INTRODUCTION TO THE WORLD OF THE QUALIFIED SUPPORT PROFESSIONAL (QSP)
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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 Support 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
What is a Qualified Support Professional?

What is a Qualified Support Professional? Let’s consider each part of this term, word by word:

Qualified—Someone who is knowledgeable, experienced, competent and ethical.

Support—Someone who seeks to assist WITH, not control and work ON others.

Professional—Someone who uses their knowledge, experience and skills in a competent manner and considers their work a career and a calling, not “just a job.”

Why do we need QSPs?

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), now referred to as Qualified Support Professional (QSP), in the State of Illinois. However, in the federal language, they are still known as QMRP.

In the role as a QSP 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
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 QSPs 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*
Agency QSP Job Description

(Insert and discuss your agency’s QSP 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 QSP 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 QSP. They will also be used throughout the training modules.

<table>
<thead>
<tr>
<th>Active treatment</th>
<th>People’s positive outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advocacy</td>
<td>People first language</td>
</tr>
<tr>
<td>Choice and preference</td>
<td>Quality enhancement</td>
</tr>
<tr>
<td>Communication and active listening</td>
<td>Respect and dignity</td>
</tr>
<tr>
<td>Confidentiality</td>
<td>Rights and responsibilities</td>
</tr>
<tr>
<td>Documentation</td>
<td>Self-advocacy and empowerment</td>
</tr>
<tr>
<td>Involvement and participation</td>
<td>Customer satisfaction</td>
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<tr>
<td>Normalization</td>
<td>Appreciation and diversity</td>
</tr>
<tr>
<td>Self-Directed Support</td>
<td>Person-Centered Planning</td>
</tr>
</tbody>
</table>
## Roles and Responsibilities of a QSP

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

<table>
<thead>
<tr>
<th>Roles &amp; Responsibilities</th>
<th>Yes</th>
<th>No</th>
<th>If no, who?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assure rules and regulations are being followed</td>
<td></td>
<td></td>
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<tr>
<td>Manages financial matters</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Trains staff</td>
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</tr>
<tr>
<td>Facilitates the ISP planning process</td>
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<tr>
<td>Coordinates the planning process</td>
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<td></td>
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<tr>
<td>Completes the review process</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Writes goals &amp; objectives</td>
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<td></td>
<td></td>
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<tr>
<td>Participates in and scheduling daily activities</td>
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<tr>
<td>Counsels individuals, guardians, and direct staff</td>
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<tr>
<td>Leads or chairs meetings</td>
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<tr>
<td>Acts as a community liaison</td>
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<td></td>
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<tr>
<td>Facilitates estate planning &amp; wills</td>
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<tr>
<td>Monitors the plan</td>
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<tr>
<td>Writes &amp; develops plans</td>
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<tr>
<td>Develops a quality enhancement process</td>
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<tr>
<td>Intervenes in crises</td>
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<tr>
<td>Participates in the development of behavior intervention plans</td>
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<tr>
<td>Assures medical needs are met</td>
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<tr>
<td>Supervises and leads team meetings</td>
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</tr>
<tr>
<td>Assures rights &amp; responsibilities are known and met</td>
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<td></td>
</tr>
<tr>
<td>Assures due process of law is followed if individuals’ rights need to be restricted</td>
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<td></td>
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<tr>
<td>Keeps records</td>
<td></td>
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</tr>
<tr>
<td>Assures quality of life, health and safety are met</td>
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<tr>
<td>Participates in and coordinates transition planning</td>
<td></td>
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<tr>
<td>Shares responsibility for direct service work</td>
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<tr>
<td>Effectively communicates with all staff and the people they serve</td>
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</tr>
<tr>
<td>Understands Active Treatment</td>
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<td></td>
</tr>
<tr>
<td>Models agency’s values and principles</td>
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<td></td>
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<tr>
<td>Assists individuals to become self-advocates</td>
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<tr>
<td>Understands appropriate rules (115, 116, etc.)</td>
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</tbody>
</table>
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, 4th 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:

<table>
<thead>
<tr>
<th>TERM</th>
<th>EQUIVALENT IQ RANGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>50 - 55 to about 70</td>
</tr>
<tr>
<td>Moderate</td>
<td>35 - 40 to 50 - 55</td>
</tr>
<tr>
<td>Severe</td>
<td>20 - 25 to 35 - 40</td>
</tr>
<tr>
<td>Profound</td>
<td>Below 20 - 25</td>
</tr>
</tbody>
</table>

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/](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 wheelchair. He cannot speak clearly, but he uses an electronic board, called a communication board, to talk to people. He has programmed several phrases into his communication board. Ted cannot lift himself from his wheelchair.

**Q:** Does Ted have a developmental disability? 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](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/](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.


**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.


**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.

Life Stressors and Mental Health

An individual with a developmental disability experiences life stressors. As a QSP, 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 QSP, 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 QSP?

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 QSP

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 QSP.
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.”

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