

Guidelines for Understanding and Serving People with Intellectual Disabilities and Mental, Emotional, and Behavioral Disorders



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General Overview

Just a few decades ago, it was believed that people with intellectual disabilities could not have a mental illness. Therefore, all behavioral issues were associated with the intellectual disability, and it was thought that mental illness had no role in the presence of the behavior or the treatment. It was also believed that the behavioral problems were learned behaviors, and behavioral management practices alone would be able to address the issues. Anyone who has worked with persons with intellectual disabilities and mental disorders knows that this approach does not address the full issue.

Emerging research from the mid-1970's forward has shown that persons with intellectual disabilities have mental and emotional disorders as do the rest of the population. In fact, the prevalence level for this population is estimated to be higher than that in the general population. The estimates range from 15% (Cadman, Boyle, Szatmari, & Offord, 1987) to 41% (Einfeld & Tonge, 1996). A more recent summary of the research indicates a 30% prevalence rate (Fletcher, Loschen, Stavrakaki, & First, 2007). A study by Baker et al. (2003) found the same level of emotional issues in children younger than 4 years of age with mild intellectual disabilities.

These facts require action. Persons with disabilities, family members, and professionals must work with both systems of care to ensure that persons with intellectual disabilities receive appropriate diagnosis and treatment for their mental, emotional, and behavioral disorders. Fletcher et al. (2007) argue that children and adults with intellectual disabilities and psychiatric disorders may be one of the most underserved groups of people in the United States. These individuals frequently fall between the cracks, because the systems responsible for mental health and developmental disabilities are unable to provide treatment, services and supports.

Unfortunately, the age old argument of primary disability is still heard. Mental health organizations may argue that the person's mental, emotional, and behavioral issues are due to the intellectual disability and there is no evidence that there is a mental illness. The new understanding of brain development and the fact that cognitive abilities, emotional status, and physical health are intertwined makes this discussion out of date. Even if the mental health organizations accept their responsibility for a portion of the treatment, they often do not have the knowledge and skills to provide the services. Unfortunately these barriers result in denial of services or provision of inappropriate services to this population.

The high risk for mental, emotional, or behavioral disorders in persons with intellectual disabilities is not surprising when contributing factors that impact vulnerabilities for mental illness are reviewed. The interactions of biology and environmental factors can predispose an individual for mental disorders. Recent research on brain development provides new insight into the genetic influence on mental disorders. Although it appears that the influence of individual genes on the risk for developing a mental, emotional, or behavioral disorder is rare, the complex interaction of genetic influences result in a higher risk for individuals. The eventual expression of the genes emerges through the developmental process, impacting several aspects of brain development such as molecular configurations, variation in genetic interactions, and neurological development. The research shows that, although genetics have a significant role in creating a predisposition for a mental disorder, it is the interaction with environmental factors that impacts

how that predisposition will be expressed in the individual. Factors during the prenatal period interact with the biological vulnerabilities and can result in later disorders. For example, prenatal infections such as influenza can increase the risk of intellectual disabilities and mental disorders such as schizophrenia. Exposure to cigarette smoke, toxins (some of which are found in common household cleaning products), and alcohol can have a significant impact on development. The destructive nature of alcohol exposure has been clearly demonstrated through the extensive research into Fetal Alcohol Syndrome and Spectrum. Premature and low birth weight also places a child at greater risk for learning disabilities, intellectual disabilities, and serious mental disorders (O'Connell, Boat, & Warner, 2009). This interaction of environment and the biological characteristics of an individual plays out across the person's lifespan. There is evidence that the brain changes and adapts to some extent throughout life. This dynamic is referred to as plasticity.

The influence of the environment directly impacts the neurological development of the brain. The quality of attachment between the primary caregiver and an infant has a critical impact on the child's lifelong capacity for social and emotional learning as well as on resilience and risk for psychopathology. When children have developmental disabilities, many factors may impact the interaction between the infant and the primary caregiver, such as extended hospitalization, difficulty in meeting all the demands in taking care of an infant with special needs, etc. Support for families with infants and toddlers with special needs is critical. Interventions should include assistance with parenting and attachment, if needed, as well as the more traditional therapies.

Social relationships are usually difficult for people with mental, emotional, and behavioral disorders. Researchers believe that this may be the result of distinct neural systems in the temporal cortex which may impact the understanding the actions of others and in determining one's intentions and the intentions of others (O'Connell et al., 2009). Persons with intellectual disabilities also have a tendency to be lonely and socially isolated. They may not be included in activities of peers their own age and may be dependent upon family for social relationships. Also, the person with the intellectual disability may develop a poor self-identity and may not develop coping skills that can help them face and deal with adversities. If the individual has experienced negative social interactions, has a poor self-image, and has not learned to cope with situations without outside assistance, they will not have much resilience making them more vulnerable to adjustment issues. They may face stressors without protective coping skills and therefore are more vulnerable to mental disorders. These circumstances, coupled with the fact that many persons with intellectual disabilities have challenges in communicating their feelings and needs, can result in increased environmental stressors with little relief.

Regulatory control is another important capability that, if appropriately developed through childhood to adulthood, prepares the individual to manage their behavior in multiple situations. The capacity for self-regulatory control is considered one of the strongest predictors of long-term positive outcomes for people with mental, emotional, and behavioral disorders. Disturbances in the brain functions associated with regulatory control systems have been observed in Attention Deficit Hyperactivity Disorder (ADHD), Bi-Polar disorder, Tourette syndrome, Obsessive-Compulsive Disorder (OCD), and eating disorders.

The devastating impact of trauma on mental well-being is now well documented. Traumatic experiences in childhood and adolescence seem to predispose the individual to severe mental pathologies in adulthood (O’Connell et al., 2009). Traumatic exposure disrupts the development of the self-regulatory process, which results in chronic poor behavioral regulation, destructive behavior toward self and others, learning disabilities, dissociative problems, somatization, and distortions in self concept and understanding others (Fletcher et al., 2007). The younger the child is at the time of trauma, the more self-directed the aggression. Children with developmental disabilities are at an increased risk for abuse and neglect (Ammerman, Hersen, Van Hasselt, Lubetsky, & Sieck, 1994, and Dykens, 2000).

Researchers have identified a set of adverse childhood experiences that have shown through multiple longitudinal studies to negatively impact the emotional health of adults. The number of adverse situations experienced by an individual has a compounding effect on the degree of mental and physical disorders. These findings suggest that these experiences are major risk factors for both physical and mental illness and a leading cause of poor quality of life. The factors that were measured in the study are listed below.

Adverse Childhood Experiences	
Category	Experience
Abuse	Emotional abuse
	Physical abuse
	Sexual abuse
Neglect	Emotional neglect
	Physical neglect
Household Dysfunction	Mother treated violently
	Household substance abuse
	Household mental illness
	Parental separation or divorce
	Incarcerated household member

Given the vulnerabilities for mental, emotional, and behavioral disabilities, it is likely that that these adverse childhood experiences could have a very serious impact on mental well-being with persons with intellectual disabilities.

There are a disproportionate number of children in the welfare system with developmental delays and intellectual disabilities. Studies reported by Cohen and Youcha (2004) show that young children five years and below who have experienced physical abuse have lower social competencies, have problems accurately recognizing emotions in others, have a reduced level of empathy, have higher rates of aggression, and show insecure attachment to

caretakers. These factors place these children at very high risk for serious mental, emotional, and behavioral disorders (Shonkoff & Phillips, 2000). Sevin, Bowers-Stephens, & Crafton (2003) found that 63% of children and youth with developmental disabilities admitted to psychiatric inpatient services had been victims of physical or sexual abuse. In 2006, state data showed that 70% of children and youth admitted to the Florida Statewide Inpatient Psychiatric Program (SIPP) were from the child welfare system with likely histories of abuse and neglect. As the ACE study suggests, family functioning and previous parental mental health are associated with psychopathology in children with intellectual disabilities (Wallander, Dekker, & Koot, 2006).

Relationships between Intellectual Disabilities and Mental, Emotional, and Behavioral Disorders

Given that intellectual disabilities and mental, emotional, and behavioral disorders are both the result of brain disorders, it is not surprising that persons with intellectual disabilities have a higher rate of mental, emotional, and behavioral disorders than the general population. It is also important to note that behavioral problems occur with people from mild to profound levels of functioning and that these behavioral disturbances should not be considered solely a component of the intellectual disability. The presence of clinically significant behavioral disturbances requires that the presence of mental disorders be considered.

Research has documented the relationship between several developmental syndromes and mental, emotional, and behavioral disorders. Below is a summary of the findings.

- Down Syndrome – Children with Down’s syndrome have a tendency for externalizing behaviors, such as ADHD (25%) and task avoidance.
- Fragile X Syndrome – Up to 80% of children with this syndrome are also diagnosed with ADHD. Over stimulation may lead to aggression. Children may be shy and anxious in social situations; hand biting is seen in stressful situations. Females are prone to anxiety and social avoidance.
- Prader-Willi Syndrome – About 50% of the children with this syndrome also have behavioral outbursts, anxiety, and skin picking.
- Klinefelter Syndrome – During young childhood, the child is often withdrawn; but after adolescence, impulse control problems may become evident as well as over assertive behaviors.
- Williams Syndrome – Individuals with this diagnosis often have attention, anxiety, eating, and sleeping problems, and can be very perceptive of the feeling of others.
- Tuberous Sclerosis – Individuals with this disorder are often hyperactive, with autism present in up to 50%. They may also have serious sleep disturbances.
- Angelman Syndrome – People with this diagnosis often have poor attention spans and can break into episodes of unexplained laughter (Mahoney, 2002).

The interconnection between the brain dysfunction related to intellectual disabilities and mental, emotional, and behavioral disorders is complex. As stated earlier, it is inappropriate to overlook the mental health component of the syndrome just because it is also related to an intellectual functioning. Also, it must be recognized that there are many individuals with

intellectual disabilities with either unknown etiology or other syndromes that experience mental, emotional, and behavioral disorders.

Psychiatric Diagnoses

Persons with intellectual disabilities can have any number of diagnosable psychiatric disorders. To understand the impact of mental, emotional, and behavioral disorders (also known as psychiatric disorders) it is important to have a basic understanding of the range of psychiatric conditions that a person may experience. This next section provides a brief overview of the most common psychiatric diagnoses.

The standard manual used for diagnosis of mental disorders in the United States is the *Diagnostic and Statistical Manual of Mental Disorders*, known as the DSM. The most current revised DSM manual is known as the DSM-IV-TR. Most clinicians will use this manual in making a diagnosis. Yet, in the State Medicaid system, the diagnostic system used to bill for services is the *International Classification of Diseases* known as the ICD-9. Although there is a 10th edition of this manual, the State still uses the 9th edition for billing purposes. Most people refer to this as the ICD-9 (World Health Organization, 1977). The DSM-IV-TR and the ICD-9 do not look the same, so it is common to see both used in professional conferences, reports, and in clinical records.

Some of the information below is taken from the Florida Certification Board's draft *Behavioral Health Technician Study Guide* (Putnam & Huckshorn, 2006) and is presented below with the permission of the Florida Certification Board.

Anxiety Disorders

Anxiety disorders are the most common group of mental disorders. The term anxiety means being very nervous, having a lot of tension, feeling apprehensive, or feeling fear like the feeling of danger. The anxiety is usually considered to be greater than should be experienced given the individual's life situation. For example, it is normal to feel fear if you are walking down a lonely dark street and hear footsteps fast approaching from behind. It usually is not normal to feel great fear about entering a classroom full of people that you know. Descriptions of anxiety disorders will now be given.

Panic disorder.

Some people have panic disorders and have panic attacks. A panic attack is a period of intense fear or discomfort that develops very quickly and reaches its height within a few minutes. The person may experience hyperventilation, trembling, sweating, dizziness, numbness, or feel like they are choking. The person may feel as if they are dying or are going to do something uncontrollable. Panic attacks are very frightening, and the person may be very afraid that they will experience them again.

Phobia.

When individuals develop fear related to an activity, person, or situation, the anxiety disorder is called a phobia. The situation, activity, person, place, or thing is dreaded, feared, and something that the person wishes to avoid. Examples of some well known phobias are fear of open spaces (agoraphobia), fear of being around others (social phobia), or fear of being in a confined or enclosed space (claustrophobia). The person may avoid these encounters to the extent that they do not go places, travel, or do other routine activities. Phobias can be very intense and prevent the person from living a normal life. Panic attacks are sometimes associated with phobias, but phobias can exist without full panic attacks.

Generalized anxiety disorder.

When there is no specific focus of the anxiety the disorder, it is called a generalized anxiety disorder. This disorder involves excessive worry and fearfulness that something bad will happen in the individual's life. These feelings must occur most days over a six-month period for the person to be diagnosed with an anxiety disorder. The fears and worries are not directly related to something actually happening in the person's day-to-day events or are stronger than would be expected given their situation.

Obsessive Compulsive Disorder.

OCD is an anxiety disorder where the person is compelled to complete activities or have continual thoughts that cause them anxiety. Obsessions are thoughts that are repeated over and over again in the person's mind and may keep them from paying attention to other issues. Also, the person may experience impulses to do certain things and the impulses also cause them anxiety. Examples of obsessions are being afraid of hurting others, fear of germs, or being afraid of making a mistake. The feelings are much stronger than are normally experienced when people worry about such issues. Compulsions are rituals or acts that are repeated over and over again, and the person feels driven to do them. The person experiences anxiety if they cannot complete the acts. Examples of these rituals are repeated hand washing, checking something continually to be sure that it is correct, and repeating words to themselves. These thoughts and actions can seriously keep the person from doing the activities that they are required to do in their daily lives.

Post-traumatic stress disorder (PTSD).

Sometimes when individuals experience a terrible event, such as witnessing death, abuse, rape, combat, or violence, they develop a mental disorder known as PTSD. When persons suffer from PTSD, they re-experience the trauma through re-occurring images or thoughts, dreams, or actually believing that they are reliving the event. People with PTSD often have problems sleeping, can be irritable, watch everything closely all the time (hypervigilance), and have an exaggerated startle response. They often try to avoid activities, feelings, and thoughts associated with the traumatic event.

ADHD and Disruptive Behavioral Disorders

ADHD.

The National Institute on Mental Health (NIMH) defines ADHD as “one of the most common childhood disorders and can continue through adolescence and adulthood. Symptoms include difficulty staying focused and paying attention, difficulty controlling behavior, and hyperactivity (over-activity)” (National Institute on Mental Health, 2008, What is attention deficit hyperactivity disorder? ¶ 1).

Conduct disorder.

According to the NIMH, “this condition includes behaviors in which the child may lie, steal, fight, or bully others. He or she may destroy property, break into homes, or carry or use weapons. These children or teens are also at a higher risk of using illegal substances. Kids with conduct disorder are at risk of getting into trouble at school or with the police” (National Institute on Mental Health, 2008, What conditions can coexist with ADHD? ¶ 3).

Oppositional defiant disorder.

A condition in which the child is overly stubborn or rebellious, often argues with adults, and refuses to obey rules (National Institute on Mental Health, 2008, What conditions can coexist with ADHD? ¶ 2).

Psychoses

Psychosis is a thought disorder. It refers to the inability to determine what is real and what is not. People who have a psychosis cannot easily tell the difference between what is really happening in their environment and what is happening inside their thoughts. This can be, and often is, a very scary and disturbing experience for them. Their psychosis “tells” them that the problems are real and not in their mind. However, the part of the person that is still based in reality knows something is wrong. The most common psychotic symptom is withdrawal from others due to delusions or hallucinations.

When people begin to become ill with a thought disorder, it is so troubling that they want to be isolated and avoid other human contact. They can become overwhelmed by their thoughts. With hallucinations, the person’s sensory perceptions—such as seeing, hearing, or touching—are disturbed. The person believes that something is happening that is not, and may “see”, “hear”, or “feel” something that others do not. Hallucinations can also include smell, but this is quite rare and usually indicates that some overt physical problem is happening. Delusions happen when the person has a belief about something that is false, such as that the TV is talking to them or someone is trying to harm them. Hallucinations and delusions are very serious symptoms of illness and are difficult for the person who is experiencing them to handle. They are frightened and confused because they don’t know whether something is happening to them or not.

In some cases, symptoms of psychosis can occur when the person has a brain tumor, infections, or a reaction to drugs. These symptoms tend to last only while the person is under the influence of drugs or during the illness. People may make a full recovery from these symptoms when they are caused by the above situations. This is why a thorough physical exam should be required for all people who are seeking behavioral health services, since other medical conditions may be causing symptoms that look like mental illness but are not.

Schizophrenia.

Psychotic symptoms that are a result of mental disorders can be long lasting. Schizophrenia is a mental health disorder where the individual experiences psychotic symptoms and is considered to have psychosis at least part of the time. These symptoms can result in very strange behaviors. The person may have serious problems with language and talking, what they are thinking about, how they view things around them, and how they view themselves. Their symptoms may include some or all of the above conditions, hallucinations, delusions, or thought disorders (general problems understanding what is going on around them.). The symptoms often are grouped and clinicians refer to the type of schizophrenia by the grouping of these symptoms. These are described below:

- Paranoid Type – The major symptoms are auditory (hearing) hallucinations and delusions. This kind of disorder is present in people who think that others are out to do them harm. The person may think that the television is sending threatening messages to them, think that they are being chased by the police, or think they are going to be hurt or harmed by some group. However, the facts do not support their beliefs.
- Disorganized Type – The major symptoms with this type are problems with speech and odd, silly behavior. The person may giggle or make faces inappropriately and act inappropriately in social situations. The problems are much more serious than giggling when a person is nervous or sometimes “goofing off”. The behaviors are very odd and can be observed in many situations in the treatment setting.
- Catatonic Type – A person with this type of schizophrenia develops serious problems in their speech, their senses, and movements. They may stand in one position continually, or walk up and down a hall constantly, or refuse to talk. They sometimes will go into a stupor where they will not respond to anything and then quickly start acting very excited. This type of schizophrenia is very rare.
- Undifferentiated Type – With this type, there is no single symptom or group of symptoms.
- Residual Type – In this type, the major psychotic symptoms have been reduced, but the person is considered to have an illness that needs treatment to help them continue to do well.

People diagnosed with schizophrenia are described as having negative and positive symptoms. Positive symptoms are those conditions that are experienced in the mind but that should not be present. They are pretty obvious, and include hallucinations, delusions, problems in thinking, and agitation. These have been focused on above, and dealing with these symptoms has been the primary purpose of treatment, usually with medications. Medications and treatment

can reduce or eliminate many of these symptoms, but the person may still experience other symptoms of the disease that can greatly affect their lives. In addition, medications that treat positive symptoms also cause side effects that are difficult to deal with. The term “positive” is a little misleading because it does not describe conditions that are good for the person. Instead, positive means that the person is experiencing symptoms that are obvious and of concern.

The negative symptoms of thought disorders are just as difficult for the person as positive symptoms. In fact, it is the negative symptoms that often cause the person to not be able to do the activities of their daily living. The negative symptoms include flat or blunted affect (not showing any emotion), childlike thinking and inability to think abstractly, inability to experience pleasure (anhedonia), and poor motivation, spontaneity and showing initiative. Family, friends and people working with persons with schizophrenia sometimes do not understand that the lack of motivation or follow-through on tasks is not out of laziness or not caring, but is in fact a behavior that is a part of the illness.

Schizophreniform disorder.

Although schizophrenia is the best-known psychotic disorder, there are other types of psychotic disorders. Schizophreniform disorder has many of the symptoms of schizophrenia but is different because the beginning of the disorder is sudden and the person often recovers within a few weeks. Some people have the condition more than once across a period of time.

Schizoaffective disorder.

Schizoaffective disorder includes delusions, auditory hallucinations, or problems with thinking, but the person also has symptoms similar to those of a mood disorder. People with schizophrenia often appear to be without emotions. People with schizoaffective disorders have similar signs of a thought disorder but their display of emotions doesn't seem to be affected (see below). Individuals with the diagnosis of delusional disorders have well developed delusions, but lack the other symptoms usually present with other psychotic disorders. There are six types of delusional disorders: persecutory (thinks people are trying to hurt them), grandiose (think that they have greater abilities than they really do), jealous, somatic (think they have some type of physical illness), and unspecified (no one type of delusion).

Mood Disorders

Most people understand the meaning of the word mood. It addresses feeling like sadness, anger, guilt, or happiness. Some people cannot regulate their feelings and can have extreme feelings of happiness and excitement, or become very sad. These conditions are called mood disorders. Persons with mood disorders often have problems sleeping or sleeping too much, changes in how much and how frequently they eat, or problems with concentration, memory, and a general feeling that life is hard and not enjoyable.

Major depression.

Major depression is a serious type of mood disorder. A person with this disorder may be extremely depressed for at least two weeks at a time. During the period of depression, the person often feels worthless and has problems making decisions. They may have a loss of energy and may feel that the slightest activity or action requires overwhelming effort. The person also may have no interest in doing activities of daily living and may avoid friends and family. Persons with major depression can have serious episodes many times in their life. Untreated, the condition can last for many months.

Mania.

Another set of behaviors and feelings are called mania. When experiencing mania the person feels extreme pleasure in every aspect of their life. They become very active (hyperactive), sleep very little, develop very grand plans—thinking they are going to be famous or make large amounts of money—or spend large amounts of money on shopping. The person also may talk very fast and excitedly, but not make good sense as they talk (incoherent). The person may not continue to work and may experience serious problems socially. Without treatment, the condition can last up to about six months. People can have mania or another stage called hypo-mania where they act similar to the activities above, but do not lose touch with reality. Many famous people have been diagnosed with these kinds of illnesses. The symptoms can result in high levels of creativity.

Bi-polar.

When a person just experiences one type of mood problem the condition is described as unipolar. Mania usually does not happen alone. Sometimes, people who experience episodes of mania have times when they are not manic but depressed. This condition is known as bi-polar. The mania occurs for a period of time and then stops, with the person starting to feel very depressed. The person goes from feeling terrific to despair. Clinicians describe bi-polar disorders as bi-polar II and bi-polar I. In bi-polar II, the person has severe depression but does not experience full-blown mania and can function fairly well during the manic stage. Bi-polar I disorders include both severe depression and full manic episodes (Durand & Barlow, 2003).

Personality Disorders

Another set of disorders is also very important when discussing mental disorders. These conditions are different from those discussed above and are included in Axis II of the diagnoses. Personality disorders are patterns in the way that the person thinks about their life and environment and are part of the person's way of thinking and behaving. The beliefs are usually problematic and cause the individual difficulties when relating to others and functioning in their daily lives. They are not easily treated. Unlike anxiety, psychosis, and mood disorders, personality disorders are not illnesses that a person contracts. Instead, they are fundamental problems about who they are, how they feel, how they see themselves, how they cope with problems, and how they act with other people (Hales & Hales, 1995). These personality

problems are very hard to change and can cause the person considerable difficulties throughout their life. The DSM-IV lists specific personality disorders. These are briefly described below:

- Antisocial personality disorder – A person with this disorder has a history of antisocial behavior, such as academic failure, poor job performance, illegal activities, recklessness, and impulsive acts. Symptoms may include the inability to tolerate boredom, feeling that they are a victim, and a reduced ability to form intimate relationships.
- Borderline personality disorder – A person with this disorder has unstable moods and self-image, and unstable, intense, interpersonal relationships. These people often display extremes of over-valuing themselves and under-valuing themselves. They have mood shifts, and experience intense anxiety and impulsiveness.
- Narcissistic personality disorder – This disorder has an overriding pattern of the person feeling that they are great and can do great things, but they lack a sense of concern for others and are very sensitive to criticism from others.
- Passive-aggressive personality disorder – A person with this disorder lacks the ability to be appropriately assertive with others. They do not directly challenge a situation but are passively resistant. They usually do not realize that they are resentful and hostile toward others and that they are showing this through their passive resistance.
- Avoidant personality disorder – This disorder includes social discomfort and an increased sensitivity to both criticism and rejection. Such persons may appear timid, and have some depression, anxiety, and anger about their problems with social situations.
- Obsessive-compulsive personality disorder – A person with this disorder wants to have everything perfect and can be very inflexible. Symptoms may include distress about having to make decisions and expressing tender feelings. They may experience feelings of depression and anger about being controlled by others. The person may also be very sensitive to criticism. They are also extremely conscientious, very honest, and judgmental.
- Histrionic personality disorder – A person with this disorder is very emotional and seeks attention excessively. Behavior may include constant seeking of approval or attention. The person may be described as very self-centered or sexually seductive at inappropriate times.
- Dependent personality disorder – A person with this disorder may think that they need a lot of help and assistance from others, and may be very submissive. They often feel anxious and depressed, and may experience intense discomfort when alone for more than a brief period of time.
- Paranoid personality disorder – Individuals with this disorder interpret the actions of others as intentionally threatening, demeaning, and untrustworthy.
- Schizoid personality disorder – A person with this disorder shows indifference to social relationships and has a limited amount of emotions and expressions.
- Schizotypal personality disorder – A person with this disorder has problems with interpersonal relationships and may have bizarre ideas, appearance, and behavior. The person also may have anxiety and depression (Prinz, 2004).

Please note that Pervasive Developmental Disorders are not included in this description because in Florida they are considered a developmental disability. However, co-occurring conditions may exist.

Psychiatric Disorders with Persons with Intellectual Disabilities

As stated above, persons with intellectual disabilities at any functioning level may experience any one or more of the psychiatric diagnoses discussed above. Below is a brief discussion of how these disorders may present with persons with intellectual disabilities. However, it must be acknowledged that each person is different, and the disorder may have many different symptoms that a mental health professional should review. The information for this section is taken primarily for Fletcher et al. (2007) and Gabriel (2004) unless otherwise indicated.

Anxiety Disorders

Anxiety disorders are one of the most common disorders with persons with intellectual disabilities. All types of anxiety disorders are prevalent in persons with intellectual disabilities and are as common or more common than with the general population. Also, when the individual does not have the ability to communicate the anxiety, it may manifest as a behavioral disorder. Often, OCD will present as aggression in persons with intellectual disabilities and limited communication abilities. PTSD is unfortunately common in persons with intellectual disabilities since this population has been subjected to higher than average abuse and neglect. Additionally, researchers state that people with intellectual disabilities are more vulnerable than the general population to the disruptive effects of trauma. It is also thought that exposure to trauma or re-traumatizing situations with persons with lower developmental levels may result in self-injurious behaviors. Other symptoms that are often attributed to the intellectual disability—such as “acting out” when distressed—may be directly related to past exposure to traumatic events. In people with lower functioning levels, the externalizing behavioral issues may also be due to trauma. It is very important for caregivers and practitioners to know the history of the people that they serve. Many individuals with intellectual disabilities cannot or will not describe the traumatic events that have occurred in their lives.

Psychoses

Psychotic disorders such as schizophrenia are very difficult to diagnosis unless the person has sufficient verbal skills to communicate their psychological state. Persons with mild functioning limitations may be diagnosed with schizophrenia if their communication skills are sufficient. This is not to say that other persons with intellectual disabilities do not experience psychotic symptoms, but without verbal communication the diagnostic criteria cannot be applied. Chapin et al. (2006) found that persons with schizophrenia and intellectual disabilities had more severe psychotic symptoms and reduced functioning and fewer medications to address their disorder. The authors state that this group needs to be a focus for improved services. This group is also more likely to be admitted to psychiatric hospitals due to the severity of their symptoms and the presence of aggression (Cowley, Newton, Sturmey, Bouras, & Holt, 2005).

Mood Disorders

It is thought that persons with intellectual disabilities may experience and react to mood disorders in a manner similar to those of their developmental age. Children and adults with

intellectual disabilities have been noted to present with increased rates of conduct problems, social withdrawal, and irritable mood. The individual may engage in externalizing behaviors when distressed or irritable. Persons with intellectual disabilities have a limited range of behaviors and therefore react to emotional issues through their only sources of communication, frequently with changes in behavior. Hurley (2008) found that behavioral issues were somewhat different depending upon the diagnosis. He found that challenging behaviors were the most serious when associated with bi-polar disorder. For depressed patients, there was an increase in aggression and impulsivity. Also, central nervous system dysfunction associated with the intellectual disability may contribute to the likelihood of behavioral problems. Persons with intellectual disabilities may not have had the opportunity to learn alternative coping strategies which can result in impulsivity, or irritability, or “affective aggression”. Persons with good communication skills can often describe their feelings of sadness, hopelessness, etc.; but persons with lower level skills may not be able to identify the reason for their mood. Hurley (2008) found that many of the patients were not able to meet the diagnostic criteria for a mood disorder even though one was suspected. His findings suggest that deficiencies in the ability to self-report and inadequate observational data from caregivers contributed to the problem.

Personality Disorders

As with schizophrenia, personality disorders are very difficult to diagnosis in persons with intellectual disabilities. The same issues are present; that is, the person must be sufficiently verbal to describe their thought patterns and sense of self for a diagnosis to be made. Also, the personal disorder section of the DSM-IV-TR is based upon the expectations of patterns of behavior in the general population. These criteria assume a certain set of life experiences to which persons with intellectual disabilities may not have been exposed. However, one should not assume that this population does not have personality disorders. It is the application of the diagnostic category that is problematic.

Diagnosis of Mental, Emotional, and Behavioral Disorders with People with Intellectual Disabilities

Individuals with mild intellectual disabilities often present as do the general population and usually have adequate verbal skills to report symptoms for appropriate diagnostic work. However, many people with intellectual disabilities have a limited behavioral repertoire and lack communication skills, resulting in behavioral reactions to their symptoms. This makes diagnostic work very difficult but still important. Persons with mental illness need relief from the symptoms which usually comes through a combination of therapeutic treatment, supports, and a medication regime. Good diagnostic work is essential to determine these components of the treatment plan. The difficulty in this work has been documented for over two decades.

In 2007, the National Association for Dual Diagnosed published the Diagnostic Manual-Intellectual Disability (DM-ID) to serve as a companion guide to the DSM-IV-TR. The DM-ID offers recommended adaptations of the diagnostic criteria contained in the DSM-IV-TR for persons with intellectual disabilities. The publication addresses the diagnostic categories in the DSM-IV-TR in detail and provides information about how to view the behaviors of persons with intellectual disabilities related to the determination of mental, emotional, and behavioral

disorders. The work was designed to provide comprehensive, research-based information, to improve treatment through accurate diagnosis and treatment planning. The DM-ID is intended to be used by qualified, licensed, mental health professionals and provides an excellent resource for the field.

Below is a discussion of the diagnostic issues associated with determining mental, emotional, and behavioral disorders with persons with intellectual disabilities. This process can be complicated and time consuming, but can result in appropriately identifying the treatment regime for persons with dual diagnosis.

Assessments

A portion of the information presented below is taken from the FDDC paper *Best Practices for the Care of Dually Diagnosed Children and Adolescents with Developmental Disabilities and Their Families Served in Florida's SIPP Programs* (Putnam, Claps, & Thyer, 2006). Assessments for persons with dual diagnoses can be extensive and usually consist, at a minimum, of a mental status exam, a psychosocial history, psychological evaluations, and functional assessments. The literature consistently recommends the use of a biopsychosocial assessment.

The areas of assessment in a biopsychosocial model include the following:

- Bio or medical – Includes the necessary medical exams and tests to determine the degree of physical medical conditions, presence of psychiatric problems, medication reactions, and neurological conditions that may be impacting behavior. Genetic testing or determination of the type of syndrome that contributes to the developmental disability should be completed under this component to determine if the syndrome has inherent characteristics that could contribute to the behavior. Screening tools, such as the instrument for Fragile X syndrome, have been developed to help the clinician determine various syndromes (Butler, Mangrum, Gupta, & Singh, 1991).
- Psycho (Psychological) – Includes the current psychological features, skills, and skill deficits. This section includes psychological testing to determine cognitive level of functioning, gathering a psychological history, and measuring adaptive functioning. Also included under this component is the determination of the presence of a mental disorder. There are numerous means of determining mental disorders in persons with dual diagnoses. Behavioral analysis techniques and numerous instruments have been developed to assist the clinician in identifying specific disorders. These techniques and instruments are discussed in greater detail below.
- Social – Includes the environmental, interpersonal, and programmatic conditions that may be impacting the individual. It is in this section that most of the behavioral analysis is completed to determine what is contributing to and maintaining particular behaviors.

Biomedical Factors

Medical conditions can have a direct or indirect impact on behavior. It has been estimated that a significant number of persons who have behavioral challenges actually have

undiagnosed medical conditions (Ryan & Sunada, 1997). Common medical conditions that can affect behavior include thyroid disorders, sleep apnea, blocked shunt, migraine headaches, seizure disorders, mitral valve prolapse, and many others (Summers, Stavrakaki, Griffiths, & Cheetham, 2002). A thorough biopsychosocial assessment must include a careful medical and medication history and physical examinations (Loschen & Osman, 1992). Other studies might include laboratory work-ups, neurological testing, and other medical diagnostic techniques. Since many of the children have experienced abuse and neglect, a neurological test may be warranted. Also, there are certain behavioral issues and conditions associated with specific syndromes that should be considered (see above).

The mental status exam is the core of most psychiatric diagnoses. The exam includes the systematic observation of the patient's behavior and is usually completed through one or a series of interviews. The clinician forms their opinions based on the information reported by the individual and their behavior during the interviews. The exam covers five basic categories that are briefly described below:

- Appearance and behavior – The clinician watches the individual's overt behaviors, carefully observing their appearance, posture, and facial expressions, looking for any tics, twitches, or very slow motor behavior.
- Thought processes – During the interview, the clinician assesses the thought process by listening carefully to what the person is saying and how they are expressing themselves. The key questions focus on possible descriptions of hallucinations, delusions, or loose association. The clinician usually asks specific questions to try and determine the presence of any of these abnormalities.
- Mood and affect – Mood is the predominant feeling state presented by the individual. Does the person seem depressed or abnormally elated? Is the affect appropriate for the subject matter? Do emotions seem blunted or flat?
- Intellectual functioning – The clinician attempts to ascertain whether the person's intellectual behavior appears normal, with an adequate vocabulary and ability for abstract thought. This part of the interview does not substitute in any way for intelligence testing.
- Sensorium – This is defined as the general awareness of the person within their surroundings. For example, does the individual know their name, what day it is, where they live, and so on (Durand & Barlow, 2003).

The clinician relies heavily on the individual to self-report, and observes the individual's behavior within a relatively short period of time in the interview. This process is dependent on the individual's ability to relate their internal thinking and emotional experiences to the clinician. The presentation of psychopathological disorders in children and youth with mild developmental disabilities is more likely to resemble the presentation found in the general population, with the children often able to describe, with assistance, their experiences. As the level of disability increases—especially in the area of communication skills—the individual is less able to describe their thinking and emotional issues. This makes it much more difficult for the clinician to make a diagnosis, and requires that other instruments and diagnostic techniques be used to supplement the exam (see below).

Numerous studies have shown that accurate psychiatric diagnosis in children and youth with developmental disabilities can be very time consuming and complex. Researchers from Southeast Louisiana State Hospital found considerable disagreement in diagnoses from the different providers when multiple providers treated children with intellectual disabilities. They found that when the child saw a new physician, the diagnosis was changed and these changes resulted in medication changes as well. More than 25% of the children had been tried on all four drug classes, suggesting serious differences in diagnostic expertise, procedures, or the use of medication protocols (Sevin et al., 2003). This study illustrates the ongoing challenges associated with obtaining an accurate psychiatric diagnosis in this population.

Recommendations for special attention during the interview include the following:

- Use very simple vocabulary;
- Create short sentences;
- Do not ask “yes” or “no” questions, because persons with intellectual disabilities tend to want to please and may answer “yes” when it does not reflect the true situation;
- Ask one simple question at a time;
- Wait for the answer before proceeding;
- Check back with the individual for confirmation that he/she has correctly understood the question; and
- Remember that persons with intellectual disabilities are concrete and may answer based on their experiences, not understanding the implications of the question. (Hurley, Levitas, Lecavalier, & Pary, 2007).

Historically, there have been serious problems with psychiatric diagnoses of persons with intellectual disabilities. These issues have resulted in either the clinician not being able to give a diagnosis or in an incorrect diagnosis. King and Carey (2002) provide a discussion of some of these challenges faced by clinicians in determining a diagnosis, quoted below:

1. Behavioral Overshadowing – The attribution of an increase in the intensity or frequency of maladaptive behavior to learned behavior, rather than overt behavioral expressions of an underlying disorder.
2. Diagnostic Overshadowing (Reiss, Levitan, & Szyszko, 1982) – Identifying maladaptive behavior as being a direct outcome of the individual having a developmental disability.
3. Baseline exaggeration – Failing to recognize that an increase in the frequency or intensity of a maladaptive behavior may be signaling the onset of underlying mental or physical illness, or an adverse effect of a medication.
4. Failure to account for the impact of impoverished life experiences and communication deficits on the expression of signs and symptoms of mental illness.
5. Failure to recognize that complex, concurrent disorders may occur at the same time.
6. Misidentification of non-specific, stress-induced loss of adaptive functioning as an indication of a psychotic disorder (Sovner & Hurley, 1983). (pp. 222-223)

When completing mental status exams clinicians use unstructured, structured, or semi-structured interviews. In an unstructured interview, the clinician follows no systematic process and instead asks questions based upon their past experience and clinical training. In structured interviews, the clinician follows a pre-set series of questions designed to measure the five components of the mental status exam. Structured interviews can feel stilted to the patient and may be too rigid to collect all the necessary information. Most clinicians use a semi-structured interview that consists of questions that have been carefully phrased and tested to elicit useful information in a consistent manner. However, the clinician feels free to depart from these questions to continue inquiry about something that may have been said. This allows the clinician to use their judgment on further exploration of certain issues (Durand & Barlow, 2003). Interviews conducted by clinicians trained to work with persons with developmental disabilities will likely be semi-structured and address the special considerations listed above. The DM-ID published in 2007 is an invaluable tool for clinicians working with persons with intellectual disabilities.

Also, clinicians may use tools that have been pre-tested to determine certain types of psychopathology. The accuracy of the mental status exam can be improved through the use of structured or semi-structured tools developed and validated for this population. Examples of specialized tools are listed below:

- Aberrant Behavioral Checklist (Aman & Singh, 1994) – The purpose of this instrument is to evaluate the impact of pharmacological interventions on maladaptive behaviors, and to assess behavior problems in children, adolescents, and adults with mild to profound developmental disabilities.
- Assessment for Dual Diagnoses (Matson, 1997) – This instrument is designed to screen for psychopathology for individuals with mild or moderate developmental disabilities.
- Developmental Behavioral Checklist-Parent/Caregiver or Teacher (Einfeld & Tonge, 1994) – This instrument assesses emotional and behavioral disorders in children and adolescents with developmental disabilities.
- Emotional Problems Scales-Self Report and Behavior Rating Scales (Prout & Strohmmer, 1991) – These scales are designed to help identify psychopathology and emotional problems in individuals 14 years of age and older with mild developmental disability.
- Reis Scales for Children’s Dual Diagnoses (Reiss & Valenti-Hein, 1990) – This instrument is one of the most frequently cited measurements for dual diagnosis in children aged 4 through 21 years with mild to severe developmental disability.
- Devereux Scales of Mental Disorders (Naglieri, Pfeiffer, & LeBuffe, 1994). (Adapted from Summers et al., 2002)
- Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD) – This is a semi-structured interview guide to use with third party informants such as family members, caregivers, and others who know the individual well (Moss et al., 1993).

For persons who are having difficulty self-reporting, clinicians often use a multi-informant method. This allows the clinician to gain a better perspective on the condition through interviews with several persons, including the person presenting for treatment. Although this format is often very necessary, it should be noted that sometimes others in the person’s

environment may not see issues in the same way as the person with the intellectual limitation. It is very important for the clinician to meet with and talk with the person with the intellectual disability.

The need to illicit from the person with the intellectual limitations their own view of their emotional world is illustrated in a study completed by Harper and Wadsworth in 1993, and reported by Kroese in 1998. The researchers studied a group of persons with developmental disabilities who had experienced a significant loss and asked them to report their reaction. The persons with developmental disabilities reported mainly emotions, such as anxiety, depression, and worry. Their caretakers and professionals, however, reported behaviors such as crying, hostility, and sleep problems. In the past, there has been a tendency to focus more on the observable behaviors of persons with developmental disabilities and less on their psychological state.

The components of a full psychiatric/behavioral assessment for persons with intellectual disabilities are discussed below.

Psychosocial History

The person's psychosocial history is important in understanding the person's life and relevant issues that have shaped their psychological profile. Components of a psychosocial history to address with the persons interviewed should include areas such as:

- A longitudinal history to correlate with concurrent events, such as stressors, medical problems, and medication changes;
 - Indications of emotional/physical or sexual abuse;
 - Significant medical procedures or traumas;
 - Family issues, such as disruption, removal from the home, and interaction with siblings;
 - Educational performance; and
 - Multiple changes in living arrangements, loss of caregivers, abandonment, etc.
- (Summers et al., 2002)

Intellectual Testing

A current psychological test to determine intellectual functioning also should be available. These tests are used to determine the child's ability to reason and problem-solve, as well as their spatial and perceptual abilities. Associated with the psychological testing are measures of adaptive functioning that assess the child's ability to cope with environmental demands. Both intellectual testing and the measurement of adaptive functioning are common in developmental disability service delivery systems, and are often used to determine eligibility. Results of the psychological testing can also assist in determining the presence of a mental disorder, with the relationship of certain scores on subtests a possible indicator. For example, lower scores on the digit span subtests may indicate possible anxiety, while a person with schizophrenia may have a very unusual pattern of responses on the verbal portion of the test (Hurley, 1989).

Functional Assessments

Behavioral assessments are an essential component to a biopsychosocial assessment, and are used to determine the function of a particular behavior, what is causing the behavior, and what events are maintaining the behavior. Behavior analysis has been a favored technique to address behavioral issues with persons with developmental disabilities since applied behavioral analysis surfaced in the 1970s, and has been recommended for use with persons with developmental disabilities ever since. The use of these strategies received some criticism recently, when the process was used too narrowly. Gardner (2000) has warned that the over use of medication and behavioral procedures to suppress symptoms, in the absence of a comprehensive biopsychosocial assessment, may temporarily decrease behaviors but not address the neurological/mental health conditions that caused the behavior. When those conditions are mental disorders, focusing only on behavioral management without attention to alleviating the underlying cause could result in even greater psychological distress to the individual. Gardner and others have recommended the biopsychosocial model described above as the best practice in this area, recommending that comprehensive functional assessments and analysis supplement the traditional psychiatric exam to determine an appropriate psychiatric diagnosis.

As part of a functional assessment, behavior analysts look at environmental or physiological states as events that directly impact the occurrence or maintenance of behaviors. Their work is based on the premise that many behaviors are learned or maintained due to the events that immediately follow the behavior. These events (stimuli, etc.) are called positive or negative reinforcers. Positive reinforcement is defined as an event that, when presented after the behavior is exhibited, increases the frequency of the behavior. If the frequency of a behavior increases when an event is removed, the event is called a negative reinforcer. As examples, Griffiths and Gardner (2002) provided a list of reinforcing influences that may impact the child's behavior:

- Physical environment – Removal from a place, and reduction or avoidance of unpleasant conditions or an over- or under-stimulating environment.
- Social situations – Avoidance of undesired personal contact, and access to desired social interactions.
- Program situations – Avoidance of boring or too difficult tasks, or access to a change in routine.
- Psychological situations – Access to pleasant sensory stimulation, or avoidance of unpleasant stimulation, or actions taken to reduce discomfort or anxiety.
- Medical conditions – Actions to reduce physical pain or distress.
- Psychiatric/neuropsychiatric interventions – Actions to decrease an aversive event related to disorientation, hallucinations, or dysphoria, or to seek comforting situations during periods of psychological distress.

Reinforcing situations are quite individual in nature and are often not obvious to the observer. This becomes more complicated when the individual is unable to express the purpose of their behavior.

Research in applied behavioral analysis has shown that a problem behavior may occur when an individual is trying to escape demands, unpleasant situations, or certain people. In some of these cases, the person may be attempting to escape internal stimuli such as physical pain, illness, or discomfort due to the side effects of medication (Carr & Smith, 1995; Kennedy & Thompson, 2000; Baker, Blumberg & Freeman 2002). Gardner (2002) sees challenging behaviors as a symptom and not as the issue per se. Mahoney (2002) states that children with developmental disabilities may express their emotions through certain behaviors. Physiological influences can be internal events within the person's biological system that may determine the individual's response to their environment, or changes in their physiological state can serve as an antecedent to the subsequent behavior. Mental illness and pharmacological interventions can impact the physiological status of the individual and be directly related to the functional aspects of their behavior. Several researchers have stated that many challenging behaviors may be instigated by aberrant neurological-chemical influences (Mace & Mauk, 1999; Griffiths & Gardner, 2002).

Therefore, when working with individuals with intellectual disabilities and challenging behaviors, it is essential that a functional assessment be completed. The challenging behavior should not be seen as the issue. Instead, the therapist must determine what function the behavior has for the individual and what changes can be made to provide a more appropriate alternative to the challenging behavior. As discussed earlier, persons with a limited behavioral repertoire may show unwanted behaviors such as aggression when dealing with many different types of distress. Behaviors resulting from mental illness tend to be present throughout the day and in many different environments while behavioral issues associated with the environment may only occur under certain circumstances (Hurley, Levitas, Lecavalier, & Pary 2007). For persons with limited verbal communication skills, behavior may be their only way to communicate with others. The use of well designed behavioral evaluations can be very helpful in determining the specific nature of the behavior.

Functional assessments are designed to gather information about the antecedents (events before the behavior occurs) and the consequences that are functionally related to the behavior (Summers et al., 2002). There are three types of functional assessments: indirect, direct observation, and functional analysis. The clinician must determine which type or combination of assessment methods is most appropriate for the situation. The three types of assessments are briefly described below.

Indirect assessment methods.

This method involves gathering information through interviews, reviewing records, using checklists and questionnaires, or some combination of these activities (Baker et al., 2003). Interviews with the individual and others help identify and narrow the range of variables that may be influencing the behavior. It is very important to recognize the role of the parent or caretaker when collecting this information. Also, as stated above, other team members have also interviewed key persons as part of the clinical interview or mental status exam. Coordination of these activities to avoid duplication makes the assessment process more efficient. Instruments have been developed to help the therapist collect the necessary information, but these should be

used in conjunction with direct observation or functional analysis (Zarcone, Rodgers, Iwata, Rourke, & Dorsey, 1991).

The Motivational Assessment Scale (MAS) was published by Durand and Crimmins in 1992 and includes a 16-item report questionnaire through which the motivation of a specific behavior is determined. Another commonly used format is the Functional Assessment Interview (FAI). This instrument, developed by O'Neil, Horner, Albin, Story and Newton in 1997, is divided into 11 sections and provides a quick and organized method for collecting behavioral information (Summers et al., 2002).

Direct observation.

Direct observation provides a more accurate method of gathering information, but is more time consuming. Trained behavioral analysts should have the skills to complete these functions. Data collection usually includes the Antecedent-Behavior-Consequence (ABC) observation, the use of observation cards, scatter plots, and formal functional assessment observation, or the techniques used in direct observation. As with indirect assessment methods, many tools and techniques have been developed to aid the behavioral analyst. These include the Hurley (1997) training guide for using the ABC sheet to collect and analyze data; Gardner and Sovner (1994) procedures for using data recording cards; Touchette, McDonald, and Langer's (1985) scatter plot technique; and the Functional Assessment Observation Form developed by O'Neill et al. in 1997 (Summers et al., 2002).

Functional analysis.

The most complex method for a functional assessment is a thorough functional analysis. In this approach, the behavioral analyst conducts repeated sessions in which they manipulate the antecedents and consequences to determine the instigating and maintaining events. This procedure can be very time consuming. Summers et al. (2002) stated that, to address this issue, researchers have developed a single 90 minute evaluation session that has been found to produce comparable results to the more detailed process (Arndorfer, Miltenberger, Woster, Rortvedt & Gaffaney, 1994). Time is of the essence in many situations in which the unwanted behavior is putting the person or others in danger or at risk of losing their services. Therefore, clinicians should consider the time required for each activity and plan according to the specific situation.

In summary, a comprehensive biopsychosocial assessment addresses all aspects of the life of the child and youth that could be associated with their behavior. The first step in such an assessment is to involve the individual and the family in discussing the issues and identifying both the child's strengths and challenges they are facing. The assessment includes a complete physical exam and review of medical conditions; a mental status exam; an intellectual test; a psychosocial history; and a functional assessment of the child's behavior, including the antecedents and reinforcers evident in the case. These biopsychosocial assessments are especially important with children and youth whose communications skills may be limited and who have a reduced ability for abstract thinking.

Compiling and Using the Information

Complicated assessment procedures, as described above, require the commitment of an interdisciplinary team that is willing to examine the behavioral and emotional issues from multiple perspectives and work together in formulating a diagnosis. The team should discuss the diagnostic work that will be performed before the assessments are undertaken and should share with one another what they have learned throughout the process. When all the information is collected, the team should discuss the findings and establish a diagnosis and recommended treatment, recognizing that these may need to be modified during the course of treatment. The family, individual with intellectual disabilities, and persons who know them well must be part of the team.

Mental, Emotional, and Behavioral Approaches to Treatment

Psychotherapy.

Psychotherapy is one of the most frequently used methods of treatment for mental health disorders, yet there is evidence that counseling and psychotherapy are less likely to be included in treatment and support plans for persons with mental retardation. Clinicians tend to recommend more behaviorally oriented interventions and are less likely to offer a broad range of more typical mental health services (Prout & Nowak-Drabik, 2003). Early research indicated that psychotherapy was not effective for this population, but clinicians have argued that just because the therapeutic techniques used were not effective, the conclusion that people with developmental disabilities did not require psychotherapy was erroneous. Lovett (1985) observed that the focus on behavioral interventions without careful inquiry into the emotional aspects of the individual's experience could lead to inappropriate identification of target behaviors. He found that caretakers and professionals often described the individual's behavior in very observable terms such as "aggression, acting out, attention seeking" without identifying the emotion driving the behavior (such as loneliness, wanting friends, and feeling rejected, among others), thus ignoring the meaning of the behavior and labeling the person's attempt for human interaction as a negative behavior (Kroese, 1998).

Recent studies have shown that psychotherapy can be effective with persons with mild developmental disabilities. Prout and Nowak-Drabik (2003) found a moderate level of effectiveness of psychotherapy and concluded that psychotherapeutic interventions should be considered as part of overall treatment plans for persons with intellectual disabilities. Other researchers showed that persons with intellectual disabilities did benefit from the therapy (Nezu & Nezu, 1994; Kroese, 1998; Newman & Beail, 2005). Although dedicated to psychotherapy for this population, practitioners that work with persons with intellectual disabilities acknowledge that, to be effective, the therapeutic approach must be modified to address issues (such as dependency) and involve others in the treatment process. This latter requirement, however, can cause some ethical issues for the therapist. Psychotherapy is usually a very personal experience and requires a high level of confidentiality on the part of the therapist. When the therapist is working with a treatment team, the therapist must be able to maintain these professional responsibilities. At times, there also may be conflict regarding the desired end state of the therapy. For example, the individual with a developmental disability may desire more self-

determination, autonomy, and independence, while the service system may be more concerned with reducing or eliminating certain behaviors. In other situations, the person's learned passivity may need to be challenged, and the person may wish learn to rely more on their own judgment and address their personal goals (Lynch, 2004).

Necessary modification for therapy is discussed in the literature and is reported below. It must be noted that comprehensive empirical research on these techniques has not been completed. Each set of suggestions, however, is backed by extensive experience and limited experimental study, though not by multiple controlled experiments.

One of the key components of effective therapy is for the patient to be able to self-report. Although persons with developmental disabilities may have limitations in this area, they are able to participate when modifications are made. Some approaches that have been used include using pictures to help describe situations, using open-ended rather than leading questions to avoid acquiescence, and inserting probes after questions to elicit examples or further detail to ensure that the patient understands the question (Kabzems, 1985; Kroese, 1998). Another set of research by Jahoda, Markova and Cattermole in 1988 demonstrated the additional skill and time necessary to conduct effective therapy with this population. To gain accurate information, an interviewer spent about 12 hours prior to the diagnostic interview with each interviewee to gain their confidence and to reduce interfering variables, such anxiety and incomprehension. Kroese (1998) concludes that, with modifications in techniques, self-report can be valid and reliable in persons with intellectual disabilities, especially if the therapists check with others about certain issues to determine that self-reports are fairly accurate. Kroese goes on to say that the therapist must be prepared to be more didactic if comprehension of more abstract concepts is inaccurate or confused. Additionally, the therapist should encourage self-regulation and self-determination.

Aman et al. (2004) state that cognitive-behavioral therapy which focuses on underlying thought processes, biased perceptions, and unrealistic expectations, attitudes, and emotions is recommended for persons with intellectual limitations. This treatment modality is specifically recommended for major depressive disorder, PTSD, OCD, and prominent anxiety symptoms in individuals with mild to moderate intellectual limitations.

For any psychotherapy treatment regime to be successful with persons with intellectual disabilities, the treatment process should be modified to accommodate the individual needs of the person receiving treatment. Lynch (2004) recommends several modifications to the therapeutic approach which are listed below:

- Simplify language, presenting information at a slower rate;
- Check for comprehension of concepts, repeating concepts;
- Use concrete language;
- Increase the structure of the therapy session;
- Minimize distractions and shorten the length of the session;
- Use a more direct approach, and use recent real-life situations to make concepts more relevant;
- Allow more time for the person to respond, and use more non-verbal communication;
- Be more goal-focused; and

- Use visual materials and role-playing to bolster learning.

The National Child Traumatic Stress network presented a list of suggestions for therapists working with persons with intellectual disabilities. Using the work of Avrin, Charlton and Tallant (1998), they recommend that the therapist:

- Slow down their speech;
- Use visuals whenever possible to reinforce their verbal message by
 - drawing pictures, and
 - writing down suggestions for change in brief, outline form;
- Present information one item at a time;
- Ask for feedback after each item to ensure clear comprehension;
- Be specific in making suggestions for change;
- Practice different ways of handling tough situations the client is likely to encounter;
- Format the therapy session so that several repeats of key information occur, such as:
 - reviewing information covered in the previous meeting,
 - discussing how the week has gone,
 - working on specific ways of handling various troublesome events that occurred,
 - reviewing the key things the client should work on during the week, and
 - writing the homework assignment out and reviewing it with the client to be sure it is clear;
- Work on building coping skills rather than insight;
- Remember that, with these clients, change will occur more slowly than with others, and be content to measure change with a micrometer rather than a yardstick; and
- Remember that effective treatment for people with developmental disabilities must also include a variety of support and educational services for families and caregivers.

Lynch (2004) cautions that persons with intellectual disabilities may not benefit from short-term therapy. Because of their intellectual disabilities, they may need more time to learn and incorporate strategies. Also, they may need booster sessions as often as monthly to review their coping strategies and application of the therapeutic gains. In the world of managed care, acquiring this level of service in an outpatient setting may be a challenge.

Behavioral interventions.

Behavioral interventions have long been established as an effective technique in teaching skills and reducing maladaptive behavior (Benson & Havercamp, 1999). Originally, behavioral analysts worked from the premise that behavior was primarily affected by the conditions existing in the person's environment and not by intrapsychic dynamics. The focus remains on the interaction between the environment and the individual. However, as discussed above under assessments, behavioral analysts are now frequently involved in a holistic assessment of the individual and, as part of the biopsychosocial assessment, consider biological influences on the behavior. Also as discussed above, biological issues can include the psychological and physiological distress associated with mental illness. With this approach, behavioral interventions are now often one part of a treatment approach that includes pharmacotherapy and other interventions, such as the psychotherapy described above.

The effectiveness of behavioral interventions for daily living skill development and reduction of behavioral problems is clear. However, there are other applications of these techniques that merit consideration. These include treatment of anxiety, mood, and psychotic disorders that, although they have not been addressed as extensively either in research or practice, show considerable promise. For example, behavioral techniques have been used to improve social skills in persons with mild intellectual disabilities who were diagnosed with schizophrenia. The techniques included primarily targeted role-playing to reduce inappropriate social responses and increase socially acceptable interactions (Benson & Havercamp, 1999; Aman et al., 2004).

Teaching self-management techniques has also been successful in the treatment of depression and anger management with persons with mild intellectual disabilities. The interventions for depression include modeling, praise, self-evaluation, and self-reinforcement. The anger management program uses relaxation training, self-instructional training, and problem-solving skills that help develop self-regulation. Though perhaps helpful in managing behaviors in a residential environment, techniques such as point systems and contingency management programs do not develop self-management skills that will generalize to other settings.

Psychiatric rehabilitation interventions.

Benson and Havercamp (1999) and others recommend using psychiatric rehabilitation programs with persons with developmental disabilities. These would include programs developed by Lieberman and the Boston Center for Psychiatric Rehabilitation. Problem Solving Skills Training is an evidence-based practice that has shown effectiveness with persons with intellectual disabilities and mental illness that have problem-solving deficits, and has been shown to help persons achieve self-regulation. As discussed above under psychotherapy, persons with mild intellectual disabilities feel anxious and depressed because they are reliant on others for assistance in life management. Benson (1995) considers problem-solving skills training as part of a cognitive-behavioral approach. Problem-solving skills training can focus on two components for problem-solving, process and performance. One approach teaches youth the key steps to problem-solving. The second component of performance training requires that the individual demonstrate the ability to determine appropriate responses and perform those responses in real world circumstances. Benson states that training programs are appropriate for persons with mild or moderate mental retardation, and that both components of the program should be taught.

When using problem-solving skills training, accommodations must be made for persons with developmental disabilities. Trainers could demonstrate the problem for the participants in a role-playing session. Extra assistance could be provided in stating the problem during the beginning of the training program. Trainers also could provide additional support in generating possible solutions. Persons with mild mental retardation are able to state some of the anticipated consequences of certain choices and with assistance can also learn to look at the longer-term consequences. As with any training program for persons with developmental disabilities,

generalization is of concern. Practitioners have found that practicing skills in situations similar to those that the person will encounter in their daily life is helpful.

Trauma informed care.

As was discussed in the Prevalence section of these guidelines, persons with intellectual disabilities have a higher than average rate of abuse and neglect. Also, because of their increased vulnerability, persons with intellectual disabilities may experience a traumatic response to situations that the general population would not. Researchers are now showing that the long-term psychological impact of trauma can be substantial. The term “complex trauma” is used to describe children’s exposure to multiple traumatic events that occur in the care-giving system. Typically, complex trauma refers to simultaneous or sequential occurrences of child maltreatment, including emotional abuse, neglect, sexual abuse, physical abuse, and witnessing domestic violence. The trauma usually begins in early childhood and is chronic (Cook, Blaustein, Spinazzola, & van der Kolk, 2003). Of course other traumatic events—such as sexual abuse, rape, witnessing or being a victim of violence, etc.—can lead to traumatic responses throughout the lifetime. Clinicians working with persons with intellectual disabilities need to be aware of the possibility of a history of trauma and use trauma informed techniques with these individuals when warranted.

Use of Psychopharmacology with Persons with Developmental Disabilities

Prior to prescribing any medication, it is recommended that the following areas be reviewed. These align with the assessment process discussed earlier in the paper and are summarized below:

- Medical conditions,
- Psychosocial and environmental conditions,
- Health status and history,
- Current medications,
- Psychiatric diagnosis,
- History of previous interventions and their results, and
- Functional analysis of behavior.

The decision to use a psychotropic medication and the choice of the medication is much more straightforward in the presence of a clear psychiatric diagnosis. If the diagnosis is not clear, there should be a behavioral-pharmacologic hypothesis from which the physician is working. A functional assessment is required if the psychiatric diagnosis is not clear, and is beneficial even if the physician has a reliable specific diagnosis (Kalachnik et al., 1998; Aman et al., 2004).

Psychotropic medications should only be used with persons with developmental disabilities within the biopsychosocial treatment model and not in isolation of other treatment. An interdisciplinary team is necessary throughout the assessment/diagnostic process, treatment planning, and on-going therapeutic interventions. The team should be knowledgeable in appropriate biopsychosocial treatment approaches and behavioral analysis.

Medication management for persons with developmental disabilities is more challenging than with the general population. They are at a higher risk for side effects and past practices have shown that they are also more likely to have multiple medications, increasing the risk of adverse drug interactions. The Centers for Medicare and Medicaid Services (CMS) have developed general recommendations for the use of medications in this population. Aman et al. (2004) provide a summary of these strategies, which are quoted below:

Dosing strategies.

- Keep the medication regimen as simple as possible. Consider use of once-a-day dosing and extended-release formulations when possible.
- Start low and go slow. Use lower initial doses and increase more slowly than in individuals without mental retardation.
- Use the same (or lower) maintenance and maximum doses as in individuals without mental retardation.
- Periodically consider gradual dose reduction (at the same rate or more slowly than in individuals without mental retardation),
- Avoid frequent drug and dose changes unless there is a valid reason for change, such as no response or adverse effects.

Evaluating treatment effects.

- Collect baseline data before beginning medication.
- Evaluate medication efficacy by tracking specific index behaviors using recognized behavioral measurement methods (e.g., frequency counts and rating scales).
- Evaluate the medication's side effect on functional status.

Evaluating side effects.

- Monitor for side effects regularly and systematically (at least once every 3 to 6 months and after any new medication is begun or the dose is increased). A standardized assessment instrument can be helpful in monitoring for side effects.
- If an antipsychotic is prescribed, assess for tardive dyskinesia at least every 3 to 6 months.
- If on an atypical, monitor for changes in weight and glucose and lipid levels, per recently released guidelines by the American Psychiatric Association.

Whether to include psychotropic medication with an initial treatment plan can be a difficult decision when working with people with developmental disabilities (in this discussion, people with mental retardation). The CMS General Safety Precaution #4 recommends that, before using medication to manage psychiatric or behavioral symptoms, clinicians should intervene in the least intrusive manner and with the most positive intervention (Aman et al., 2004). However, Aman et al. (2004) provided additional guidance on when psychotropic medications should be recommended on the initial treatment plan (when not to wait to try less restrictive measures).

- Clinical Diagnosis:
 - Schizophrenia
 - Bipolar disorder
 - Major depressive disorder
 - Psychotic disorder NOS
 - OCD
- Target symptoms without a clear diagnosis:
 - Suicidal ideation/behavior
- Other factors that suggest the need for medication on the initial treatment plan:
 - History of behavioral deterioration when off medication
 - Self-injurious behavior with risk of physical risk
 - Very severe symptoms
 - Previous good response to medication
 - Lack of response to psychosocial interventions
 - Symptoms that interfere significantly with individual's ability to participation in education and/or rehabilitation

Aman et al. (2004) also included a section on the recommended initial set of medications by disorder, the selection of medications for target symptoms, and preferred medications within different classes. This is an excellent updated source of information regarding the use of medication with people with intellectual disabilities. It also includes a brief literature review and an extensive list of references. The document can be downloaded from the web at www.psychguidelines.com.

In 2008, the journal, *Research in Developmental Disabilities*, published a set of practical guidelines for the use of new generation antipsychotic drugs in adults with intellectual disabilities (de Leon, Greenlee, Barber, Sabaawi, & Singh 2008.) The full article is included in this Tool Kit with permission of the authors.

Other resources on medication guidelines include the following:

- *Treatment Recommendations for the Use of Antipsychotics for Aggressive Youth (TRAYY)* (Schur et al., 2003).
- *Treatment of Psychiatric and Behavioral Problems in Mental Retardation* (Rush & France, 2000).

Monitoring the use of psychotropic medications.

One effective means to monitor the use of psychotropic medications is through a retrospective review of outlier practices. The term “outlier” refers to prescribing practices that deviate from the expected clinical guidelines and algorithms. Through electronic databases or on-sight reviews, clinicians can look at the prescribing practices to determine if there is a reason for further inquiry. For example, some of the medications prescribed for children in the Statewide Inpatient Psychiatric Programs (SIPP) and some of the possible combinations of medications may indicate a need to provide additional expert peer review in some of the cases. An example of an outlier pharmacotherapy practice for schizophrenia is listed below:

Polypharmacy	Concurrent use of two or more antipsychotic agents for 45 or more consecutive days
	Concurrent use of three or more antipsychotics
	Concurrent use for periods of 90 or more days
	Combination of two or more agents from any class for 45 or more days
	Concurrent use of five or more psychotherapeutic drugs for 90 or more consecutive days (very unusual practice)
Dosing	Use of excessively high dose of antipsychotic agent over a 30-day period
	Use of very low doses of antipsychotic agent
Other practices and system issues	Two or more switches of antipsychotic agent over a 30-day period
	No new prescription of antipsychotic within 15-30 days of prescription ending
	Multiple prescribers of psychotherapeutic agents for a patient
	Use of antidyskinetic agent in conjunction with antipsychotic for 45 or more consecutive days.

(Constantine et al., 2006)

Summary

The purpose of this paper is to provide an overview to practitioners working with persons with intellectual disabilities who also have or are suspected of having a dual diagnosis of mental illness. It is important for support coordinators and other service providers to understand that persons with intellectual disabilities do, more often than the general population, have mental health disorders. These disorders can substantially impact their quality of life, result in disruptive and challenging behaviors, and cause the person serious physiological pain. Knowing what to look for and what to ask for, when working with this population, is essential in obtaining the appropriate services. Referral for interdisciplinary assessments and forming an interdisciplinary team for treatment is essential to provide the best treatment for this population.

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