

## **PRESENTER – Materials Needed for Module 1**

- ❖ **Agency QIDP Job Description**
- ❖ **Agency Mission Statement**

## **PRESENTER – Agency QIDP Job Description**

Presenter should be prepared to distribute agency QIDP job description to trainees. Discuss the job description as it relates to the Agency' Mission and core values and principles.

## **PRESENTER - DEVELOPMENTAL DISABILITY DEFINITIONS**

It is important that you understand the difference between, and the criteria for, both developmental and intellectual disabilities. However, as a QIDP, it is unlikely that you will actually be assessing people for the purpose of making a diagnosis. Most children and adults who are receiving services from your agency will have already been diagnosed.

## **PRESENTER – Cerebral Palsy**

**Cerebral palsy** is an umbrella term used to classify conditions that impair motor coordination caused by brain damage. Cerebral palsy is caused by brain damage occurring before, during, or after birth. Any brain damage inflicted up until approximately the age of three can result in cerebral palsy. The part of the brain that is damaged is the determining factor on how the condition affects the patient.

A type of cerebral palsy, called spastic cerebral palsy, occurs when the brain damage occurs in the cerebral cortex, the outer layer of the brain. Spastic cerebral palsy is the most common form of cerebral palsy, affecting 70 to 80 percent of patients. Spastic cerebral palsy has varying forms depending on the areas of the body it affects, whether its one side of the body or just the legs.

**Spastic cerebral palsy** refers to the increased tone, or tension, in a muscle. Normal muscles work in pairs. When one group contracts the other group relaxes, allowing free movement in the desired direction. Due to complications in brain-to-nerve-to-muscle communication, the normal ebb and flow of muscle tension is disrupted. Muscles affected by spastic cerebral palsy become active together and block effective movement. This causes the muscles in spastic cerebral palsy patients to be constantly tense, or spastic. Spastic cerebral palsy patients may have mild cases that affect only a few movements, or severe cases that can affect the whole body. Although spastic cerebral palsy is not thought to be a progressive disorder, as brain damage does not get worse over time, spasticity in muscles can increase over time. This increased muscle tone and stiffness in spastic cerebral palsy can limit the range of movement in the joints. The effects of spastic cerebral palsy may increase with anxiety or exerted effort, leading to excessive fatigue.

Treatments for spastic cerebral palsy vary depending on the severity of the symptoms in the individual. Oral medications, such as Valium and baclofen, have been tried but the general consensus is that they do not reduce spasticity. Baclofen infusion, however, a relatively new procedure, has been slightly more effective in spastic cerebral palsy. Using a pump inserted in the abdomen, baclofen is distributed to muscles, reducing spasticity. However, when baclofen treatment is stopped, spasticity returns. Risks associated with baclofen include overdose, meningitis, and other complications, and since it is a relatively new treatment, long-term affects are currently not known.

Botox injections placed in the muscles of spastic cerebral palsy patients are also a relatively new treatment. When injected into affected muscles, botox weakens the group of muscles, reducing spasticity. Botox injections usually last 3 to 4 months and side effects appear to be minimal.

Orthopedic operations are also used for the treatment of spastic cerebral palsy. Orthopedic surgery usually involves lengthening tendons and muscle release to improve range of motion. Surgery will not reduce spasticity directly, but does reduce the consequences of it.

**Spastic diplegia cerebral palsy** tends to affect the legs of a patient more than the arms. Spastic diplegia cerebral palsy patients have more extensive involvement of the lower extremity than the upper extremity. This allows most people with spastic diplegia cerebral palsy to eventually walk. The gait of a person with spastic diplegia cerebral palsy is typically characterized by a crouched gait. Toe walking and flexed knees are common attributes and can be corrected with proper treatment and gait analysis.

In many cases the IQ of a person with spastic diplegia cerebral palsy may be normal. However, other side effects like strabismus are common. Strabismus, the turning in or out of one eye, commonly called cross-eye, affects three quarters of people with spastic diplegia cerebral palsy. This is due to weakness of the muscles that control eye movement. In addition, these individuals are often nearsighted. If not corrected, strabismus can lead to more severe vision problems over time.

**Ataxic cerebral palsy** is caused by **damage to the cerebellum**, which is in the base of the brain. The cerebellum is the control center for balance and coordination and coordinates the actions for different groups of muscles. Ataxic cerebral palsy therefore affects coordination of movement. Ataxic cerebral palsy usually affects all four limbs and the trunk. In addition, ataxic cerebral palsy is characterized by poor or low muscle tone, also known as hypotonic.

Ataxic cerebral palsy can affect an individual in several ways. A person with ataxic cerebral palsy will usually have a wide-based gait, or walk. Because of their poor sense of balance they tend to walk with their feet unusually far apart. In appearance, a person with ataxic cerebral palsy will look very unsteady and shaky. This is due to low muscle tone where the body is constantly trying to counter-balance itself.

The most significant characteristic of ataxic cerebral palsy is tremor, especially when attempting quick or precise movements, such as writing or buttoning a shirt. Also known as intention tremor, this symptom of ataxic cerebral palsy worsens when attempting a voluntary movement. For example, when reaching for an object, such as a book, the hand and arm will begin to shake. As the hand gets closer to the object the trembling gets more severe, increasing the completion time necessary for the task.

Athetoid cerebral palsy is a form of athetonia, which is marked by slow, writhing involuntary muscle movement. A mixed muscle tone where some are too high and others too low also characterize **Athetoid cerebral palsy**. Damage to the basal ganglia, located in the midbrain, is the cause of athetoid cerebral palsy. Approximately 25 percent of cerebral palsy patients are affected by athetoid cerebral palsy. Athetoid cerebral palsy can also be referred to as **dyskenetic cerebral palsy**.

The slow, writhing movements associated with athetoid cerebral palsy usually affect the hands, feet, arms, or legs. In some cases, athetoid cerebral palsy can affect the muscles of the face and tongue, causing grimacing and drooling. The involuntary and uncontrollable muscle tone fluctuations sometimes affect the whole body. The movement caused by athetoid cerebral palsy often increases during times of heightened emotional stress. Symptoms usually tend to disappear completely during sleep.

Several difficulties are common with athetoid cerebral palsy. The main cause for these problems is the muscles alternating between floppy and tense. Unwanted movements may be small or big, rapid, irregularly repetitive, random, or jerky. Athetoid cerebral palsy can also cause a person to appear restless and constantly moving, only being still when fully relaxed and sometimes only when asleep.

People with athetoid cerebral palsy often show a lot of movement in their face. **Athetoid cerebral palsy can also affect speech**. This condition is known as dysarthria. Speech is affected to a degree in every case of athetoid cerebral palsy because of difficulty controlling the tongue, breathing and vocal chords. Similarly, the person may experience difficulties with eating and drooling.

A person with athetoid cerebral palsy can also have difficulty holding onto an object, like a pencil or eating utensil, because of the mixed tone of muscles. Athetoid cerebral palsy can make a person work and concentrate harder than usual to get their hand to a certain spot, like scratching their nose. This is also concurrent with big, involuntary movements and is found through the entire body rather than being restricted to a certain area. The treatment of athetoid cerebral palsy varies on the concentration of symptoms. For those suffering from dysarthria, (Dysarthria is a disorder caused by paralysis, weakness, or inability to coordinate the muscles of the mouth). Speech therapy can help improve swallowing and communication. A speech therapist also can work with the child to learn to use special communication devices like computers with voice synthesizers.

The most common combination of mixed cerebral palsy involves both spasticity and athetoid movements, but other combinations are also possible. The least common mix is athetoid and ataxic cerebral palsy, however any mix of types may occur. It is possible to have a mix of all three types of cerebral palsy: spastic, athetoid and ataxic.

Mixed cerebral palsy with **spastic and athetoid cerebral palsy** is the most common type of mixed cerebral palsy, accounting for nearly 10 percent of mixed cerebral palsy cases. Spastic cerebral palsy causes one or more tight muscle groups, which limit movement in the patient. Children with spastic cerebral palsy have stiff and jerky movements. They often have trouble moving from one position to another and have a difficulty holding and letting go of objects.

Mixed cerebral palsy with athetoid characteristics are caused by damage to the cerebellum or basal ganglia. These areas of the brain are responsible for processing the signals that enable smooth, coordinated movements as well as maintaining body posture. Injury to these areas may cause a child to develop involuntary, purposeless movements, especially in the face, arms, and trunk.

## **PRESENTER - Epilepsy - Symptoms**

Seizures are the only visible symptom of epilepsy. There are different kinds of seizures, and symptoms of each type can affect people differently. Seizures typically last from a few seconds to a few minutes. You may remain alert during the seizure or lose consciousness. You may not remember what happened during the seizure or may not even realize you had a seizure.

Seizures that make you fall to the ground or make the muscles stiffen or jerk out of control are easy to recognize. But many seizures do not involve these reactions and may be harder to notice. Some seizures make you stare into space for a few seconds. Others may consist only of a few muscle twitches, a turn of the head, or a strange smell or visual disturbance that only you sense.

## Partial seizures

Partial seizures begin in a specific area or location of the brain. The most common types of partial seizures are:

- **Simple partial seizures.** Simple partial seizures do not affect consciousness or awareness.
- **Complex partial seizures.** Complex partial seizures do affect level of consciousness. You may become unresponsive or may lose consciousness completely.
- **Partial seizures with secondary generalization.** Partial seizures with secondary generalization begin as simple or complex partial seizures but then spread (generalize) to the rest of the brain and look like generalized tonic-clonic seizures. These two types can easily be confused, but they are treated differently. Most tonic-clonic seizures in adults begin as partial seizures and are caused by partial epilepsy. Generalized tonic-clonic seizures are more common in children.

## Generalized seizures

Seizures that begin over the entire surface of the brain are called generalized seizures. The main types of generalized seizures are:

- Generalized tonic-clonic seizures (grand mal seizures), during which the person falls to the ground, the entire body stiffens, and the person's muscles begin to jerk or spasm (convulse).
- Absence seizures (petit mal seizures), which make a person stare into space for a few seconds and then "wake up" without knowing that anything has happened.
- Myoclonic seizures, which make the body jerk like it is being shocked.
- Atonic seizures, in which a sudden loss of muscle tone makes the person fall down without warning.
- Tonic seizures, in which the muscles suddenly contract and stiffen, often causing the person to fall down.

People may refer to seizures as convulsions, fits, or spells. But seizure is the correct term. Convulsions, during which the muscles twitch or jerk, are just one characteristic of seizures. Some seizures cause convulsions, but many do not.

## **Signs and Symptoms of Autism Spectrum Disorder (ASD)**

ASDs begin before the age of 3 and last throughout a person's life, although symptoms may improve over time. Some children with an ASD show hints of future problems within the first few months of life. In others, symptoms might not show up until 24 months or later. Some children with an ASD seem to develop normally until around 18 to 24 months of age and then they stop gaining new skills, or they lose the skills they once had.

A person with an ASD might:

- Not respond to their name by 12 months
- Not point at objects to show interest (point at an airplane flying over) by 14 months
- Not play "pretend" games (pretend to "feed" a doll) by 18 months
- Avoid eye contact and want to be alone
- Have trouble understanding other people's feelings or talking about their own feelings
- Have delayed speech and language skills
- Repeat words or phrases over and over (echolalia)
- Give unrelated answers to questions
- Get upset by minor changes
- Have obsessive interests
- Flap their hands, rock their body, or spin in circles
- Have unusual reactions to the way things sound, smell, taste, look, or feel

From Centers for Disease Control Website at <http://www.cdc.gov/ncbddd/autism/facts.html>

## **PRESENTER – Mental Health**

Many people with developmental disabilities have spent much 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 this person-centered world.

## **Mental Illness**

### ***Presenter's Script***

*It is important to understand that mental illness and developmental disabilities **are not the same.***

- Mental illnesses are disorders of the brain in which behavior, mood, thought processes, relationships and ability to cope with life stressors are disturbed or outside the norm.
- Mental illnesses CANNOT be overcome through "will power."
- Mental illnesses ARE NOT a reflection of choice or character.
- MI in the DD population is often hard to recognize. It is important to note that
- Signs/symptoms of mental disorders cause clinically significant distress or impairment in social, occupational, or other important areas of functioning. (Just being a little weird" or eccentric doesn't necessarily mean you have a mental disorder).

### **MI Causes and Treatments**

- Mental illnesses are biologically-based brain disorders, NOT result of personal weakness
- Causes are largely unknown, but can include:
  - Imbalance of neurotransmitters
  - CAT scans reveal physical differences
  - Mental illnesses are treatable, not "curable", with goals of symptom reduction and return to prior level of functioning

## **An Overview of the Major Mental Illnesses**

### **Thought Disorders:**

#### **Schizophrenia is:**

- ❖ a disorder characterized by disorganized thought processes
- ❖ Means “split mind” NOT “split personalities” or “multiple personalities”
- ❖ Emerges in late teens, twenties

#### **Symptoms of Schizophrenia include:**

- Disorganized thoughts/speech
- Inappropriate or flat emotions/affect
- Avolition, lack of motivation
- Lack of insight into illness
- Hallucinations (seeing, hearing, smelling, feeling things that aren't there)
- Delusions (believing things others don't believe)
- Paranoia
- [Symptoms can come and go in cycles]

#### **Differentiating Schizophrenia. . .Use caution with:**

- Developmentally appropriate self-talk
- Imaginary friends/fantasy play
- May be confused with hallucinations or delusions, in particular with clients with
- Downs Syndrome or ASD

#### **Mood Disorders:**

Mood Disorders are disorders characterized by:

- Longer periods (than normally experienced) of marked shifts in emotional state
- Significant impairment in functioning
- Components of mood disorders are depression and/or mania:

## **Depression**

Symptoms include:

- Feeling excessively down, sad
- Tearfulness
- Trouble sleeping/sleeping too much
- Not eating/over-eating
- Loss of interest/pleasure in everyday activities
- Trouble concentrating
- Lack of goal-directed behavior
- Irritability

Anxiety Disorders are disorders characterized by:

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

## **Bipolar Disorder**

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

## **Mania**

Symptoms include:

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

## **Differentiating Bipolar Disorder.**

Some things can be difficult to attribute to Intellectual disability, bipolar condition, or just a bad day:

- Poor judgment
- Distractibility
- Excessive activity

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

## **Anxiety Disorders:**

### **Obsessive-Compulsive Disorder (OCD)**

Obsessive, intrusive thoughts (sometimes relieved only by engaging in ritual)

Repetitive, ritualistic behavior (only temporarily relieve anxiety)

Overwhelming need to have things a certain way

Symptoms may include:

- Hand washing
- Cleaning/fear of germs
- Hoarding
- Touching in patterns/or number of times

### **Other Anxiety Disorders**

#### **Phobias**

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

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

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

**Generalized Anxiety Disorder** has the following symptoms:

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

**PTSD (Post Traumatic Stress Disorder)**

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

PTSD can cause problems like:

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

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

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

- Maladaptive
- Disruptive to social, occupational, relationships
- Pervasive & inflexible
- Stable over time
- Leads to distress or impairment

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

**Borderline Personality Disorder**

Symptoms Include:

- Affects mood, self-image, relationships
- Mood changes quickly, easily enraged
- Create a crisis or act out in a crisis to put focus back on them
- Impulsive behavior
- Self-injury/harm
- Manipulation
- Overly dramatic, hostile, friendly
- Moves into serious relationships very quickly, moves between relationships very quickly

## **Avoidant**

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

### A person with avoidant personality disorder may:

- Be easily hurt by criticism or disapproval
- Hold back too much in intimate relationships
- Be reluctant to become involved with people
- Avoid activities or occupations that involve contact with others
- Be shy in social situations out of fear of doing something wrong
- Exaggerate potential difficulties
- Hold the view they are socially inept, inferior, or unappealing to other people

## **Dependent**

- ❖ Dependent personality disorder usually begins in childhood. However, the cause of this disorder is unknown. It is one of the most common personality disorders, and is equally common in men and women.
- ❖ People with this disorder do not trust their own ability to make decisions. They may be devastated by separation and loss. They may go to great lengths, even suffering abuse, to stay in a relationship.

### A person with dependent personality disorder may:

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

## **Schizoid**

### A person with schizoid personality disorder:

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

## **Anti-Social**

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

A person with antisocial personality disorder:

- Breaks the law repeatedly
- Lies, steals, and fights often
- Disregards the safety of self and others
- Does not show any guilt
- To receive a diagnosis of antisocial personality disorder, a person must have shown behaviors of conduct disorder during childhood.

People with antisocial personality disorder may have the following signs:

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

Submitted by Shannon Paul of Clearbrook with additions by Dr. Pat McGuire, Div. of DD

## **Dual Diagnosis (MI/DD)**

Someone who has both a developmental disability and a mental illness

**Note:** the same term ("dual diagnosis") can be used to describe someone with MI and a substance abuse disorder or MR and a substance abuse disorder.

## **PRESENTER- A Day in the Life of the Other Guy**

After trainees read the selection discuss in class. Be sure to emphasize the significant role that Direct Service Providers have in the lives of the people they help support.