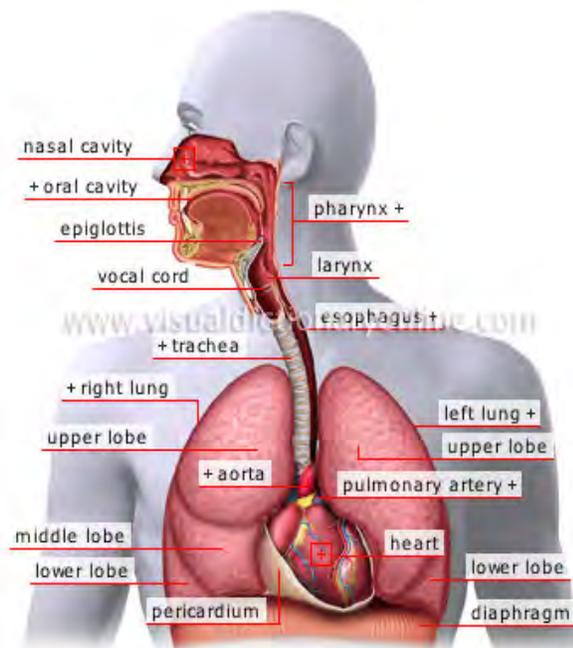
Volume of pulse is determined by size of pulse wave against fingers being used to take pulse.

## Respiration

Respiration is the act of breathing. It is a continual process of drawing in and expelling air from lungs; the taking in of oxygen and elimination of carbon dioxide, water and other products of oxidation. Oxidation is process of substance combining with oxygen. Respiration is exchange of gases between an organism and its environment. This is common characteristics of all living things. It is essential for chemical changes of metabolism which must take place if life is to be maintained.

### Organs of Respiration:

- ❖ **Lungs**
- ❖ **Nose** - external organ in which air is inhaled and exhaled. Purpose: warms, moistens and filters air before it enters respiratory tract.
- ❖ **Pharynx** - muscular membranous tube between mouth and larynx.
- ❖ **Larynx** - structure of muscle and cartilage, lined with mucous membrane and located at the top of the trachea.
- ❖ **Trachea** - cylindrical, cartilaginous tube extending from larynx to bronchi.
- ❖ **Bronchi** - two main branches of trachea which extend into lungs.
- ❖ **Bronchioles** - subdivisions of bronchial tree within lungs leading to alveoli.
- ❖ **Alveoli** - functional units of respiration. Resembling microscopic sacs. This is where exchange of gases takes place.



## **Mechanics of Respiration:**

- ❖ Each cell in body requires oxygen and food for maintenance of life and normal functioning.
- ❖ Chemical processes of metabolism takes place within cells so food and oxygen must be supplied to all body cells. Universal waste product of metabolism is carbon dioxide, which must be eliminated not only from cells, but from the body itself.
- ❖ Exchange of gases in man is a combined action of respiratory and circulatory systems.
- ❖ Usual ratio of respiration and pulse is approximately 1 to 4.

## **Factors causing variation in respiration:**

- ❖ Age
- ❖ Gender (females slightly more rapid than males.)
- ❖ Rate - increased respiratory rate causes breathing to be shallow. If respiration rate is decreased, depth of respiration may increase.
- ❖ Exercise - muscular activity causes temporary increase in respiration.
- ❖ During digestion - due to muscular and metabolic activity.
- ❖ Disease conditions - depends on disease.
- ❖ Drugs - depressant drugs, i.e., morphine and general anesthetics cause respiration to be slower and deeper. Caffeine and atropine stimulate respiration, thereby increasing respiration rate and shallow breathing.
- ❖ Emotion - strong emotion i.e., fear, causes increased rate.
- ❖ Application of cold - stimulates nerve endings in skin and therefore breathing may be fuller and deeper.
- ❖ Application of heat - may increase respiratory rate temporarily and cause shallow breathing.
- ❖ Pain - severe pain causes increased respiratory rate and depth.
- ❖ Toxins - acute infections stimulate respiratory center and cause increased respiratory rate and sometimes depth.
- ❖ Fever - causes increase in pulse and respiratory rate.

- ❖ Hemorrhage - decreased volume of blood with subsequent decrease in oxygen carrying capacity causes increased respiratory rate and depth.
- ❖ Change in atmosphere pressure - in high altitudes, respiratory rate and depth increases as insufficient oxygen is available for external respiration. Normal amount of oxygen in the air is ample to meet needs of the body.
- ❖ Shock - when blood pressure falls below life sustaining levels, it causes increased respiratory rate and depth.

### **Conditions related to respiration:**

- ❖ Apnea - a usually temporary period when breathing has ceased.
- ❖ Dyspnea - difficult or painful breathing.
- ❖ Cyanosis - blueness of skin and mucous membrane caused by lack of oxygen.

## **Blood Pressure**

Blood pressure is the force exerted by the blood against the walls of the blood vessels as it flows through them. It is produced by a combination of heart rate, amount of blood ejected from the heart each time it contracts, body blood volume and blood vessel size.

- ❖ Systolic pressure is the highest degree of pressure exerted by the blood against the artery walls as the left ventricle contracts and forces the blood from it into the aorta.
- ❖ Diastolic pressure is the lowest degree of pressure or the point of lessened pressure when the heart is in its resting period which is just before contraction of the left ventricle. It is produced by body blood volume and vessel size.
- ❖ Pulse pressure is the difference between systolic and diastolic pressure and represents volume output of the left ventricle. Pulse pressure indicates tone of the arterial walls and is valuable in diagnosis and treatment.
- ❖ Hypertension is a condition of abnormally high blood pressure.
- ❖ Hypotension is a condition of abnormally low blood pressure.

- ❖ Blood pressure readings may vary by time of day and body position. Blood pressure readings are taken for the purpose of comparison, therefore, they should be taken daily at the same time and with the individual in the same position each time (i.e. sitting).

### Normal Blood Pressure

- ❖ Blood pressure readings are recorded as a number of millimeters of mercury.
- ❖ Equipment used:

- Sphygmomanometer - (mercury or aneroid) - device used to measure blood pressure. It is a device which may have a dial on which blood pressure is recorded, or a graduated scale on which the height of a column of mercury is indicated.
- Stethoscope - various types are available. These are used basically for amplification and tone control.
- Electronic sphygmomanometer - device that records BP and pulse on a digital display; no stethoscope is needed.



### Factors Causing Variation in Blood Pressure:

- ❖ Age: Blood pressure is lower in children than in adults; i.e., blood pressure of a young adult - 120/80; blood pressure of an older adult - 140/90
- ❖ Gender: Men usually have higher blood pressure than women in the same age bracket.
- ❖ Body Build: Obese people usually have higher blood pressure.
- ❖ Exercise: Muscular exertion will increase blood pressure, although return to normal will occur shortly after exercise is discontinued.
- ❖ Pain: Severe pain may cause a temporary and marked increase in blood pressure.
- ❖ Emotions: Fear, worry, excitement and other emotions will cause blood pressure to rise sharply.

- ❖ Disease: Diseases affecting the circulatory system may cause an increase in blood pressure; e.g., arterio or athero sclerosis, kidney diseases and diseases caused by bacterial toxins; diseases that weaken the heart action may lower blood pressure.
- ❖ Hemorrhage: This causes lower blood pressure by decreasing volume of blood in the vessels.
- ❖ Intra cranial pressure: Increased pressure within the cranium usually produces an increased blood pressure.
- ❖ Shock: lowered blood pressure is a symptom of shock and requires emergency treatment.

QIDP's should know their agency's procedures and staff responsibilities concerning ordering medication, filling prescriptions, and administering and recording medication administration. Know what your specific role is in these procedures. Some of all of the following Medication Tips may apply to you:

## **Medical Protocols & Guidelines**

Protocols are written instructions for caregivers to follow when individuals have specific or frequent problems from a health concern that usually has a predictable outcome. Protocols give guidance to caregivers on signs and symptoms to look for, when and how to intervene and who to notify.

Protocols are sometimes confused with procedures.

Procedures are task oriented. They provide step-by-step instructions on how to do a task.

Protocols are problem oriented. They explain what to do about a health problem.

## **Common Health Problems for Individuals with Developmental Disabilities**

There are four major health issues that are more common in people with developmental disabilities than in the general population that can lead to severe morbidity and even death. They are frequently referred to as the “fatal four” risks:

- ❖ Aspiration
- ❖ Dehydration
- ❖ Constipation
- ❖ Epileptic seizures.

Aspiration, dehydration and constipation may be insidious conditions that often go unrecognized. Many of the symptoms are subtle and persons with disabilities may not be able to express their discomfort or give indications that they are not feeling well.

## Dysphagia/Aspiration

Dysphagia is the medical term which means difficulty swallowing. Aspiration is when bits of food, fluid, saliva or other materials are inhaled into the lungs. Aspiration often happens as a consequence of dysphagia. These two important medical problems are often not recognized promptly in people with developmental disabilities. The following information is meant to increase the awareness of these issues and help to recognize the signs and symptoms of these serious medical conditions.

### Factors that place individuals at risk for aspiration:

- ❖ Being fed by others.
- ❖ Inadequately trained caregivers assisting with eating/drinking.
- ❖ Weak or absent coughing/gagging reflexes, commonly seen in persons who have cerebral palsy or muscular dystrophy.
- ❖ Poor chewing or swallowing skills.
- ❖ Gastroesophageal reflux disease (GERD, GER) which can cause aspiration of stomach contents.
- ❖ Food stuffing, rapid eating/drinking and pooling of food in the mouth.
- ❖ Inappropriate fluid consistency and/or food textures.
- ❖ Medication side effects that cause drowsiness and/or relax muscles causing delayed swallowing and suppression of gag and cough reflexes.
- ❖ Impaired mobility that may leave individuals unable to sit upright while eating.
- ❖ Epileptic seizures that may occur during oral intake or failure to position a person on their side after a seizure, allowing oral secretions to enter the airway.

### Mealtime behaviors that may indicate aspiration

- ❖ Eating slowly.
- ❖ Fear or reluctance to eat.
- ❖ Coughing or choking during meals.
- ❖ Refusing foods and/or fluids.
- ❖ Food and fluid falling out the person's mouth.
- ❖ Eating in odd or unusual positions, such as throwing head back when swallowing or swallowing large amounts of food rapidly.
- ❖ Refusing to eat except from a "favorite caregiver."

## **Signs and symptoms that may indicate aspiration**

- ❖ Gagging/choking during meals.
- ❖ Persistent coughing during or after meals.
- ❖ Irregular breathing, turning blue, moist respirations, wheezing or rapid respirations.
- ❖ Food or fluid falling out of the person's mouth or drooling.
- ❖ Intermittent fevers.
- ❖ Chronic dehydration.
- ❖ Unexplained weight loss.
- ❖ Vomiting, regurgitation, rumination and/or odor of vomit or formula after meals.

## **Interventions for aspiration**

- ❖ Chin-down position
- ❖ Nectar-thickened liquids
- ❖ Honey-thickened liquids
- ❖ Dental soft diet
- ❖ Pureed diet

Individuals who may exhibit these behaviors or who are at risk for dysphagia and aspiration should be seen by a medical provider for further work up and treatment as indicated. The evaluation generally consists of a swallowing evaluation done by a speech language pathologist.

## Constipation

Constipation is when an individual has difficulty passing stool; the stools are hard, dry and often look like marbles. The frequency of bowel movements varies greatly from person to person. Bowel movements are considered normal as long as the feces is soft, normal sized and is passed easily out of the bowel.

### **Factors that place individuals at risk for constipation:**

- ❖ Neuromuscular degenerative disorders that impair the central nervous system's response for the need to eliminate.
- ❖ Spinal cord injuries or birth defects that affect neural responses needed for elimination such as spina bifida.
- ❖ Individuals with muscle weakness who lack the strength and tone needed for adequate bowel function.
- ❖ Diets that do not contain enough fiber and fluids.
- ❖ Poor swallowing skills with aspiration risk making it difficult to eat and drink adequate amounts of fiber and fluid.
- ❖ Inadequate or inconvenient access to the bathroom.
- ❖ Immobility and poor body alignment that does not allow for optimum positioning for bowel elimination.
- ❖ Poor toileting habits and routines or lack of privacy and time for toileting.
- ❖ Medications that slow down gastric motility or draw too much fluid from the GI tract.
- ❖ Hemorrhoids or other conditions that make bowel elimination painful.
- ❖ History of frequent bowel stimulant use leading to decreased bowel reactivity.
- ❖ Repression of the urge to defecate due to psychiatric issues.

**Signs and symptoms of constipation**

- ❖ Spending a lot of time on the toilet.
- ❖ Straining and grunting while passing stool.
- ❖ Refusing to eat or drink.
- ❖ Hard, small, dry feces.
- ❖ Hard, protruding abdomen (usually an emergency).
- ❖ Vomiting digested food that smells like feces (is an emergency).
- ❖ Bloating and complaints of stomach discomfort.

**Interventions for Constipation issues**

- ❖ Dietitian consultation regarding the type of food, texture, fiber content and fluid requirements to enhance elimination.
- ❖ Implement an individual constipation protocol and train caregivers how to identify constipation symptoms, what to do if they occur and who to notify.

**Observations that should prompt concern**

- ❖ No bowel movement for more than three days.
- ❖ Last two bowel movements were hard and/or small.
- ❖ In the last three days, only small bowel movements recorded.

**Observations that should prompt a review by a health professional**

- ❖ Abdomen firm to touch and/or looks distended and bloated.
- ❖ Complaints of stomach pain.
- ❖ Vomiting without any fever or flu-like symptoms and/or vomiting material that smells like fecal material (call 911).
- ❖ Runny liquid stools after several days of passing small hard stools, small liquid stools or no bowel movements.

## Dehydration

Dehydration occurs when an individual does not drink enough fluids. Fluids are needed for temperature control, chemical balance and for cells to make energy and get rid of waste products. Dehydration occurs when the body loses more fluid than is replaced.

### Factors that place individuals at risk for dehydration

- ❖ Unable to access fluids without assistance.
- ❖ Needing assistance with drinking.
- ❖ Dysphagia with coughing and choking during meals.
- ❖ Food, fluid and saliva falling out of a person's mouth.
- ❖ Frequently refusing food and fluids.
- ❖ Suppression of thirst mechanism that results in the inability to recognize thirst.
- ❖ Unable to effectively communicate thirst to caregivers.
- ❖ Medical conditions where fluid loss can potentially cause dehydration, such as kidney disease or diabetes.
- ❖ Conditions where the individual loses body fluids, such as drooling, diarrhea, sweating and vomiting.
- ❖ Taking medications that affect body fluid balance, such as diuretics.

### Signs and symptoms that an individual may be dehydrated

- ❖ Dry skin and poor skin elasticity.
- ❖ Extreme thirst.
- ❖ Dry, sticky mucous.
- ❖ Lethargy and decreased alertness.
- ❖ Fever.
- ❖ Increased heart rate and decreased blood pressure.
- ❖ Decreased urination, dark colored urine and concentrated urine smell.

### Interventions for Dehydration

- ❖ Offer fluid intake if the individual is alert and able to drink safely.
- ❖ If unable to take fluid safely, call health care professional for administration of intravenous fluids.

## Seizure Disorder (Epilepsy)

Epilepsy is a disorder of the brain that is characterized by recurring seizures. Individuals with developmental disabilities are more likely to have epilepsy because of an underlying brain dysfunction. Head injuries, brain tumors, and brain congenital abnormalities are some causes of epilepsy. The clinical expression of an epileptic seizure varies according to where it starts in the brain.

### Factors that place individuals at risk for epilepsy

- ❖ Prenatal and postnatal brain injury, such as trauma, anoxia, infection.
- ❖ Congenital brain malformations.
- ❖ Brain tumors, clots, hemorrhage, and aneurysms.
- ❖ Traumatic brain injuries.

### Immediate interventions when an individual has a seizure

- ❖ Stay with the person and guide gently away from or prevent access to dangerous areas.
- ❖ Do not place anything in the person's mouth.
- ❖ Move objects away from the person to prevent injury.
- ❖ Only move the person if in an unsafe area such as a roadway or stairwell.
- ❖ If in water, keep the person's head above the water.
- ❖ Don't restrain the person's movements.
- ❖ Pad under the person's head, arms and legs.
- ❖ Keep track of how long the seizure lasts.

### After the seizure

- ❖ Loosen clothing.
- ❖ Check for injuries and treat appropriately.
- ❖ Document the seizure on a seizure calendar or record.
- ❖ Allow the person sufficient time to recover before returning to activities.

## General interventions

- ❖ Keep an accurate description of seizures and track all seizures in a consistent manner.
- ❖ Monitor for medication side effects.
- ❖ Keep the environment safe. Precautions must be considered when bathing/swimming if there has been a seizure in the past 12 months or antiepileptic medications have been changed within the last 6 months.
- ❖ Individualized seizure protocol with caregiver trainings.

## Incontinence and Urinary Tract Infections (UTI)

Some people that you help support, like millions of others, may experience the frustration and embarrassment of urinary tract infections, otherwise known as UTIs. When this happens, clothing gets wet, odors develop, and the person gets uncomfortable. Being incontinent is beyond the person's control and dealing with it as a professional requires understanding, kindness and patience.

### Urinary Incontinence

This is the inability of the person to contain urine in the bladder. The extent can range from an occasional leakage of urine, to a complete inability to hold any urine.

### Common Causes of Incontinence

There are a number of reasons someone you support may be incontinent. Incontinence can develop suddenly, be only temporary or be ongoing. Some causes of sudden or temporary incontinence include:

- Urinary tract infection or inflammation
- Prostate infection or inflammation
- Stool impaction from severe constipation which causes pressure on the bladder
- Side effects of medications

Causes that may be more long term include:

- Spinal injuries
- Alzheimer's disease
- Enlarged prostate
- Neurological conditions (multiple sclerosis)
- Weakness of the sphincter (the round muscle of the bladder responsible for opening and closing it)
- Bladder cancer
- Cognitive disability

**Fecal Incontinence** is loss of control of the bowels. This may lead to stool leakage from the rectum. Muscle damage is a common cause of fecal incontinence. Damage to the nerves that are responsible for rectal sensation is also a common cause. Diseases such as diabetes, spinal cord tumors and multiple sclerosis can cause nerve injury which can cause fecal incontinence.

**Interventions for Fecal Incontinence**

- ❖ Adequate fluid intake daily
- ❖ Regular exercise
- ❖ Positive mental outlook
- ❖

[www.oregon.gov/DHS/spd/provtools/.../ddmanual/companion.pdf](http://www.oregon.gov/DHS/spd/provtools/.../ddmanual/companion.pdf)

## Bedsore

### Definition

Bedsore, more accurately called pressure sores or pressure ulcers, are areas of damaged skin and tissue that develop when sustained pressure cuts off circulation to vulnerable parts of your body, especially the skin on your buttocks, hips and heels. Without adequate blood flow, the affected tissue dies.



Although people living with paralysis are especially at risk, anyone who is bedridden, uses a wheelchair or is unable to change positions without help can develop bedsore.

Bedsore can develop quickly, progress rapidly and are often difficult to heal. Yet health experts say many of these wounds don't have to occur. Key preventive measures can maintain the skin's integrity and encourage healing of bedsore.

Bedsore fall into one of four stages based on their severity. The National Pressure Ulcer Advisory Panel, has defined each stage as follows:

**Stage I.** A pressure sore begins as a persistent area of red skin that may itch or hurt and feel warm and spongy or firm to the touch. In blacks, Hispanics and other people with darker skin, the mark may appear to have a blue or purple cast, or look flaky or ashen. Stage I wounds are superficial and go away shortly after the pressure is relieved.

**Stage II.** At this stage, some skin loss has already occurred — either in the outermost layer of skin (the epidermis), the skin's deeper layer (the dermis), or in both. The wound is now an open sore that looks like a blister or an abrasion, and the surrounding tissues may show red or purple discoloration.

**Stage III.** By the time a pressure ulcer reaches this stage, the damage has extended to the tissue below the skin, creating a deep, crater-like wound.

**Stage IV.** This is the most serious and advanced stage. A large-scale loss of skin occurs, along with damage to underlying muscle, bone, and even supporting structures such as tendons and joints.

People who use a wheelchair are most likely to develop a pressure sore on:

- tailbone or buttocks
- shoulder blades and spine
- backs of your arms and legs where they rest against the chair

When people are bed-bound, pressure sores can occur in any of these areas:

- The back or sides of the head
- The rims of the ears
- Shoulders or shoulder blades
- Hipbones, lower back or tailbone
- Backs or sides of your knees, heels, ankles and toes

Contact a doctor if you notice any broken skin or open sores, signs of infection such as fever, drainage from the sore, a foul odor, or increased heat and redness in the surrounding skin on the individuals you support.

The first step in treating a sore at any stage is relieving the pressure that caused it. You can reduce pressure by:

**Changing positions often.** Carefully follow a schedule for turning and repositioning — approximately every 15 minutes for people in a wheelchair and at least once every two hours when they are in bed. Using sheepskin or other padding over the wound can help prevent friction when people are moved.

**Using support surfaces.** These are special cushions, pads, mattresses and beds that relieve pressure on an existing sore and help protect vulnerable areas from further breakdown.

Other nonsurgical treatments of pressure sores include:

**Cleaning.** It's essential to keep wounds clean to prevent infection. A stage I wound can be gently washed with water and mild soap, but open sores should be cleaned with a saltwater (saline) solution each time the dressing is changed. Avoid antiseptics such as hydrogen peroxide and iodine, which can damage sensitive tissue and delay healing.

Controlling incontinence as far as possible is crucial to helping sores heal.

### **Prevention**

Bedsore are easier to prevent than to treat, but that doesn't mean the process is easy or uncomplicated. Although wounds can develop in spite of the most scrupulous care, it's possible to prevent them in many cases.

The first step is to work with your agency's nurses and doctor to develop a plan that caregivers can follow. The cornerstones of such a plan include position changes along with supportive devices, daily skin inspections and a maximally nutritious diet.

### **Skin inspection**

Daily skin inspections for pressure sores are an integral part of prevention. Pay special attention to the hips, spine and lower back, shoulder blades, elbows and heels.

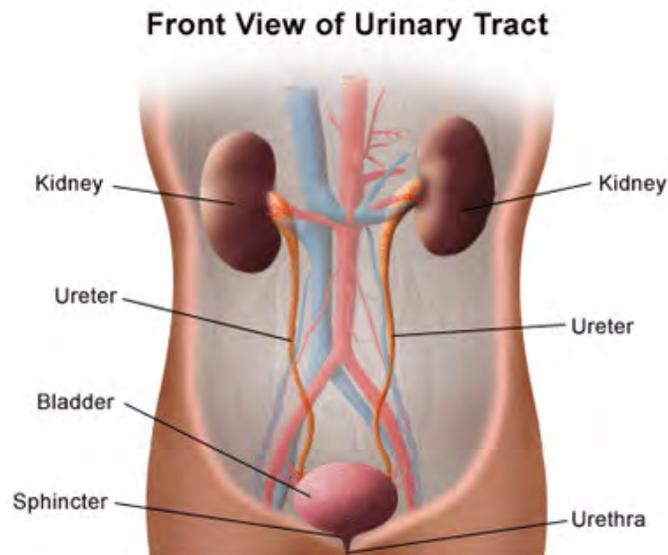
Source: <http://www.mayoclinic.com/health/bedsores/DS00570>, downloaded 3/30/11.

## Urinary Tract Infection

A urinary tract infection (UTI) is an infection anywhere in the urinary tract. The urinary tract is the system of organs that collect and store urine and release it from the person's body. A UTI is caused by bacteria that can live in the digestive tract, the vagina, or around the urethra, which is the entrance to the urinary tract. These bacteria can enter the urethra and travel to the bladder and kidneys. Usually the person's body removes the bacteria during urination and people have no symptoms, but some people are more prone to infection.

### Why are some people more prone to infection?

- Blockage in the urinary tract that obstructs the flow of urine
- An enlarged prostate gland
- Any disorder that suppresses the immune system
- Poor hygiene
- Catheters
- Diabetes



### Interventions for UTI

- ❖ Wash hands frequently.
- ❖ Encourage intake of protein- and calorie-rich foods.
- ❖ Encourage fluid intake of 2000 ml to 3000 ml of water per day (unless contraindicated).

## Unplanned Weight Change

Unplanned significant loss of weight can arise from many causes. Its presence may signal the worsening of a life-threatening illness, and it should always be seen as a dramatic indicator of the resident's risk of sudden decline. Unplanned weight loss is an indicator of declining nutritional status.

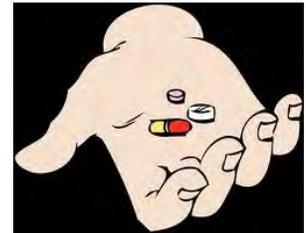
- Determine if the service plan was evaluated and revised based on the response, outcomes, and needs of the resident.
- Determine if the person has experienced an emotional trauma or loss.
- Observe the delivery of care as described in the service plan, e.g., staff providing assistance and/or encouragement during dining; serving food as planned with attention to portion sizes, preferences, nutritional supplements, and/or between-meal snacks, to determine if the interventions identified in the service plan have been implemented.
- Observe at least two meals during the survey.
- For each sampled resident being observed, identify any special needs and the interventions planned to meet their needs.
- Observe whether each resident is properly prepared for meals. For example:
  - Resident's eyeglasses, dentures, and/or hearing aids are in place;
  - Proper positioning in chair, wheelchair, geri-chair, etc., at an appropriate distance from the table (tray table and bed at appropriate height and position);
  - Assistive devices/utensils identified in service plans provided and used as planned.
- Observe the food service for:
  - ❖ Appropriateness of dishes and flatware for each resident, as applicable;
  - ❖ Delivery to residents in a timely fashion;
  - ❖ If a substitute was needed or requested, did it arrive timely; and
  - ❖ Were diet orders, portion sizes, preferences, and condiment requests being honored.
- Determine whether residents were being promptly assisted to eat or provided necessary assistance/cueing in a timely manner after their meal was served. Note whether residents at the same table or in resident rooms, are being served and assisted concurrently.

- Determine how much of the meal the sampled resident consumed.
- Interview the resident, family and/or significant other regarding food quality, eating habits, preferences, weight change, etc.
- Interview staff regarding the residents ability to eat, preferences, assistance needed, usual consumption of food, etc.
- Determine if the meals served were palatable and nutritious and met the needs of the resident. Note the following:
  - Whether the resident voiced concerns regarding the taste, temperature, quality, quantity and appearance of the meal served;
  - Whether mechanically altered diets, such as pureed, were prepared and served as separate entree items (except for combined foods, e.g., stews, casseroles, etc.);

[http://www.oregon.gov/DHS/spd/provtools/ralf/weight\\_chg.pdf](http://www.oregon.gov/DHS/spd/provtools/ralf/weight_chg.pdf)

## Self-Medication

Some individuals have been taught to take their own medication. Others may be capable of learning this valuable skill. The ability to handle one's own medication allows an individual to have more choices of living arrangements.



An assessment should be made of each individual's ability to self medicate. The assessment of the IDT and the physician will determine whether the individual is currently independent and whether or not he/she would benefit from training. A physician's order is required, as well as, the approval of the IDT.

If the individual is determined not to be fully competent in self medicating, a training program must be implemented. Almost any individual could benefit from some level of training, something as simple as identifying their own medication to something as complicated as making their doctor's appointments and filling their own prescriptions.

## Ten Medication Principles to Remember

- I. Medications may not always work as intended.
- II. Medications may produce an effect that is different from the effect that was desired.
- III. Medications may produce no effect.
- IV. Medications may produce an opposite effect than the desired effect.
- V. Medications may make a problem worse. These are called adverse effects (life threatening) or side effects (undesirable).
- VI. Some medications can have good or bad reactions with other medications already being taken.
- VII. Many medications taken for mood and behavior may take time to work (such as antidepressants).
- VIII. Be patient when new medications are started. They may take 3-4 weeks to work and side effects may begin at once.
- IX. Give medications on time and as prescribed.
- X. If someone has kidney or liver problems, medications may make these conditions worse. For any person taking medications, monitor and report the following:
  - changes in the color of the stool
  - changes in the color of the white part of the eye
  - changes in the color of tissue under the tongue
  - stomach pain or increase in size of the stomach
  - weight gain or swelling (edema)
  - cloudy urine with increased odor
  - blood in the urine or stool
  - increased, frequent, or decreased urine output.

**<http://www.irtces.com>**

## **TARDIVE DYSKINESIA**

### **What is Tardive Dyskinesia?**

Tardive dyskinesia is a neurological syndrome caused by the long-term use of neuroleptic drugs. Neuroleptic drugs are generally prescribed for psychiatric disorders, as well as for some gastrointestinal and neurological disorders. Tardive dyskinesia is characterized by repetitive, involuntary, purposeless movements. Features of the disorder may include grimacing, tongue protrusion, lip smacking, puckering and pursing, and rapid eye blinking. Rapid movements of the arms, legs, and trunk may also occur. Involuntary movements of the fingers may appear as though the patient is playing an invisible guitar or piano.

### **Is there any treatment?**

There is no standard treatment for tardive dyskinesia. Treatment is highly individualized. The first step is generally to stop or minimize the use of the neuroleptic drug. However, for patients with a severe underlying condition this may not be a feasible option. Replacing the neuroleptic drug with substitute drugs may help some patients. Other drugs such as benzodiazepines, adrenergic antagonists, and dopamine agonists may also be beneficial.

### **What is the prognosis?**

Symptoms of tardive dyskinesia may remain long after discontinuation of neuroleptic drugs; however, with careful management, some symptoms may improve and/or disappear with time.

#### **Source:**

National Institute of Neurological Disorders and Stroke  
National Institutes of Health  
Bethesda, MD 20892

<http://www.ninds.nih.gov/disorders/tardive/tardive.htm>

## Infection Control

See the Occupational Safety & Health Administration link below for comprehensive information on preventing the transmission of blood borne pathogens.

<http://www.osha.gov/SLTC/bloodbornepathogens/index.html>

In order to understand the basic principle of infection control, the QIDP must have completed a basic course in Universal Precautions and Blood borne pathogens.

It is imperative to exercise good infection control procedures and to model those principles for the individual so that he/she will also practice those principles. Infection control promotes good health and dramatically reduces frequency of illness.

The most important guideline that the QIDP can stress is good and frequent hand washing. Encourage hand washing: after toileting, before eating, drinking or smoking, before preparing food, before taking medication, before and after tooth brushing, after handling unclean items, after petting animals, after blowing nose, or coughing/sneezing, etc.



## Preventing the Occupational Transmission of Blood-borne Disease

Healthcare-associated infections (HAIs) are infections caused by a wide variety of common and unusual bacteria, fungi, and viruses during the course of receiving medical care.

Wherever patient care is provided, adherence to infection prevention guidelines is needed to ensure that all care is safe care. This includes traditional hospital settings as well as outpatient surgery centers, long-term care facilities, rehabilitation centers, and community clinics. The information on this website is intended to inform staff concerning reducing the risks of contracting HAIs.

<http://www.cdc.gov/hai/>

## CURRENT REGULATIONS

Four currently existing standards have been coordinated to provide an enforcement strategy to prevent the occupational transmission of blood-borne disease. These standards are:

29 CFR 1910.132 – Personal Protective Equipment

[http://www.osha.gov/pls/oshaweb/owadisp.show\\_document?p\\_table=STANDARDS&p\\_id=9777](http://www.osha.gov/pls/oshaweb/owadisp.show_document?p_table=STANDARDS&p_id=9777)

29 CFR 1910.22(a)(1) and (a)(2) – General Requirements/Housekeeping

[http://www.osha.gov/pls/oshaweb/owadisp.show\\_document?p\\_table=STANDARDS&p\\_id=9714](http://www.osha.gov/pls/oshaweb/owadisp.show_document?p_table=STANDARDS&p_id=9714)

29 CFR 1910.141(a)(4)(I) and (ii) – Sanitation; Waste Disposal

[http://www.osha.gov/pls/oshaweb/owadisp.show\\_document?p\\_table=STANDARDS&p\\_id=9790](http://www.osha.gov/pls/oshaweb/owadisp.show_document?p_table=STANDARDS&p_id=9790)

29 CFR 1910.145(f) – Specifications for Accident Prevention Signs and Tags

[http://www.osha.gov/pls/oshaweb/owadisp.show\\_document?p\\_table=STANDARDS&p\\_id=9794](http://www.osha.gov/pls/oshaweb/owadisp.show_document?p_table=STANDARDS&p_id=9794)

### 29 CFR 1910.132 - Personal Protective Equipment

Occupational Safety and Health standards mandate Protective equipment, including personal protective equipment for eyes, face, head, and extremities, protective clothing, respiratory devices, and protective shields and barriers, shall be provided, used, and maintained in a sanitary and reliable condition wherever it is necessary by reason of hazards of processes or environment, chemical hazards, radiological hazards, or mechanical irritants encountered in a manner capable of causing injury or impairment in the function of any part of the body through absorption, inhalation or physical contact.



Disposable gloves are to be worn when employees are exposed to blood or body fluid. This is particularly important in the following instances:

- ❖ If the health care worker has abraded, chapped, cut, or otherwise non-intact skin.
- ❖ During instrumental examination of the oropharynx, gastrointestinal or genitourinary tracts.
- ❖ When examining non-intact skin or active bleeding.
- ❖ During all invasive procedures.
- ❖ During cleaning or disinfection of articles or surfaces contaminated with blood or body fluid.

**Gloves are not required for routine care or support activities.**

Gloves must be appropriate fit and type. Surgical and exam gloves must not be washed for reuse. General purpose rubber gloves used for housekeeping duties may be decontaminated for reuse. However, they must be discarded when signs of deterioration develop. For those with a latex allergy, hypo-allergenic gloves are available.

Gowns should be worn whenever the potential for splashing exists. They are to be made from or lined with impervious material, and should cover all exposed skin surfaces.

Face and eye protection such as masks and safety goggles or full face shields are required when mucous membrane exposure may occur from splashing or aerosolization. Examples of these situations include surgical and dental techniques. Gowns are not required for routine care or support activities.

[http://www.osha.gov/pls/oshaweb/owadisp.show\\_document?p\\_table=STANDARDS&p\\_id=9777](http://www.osha.gov/pls/oshaweb/owadisp.show_document?p_table=STANDARDS&p_id=9777)

### 29 CFR 1910.22(a)(1) and (a)(2) – Housekeeping

All work areas are to be kept clean, orderly and in a sanitary condition, cleaning as often as necessary. Germicides and disinfectants approved as tuberculocidal are acceptable for HBV and HIV decontamination. A solution of 5.25% Sodium Hypochlorite (household bleach) in a dilution between 1:10 to 1:100 is also effective.

[http://www.osha.gov/pls/oshaweb/owadisp.show\\_document?p\\_table=STANDARDS&p\\_id=9714](http://www.osha.gov/pls/oshaweb/owadisp.show_document?p_table=STANDARDS&p_id=9714)

### 29 CFR 1910.141(a)(4)(I) and (ii) – Sanitation: Waste Disposal

The disposal of contaminated needles, blades, and other sharp objects need to be a major focus of the infection control program. These objects must be immediately disposed in a puncture resistant, spill proof container. Containers shall be in all areas where needles are commonly used to ensure easy employee access. Needles shall not be recapped.

Containers used for blood or body fluids must be designed for safe transportation and disposal. The container must be leak proof, and must be designed for adequate decontamination if reusable. Wastes must be removed as often as necessary to maintain a sanitary condition.



All bags of waste contaminated with blood or other potentially infectious body fluid must be carefully handled and double bagged if outside contamination or puncture is likely.

[http://www.osha.gov/pls/oshaweb/owadisp.show\\_document?p\\_table=STANDARDS&p\\_id=9790](http://www.osha.gov/pls/oshaweb/owadisp.show_document?p_table=STANDARDS&p_id=9790)

### 29 CFR 1910.145(f) – Accident Prevention Tags

Every bag of material contaminated with blood or potentially infectious body fluid must be securely marked with tags or other forms of warning. If tags are used, they shall have a signal work or symbol for “Biohazard”, and a major message legible at five feet. The message shall state the specific hazard or hazards, and may be written, pictographic, or both. Employees must receive training about the tags.



[http://www.osha.gov/pls/oshaweb/owadisp.show\\_document?p\\_table=STANDARDS&p\\_id=9794](http://www.osha.gov/pls/oshaweb/owadisp.show_document?p_table=STANDARDS&p_id=9794)

## INFECTION CONTROL PROGRAM

**Universal Precautions** for blood borne pathogens are part and parcel of Standard Precautions. It treats all blood and other potentially infectious materials as if they were known to be infected with bloodborne diseases. Blood and other materials that can carry pathogens that causes serious diseases. Materials include human body fluids, unfixed tissue or organs, and HIV/HBV-containing cell or tissue cultures. **The intent of Universal Precautions is to protect the healthcare worker from bloodborne diseases.**

The United States Department of Labor and Occupational Health and Safety Administration Standards for dealing with bloodborne pathogens can be found at:

[http://www.osha.gov/pls/oshaweb/owadisp.show\\_document?p\\_table=STANDARDS&p\\_id=10051](http://www.osha.gov/pls/oshaweb/owadisp.show_document?p_table=STANDARDS&p_id=10051)

The CDC guidelines stress that each health care work site needs an effective infection control program. The program can either provide written or oral instruction and must include the following:

- Identification of employees at substantial risk from direct patient care and housekeeping chores involving direct cleanup of blood and body fluid.
- Proper use of protective gear.
- Proper use of warning signs and tags
- Decontamination of instruments and areas, and safe disposal of used instruments and potentially infectious waste.
- Employee training and education.
- HBV vaccination program.



### Handwashing

Handwashing remains the single most effective means of removing organisms acquired from infected patients. Handwashing consists of a soap and water wash for longer than 10 seconds using a rubbing action that creates a lather over the entire hand surface and is then fully rinsed for 20 – 30 seconds with running water. Hands should be dried with disposable or single-use towels or an air dryer.

## **Hand Disinfection**

- Plain soaps – (Dispenser soap, bar soap)
  - Removes most transient organisms
- Antiseptic Hand Soaps – (chlorhexidine)
  - Removes transient flora
  - Decreases resident flora
  - Residual effect up to 6 hours

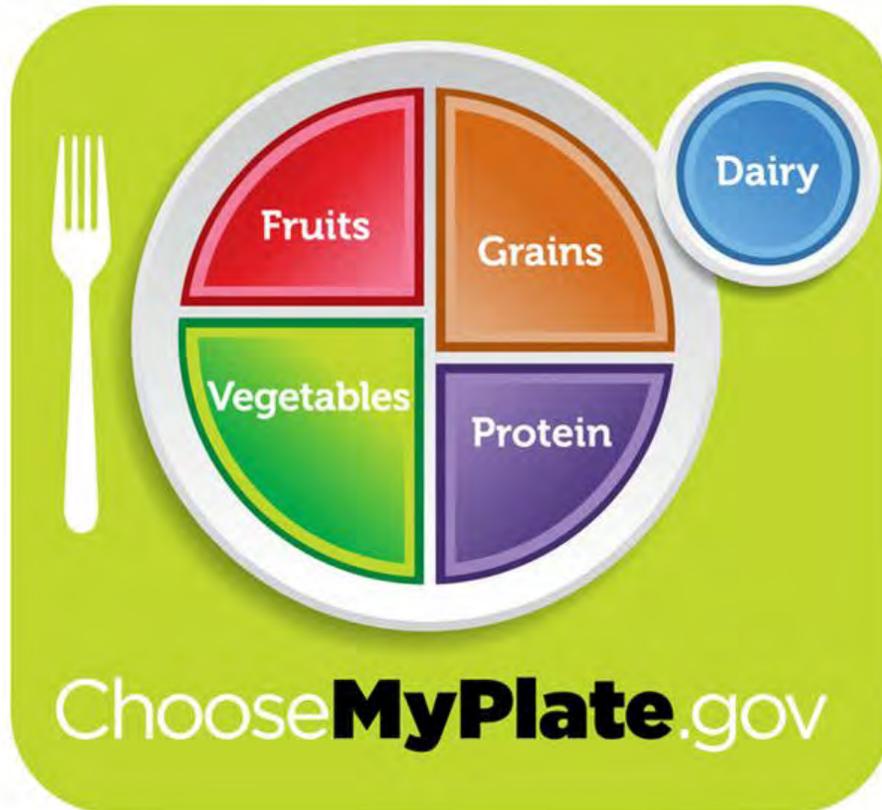
## **Antiseptic Waterless Products (Alcohol Hand Disinfectants)**

- Hands not visibly soiled
- Rapid, effective activity
- Remove transient flora
- No residual activity

## **Hand Lotions**

- Skin irritation increases the number of organisms
- Hand lotions maintain skin integrity
- Only lotions that do not inhibit the residual activity of chlorhexidine
- Petroleum based hand lotions interfere with the integrity of latex gloves
- Bottles with pump dispensers to avoid cross contamination

## NUTRITION



**One size doesn't fit all.** MyPlate offers personalized eating plans and interactive tools to help you plan/ assess your food choices based on the Dietary Guidelines for Americans.

There are many special diets that may be prescribed to the individuals at your agency. It is your responsibility to ensure that these diets are followed. In order to understand the importance of these diets, it may be helpful to understand why they may be needed (i.e., food intolerance, diabetic, special nutrients; thickened liquids, etc.)

**Visit: [www.ChooseMyPlate.gov](http://www.ChooseMyPlate.gov) for all the latest on the food pyramid.**

In order to complete the checklist below, you will need to know people’s dietary needs and restrictions, look through the food supplies in the pantry and refrigerator/freezer, observe at mealtime and speak to the cooking staff.

### **Fundamentals of Diet & Nutrition**

<b>Required Condition</b>	<b>Action to take if condition</b>
Meals are planned based on individual's nutritional needs and preferences.	
Meals are prepared according to plan.	
Where necessary, a monitoring mechanism is in place for determining if the individual is consuming food according to the plan.	
Nutritional snacks are available.	
The diet is varied.	
Food is prepared and stored in sanitary manner.	
Adaptive devices are provided to maximize independence in eating and preparing food.	
The meal planner is aware of drug/food interactions and other dietary restrictions/requirements.	
The individual is being provided diet and preparation education.	
Food choices and preferences are valued.	
Food substitutions are available.	

## The Experience of Loss

All people experience losses in their lives. The individuals we support are no different.

**Directions:** List below as many types of loss that you or others might experience.

- Death of family, friends, staff
- Loss of ability due to illness
- Loss of employment
- Loss of home
- 
- 
- 
- 



## The Grief Process

The response to loss is known as the grief process. These were made known by Elizabeth Kubler-Ross. While not all people will follow or experience all of these steps, there is a general consensus that they are fairly predictable in type and sequence.

Following is a summary of the grief process as presented by Elizabeth Kubler-Ross.

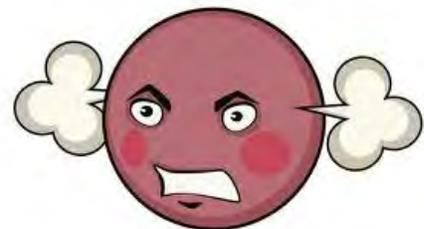
**Denial:** People confronted by their own or someone else's impending death may deny the fact. There are many forms of denial:

- ❑ Denying that the person is ill at all.
- ❑ Denying the specific diagnosis.
- ❑ Denying that the diagnosed condition is fatal.
- ❑ Minimizing the threat of the illness.
- ❑ Acting in ways that ignore the fact of impending death. (E.g., Making plans far into the future or making unwarranted and overly optimistic comments about the treatment.)



**Anger:** This the *Why me?* stage. The person becomes bitter, irritable and angry. The anger can take several forms:

- ❖ Directed at the fact that the person is dying.
- ❖ The anger is often expressed toward God, even by devoutly religious people.
- ❖ Directed at other things and people. Sometimes staff members can become the object of this displaced anger.
- ❖ The person may not complain about anything in particular, but just act gruff and hostile.



**Bargaining:** In this stage, there is a partial acceptance.

The person acknowledges the situation but still sees a chance to change things or at least to postpone death. Some versions of bargaining are:

- ❖ To pray for time.
- ❖ To make a deal ("If I get better, I'll...")
- ❖ To target some event to reach before dying (a birthday, wedding, etc.)
- ❖ To seek time to undo wrong.



**Depression:** In this stage, the person recognizes the inevitability of death and the full impact of what he or she is going to lose, coupled with the realization of increased deterioration and perhaps increased pain. The result is depression.

**Acceptance:** In this stage, the person becomes serenely calm, even as weakness, pain, and deterioration increases. The person *comes to terms* with his or her death. We also know that:

- ❖ Not everyone experiences each stage.
- ❖ Stages co-exist.
- ❖ None of the stages are necessarily a bad thing. They are all ways of dealing with the overwhelming fear, loss, and upsetting thoughts brought on by an acknowledgment of one's death. A given stage only becomes problematic when it distorts the person's perceptions and communication to the point where his or her relationships suffer or where self-destructive behaviors appear.
- ❖ A given stage can end and then reappear.
- ❖ People experiencing loss or grief, often go through these same stages.



Individuals with intellectual disabilities may express their grief through their behavior. This can include acts of aggression, rage, crying, withdrawal, etc. As a QIDP, you need to be supportive and alert since they may have difficulty expressing their thoughts.

## Assistive/Corrective Devices & Prosthesis

Assistive devices and prosthesis improve the quality of life for individuals. They provide the means to greater independence by maximizing the functional abilities an individual has. Included are:

- ❖ Adapted glasses, cups, plates
- ❖ Switches
- ❖ Adapted eating utensils
- ❖ Artificial limbs
- ❖ Wheelchairs, crutches, walkers
- ❖ Telecommunication Device for the Deaf (TDD)
- ❖ Video Relay Service (VRS)
- ❖ Communication devices – language boards, computers, picture schedules
- ❖ Photo/Picture telephone
- ❖ Hearing aids
- ❖ Eye glasses
- ❖ Dentures
- ❖ Splints
- ❖ Ankle foot orthotics (AFOs)
- ❖ Teletypewriter (TTY)
- ❖ Voice Activated Software

Many of these devices are commercially available. Others are homemade devices. This is an area where it is especially important to know the individual. You must study the person to see what they can control. The Illinois Assistive Technology Project can use this information to come up with a way of providing greater independence. In many cases, this requires *thinking outside the box*.

**<http://www.iltech.org/>**



## Positioning and Transferring

To learn about the anatomy of lifting; lifting patients from beds and wheelchairs; lifting patients with needs; using assistive devices; risk management; body mechanics; and lifting and moving safely, visit:

**[www.cdc.gov/niosh](http://www.cdc.gov/niosh)**

Before attempting any transfer:

- ❖ Always thoroughly explain the procedure to the person.
- ❖ Ask permission before touching the person.
- ❖ Be sure to use good body mechanics to prevent injury.
- ❖ General Rule -- be sure to reposition persons at least every two hours to prevent sores, contractures, circulation problems, breathing problems, constipation.
- ❖ Basic positions are supine, prone, side lying, sitting.
- ❖ Maintain good body alignment when positioning the person.
- ❖ Use positioning aids as appropriate (pillows, bolsters, handrails, etc).
- ❖ If working with people who are immobile, it is recommended further training be obtained from a nurse or a physical therapist or positioning and moving specific individuals, passive range of motion (P.R.O.M.), etc.



2. Transfer between a bed and a wheelchair

## Common Causes of Back Injuries

Not all back injuries are a result of sudden trauma but rather the cumulative damage suffered over a long period of time. There are certain actions, movements and motions that may be more likely to cause and contribute to back injuries than others. They include:

- Repetitive motions—When you use repetitive motions, such as stacking items, remember your back is always working.
- Twisting at the waist—This frequently happens when using a shovel or transferring someone.
- Reaching and stretching—When you reach and stretch for items, especially in high places, you are at risk for injury.
- Lifting or carrying—Lifting or carrying objects with awkward or odd shapes.
- Working in an awkward or uncomfortable position—This includes kneeling, or tasks that require bending over for long periods of time.
- Slipping—Slipping on a wet floor, ice or steps.
- Standing or sitting—Standing or sitting too long in one position.
- Pushing or pulling—Pushing or pulling large objects such as trash bins can be as hard on your back as heavy lifting.

## Safe Lifting

Because most back injuries are a result of improper lifting, you need to learn to lift properly. The following are the six steps to proper body mechanics. You and the people you support should follow these six steps every time you lift:

- 1) Maintain a wide base of support—Position your feet about shoulder width apart, with one foot slightly in front of the other.
- 2) Bend at your knees—Bend at your knees and squat down, keeping your back straight.
- 3) Turn, don't twist—Move your body as a single unit. Don't twist while lifting or lift while twisted. Make turns with your feet, not your waist.
- 4) Lift with your legs—Let your powerful leg muscles do the work of lifting, not your weaker back muscles. Maintain your three natural curves.
- 5) Keep the load close—Do not hold the load away from your body. The closer it is to your spine, the less force it exerts on your back.
- 6) Keep your back straight—Whether you are lifting or setting down the load, do not add the weight of your body to the load.

## Scenario Seven

Over the past 3 months, staff has noticed a decrease in Rachel's activity level and social interaction. She has become progressively less talkative and spends excessive time lying in bed. She has become disinterested in her DT programming and frequently refuses to get up even for breakfast. She has completely refused workshop for the past week and a half. She complains of non-specific aches and pains. When attempts are made to motivate Rachel to work or even participate in leisure activities, she becomes irritable and at times will scream or cry excessively.

Yesterday, Rachel was noted walking aimlessly outdoors. A staff member had to stop her car abruptly in the parking lot as Rachel walked in front of it acting as if she did not notice it. Rachel is normally very careful when crossing streets or walking in the parking lot. She responded to the staff member's concern by yelling and returning to her bed.

In addition to these behavior changes, Rachel has become apathetic towards food. This is noticeably abnormal behavior for her. Even her parents are concerned as she no longer seems to enjoy her trips to her favorite restaurant and picks at her favorite foods. Despite the decreased appetite, Rachel has gained 9 lbs. over the last 3 months.

Since Rachel has also missed her last 2 periods, a pregnancy test was done. Results were negative.

Some staff suspects that Rachel is acting out in opposition to the recent addition of time-out in her behavior program. Some believe that Rachel is upset due to the resignation of her favorite staff member.



## Discussion and Questions

1. What are some of the possible reasons for the changes in Rachel's behavior that should be considered? What other information might you need to assess this situation?
2. A pregnancy test was done. Should other medical possibilities be explored? Why or why not?
3. What should the Q do to insure that medical considerations are addressed?
4. Should psychiatric possibilities be explored even though there is not previous history of mental illness? Why or why not?



## Scenario Eight

Rachel was recently diagnosed with an eye infection. This is the third occurrence in the last 6 months. The drainage from Rachel's eyes is contagious. Drainage can be carried by hand to hand contact. Infection occurs when the contaminated hand comes in contact with one's eye.



Rachel is very affectionate and enjoys physical contact with staff. She also lacks good hand washing skills and is reluctant to wash her hands at the times she should. She complains of itchy eyes and rubs her eyes frequently even when infections are not present.

### Discussion and Questions

1. What are the infection control concerns for Rachel, staff, and other individuals?
2. What medical concerns should be evaluated? Examples: Cause of infection, cause of itchy eyes, etc.
3. What types of training are necessary for staff and for Rachel?
4. How could more frequent hand washing and improved hand washing skills benefit Rachel, staff and other individuals?

## **SAMPLE LETTER TO HEALTH CARE PROVIDER ON BEHALF OF A PERSON WITH DEVELOPMENTAL DISABILITIES**

Note: This is a great suggestion. We recommend it highly.

-- Rice Brooks, Health Promotion Project.

Robin Jones, MD  
555 Center Street  
Madison, WS 53700

Dear Dr. Jones:

I am writing to tell you about myself so that we can better work together to keep me healthy.

Mary Sawyer, who has known me very well for several years, helped me write this letter. I live with her and her high school age children in an Adult Family Home. Another person who knows me well is my case manager from Dane County Adult Community Services; his name is Brad Fields. Brad told me about you and suggested that you would be a good choice for a doctor to meet my needs.

Although I only use a few words, I understand a great deal and pay attention very well--especially in a new place or with unfamiliar people. I am 38 years old and usually in good health. I have always had checkups with my doctor and dentist at least once a year. Since I have seizures and they are not completely controlled, I also tend to need stitches (because of falls) or medication reviews from time to time.

Mary and I work together at home on health concerns. We have a file folder with my records and write important things on a calendar that we keep from year to year. Since my medication schedule is fairly complicated, Mary helps me remember to take the right medicines on time and we record each dose when I take it. I always remember to bring my folder to each appointment.

Mary accompanies me for appointments, but remains in the waiting area until the exam is over unless there is a specific reason for her to participate in some way.

Here are some things that are helpful for me during exams:

- ❖ Please tell me what you will do each step of the physical exam. When I see and understand what is next, I will be able to be more relaxed.
- ❖ I am very ticklish and will bring my legs up fast when you check my abdomen unless you first have me put my hands where you will begin. Place your hands over mine and then tell me I can take mine away. Use firm touch and a calm, quiet voice.

If I need to have an examination or procedure that might be uncomfortable, here is what helps me best:

- ❖ Tell me why the procedure or treatment is important.
- ❖ Show me the equipment you will use and tell me in a simple way what you will do.
- ❖ Ask me if you would like Mary to come into the room and give me support. Wait for her to join us before you proceed.
- ❖ Then ask me to let you know when I am ready. Say, "Are you ready now, Joe?" Watch my face, because I will nod when I am ready.
- ❖ If you would usually offer someone a local anesthetic (for example for a few stitches or filling a tooth), show me the syringe and ask me if I want it. I usually prefer to do without it. I will take your arm and bring it towards me as a sign I want you to go ahead without anesthesia. Sometimes I do this quickly, so you should not be startled. You can ask me how I am doing as you go ahead. I almost always do fine without it. I can hold still best when you keep talking to me and telling me how things are going.

At the end of every appointment, it is important for Mary to join us to talk thing over. Since she knows me so well, she might be able to ask questions or get clarification about something that could be of concern to me. Also, since we work together on my health, she needs to be informed about changes in my treatment so we can follow up appropriately.

My parents are my guardians. They live in town and we get together 1-2 times a month for brief visits. They will be happy to talk with you by phone about my health and sign documents as needed. Mary keeps them informed of any changes or problems, so they know how I am doing.

Thank you for reviewing this information. I will see you next month for my annual checkup.

Sincerely,

Joseph Smathers  
1234 Lake Street  
Madison, WS 53700  
Telephone: 211-1234

**Additional information on Health and Disability can be found at:**

**<http://www.aahd.us/page.php>**



## **MODULE 9**



# **APPLYING RULES AND REGULATIONS**

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*"Recognizing and respecting differences in others, and treating everyone like you want them to treat you, will help make our world a better place for everyone. Care . . . be your best. You don't have to be handicapped to be different. Everyone is different!" -*

*Kimputer, Kim Peek, inspiration for Rain Man*

Directions: Review the list of rules and regulations listed below. Discuss with your class and trainer those that apply to your organization and mark them as applicable.

<b>Rules &amp; Regulations</b>	<b>Applicable</b>
Those applying to guardianship & Advocacy	
Special education amendments	
Rule 115	
Rule 116	
Rule 119	
Confidentiality Act	
Reporting Regulations (abuse & neglect) Rule 50	
Nursing Home Reform Act	
Council on Quality and Leadership	
Commission on Accreditation of Rehabilitation Facilities (CARF)	
Medicaid Waiver	
Centers for Medicare & Medicaid Services (CMS)	
Joint Commission on Accreditation of Healthcare Organizations (JACHO)	
Occupational Safety & Health Administration/IL Department of Labor (OSHA)	
Mental Health Code	
Respite	
Those generated by Healthcare & Family Services (HCFS)	
Those generated by the Department Of Rehabilitation Services (DRS)	
Those generated by the Department of Human Services (DHS)	
Americans with Disabilities Act (ADA)	
Social Security Act	
Those generated by Illinois Department of Public Health (IDPH)	
Consumer rights	
Nurse Practice Act	
Health Insurance Portability and Accountability Act (HIPAA)	
Individuals with Disabilities Education Act (IDEA)	

## **Importance of Rules & Regulations**

Many of us may be inclined to think of rules and regulations as a nuisance. However, they have been developed to ensure quality services are provided to individuals.

As a QIDP, you have an obligation to make sure that the rules and regulations that apply to your organization are followed. Failure to comply with these rules and regulations can impact:

- Quality of services provided to individuals receiving services from your center/agency;
- Funding;
- Licensure;
- Credibility of services;
- Attitudes of staff;
- Working relationships/cooperation with agencies, community resources, volunteers, fund raising, etc; and
- Longevity of the agency.

## **Mental Health & Developmental Disabilities Code**

The Mental Health & Developmental Disabilities Code addresses issues related to the rights of individuals with mental health and/or developmental disabilities. In addition, it covers services, admission, transfer, and discharge procedures.

Chapter II is especially important to your work as a QIDP. Following are each of the areas discussed in this section:

- Deprivation of rights, benefits, privileges or services
- Legal disability - determination
- Care and services - Psychotropic medication - Religion
- Mail - Telephone - Visits
- Personal property - Restrictions - Discharge
- Money - Deposits - Payees
- Labor - Wages

- Refusing services - Medications- Informing of risks
- Administration of psychotropic medication upon application to a court
- Review of medication treatment - Convening of panel
- Use of restraint
- Seclusion
- Electro-convulsion therapy - Psychosurgery - Consent
- Medical or dental emergency - Consent
- Freedom from abuse and neglect
- Notification of admission
- Attorneys or advocates - Representation of recipients
- Notice of Rights
- Restrictions, restraints or seclusion - Notice - Records
- Policies and procedures

Please take time to read Articles I and II of Chapter II. You will find them in the Mental Health and Developmental Disabilities Code.

## **HB5132**

With HB 5132, the MH and DD Act and DCFS Act were changed.

(DHS) OIG now accepts referrals of abuse/neglect allegations for individuals with a disability who are age 18 and over and are still in school with an Individual Education Program (IEP). If they can investigate under Rule 51, they will. If not, they will refer to appropriate law enforcement agency. In the Act, "Adult student with a disability" means an adult student, age 18 through 21, inclusive, with an Individual Education Program, other than a resident of a facility licensed by the Department of Children and Family Services in accordance with the Child Care Act of 1969.

DCFS will investigate abuse/neglect allegation of the individuals who are 18 and over, residing in DCFS-licensed homes and institutions. "Adult resident" means any person between 18 and 22 years of age who resides in any facility licensed by the Department under the Child Care Act of 1969.

## Confidentiality

You will frequently receive requests for information regarding an individual you support. Before releasing the information, you must make sure certain conditions, as stated in the Confidentiality Act, are met.

Required Condition	Action to take if condition is not present
Presence of a release of information.	Obtain release of information.
Requestor listed to receive information.	Individual or legal guardian must amend to include name of requestor.
Specific nature of request listed (e.g., video, audio, etc.).	Individual or legal guardian must amend to include type of request.
Release is signed and dated by individual or their legal guardian.	Individual or legal guardian must sign and date a release of information.
Time frame for release of information still valid (Should be time limited)	Must obtain a new release.
Information generated by your agency.	Request must be obtained from original source of information if other than your agency.
Requestor has a legitimate need for information.	Deny request.

**The policies and procedures must adhere to the mandates of the following Rules: Rules 115, 119, 116, and 350.**

**Section 115.100 Purpose – CILA Rule**

- Licensure and Certification Act [210 ILCS 135] is to license agencies to certify living arrangements integrated in the community in which individuals with a mental disability are supervised and provided with an array of needed services.
- The objective of a community-integrated living arrangement is to promote optimal independence in daily living and economic self-sufficiency of individuals with a mental disability. Agencies planning to develop and support community-integrated living arrangements shall do so pursuant to Department licensure in accordance with this Part.

**Section 119.200 - General Requirements – DT Programs**

- Programs shall be located to promote integration of individuals into their communities. Some examples of integration include locations near public transportation, shopping, restaurants, and recreation.
- Programs shall provide a minimum of five hours of programming per day, excluding transportation time to and from the program, and excluding mealtime unless training during meals is a documented part of the plan.
- Individuals may attend less than 5 hours if required and documented by a physician or the interdisciplinary team.
- Transportation required for individuals shall be the responsibility of the provider.
- Programs shall not be located in buildings where individuals reside.

**Section 116.10 Purpose – Medication Administration**

The purpose of this Part is to ensure the safety of individuals in programs funded by the Department of Human Services (DHS) by regulating the storage, distribution, and administration of medications in specific settings; training of non-licensed staff in the administration of medications. This applies exclusively to all programs for individuals with a developmental disability in settings of 16 persons or fewer that are funded or licensed by the Department of Human Services and that distributes or administers medications and all intermediate care facilities for the developmentally disabled with 16 beds or fewer that are licensed by the Illinois Department of Public Health.

## Rule 350

This Part applies to the operator/licensee of facilities, or distinct parts thereof, that are to be licensed and classified to provide intermediate care for persons with developmental disabilities. The license issued to each operator/licensee designates the number of beds authorized for each level, the date the license was issued and the expiration date. The operator may not admit residents in excess of the licensed capacity of the facility. An intermediate care facility licensed and classified under the Act shall not use in its title or description "Hospital", "Sanitarium", "Sanatorium", "Rehabilitation Center", "Skilled Nursing Facility

**The Illinois Mental Health Code** is an Illinois law which establishes the rights of persons who are recipients of services from mental health facilities and developmental disability facilities. Its purpose is to make sure that people who are receiving mental health treatment or developmental disability habilitation services are treated in a humane manner, free from abuse and neglect, with the greatest possible degree of freedom of individual choice.

The basic principle established by the Mental Health Code is that, people with disabilities do not lose any of their legal rights simply because they are a recipient of mental health (MH) treatment or developmental disability (DD) habilitation services. Rights as citizens are guaranteed by the U.S. Constitution and the Illinois Constitution. The Mental Health Code provides that those rights can be limited only to the extent necessary to prevent serious harm to self or others.

## Rules and Regulations: Where to Find Them

<b>Rule Number</b>	<b>Title</b>	<b>Web Address</b>
50	OIG Investigations of Alleged Abuse or Neglect in State-Operated Facilities and Community Agencies	<a href="http://www.ilga.gov/commission/jcar">www.ilga.gov/commission/jcar</a> ✓ click on 'Administrative Code' ✓ click on Title 59 ✓ click on Part 50
115	Standards & Licensure Requirements for Community-Integrated Living Arrangements	<a href="http://www.ilga.gov/commission/jcar">www.ilga.gov/commission/jcar</a> ✓ click on 'Administrative Code' ✓ click on Title 59 ✓ click on Part 115
116	Administration of Medication in Community Settings	<a href="http://www.ilga.gov/commission/jcar">www.ilga.gov/commission/jcar</a> ✓ click on 'Administrative Code' ✓ click on Title 59 ✓ click on Part 116
119	Minimum Standards for Certification of Developmental Training Programs	<a href="http://www.ilga.gov/commission/jcar">www.ilga.gov/commission/jcar</a> ✓ click on 'Administrative Code' ✓ click on Title 59 ✓ click on Part 119
350	Intermediate Care for the Developmentally disabled Facilities Code (ICFDD)	<a href="http://www.ilga.gov/commission/jcar">www.ilga.gov/commission/jcar</a> ✓ click on 'Administrative Code' ✓ click on Title 77 ✓ click on Part 350
210 ILCS 30	Health Facilities Abused and Neglected Long Term Care Facility Residents Reporting Act	<a href="http://www.ilga.gov/legislation">www.ilga.gov/legislation</a> ✓ click on 'compiled statutes' ✓ REGULATION; Chapter 210; Health Facilities ✓ click on 210 ILCS 30
740 ILCS 110	Mental Health & Developmental Disabilities Confidentiality Act	<a href="http://www.ilga.gov/legislation">www.ilga.gov/legislation</a> ✓ click on 'compiled statutes' ✓ RIGHTS & REMEDIES; Chapter 740 Civil Liabilities ✓ click on 110

<p>405 ILCS5</p>	<p>Mental Health &amp; Developmental Disabilities Code</p>	<p><a href="http://www.ilga.gov/legislation">www.ilga.gov/legislation</a>                  ✓ click on 'compiled statutes'                  ✓ HEALTH &amp; SAFETY;                  ✓ Chapter 405 Mental Health;                  ✓ click on 405 ILCS 5/</p>
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**Additional reference sheet of informational links**

Guardianship	<a href="http://gac.state.il.us/guardfaq.html">http://gac.state.il.us/guardfaq.html</a>
Illinois State Board of Education	<a href="http://www.isbe.state.il.us">http://www.isbe.state.il.us</a>
Nurse Practice Act	<a href="http://nursing.illinois.gov/nursepracticeact.asp">http://nursing.illinois.gov/nursepracticeact.asp</a>
HIPAA	<a href="http://www.hfs.illinois.gov/hipaa/">http://www.hfs.illinois.gov/hipaa/</a>
Americans with Disabilities Act	<a href="http://www.ada.gov/">http://www.ada.gov/</a>
Medicaid Waivers	<a href="http://www.hfs.illinois.gov/hcbswaivers/">http://www.hfs.illinois.gov/hcbswaivers/</a>
Centers for Medicare/Medicaid (CMS)	<a href="http://www.cms.gov/">http://www.cms.gov/</a>
Council on Quality and Leadership	<a href="http://www.thecouncil.org/">http://www.thecouncil.org/</a>
JACHO	<a href="http://www.jointcommission.org/">http://www.jointcommission.org/</a>
CARF	<a href="http://www.carf.org/home/">http://www.carf.org/home/</a>
Respite Care	<a href="http://www.frcd.org/pb_respite_care_06.pdf">http://www.frcd.org/pb_respite_care_06.pdf</a>
Illinois Dept Human Services (ILDHS)	<a href="http://www.dhs.state.il.us/page.aspx?">http://www.dhs.state.il.us/page.aspx?</a>
Illinois Dept Public Health (ILDPH)	<a href="http://www.idph.state.il.us/">http://www.idph.state.il.us/</a>
Consumer Rights Illinois:	<a href="http://www.illinoisattorneygeneral.gov/consumers/consumer_publications.html">http://www.illinoisattorneygeneral.gov/consumers/consumer_publications.html</a>
Illinois Dept of Labor	<a href="http://www.state.il.us/agency/idol/">http://www.state.il.us/agency/idol/</a>
IL Health Care and Family Services (ILHCFS)	<a href="http://www.hfs.illinois.gov/">http://www.hfs.illinois.gov/</a>

## Quality Assurance (QA) Programs

Quality Assurance programs can enhance agencies' rule compliance through:

- periodic reviews of policies to maintain current and best practices
- emphasis on keeping abreast of changes within standards
- addressing each function of your organization through performance measures.

**These review tools may be found at:**

**<http://www.dhs.state.il.us/page.aspx?item=50951>**

## Reporting Regulations

A variety of situations may require you to make an official report. Discuss with your trainer and your class the responsibilities related to each of these situations. Add additional issues to the list and review all appropriate forms.

Situation	When to Report	Who Should Report	Where to Report	Time Frame for Reporting	Form Name/Number
Abuse					
Neglect					
Injury					
Critical Incidents					
Change in Status					
Admission					
Discharge					
Transfers					

## Scenario Nine

Review the information presented on Rachel from the previous modules. Use this as the basis for your response to the following issues.

List the laws, rules, regulations, and/or standards listed on pages 4 & 5 that apply to how your organization supports Rachel.

Rachel has just returned from her part time job at the mall. While you were waiting for her to return, you overheard Rachel's roommate telling someone that her job coach slapped her.

What is your responsibility as a QIDP?

List in chronological order each of the steps you would take. Complete all the necessary paperwork.

## Scenario Ten

As we have learned in previous modules, Rachel has a blood disorder that requires daily medication and avoidance of iron. Rachel is now refusing to take her blood medication. Staff has tried everything they can think of to encourage her to take her medication. What actions or steps would you take after being told of this situation?

## **Supplemental Material**

Hey, Don't Be Getting My "Rights" All Wrong... from CQL

[http://www.c-q-l.org/uploadedFiles/Quiz\\_Rights.pdf](http://www.c-q-l.org/uploadedFiles/Quiz_Rights.pdf)