

DUAL *Diagnosis* DIAGNOSIS

A Guidebook for Caregivers



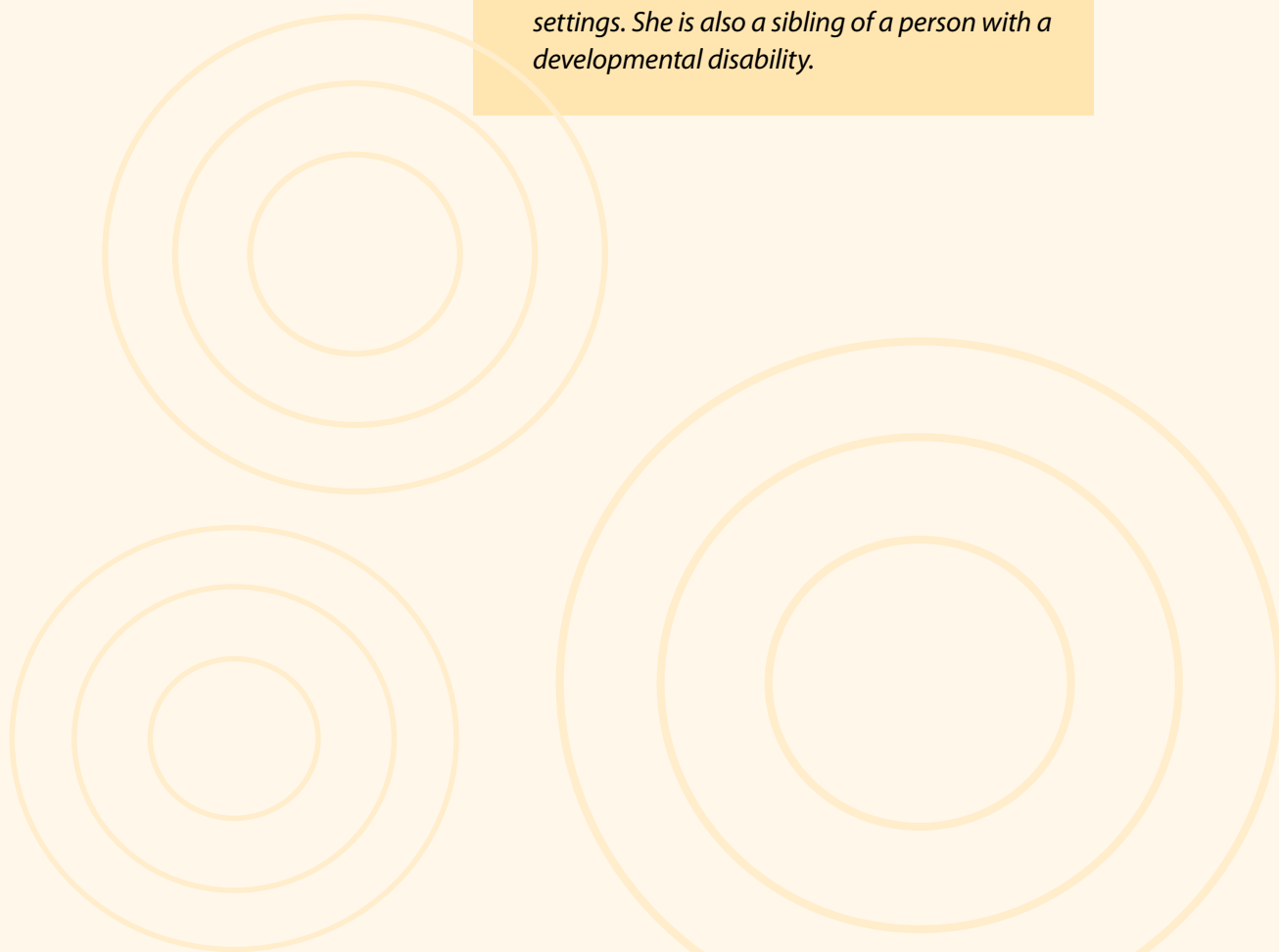
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The Psychology of Disabilities, Motivation and Emotion, Human Lifespan Development and Disorders of Childhood. Dr. Scharoun is also a Psychologist with the New York State Office for People with Developmental Disabilities. She has over twenty years of experience working with children and adults who have developmental disabilities in residential, vocational, academic and home settings. She is also a sibling of a person with a developmental disability.



Dear Caregivers,

I am a psychologist who helps people who have “dual diagnosis.” This term is used when a person with a developmental disability also has a mental illness. It is often hard to diagnose a mental illness in a person who has a developmental disability. However, in order to provide effective treatment, it is very important to differentiate symptoms of a mental disorder from behaviors associated with the developmental disability.

Many people who have a developmental disability have a difficult time conveying accurate information at the time of assessment. Parents, siblings, or even direct support staff and other service providers can be valuable resources in defining the symptoms and identifying behaviors of concern. This guidebook gives caregivers the tools they need to understand how mental illness might look in a person with a developmental disability, and information on what to do and where to go for help. It was written in order to help caregivers to partner with health care providers. The goal is high quality medical and psychiatric care for people with developmental disabilities.

This guidebook is organized into five sections that answer questions that caregivers often ask me:

WHAT is dual diagnosis?
WHY is it so hard to make this diagnosis?
HOW is a dual diagnosis established?
WHO can help?
WHERE can I go to learn more?

This guidebook was written in 2010 for the New York State Institute for Health Transition Training with grant support from the New York State Developmental Disabilities Planning Council. Kathy Ahern RN, Nienke Dosa MD, MPH, Laurie James MEd, Wendy Leonard MS, LMHC, Gregory Liptak MD, MPH, and Pat Slaski MEd reviewed drafts for this guidebook and helped to develop the reference charts. Holly Scherzi designed the diagrams and tables.

I hope that this guidebook will be helpful to people with developmental disabilities and their families. For more information about this project, and to contact us, please visit www.HealthyTransitionsNY.org.

Sincerely,

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WHAT

WHAT is Dual Diagnosis?

This section lists medical and legal definitions that are used in New York State to define developmental disability, intellectual disability, and mental health disorders.

The term dual diagnosis refers to the presence of a mental illness or mental disorder among individuals with a developmental disability. The most common developmental disability is intellectual disability (mental retardation), but individuals with autism, cerebral palsy and neurological impairment can also have a mental illness and be considered dually diagnosed. Dual diagnosis is a term that can also be used to describe the co-existence of a mental illness and substance abuse. People with intellectual disabilities can also have substance abuse problems. However in this guide, dual diagnosis refers to the co-diagnosis of a psychiatric condition in a person who has a developmental disability.

In New York State “Developmental Disability” is defined in Subdivision 22 of section 1.03 of the Mental Hygiene Law. The most recent amendment of this law was enacted on July 31, 2002. The law states:

Developmental disability means a disability of a person which:

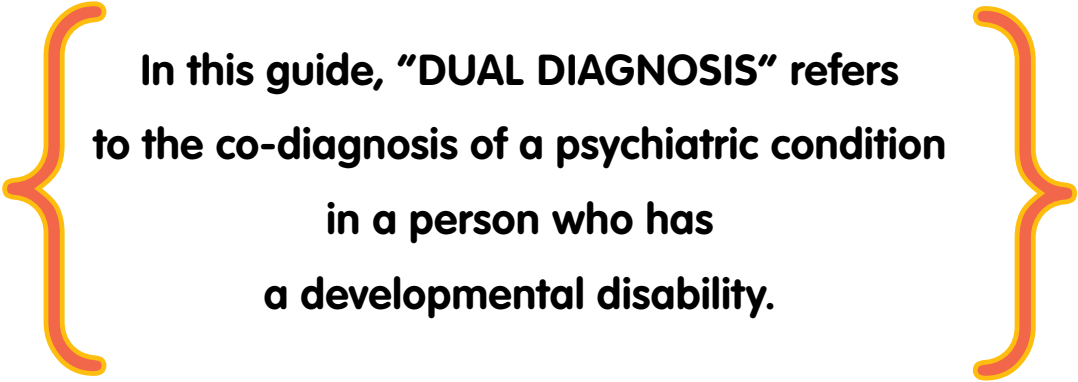
- A.** (1) is attributable to mental retardation, cerebral palsy, epilepsy, neurological impairment, familial dysautonomia or autism; (2) is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such person; or (3) is attributable to dyslexia resulting from a disability described in subparagraph (1) or (2) of this paragraph;
- B.** originates before such person attains age twenty-two;
- C.** has continued or can be expected to continue indefinitely; and
- D.** constitutes a substantial handicap to such person’s ability to function normally in society.”

It is important to understand the legal definition of developmental disability, because this definition is used to determine whether a person qualifies for services. However, the practical definition is a childhood onset condition that affects day to day functioning, as reflected by IQ scores that are more than 2 standard deviations below the mean (IQ less than 70) as well as a formal evaluation of adaptive functioning that documents daily living skills that are more than two standard deviations below the mean (less than 70).

A mental disorder or mental illness is a psychological or behavioral pattern that causes distress or disability that is not expected as part of normal development or culture. Research suggests that mental illnesses are the result of

a complex interaction of genetic, biological, personal and environmental factors. The brain, often referred to as the final common pathway for the control of behavior, cognition, mood and anxiety, is the primary organ system involved with mental illnesses. The links between specific brain dysfunction and various mental illnesses are not fully understood. Mental illness can be brought on by stressful life events. However it is important to note that mental illnesses are not the result of personal weakness, lack of character or poor upbringing. The recognition and understanding of mental disorders have changed over time and across cultures. The National Association on Mental Illness (NAMI) defines mental illnesses as medical conditions that disrupt a person's thinking, feeling, mood, ability to relate to others and daily functioning. Just as diabetes is a disorder of the pancreas, mental illnesses are medical conditions affecting brain function that result in a diminished capacity for coping with the ordinary demands of life.

Until recently, it was believed that people with developmental disabilities could not also have a mental illness. It is now recognized that persons who have developmental disabilities are at increased risk for mental illnesses, or psychiatric disorders. The exact prevalence of mental illness among persons with developmental disabilities is not known, but some experts in the field believe that it could be 5 times more prevalent than in the general population. (Rush, et al. (2008)). Thus, "dual diagnosis" is common. Unfortunately studies have shown that people with developmental disabilities often have difficulty accessing psychiatric care and mental health services. Quality of care is a concern as well. In a recent study adults with developmental disabilities were seven times more likely to report inadequate emotional support, compared with adults who do not have disabilities.(Havercamp, et al. 2008). This guidebook was written in order to improve the access to care and the quality of care that is provided to people who have a dual diagnosis.



In this guide, "DUAL DIAGNOSIS" refers to the co-diagnosis of a psychiatric condition in a person who has a developmental disability.

WHY

WHY Is It So Hard To Make This Diagnosis?

In this section I talk about “diagnostic overshadowing” and give information about a very important reference for professionals called the “Diagnostic Manual – Intellectual Disability: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability” (DM-ID). Descriptions of all the common mental illnesses that are referenced in the *DM-ID* are provided.

Why is it so hard to properly diagnosis a mental illness in a person with an intellectual or developmental disability? A phenomenon referred to as **diagnostic overshadowing** is part of the problem. The term diagnostic overshadowing refers to the tendency clinicians have to attribute all the behavioral and emotional problems to the developmental disability instead of the mental illness. Because of this, many psychologists, social workers and psychiatrists miss anxiety, depression, and even psychotic symptoms. They believe the symptoms are due to intellectual or developmental disability instead of mental illness. The intellectual or developmental disability overshadows the other diagnosis.

Another problem is that many professionals in the field of mental illness simply do not have training or experience in the field of intellectual disability and developmental disabilities and therefore erroneously attribute psychiatric problems to the other condition. An excellent resource was recently published to help professionals to accurately diagnose psychiatric conditions in people with developmental disabilities. **The Diagnostic Manual—Intellectual Disability: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability (DM-ID)** is a guide for diagnosing mental illness in people who have intellectual disability. More information about the DM-ID is available at <http://www.thenadd.org>, the website of NADD, an association for persons who have a developmental disability and mental health needs.

Definitions, assessments, and classifications of mental disorders can vary. For the sake of consistency, in this guidebook we will use criteria identified in the Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition) DSM-1VTR and the Diagnostic Manual – Intellectual Disability: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability (DM-ID). The Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition) DSM-1V-TR (DSM—IV-TR) is a manual published by the American Psychiatric Association that is used by clinicians in the field of medicine and psychology to properly diagnose people with mental illnesses. As noted previously, the Diagnostic Manual – Intellectual Disability: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability (DM-ID) is a recently published guide for diagnosing mental illness in people who have intellectual disability.

The four major categories for mental health disorders are Attention Disorders, Anxiety Disorders, Mood Disorders, and Thought Disorders. The following sections provide general information about each of these categories, followed by diagnostic and treatment considerations relevant to dual diagnosis in patients who have an intellectual disability or a developmental disability.

ATTENTION DISORDERS

The core characteristics of Attention Deficit and Hyperactivity Disorders (ADHD) are **inattention**•**hyperactivity** and **impulsivity**.

Inattention

People who display the symptom of inattention find it challenging to focus on one task or to follow through on requests or instructions. Parents and teachers of children with this symptom frequently complain that the child “won’t” listen or complete an assignment or chore. There are many different types of attention and people with AD/HD may have deficits in one or more than one type. It is important to realize that a child or adult with AD/HD typically cannot sustain attention. It is not a matter of will or will not. This is an organic condition with neurological underpinnings. Below are definitions of four types of attention.

- Attentional Capacity is the amount of information someone can remember and attend to for a short time.
- Selective Attention is the ability to concentrate on relevant stimuli and not be distracted by noise or other environmental issues.
- Distractibility is a common term used for a deficit in selective attention.
- Sustained Attention or vigilance refers to the ability to maintain a persistent focus over time.

People with ADHD can have problems with all of these forms of attention. For example, they may be highly distractible, but the primary deficit seems to be in sustained attention. People with ADHD may not be able to persist at a task even when they want to. They are particularly challenged when asked to perform uninteresting, and repetitive tasks (Mash and Wolfe, 2010).

- **yperactivity**• “Always on the Go”

The activity of many children and adults with ADHD is often described as excessively energetic, intense, and inappropriate. It is often not goal oriented. The area where they show the greatest challenge is when they are asked to slow down or sit still in response to structured tasks, such as the demands of a classroom. Not all children have hyperactivity. Some children have ADD, or Attention Deficit Disorder only. Boys are more likely to have ADHD and girls ADD, but both genders can have either one. ADHD is not just a pediatric condition. Adults can be given this diagnosis as well.

Impulsivity

Characterized by the inability to delay gratification or bridle immediate reactions, impulsivity can be in the cognitive and/or behavioral areas. When a child has impulsivity problems, it is very hard for them to stop an on-going behavior or to regulate their behavior in accordance with demands. They struggle with waiting. It is hard for them to take turns, and they frequently interrupt other’s conversations or lash out when frustrated.

The presence of both cognitive and behavioral impulsivity is believed to be one of the best predictors of problems with academic achievement, especially in reading. Behavioral impulsivity alone is a good predictor for children who may break rules and are later at risk for conduct problems (Mashe and Wolfe, 2010). Impulsive people are at risk for physical injury. They are frequent risk takers and do not stop and think before they act. The risk taking among people with ADHD can result in serious injury. For example, teaching a child to safely cross a street is a daunting task for most parents. Crossing a road can be a particularly dangerous activity for a young child with ADHD who is impulsive, and even more dangerous for a dually diagnosed adult, who is both impulsive and cognitively challenged.

Children with intellectual disabilities typically have shorter attention spans than their non-disabled peers. Impulsivity is also more common among people with developmental disabilities. How do you diagnose ADHD in a person who has an intellectual or developmental disability? When assessing developmentally inappropriate attention, assess the person’s attention by comparing him or her with peers of comparable intellectual and chronological age. When assessing developmentally inappropriate hyperactive or impulsive behavior, assess the person’s hyperactivity-impulsivity by comparing with peers of comparable developmental and chronological age, rather than with younger typical children of comparable developmental age. There must be clear evidence of clinically significant impairment in social, academic, or occupational functioning that is related to inattention, hyperactivity, or impulsivity and not just the intellectual disability. (DM-ID, pg. 85-86)

ANXIETY DISORDERS

Anxiety

A mood state characterized by strong negative emotions. A bodily feeling of tension accompanies this state. Anxiety differs from fear in that anxiety is an anticipatory response to something that might happen in the future. Fear is an immediate reaction, indicating alarm. Fear is a response to a current danger. Fear occurs in the present, and anxiety is future oriented. Although fear and anxiety have many things in common, they differ from one another too. Both elicit a strong flight or fight response in the body and the function of both is to escape potential harm (Mash and Wolfe, 2010).

Fear

Fear is marked by strong escape tendencies and a strong surge in the sympathetic nervous system. The sympathetic nervous system is primarily responsible for a flight or fight response in the body. When a person experiences fear, the overwhelming message is alarm. Anxiety, on the other hand, is marked by feelings of apprehension and lack of control over up-coming events that might be threatening. Although fear and anxiety both warn of danger or distress, only anxiety is felt when there is no real danger. Anxiety has been referred to as the “false alarm” of danger (Mash and Wolfe, 2010).

Normal Fears

People of all ages have fears. These fears change over the developmental lifespan. For example, very young children fear strangers. This may actually serve a protective function for infants and very young children. When a fear persists past a certain age in a child, it may interfere with the child’s development. There are common childhood fears which change and typically decline in number over time. Girls tend to have more fears than boys at almost every age. Common fears associated with specific developmental ages include a fear of strangers, separation from parents, animals, the dark, bodily injury, supernatural beings, tests, and social performance (Mash and Wolfe, 2010).

Normal Anxieties

Like fears, anxieties are common in childhood and adolescence. Common anxieties include separation anxiety, test anxiety and anxiety about harm to a parent. Younger children tend to experience more anxiety than do older children and again girls experience more anxiety than boys do. Anxiety symptoms may reflect a stable trait that later predisposes a child to develop excessive fear. Worrying is also normal to an extent. Worrying, in appropriate amounts, helps children prepare for up-coming events, such as a math test or a performance in the school play. Excessive or intense worrying is not productive, however, and can lead to a child’s inability to achieve his or her goals (Mash and Wolfe, 2010).

Normal Rituals and Repetitive Behavior

A strong preference for routines and rituals are common among young children. For example, young children will watch the same video show over and over again, have rigid likes and dislikes, refuse to try new foods, and may have a bedtime routines that seem to be carved in stone. Many of these rituals and repetitive behaviors disappear as children get older and gain more real and personal control over their environment. Cognitive rigidity, a thinking style marked by single mindedness and inflexibility can be seen in children and adults with intellectual or developmental disability (Mash and Wolfe, 2010; Weis, 2008). Most people with the diagnosis of autism have a strong need for routine and sameness. Predictability is also extremely important for most people with autism, and stereotypical (repetitive) behaviors are commonly observed. The stereotypical behaviors are believed to be a coping mechanism for this need. People perform a repetitive behavior that is in their control in an attempt to tune out what is out of their control. Though this appears maladaptive to an observer, it actually works well to reduce anxiety. The presence of stereotypical behaviors can indicate that the person is stressed.

Anxiety Disorders are among the most common mental health problems in childhood, adolescence, and adulthood. However, anxiety and fear can be normal behavior as well. The diagnosis depends on the intensity and the duration of the symptoms. When children experience fears and or anxiety beyond a certain age, in situations that truly pose no threat or harm and to the extent that their daily lives are affected, then a diagnosis is warranted and treatment is necessary. There are many types of anxiety disorders listed in the DSM-5 (Mash and Wolfe, 2010).

☒. Separation Anxiety Disorder Characterized by an age-inappropriate, excessive and disabling anxiety about being separated from a care-giver or from being away from home. (“Don’t leave me.”) Young children with separation anxiety frequently place excessive demands on their parents’ attention by clinging to them, or trying to sleep with them every night, or becoming upset when parents try to run short errands. They often will not even stay with other familiar adults, like grandparents. The mothers of children with this disorder are particularly burdened because they feel guilty every time they leave the child. School refusal behavior in children between the ages of 5-11 years old may be a form of separation anxiety. It can occur after a stressful event, for example, a move to a new home, a change of schools, death of relative or family pet, or an accident.

☒. Generalized Anxiety Disorder (☒AD) Chronic or exaggerated worry and tension. An almost constant anticipation of doom or disaster even when nothing seems to provoke it. Often physical symptoms accompany this disorder, such as trembling, muscle tension, headache and nausea, the “worry-wart.” There are six symptoms associated with ☒AD: restlessness, easily fatigued, difficulty concentrating, irritability, muscle tension and sleep disturbance (falling

asleep or staying asleep). In persons with a severe intellectual disability, only one of these symptoms is required. For persons with a moderate or mild intellectual disability, three symptoms are required.

☒. Specific Phobia An extreme, disabling fear of a specific object or situation that poses no real or immediate threat. Specific phobia is often referred to as an irrational fear. Fear of closed spaces, elevators, heights, animals, blood, and needles (injections) are common. In persons with ID this may be expressed by crying, tantrums, freezing, or clinging in persons with severe intellectual disability. The person should be able to recognize that the fear is excessive or unreasonable, but in children and persons with severe intellectual disability this feature may be absent. (DM-ID, pg. 197)

☒. Social Phobia Fear of being the focus of attention or scrutiny, or doing something embarrassing or humiliating. Social phobia is a marked fear of social or performance situations. Children with this disorder have strong feelings of inadequacy, which makes them more anxious. Stammering, sweating, upset stomach and rapid heartbeat are all symptoms that can be brought on by the mere thought of “performing” or speaking in public (Mash and Wolfe, 2010). In persons with intellectual disability, social phobia may be expressed by crying, tantrums, freezing, or shrinking from social situations with unfamiliar people. The person should be able to recognize that this fear is excessive or unreasonable. Persons with severe intellectual disability may not have this insight. (DM-ID, pg. 199)

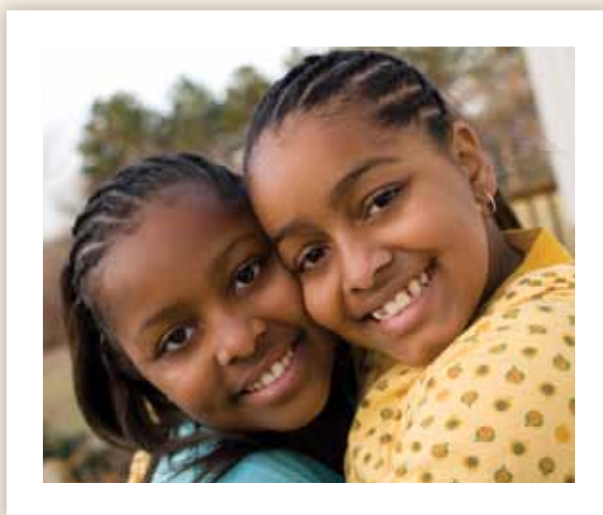
☒. Obsessive-Compulsive Disorder (OCD) Repeated, intrusive and unwanted thoughts that cause anxiety. This may result in ritualized behavior that is an attempt to relieve the anxiety. Obsessions are intrusive thoughts. Compulsions are the repetitive, purposeful and intentional behaviors that are performed in response to obsessions. It is not uncommon for people with OCD to try to hide their rituals. If the rituals become more demanding and time consuming, it may become impossible to conceal. Chronic lateness (counting ritual), inability to finish school work on time (checking ritual), fear of spending the night at someone’s house (bedtime ritual), going to public events (contamination or cleaning ritual), or participating in social or school activities (going to the movies or participating in sports events) all may be signs of OCD (Mash and Wolfe, 2010, Weis, 2008). Not all repetitive behaviors in persons with intellectual disability should be considered obsessive-compulsive behaviors. For example, repetitive behaviors that have a physiologic reward (i.e. self stimulatory behaviors) should not be considered in this diagnosis. The most common behaviors of this type are masturbation, hyperventilation, over-eating, over-drinking, smoking, humming, and pacing (DM-ID, pg. 210). Among people with an intellectual disability, aggression may be prominent. The “aggressive” actions are directed toward removing an obstacle that prevents the person with an intellectual disability from completing a ritual or a fixed way of doing things. There

is a risk of both under and over diagnosis of OCD in people with intellectual disability. A variety of checklists and assessment procedures that have been developed to accurately diagnose OCD in persons with intellectual disability are referenced in DM-ID on page 210.

6. Panic Disorder A sudden and overwhelming period of intense fear or discomfort that is accompanied by four or more physical or cognitive symptoms characteristic of the “flight or flight” response. A panic attack is accompanied by an overwhelming sense of imminent danger or impending doom and an urge to escape. The symptoms include a pounding heart, sweating, shaking or trembling, shortness of breath, difficulty with swallowing, choking, chest pain or discomfort, nausea, chills or hot flashes, lightheadedness, and a fear of losing control, going crazy, or dying (Mash and Wolfe, 2010). Panic attacks are believed to be very rare in young children, but are common in adolescents. Puberty is a critical time for the development of panic attacks, especially in girls. A common stressor may cause the child to produce too much adrenaline. This triggers the physical symptoms of a panic attack. The physical symptoms, such as a rapid heartbeat, are unexpected and can be extremely distressing to the adolescent (Mash and Wolfe, 2010, Weis, 2008). Since many people with intellectual disability cannot describe what is going on in their bodies, observed symptoms are important in making the diagnosis. A panic attack is a discrete period of observed intense fear or discomfort, in which three (or more) of the following symptoms develop abruptly and reach a peak in 10 minutes: pounding or racing heart, sweating, trembling or shaking, shortness of breath, feeling of choking, chest pain or discomfort, nausea or abdominal distress, feeling dizzy or unsteady and chills or hot flashes. Extreme panic attacks may result in irritability, aggression and destructive behavior and may also cause lashing out of arms and legs and head banging. (DM-ID, pg. 190-191)

7. Panic Disorder with Agoraphobia Anxiety about having a panic attack in a public place or anxiety about being in a place from which escape might be difficult. Common places include crowded places, like malls, large grocery stores, or airplanes (Mash and Wolfe, 2010). Since many people with an intellectual disability have limited choices in their day-to-day lives, this disorder may show up as a refusal to go to certain places, or when brought to a stressful place the person displays an increase in intensity of distress and anxiety which may lead to aggression, self-injury or destructive behaviors (DM-ID, pg 192).

8. Post-Traumatic Stress Disorder (PTSD) Persistent and frightening thoughts that occur after experiencing a frightening or traumatic event. People with this disorder re-experience the traumatic event (flashbacks), avoid associated experiences, and display symptoms of extreme arousal. In children these symptoms are both conspicuous and complex. They include intense fear, helplessness and horror. These symptoms may be expressed as agitated behavior and/or disorganization. People with PTSD may have nightmares, new fears, panic attacks or even regression to an earlier developmental period. It may show up in an older child as stranger anxiety (Weis, 2008). In people with intellectual disability, symptoms may appear in overt behavioral ways instead of as a mental phenomenon such as a flashback. Frightening dreams with unrecognizable content may occur. Non-compliance may represent the persistent avoidance of stimuli or events that are reminiscent of the traumatic event. Irritability and outbursts of anger may also be observed as a result of high arousal levels.



MOOD DISORDERS

Depression refers to a pervasive feeling of unhappiness. It affects children, adolescents, and adults in many areas of functioning. Childhood is often thought of as a carefree and happy period. Children are often seen as having no reason to be depressed. When they do show signs of sadness or irritability, caregivers frequently attribute the feelings to temporary factors, such as lack of sleep, illness, and problems with a friend or schoolwork. Depression in children and adolescents can go unrecognized and untreated, because caregivers fail to recognize the seriousness of the negative feelings and the underlying causes of them (Mash and Wolfe, 2010). Depression in young people is often accompanied by other problems, such as anxiety or even conduct disorders. Children who develop behavior problems in school should be screened for depression. Children who are depressed can't shake off sadness the way that other children do. Because of this, they often have difficulties in school and with overall functioning. Depression in children can be disabling, long lasting and even life. The DM-ID is an excellent source for a more thorough understanding of the complexity and challenges of diagnosing mood disorders in people with an intellectual disability. The authors of the manual point out the heterogeneity of people with intellectual disability, even within subgroups of people who have been identified as having mild, moderate, severe or profound intellectual disability. When diagnosing depression and related mood disorders in people with an intellectual disability, it is important to consider the following:

- The presentation of mood disorders in people with an intellectual disability often looks more like the symptoms seen in young children. It is important for a clinician to gather information about the person from someone who knew him/her before any symptoms of a mood disorder were present. In order to accurately diagnose depression or bipolar disorder, a thorough understanding of the person's usual behaviors, skills and abilities is needed (DM-ID, p. 157).
- Aggression and other externalizing behaviors can be seen in people with intellectual disability as a reaction to any number of stressors. Aggression does not appear to be "diagnostically specific." Aggression, for example, can be a behavioral display of an irritable mood, frustration, or anxiety, as well as a symptom of a mood disorder (DM-ID, p. 160).
- Determining whether there is a family history of psychiatric disorders can be helpful when trying to make a diagnosis. Mood disorders occur at elevated rates among relatives of people diagnosed with a mood disorder (DM-ID, p. 162).
- It is important to ask specific questions about constitutional symptoms of depression, such as change in appetite and change in sleep pattern. This is particularly important when the individual is non-verbal.
- Seizure disorders are common among people with intellectual disability. Seizures as well as medications for seizures, can result in sleep disturbances, over- or under-activity, aggression and mood regulation problems (DM-ID, p. 163).
- Medical conditions and known syndromes associated with mood changes are also important to consider. For example: Routine screening for hypothyroidism is recommended for people with Down syndrome. Thyroid problems not only affect mood, but they can affect metabolism, eating behaviors, constipation and cognitive functioning. Hypo-thyroidism can result in depression and hyperthyroidism can result in mania. Polycystic ovarian disease is associated with bipolar disorder in women who have intellectual disability. Neurofibromatosis is associated with irritable mood, labile affect or emotions, impulsiveness, anxiety and depression. Tuberous Sclerosis is associated with mood disorders and psychosis. Velo-cardio-facial syndrome is associated with Bipolar Disorder and Schizophrenia (DM-ID p. 163).

The main features of depression include mood, attitude, behavior, thinking style and physical changes. Depression is marked by a pervasive feeling of sadness. This sadness tends to be exaggerated and persistent. It may show up in a child or adolescent as irritability. Many children with depression experience unnecessary guilt or shame. A sense of hopelessness is common. For people with intellectual disability, the depressed mood may be observed by others as a sad facial expression, flat affect or absence of emotional expression, such as rarely smiling or laughing. The person cries often or appears tearful (DM-ID, p. 170). Change in behavior from baseline personality may be a symptom of depression. This is especially true for people who have weak verbal skills or

who are non-verbal. Increased restlessness, agitation, reduced activity, loss of feelings of pleasure or interest, and excessive crying can all be indications of depression. Observers may report that the individual with intellectual disability refuses preferred activities, appears withdrawn, spends excessive time alone, participates but shows no signs of enjoyment, becomes aggressive in response to requests he or she used to enjoy, finds previously motivating events or objects no longer motivating, avoids social activities, or becomes agitated or aggressive when prompted to attend social activities that once were enjoyed (DM-ID, p. 170).

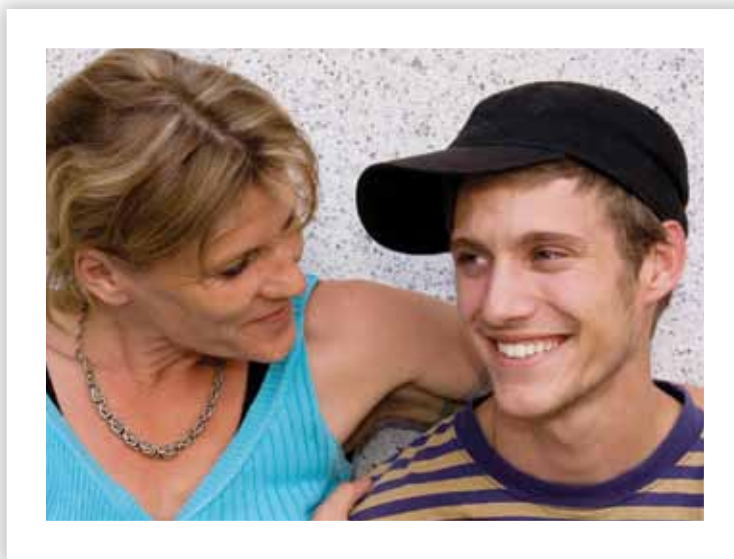
Severe depression is associated with a pessimistic thinking style that can include an exaggerated self-consciousness and self-critical thinking. This can show up as a change in attitude toward friends and school. Often depressed people experience a feeling of worthlessness and low self-esteem. It is this thinking style that makes a person at risk for suicide. They can feel that nothing matters and that things will not get any better. Cognitive behavioral therapy helps people to think differently. Observers may report that the person with an intellectual disability makes negative self-statements, identifies self as a “bad” person, expects punishment even when a history of harsh treatment is absent, blames self for problems inappropriately, has unrealistic fears of caregiver being angry or rejecting, and excessively seeks reassurances that he or she is a good person (DM-ID p. 171).

Physical changes often accompany depression in youngsters. Loss of appetite, over eating, headaches, stomach aches, excessive fatigue, low energy and change in sleep habits can all be the signs of depression. Changes in eating and/or sleeping are two of the most common physical symptoms of depression. Observers may report the individual with intellectual disability is eating to excess, is obsessing about food, is stealing food, is refusing meals, has experienced recent weight loss or gain, exhibits agitated behaviors during meal times or in relation to food such as throwing food on the floor, screaming when meals arrive etc. (DM-ID, p. 171).

Depression in people with intellectual and other developmental disabilities does not always show up as pervasive and prolonged sadness. Frequently it shows up as acting out behavior, such as irritability, crankiness, and low frustration tolerance. Arguing, temper tantrums or even excessive blaming of others can also be symptoms of depression. Acting out may be a more desirable state for youngsters than feeling the pain of depression. Depression has been called anger turned inward, but excessive and persistent outward displays of negative and destructive behaviors can be the tell-tale signs of depression (Mash and Wolfe, 2010). No one pattern or description fits everyone and there are recognized differences in the way people show signs of depression at different ages.

Dysthymic Disorder is a milder, but more chronic form of depression. It is believed that many children with dysthymia will eventually develop depression. Children with this diagnosis are often characterized by poor mood regulation. This may include persistent feelings of sadness, feeling unloved, self-deprecation, low self esteem, anxiety, and irritability. These symptoms are similar to those found in depression, but less severe. Dysthymia can have a very early onset and can last a very long time, which makes it a serious condition. The quality of a youngster’s life is negatively affected by the pervasive pessimistic and self-deprecating thinking style associated with this disorder (Mash and Wolfe, 2010).

Other Problems Associated with Depression and Dysthymia People with depression and dysthymia experience problems or deficits in a number of other areas. It is not uncommon for the youngsters to have difficulties in intellectual and academic functioning. In other words, the depression shows up in their school performance. These deficits can result from difficulty concentrating due to loss of interest in school and a slowness of thoughts and movements associated with the depression (Mash and Wolfe, 2010, Weis, 2008). Social problems are also common. Social relationships with peers and family members are frequently troubled. Children and adolescents with depression often have fewer friends, so they feel lonely and isolated. Social withdrawal, a frequent symptom of depression, can seriously interfere with the development of healthy social relationships with peers. Depressed children commonly have conflict with their parents. Because of this, the children tend to isolate from family members. This is believed to be less about social skill deficits and more about wanting to avoid conflict. Parents benefit from having insight into the reason for their child’s rejection, and from patience. Children with depression need parental support and understanding, not a negative encounter. Depression can be considered a family disorder, requiring family therapy. Family therapy can be a great resource for the parents and is encouraged (Mash and Wolfe, 2010, Weis, 2008).



There are many theories to explain the causes of depression. No one theory can explain all the types of depression. The causes of depression are numerous. For example depression can result from: the loss of a loved object or person, a perceived failure to achieve a desired goal, a lack of social skills, problems with organizing behavior toward long term goals, grief, role confusion, single parenting, social isolation, stressful life circumstances, daily hassles and/or neurobiological causes (Mash and Wolfe, 2010).

People with intellectual disability may be particularly vulnerable to problems with self-esteem in relation to a strong desire to be “normal.” A sense of hopelessness that the usual accomplishments/events of adulthood will not be forthcoming (i.e. getting a driver’s license, buying a car, having one’s own apartment, marrying, having children) can be a contributing factor. This may be more evident when the person has a sibling or friend without an intellectual disability who begins to have such experiences when the person with the intellectual disability does not. (DM-ID, p. 181)

Bipolar Disorder (BD) This diagnosis refers to severe and cyclical mood changes and outbursts. Previously this was called bipolar manic depression. A manic episode is the hallmark characteristic of this disorder. The mood states typically seen in bipolar disorder are elation and euphoria that can quickly change to anger and hostility. There are three subtypes of bipolar disorder: Bipolar I Disorder, Bipolar II Disorder and Cyclothymic Disorder. A subtype diagnosis depends, in part, on the severity of the symptoms, the frequency of the cycling and the presence of a depressive phase (Mash and Wolfe, 2010). Bipolar disorder can be very difficult to diagnose because it shows an extreme variability of clinical symptoms and overlaps with some of the more common diagnoses of childhood, such as ADHD. The symptoms of the manic episode may appear as silly, giddy, overexcited, over talkative behavior coupled with grandiose beliefs. During this phase, a person may actually believe they are a superhero with superhero powers.

There is an obvious difference between the person who is experiencing the grandiosity seen in bipolar disorder from normal behaviors, such as bragging. Restlessness, belligerence, psychomotor agitation, sleeplessness, sexual disinhibition, unrealistic elevations in self-esteem and surges of energy are also common in the manic phase. People in a manic episode can go for days with little or no sleep (Mash and Wolfe, 2010, Weis, 2008).

At all ages, people with mania showed pressured speech. They talk too fast and too much. They also have racing thoughts and “flight of ideas”, which is a fast, illogical jumping from one idea to another. During this time they can be a danger to themselves and others. They are more likely to take risks, accept dares, and show very poor judgment. In the most extreme cases, people with Bipolar Disorder can become violent and delusional, experiencing visual and/or auditory hallucinations. People with Bipolar Disorder have a high rate of co-occurring disorders that include ADHD, Anxiety, Oppositional Defiant Disorder, Conduct Disorder and Major Depression (Mash and Wolfe, 2010). The onset of this disorder is most commonly seen between the ages of 15-19 years old. Prior to age 10 years old, it is considered rare. Most children have a major depressive episode first. Because teenagers with mania present with a more complex pattern of symptoms, including psychotic symptoms, like

The following factors and recommendations are from the *DM-ID* (pgs.158-163) and should be considered when making judgments about mental illness in people with Developmental Disabilities.

- ☒ Expressive language problems can frequently interfere with an accurate diagnosis of mood disorders in people with an ID. Because of this clinicians should gather information about mood symptoms from multiple sources. This may take more time than is typically required. ☒ Genetic disorders and other syndromes should be identified if possible, as these may give critical clues about mood and behavior.
- ☒ Self-reports of symptoms of anxiety and depression may be difficult to obtain and/or rely on. Most referrals are the result of a display of disruptive behaviors, but mood disorders may involve the absence of behaviors, for example, less smiling or laughing, and more crying.
- ☒ Children and adults with intellectual disability have been noted to present with increased rates of conduct problems, social withdrawal, and irritable mood when depressed.
- ☒ Because people with an intellectual disability have a limited behavioral repertoire, the externalizing behaviors do show up more frequently. Problems with inhibiting behaviors are common and alternative coping strategies are rare.
- ☒ The externalizing behaviors such as screaming, property destruction, aggression and self-injury tend to become the primary focus of families and staff. These intense problems can distract attention from the underlying problem and more relevant symptoms that may actually be driving the disruptive behavior. Caregivers should look for disturbed mood, changes in appetite, poor sleep, pacing or slowness of movement.
- 6. The cognitive symptoms of Mood Disorders (expressions of guilt, hopelessness or suicidal thoughts) may be difficult to assess or may be absent in people with intellectual disability.
- 7. People who cannot report problems may still have them. For example, sleep problems may be present, but if the person is not disruptive, it goes unnoticed.
- 8. Mood symptoms may simply represent a departure from “typical” functioning. These may start out as very subtle changes, but if left unnoticed, they turn into more severe behaviors.
- ☒ Mood disorders frequently co-occur with anxiety. In people with an intellectual disability this may show up as more attention seeking, fearfulness, panic reactions, increased need to be in close proximity to a caregiver or an increase in ritualistic behaviors.

paranoia and hallucinations, a misdiagnosis of schizophrenia might occur (Mash and Wolfe, 2010, Weis, 2008). Cognitive symptoms of mania (i.e. inflated self-esteem or grandiosity) may be affected by the individual's developmental profile and delusions may be simplified. For example, during a manic episode, the person with an intellectual disability may believe she is getting her driver's license. Pressured speech may appear as increased vocalization (rate or volume) or gesturing in individuals who have limited expressive language (DM-ID, p. 162).

THOUGHT DISORDERS

Psychotic symptoms include delusions, hallucinations, and disorganized thinking. People with bipolar disorder can suffer from psychotic symptoms. Some may be misdiagnosed with schizophrenia. Schizophrenia is a severe disorder of the brain expressed by disturbed behavior and abnormal mental functioning. Schizophrenia is characterized by delusions, hallucinations, disorganized thinking, disorganized behavior, and limited emotional expressions. Although bipolar disorder and schizophrenia have some symptoms in common, they are distinct disorders. Bipolar disorder is a mood disorder, and schizophrenia is a thought disorder. With schizophrenia, disorganization of thoughts, perceptions and language are central symptoms. With bipolar disorder, mood disturbances are the central symptoms (Weis, 2008).

Delusions (false beliefs) are erroneous beliefs or misinterpretations of perceptions or experiences (DSM-IV-TR, p. 299). These unrealistic beliefs tend to interfere with day-to-day functioning. For people with bipolar disorder, the delusions may also be mood related, displaying beliefs associated with feelings of euphoria or grandiosity. For people with schizophrenia, the delusions may be associated with distorted and disordered thinking (Weis, 2008). Examples of delusions include persecution, or the belief that someone is out to get them, control, or the belief that others are controlling their thoughts, broadcasting thoughts, or the belief that others can hear their thoughts, and grandiosity, or the belief that they are more powerful, more famous, and more able than they really are (Weis, 2008).

- **hallucinations** (false perceptions) are erroneous or disturbed perceptions, in which things are seen, heard or sensed when in actuality they are not real. Hallucinations represent a break from reality. For people with schizophrenia the most common hallucinations are auditory, but 60% of people with schizophrenia also experience visual hallucinations. (Mash and Wolfe, 2010)



Disorganized thinking shows up as a problem with reasoning, understanding and logic. Children, adolescents, and adults who have this symptom cannot stay on track in a conversation. They appear all over the place, incomprehensible and jumbled (Weis, 2008).

Catatonic Behavior is a symptom of schizophrenia characterized by motor dysfunction ranging from wild agitation to immobility (Mash and Wolfe, 2010). Childhood Onset Schizophrenia must be distinguished from pervasive developmental disorder (PDD). Several factors distinguish children with schizophrenia from children with autism or other PDD. Schizophrenia tends to have a later age of onset, less intellectual impairment in general and less severe social and language deficits. This, however, is not always the case with children with an intellectual disability. With these children, impairments in intellectual, social and language functioning may be present and related to the intellectual disability.

The diagnosis of schizophrenia most commonly involves the presence of positive symptoms such as delusions and hallucinations, but a subtype of schizophrenia, in which negative symptoms are the central feature, is possible. Negative symptoms include a slowing of thinking, speech and movement and an indifference to social contact. These symptoms can appear as a loss of motivation, and although they are less dramatic they are often persistent and difficult to treat (Mash and Wolfe, 2010). They are also extremely difficult to recognize in persons with an intellectual disability.

In order to fully understand the complexity of diagnosing schizophrenia in a person with intellectual disability, several issues must be discussed. First, distinguishing a true hallucination from the "self talk" commonly seen in persons with intellectual disability is essential, but not easy. Second, the symptoms of disorganized speech are easy to identify in a person who is verbally fluent, but difficult to identify in a person who has speech problems resulting from the intellectual disability. Finally, as mentioned previously, distinguishing schizophrenia from

autism or other pervasive developmental disorders is challenging. This is because there is overlap of symptoms such as social withdrawal, odd behaviors, and stereotypes (DM-ID, p. 105). On the other hand, hallucinations can be the easiest symptom to recognize in a person with intellectual disability who has a co-diagnosis of schizophrenia. Careful listening and observation for behaviors suggestive of hearing voices or seeing someone is important. For example, schizophrenia should be considered if a person with an intellectual disability is seen talking in a conversational style when alone or looking around as if listening to or seeing someone. Social withdrawal, together with bizarre or disturbed behavior and/or verbal and physical aggression, are often presenting symptoms of schizophrenia in individuals with intellectual disability (DM-ID, p. 106-107). In individuals with mild intellectual disability, the current DSM-IV-TR diagnostic criteria for schizophrenia appear to be reliable and valid. However, for persons with more severe intellectual disability, establishing this co-diagnosis is often quite difficult. The key to making an accurate diagnosis is careful observation. Family caregivers are often the first to recognize a change from baseline and unusual behaviors in individuals who have intellectual disability.



Clinicians or human service providers who work on a consistent basis with people who have intellectual and or other developmental disabilities should strongly consider purchasing the DM-ID manual.

HOW

HOW is a Dual Diagnosis Established?

This section highlights medical and non-medical causes for behaviors. Charts are included that caregivers and health care providers can use when dual diagnosis is being considered.

The comprehensive evaluation and treatment of behaviors in an individual with a developmental disability can be challenging. It is important to identify whether behaviors are coming from intellectual disability, mental illness, or an interaction between the two. It is very important to consider all possible causes for a behavior, before labeling or dismissing an issue or concern as “behavioral.”

Unfortunately it is not unusual for an individual with an intellectual disability, who in fact should be considered as dual-diagnosed, to be referred to a behavior management program without receiving psychiatric evaluation or treatment. Non-psychiatric medical causes for escalating behaviors are also often overlooked. Undiagnosed pain syndromes such as a dental abscess, constipation, or even mild conditions such as allergy or dry skin can result in challenging behaviors. When psychiatric or medical conditions go undiagnosed, the individual is not given the opportunity to recover. This is because the root of the problem is being overlooked. A thorough assessment is essential to making a diagnosis and to providing effective treatment, services and supports.

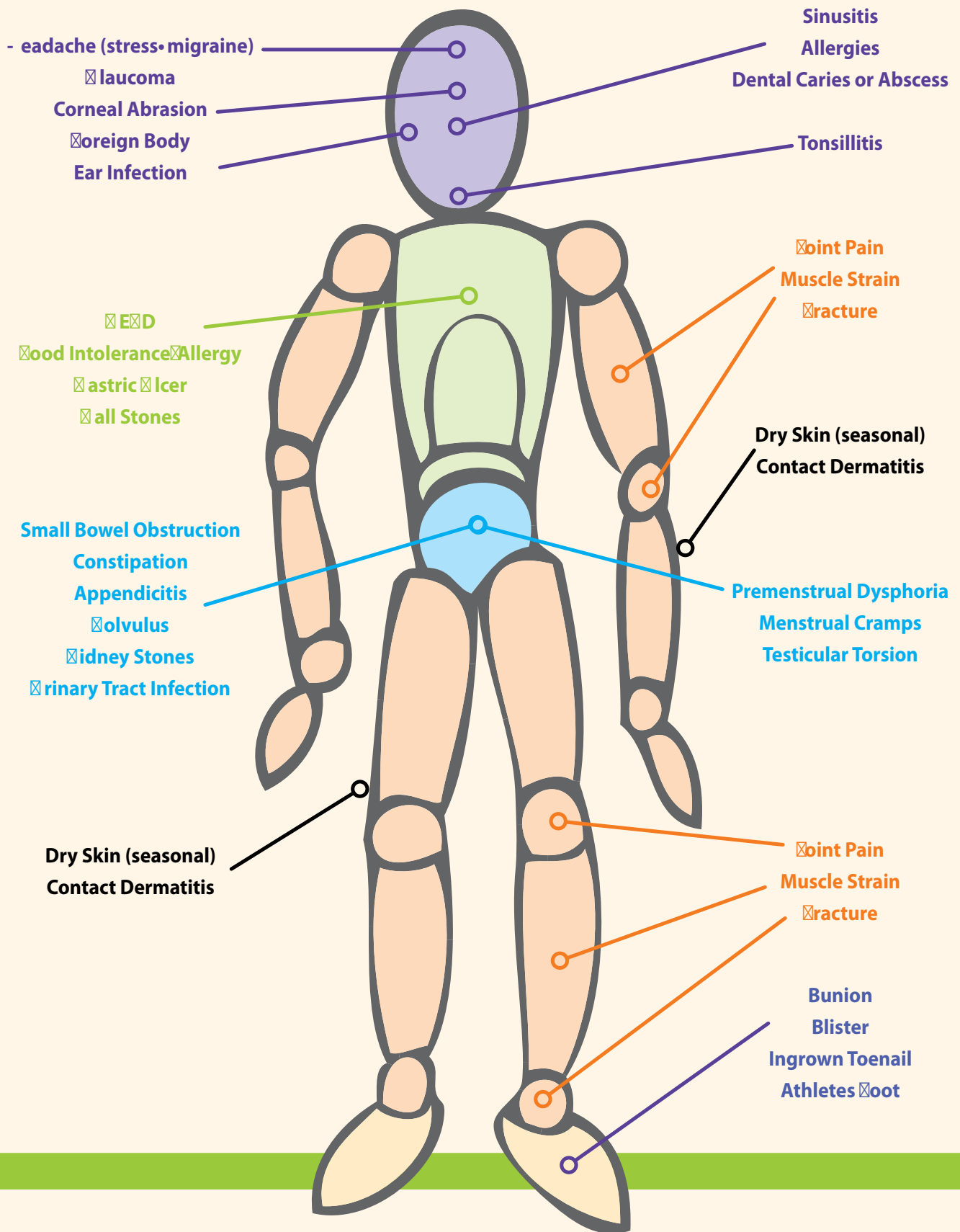
The table on page 16 outlines a strategy for **Comprehensive Evaluation and Treatment of Behaviors in People with Developmental Disabilities**. It lists medical and non-medical factors that should be considered when an individual with a developmental disability has escalating behaviors. This table can be used to guide a diagnostic work-up and to monitor the effectiveness of treatment. A thorough assessment of both physical health and mental health are book-ends to this suggested approach. The table also highlights non-medical causes, such as “learned” behaviors, sensory problems, change in routine, inadequate communication, caregiver stress, and issues related to quality of life. These non-medical factors often contribute to escalating behaviors. However, it is essential to first rule out all possible medical causes, including treatable pain syndromes. The figure on page 17 is a **Body Map of Common Pain Syndromes** that should be considered as part of any thorough medical evaluation of escalating behaviors in a person with a developmental disability.

Comprehensive Evaluation and Treatment of Behaviors in People with Developmental Disabilities

Describe Behavior

Evaluate & Diagnose		Treat
Physical Health Rule out pain syndromes (see body map facing page) <i>Also consider:</i> <ul style="list-style-type: none"> • Medication side effect • Vision/hearing loss • Seizures • Nutritional deficiency • Thyroid disorder • Substance abuse • Sleep disorder • Low blood sugar 		<ul style="list-style-type: none"> • Medical Care
Learned Behavior	Dysfunctional behavior that is “rewarded” with attention or that gets someone out of a non-preferred activity	<ul style="list-style-type: none"> • Functional Behavioral Assessment & Behavior Management Plan • Promote positive behaviors
Sensory Issues	Intolerance to noise level, lighting, crowded situations, temperature, etc.	<ul style="list-style-type: none"> • Sensory diet
Change in Routine	New aide, program, location, transportation, etc.	<ul style="list-style-type: none"> • Visual Schedule • Social Stories • Counseling
Inadequate Communication	Frustration due to inability to communicate effectively	<ul style="list-style-type: none"> • Speech Therapy Evaluation • Augmentative and Alternative Communication (AAC)
Caregiver Stress	<ul style="list-style-type: none"> • Physical exhaustion • Sleep deprivation • Financial stress • Marital distress • Social isolation • Psychiatric condition 	<ul style="list-style-type: none"> • Respite • Counseling • Circle of Support • Medical Treatment • Psychiatric Care
Quality of Life	<ul style="list-style-type: none"> • Social isolation • Lack of exercise • No outdoor activities 	<ul style="list-style-type: none"> • Self Determination • Circle of Support
Mental Health Formal evaluation using Diagnostic Manual-Intellectual Disability (DM-ID): <i>A Clinical Guide for Diagnosis of Mental Disorders in Persons with Intellectual Disability</i> http://www.dmid.org/		<ul style="list-style-type: none"> • Psychiatric Care

Body Map of Common Pain Syndromes



Multiple factors can contribute to any given situation. All potential causes for escalating behaviors should be considered and addressed systematically. “requent re-assessment is essential for accurate diagnosis and comprehensive treatment. This iterative process begins with a detailed description of the behavior of concern using a process called A-B-C charting to identify the cause(s) of a behavior.

A-B-C CHARTING

A-B-C stands for antecedent-behavior-consequence. A-B-C charting begins with the identification of a **target behavior**. This is typically a behavior that has been identified as inappropriate, harmful, or maladaptive and in need of modification. The next step is to look closely at, and systematically keep track of, the **antecedents of the behavior** (what happened just prior to the display of the target behavior) as well as the **consequences of the behavior** (what happens right after a behavior). The consequence is often a powerful reinforcement. A-B-C charting is done over several days and in multiple settings in order to identify a pattern. An **A-B-C chart** is included on page 25. More information about A-B-C charting and **An Overview of Functional Behavioral Analysis** is provided on page 23.

Once a target behavior or pattern of behaviors has been carefully described with A-B-C charting, the **Comprehensive Evaluation Table** on page 16 can be used to systematically consider medical causes and psychiatric causes, as well as non-medical factors that may be contributing to the situation. This systematic and iterative approach can help to answer whether a behavior is related to physical health or mental health, or due to non-medical causes such as “learned” behaviors, sensory problems, change in routine, inadequate communication, caregiver stress, or issues related to quality of life.

Examples for each of the categories from the **Comprehensive Evaluation Table** follow:

PHYSICAL HEALTH

A thorough medical evaluation should always take place when there are escalating behaviors. “irst and foremost it is essential to rule out a pain syndrome and to consider all other potentially treatable medical causes. “or example, hypothyroidism in a person with Down syndrome may look like the symptoms of depression. Common pain syndromes are summarized in the “igure on page 18. Other medical problems that should be considered and ruled out include blood sugar fluctuations, sleep apnea, progressive vision or hearing loss, substance abuse, seizures, and medication side effects. Any person with epilepsy must be closely monitored for drug interactions and/or side effects.

Crystal is a 17-year old young woman with autism. She is usually calm and has a very pleasant disposition. Lately she has been aggressive, spitting on people and drooling more frequently. **A-B-C chart** documents that this is a concern across all settings and with multiple caregivers. Crystal’s school nurse reviews the **Comprehensive Evaluation Table** and the **Body Map of Pain Syndromes** (Figure on page 17) with Crystal’s physician. A thorough physical exam reveals that Crystal has a dental abscess. Once her dentist has treated this, the spitting and self-striking behaviors disappear.

Sheila is a 18-year old non-verbal adolescent with cerebral palsy and vision impairment. A-B-C chart reveals that she is listless after school on the days that she is cared for at her grandparent’s house. Sheila’s physician reviews the **Comprehensive Evaluation Table** with Sheila’s grandparents and considers the possibility that this is due to low blood sugar. This is because Sheila’s grandparents give Sheila her snack at a later time than at Sheila’s after school program. The listlessness resolves when Sheila’s grandparents give her a snack as soon as she gets off the bus from school.

LEARNED BEHAVIOR

It is important to consider what motivates a person to display a specific behavior. Does s/he want the attention of a caregiver or teacher? Does s/he want to get away from something or someone, for example, an academic demand or a bothersome peer? Does s/he want a tangible object, for example, food or a toy? Does s/he do it because it feels good or is self-reinforcing, for example, rocking or hand flapping? A-B-C charting and a functional behavioral analysis can sort this out. A-B-C charting can also document the effectiveness of interventions that promote positive behaviors.

Nick is a 15-year old with intellectual disability who has a tendency to ruminate. He often places his hand in his mouth as a self-reinforcing behavior. **A-B-C chart** reveals that this is a major concern in the hallways at school whenever he transfers between classes. A careful physical exam does not reveal a medical cause other than reflux, which is treated. When the behaviors persist, the school psychologist repeats the functional behavioral analysis and reviews the **Comprehensive Evaluation Table**. A customized behavior management plan is developed for Nick that includes a “competing behavior” that prevents him from putting his hands in his mouth when he walks in the hallway. The solution is simple: Nick is given a backpack to carry between classes. He no longer puts his hands in his mouth, because his hands are needed to carry the backpack. Because this intervention has been so successful, the school psychologist expands this approach by asking Nick to carry the mailbag and deliver mail to classrooms throughout the building. Nick is proud to be given this responsibility. The self-gagging behavior fades. The intervention not only solves the “problem” it also promotes positive behaviors!

SENSORY ISSUES

People with developmental disabilities may process sensory input in different ways. Certain sounds or lighting situations may be intolerable to some. Others may seek sensory input by rocking or spinning. An occupational therapist can identify strategies to minimize these responses. An occupational therapist can also identify ways to adapt the environment so that it is more tolerable to the individual.

Amy is a 21-year old woman with autism who has difficulty adjusting to her new day habilitation program. Amy’s father and an occupational therapist from the DDSO use **A-B-C charting** to identify the cause. Amy needs time at the beginning of the day for a vigorous walk and 5-10 minutes in her swing. This is not currently part of the routine at the new day habilitation program. Without this sensory input it is difficult for Amy to focus on other activities. The occupational therapists arranges for the installation of an adapted swing at the day habilitation program. She also talks with the day habilitation staff about the importance of having a sensory “diet” for Amy that includes vigorous walking and swing time at the beginning of the day. Once the sensory diet has been implemented, Amy is better able to participate in structured activities at the day habilitation program.



CHANGE IN ROUTINE

It is common for adolescents to become attached to a favorite one-on-one aide or teacher, and natural for parents to request continuity with staff from year to year. However, young adulthood inevitably bring about a change in routine, due to staffing changes in high school, or upon graduation, when the structure and social context of high school disappears. Anxiety and depression, and/or a deterioration in behaviors can result. Pro-active caregivers and school teams can avoid this very understandable situation by giving adolescents and young adults opportunities to “try out” other settings or routines well before high school graduation. Examples include after school programs, summer camp, overnight stays with relatives, or weekend retreats. These experiences give teens the opportunity to demonstrate both to themselves, and to others, that they are able to handle change. Practice builds confidence. Communication between middle and high school teams, or between high school teams and day-habilitation staff is essential when major shifts in daily routines take place. Social stories, counselling, and giving youths the opportunity to visit, share photos, or otherwise stay in touch and relay their new experiences with a favorite teacher or aide helps to normalize the transition process.

Matthew is a 15 year old with autism who recently transferred from middle school to high school. Matthew’s mother notes that her behaviors have been “off the wall”. School staff are considering placement in a BOCES program, rather than the local high school. After physical and psychiatric causes have been ruled out, Matthew’s mother enlists the help of an educational advocate from a local agency to help sort out the situation. The educational advocate suggests that the team from Matthew’s middle school meet with Matthew’s high school team. This face-to-face meeting is very helpful for all involved. Matthew’s 1 : 1 Aide in particular has helpful suggestions for communication and for staving off behavioral outbursts. The school psychologist suggests that the high school team use picture sequences that were created for Matthew at her middle school. The “social stories” that these picture sequences convey help Matthew to better understand, anticipate, and adjust to high school routines. Weekly conference calls between the middle school and high school staff are scheduled until Matthew’s “off the wall” behaviors resolve. The school district decides to implement weekly conferences with the middle school team pro-actively for all incoming high school students who have autism.

INADEQUATE COMMUNICATION

The field of augmentative and alternative communication, and advances in universal design of communication technologies has opened up new avenues for expressive communication for people with developmental disabilities who are affected by autism, specific learning disabilities, apraxia, dysarthria, cerebral palsy and other motor disabilities. It is always important to consider the possibility that an escalating behavior in a person with a developmental disability is simply due to frustration with the limitations of the communication repertoire that is available to that person. The treatment for this situation does not involve medications or behavioral supports. The appropriate approach is a thorough assessment by a qualified augmentative and alternative communication team, and the implementation of a systematic communication plan.

Christopher is a 15 year old adolescent with cerebral palsy who is seen by his physician because he repeatedly bites his wrist. A-B-C charting helps to identify a potential cause: the biting behavior began when the wheelchair mount for his voice output device required repair. In addition, the physician observes that, due to spasticity, Christopher’s elbows are often flexed, such that his wrist is constantly near his mouth. In addition to prescribing medications to treat the spasticity, and recommending a new wheelchair, the physician also writes a prescription for an “Augmentative and Alternative Communication Evaluation”. The speech therapist at school sets up an evaluation with a team that includes a communication specialist, an occupational therapist, and a physical therapist. Eye gaze technology is identified as the most appropriate type of communication device by this “AAC team”. The wrist biting behaviors fade when Christopher has ready access to this communication device.

CAREGIVER STRESS

It is always important to consider family context whenever a person with a chronic condition has an acute change in physical, behavioral, or mental health status. This applies to people with developmental disabilities as well, since many rely on family caregivers to help with day-to-day routines. If a parent or sibling is unable to perform this role for any variety of reasons, the person with a developmental disability may present with behaviors, physical concerns, non-adherence to medications, or a change in hygiene. It is important to ask parents and siblings about caregiver stress, and to provide caregiver support when it is needed. Caregiver stress is predictably greater during times of transition, such as a move to a new home, or when there are unexpected medical complications. These changes do not necessarily directly involve the person with a developmental disability, but can have a significant impact on the ability of family caregivers to provide support.

David is a 16 year old adolescent with Fragile X Syndrome who is brought to the emergency room repeatedly on weekends. His mother brings him in because she states that he has violent outbursts. A-B-C charting reveals that these outbursts occur at home but not at school. David becomes very anxious in the emergency room, acts out, and typically is heavily medicated before eventually being sent back home. An astute social worker spends time with David's mother during one of these ED stays, and discovers that the mother has a psychiatric condition for which she has stopped taking medications. The social worker follows up with the family to make sure that David's mother is receiving the psychiatric care that she needs. The social worker also increases David's respite hours, thereby providing "care for the caregiver" so that David's mother can recover her health. The frequent emergency room visits stop when the underlying cause is identified and treated.

POOR QUALITY OF LIFE

Consideration of quality of life is central to any approach when caring for a dually diagnosed person. Quality of life expectations (such as outdoor recreation and meaningful social interactions) should be the same for everyone in our society. The needs of people who are dually diagnosed are essentially the same. However, quality of life needs of people with dual diagnosis often become medicalized. The medical model, though essential in treating the symptoms of the mental illness, does not take into consideration the underlying issue so commonly seen in the dually diagnosed, which is a lack of access to quality of life spheres.

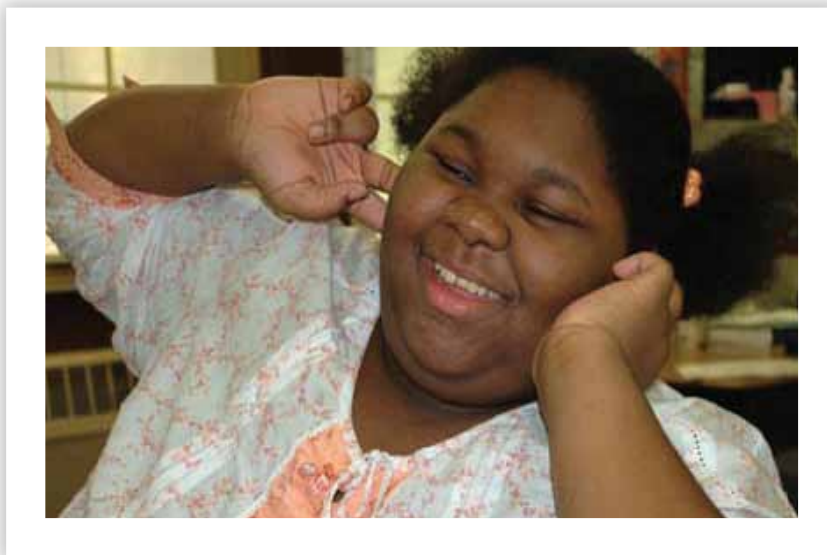
Michael is a legally blind 28-year old with intellectual disability who attends a day habilitation program during the week. He is home with his father on the weekends. Michael's father is concerned that Michael has begun to ruminate. This is an unusual behavior for his son. After a careful physical exam has ruled out medical and psychiatric causes, Michael's father discusses his concern about rumination with Michael's service coordinator. Together they visit the day habilitation program. They discover that Michael never has the opportunity to be outdoors at this day habilitation program. Light and sunshine has always been very important to Michael. Because the day habilitation program does not have adequate outdoor facilities, Michael's service coordinator arranges for Michael and his father to visit several other day habilitation programs, including one that is located on a farm that offers daily outdoor activities throughout the four seasons. In addition, Michael's service coordinator identifies a recreation therapist to develop a range of outdoor activities for Michael. The rumination becomes a non-issue almost immediately.

MENTAL HEALTH

Questions about mental health in both the person and his or her family should be part of the intake history of persons who are developmentally disabled, particularly in light of the high prevalence of dual diagnosis in this population. Intake forms should have specific questions about mental illness that are routinely asked. As noted previously, the *Diagnostic Manual –Intellectual Disabilities (DM-ID)* is a comprehensive clinical guide for health care professionals that offers diagnostic criteria for mental illness adapted for patients who have intellectual disability. The *Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD)* is a questionnaire that caregivers can use to identify mental illness. These are two important resources for identifying mental illness in people with developmental disabilities. What makes dual diagnosis challenging, however, is accurately separating out “behaviors” attributable to developmental disability from symptoms of psychiatric illness.

Alicia is a 21 year old woman with Down Syndrome who has developed a habit of twirling her hair. This has escalated such that she has several bald spots. Parents are also concerned because Alicia is repeating phrases, talking to herself more, and ruminating about her boyfriend. Mother describes Alicia as having “looping thoughts” about whether Alicia’s boyfriend will come to visit on certain days of the week. A-B-C charting reveals that the hair twirling interferes with Alicia’s performance at work. Alicia’s physician reviews the DM-ID criteria for the diagnosis of anxiety disorders in persons with intellectual disability, and prescribes a medication for obsessive compulsive disorder. Counseling is provided via the DDSO. At the follow-up visit 6 weeks later, Alicia’s mother states that all of the symptoms have “melted away”.

The vignettes listed above are examples for each of the diagnosis categories included on the Comprehensive Evaluation Table. This table is designed to help caregivers and health care providers to think carefully about all possible causes for escalating behaviors. It is important to keep in mind that behaviors can be multi-factorial in origin. Systematic consideration of each of the categories listed on the table, and frequent re-assessment with A-B-C charting is key to this iterative approach.



An Overview of Functional Behavioral Analysis

Adapted from the Center for Effective Collaboration and Practice: <http://cecp.air.org/fba>

Functional Behavior Assessment (FBA) is a tool for identifying the cause of a behavior. FBA uses a systematic approach called A-B-C charting. A-B-C stands for antecedent-behavior-consequence. A-B-C charting begins with the identification of a **target behavior**. This is typically a behavior identified as inappropriate, harmful, or maladaptive and in need of modification. The next step is to look closely at, and systematically keep track of, the **antecedents** of the behavior (what happened just prior to the display of the target behaviour) as well as the **consequences** of the behavior (what happens right after a behavior). The consequence is often a powerful reinforcement. Functional Behavioral Assessment is done over several days and in multiple settings, in order to identify a pattern. A-B-C charting can answer questions such as:

- What motivates a person to display a specific behavior?
- Does s/he want someone's attention, for example, a caregiver or the teacher?
- Does s/he want to get away from something or someone, for example, an academic demand or a bothersome peer?
- Does s/he want a tangible object, for example, food or a toy?
- Does s/he do it because it feels good or is self-reinforcing, for example, rocking or hand flapping?

The functional assessment of behavior provides hypotheses or informed guesses about the relationships between specific environmental events and behaviors. The FBA is used to identify the type and source of reinforcement for challenging behaviors as the basis for intervention efforts designed to decrease the occurrence of these behaviors or to replace them with more positive, prosocial ones. Both positive and negative behaviors can be reinforced.

The FBA technique allows a teacher, psychologist, physician, or parent to hypothesize on the motivation of the behavior. For example, if a calm child is put into a car seat and starts to scream, what is the caregiver's response? If the caregiver removes the child and the child calms down, then the hypothesis can be made that the child wanted to "escape" the car seat and used the screaming behavior to convey that. If the caregiver leaves the child in the car seat, but is able to calm the child with talking, then the hypothesis is that the child wanted the caregiver's attention and used screaming to get it. The same target behavior, screaming, can come from very different motivations. In the case of escape, the caregiver needs to look closely at the comfort of the car seat or perhaps fear as an explanation. If the child simply wants the caregiver's attention, then helping the child to get attention in a more appropriate way might be the intervention. The FBA is an excellent tool to help figure this out.

FBA utilizes direct observation of behavior under naturally occurring conditions. The ABC (antecedent-behavior-consequence) approach described above is used to record observed target behavior and any events that immediately precede and follow the target behavior across multiple settings and over several days.

The **Indirect FBA** is a method that uses structured interviews, checklists, rating scales, or questionnaires to obtain information from persons who are familiar with the person exhibiting the behavior. The intent is to identify possible conditions or events in the natural environment that correlate with the problem behavior. It is called "indirect" because it does not involve direct observation of the behavior. The Indirect FBA is based on others' recollections of the behavior. There are pros and cons to using an Indirect FBA rather than a traditional FBA and A-B-C charts. The positive aspect is that it can provide useful information and can contribute to the hypothesis. The negative aspect of the indirect technique is that informants are not always able to recall events with accuracy. Memory can fade with time.

INTERVENTIONS BASED ON AN FUNCTIONAL BEHAVIORAL ANALYSIS

Understanding the function of a behavior is critical to changing it. A thorough review of the information gathered allows for a systematic analysis of the behavior. A treatment plan based on how environmental factors influence behavior can then be developed.

The function of a given behavior typically falls under one of four motivations:

- to gain attention
- to escape a demand
- to obtain a tangible reward
- for self stimulation

Some of the interventions that result from this type of approach involve teaching specific communication skills to replace the problem behavior, as well as specifically managing the setting and/or the consequences for a behavior. A whole curriculum referred to as **Positive Approaches to Behavior Change** has evolved out of this type of analysis (Carr et. al. 2002). This approach differs from pathology-based models for evaluating and treating behaviors because the emphasis is on prevention and the focus is on personal competence, self-determination, and the participation of all stakeholders.

The **Center for Effective Collaboration and Practice** (CECP) has an excellent website, <http://cecp.air.org/fba/>, that offers a complete set of instructions for doing a Functional Behavioral Analysis as well as interview forms that can be used to do an Indirect FBA. This website also has instructions for creating positive behavior plans and supports.



A-B-C Chart

Antecedent-Behavior-Consequence Chart Instructions

Write down when and where behaviors occur, and what happens right before and right after a behavior. do this for several days and in a variety of settings. The A-B-C chart can help to identify whether there is a pattern to the behaviors.

DATE/TIME	SETTING	WHAT HAPPENS RIGHT BEFORE	BEHAVIOR	WHAT HAPPENS RIGHT AFTER

WHERE

WHERE

Can I Go to Learn More?

This section lists state and national web resources relevant to dual diagnosis. These websites are organized by topics that correspond to the table on page 16: **Comprehensive Evaluation and Treatment of Behaviors in People with Developmental Disabilities**

PHYSICAL HEALTH

NYS Office for People with Developmental Disabilities: <http://www.opwdd.ny.gov/>

The New York State Office for People with Developmental Disabilities (OPWDD) provides services and supports for people with developmental disabilities across the lifespan.

NYACTS: <http://www.nyacts.org/>

NYACTS is an initiative of the New York State Office for People with Developmental Disabilities (OPWDD) for adults and children on the autism spectrum. The NYACTS website is a portal to help families access services and supports for people with autism throughout the lifespan.

American Academy of Cerebral Palsy and Developmental Medicine: <http://www.aacpdm.org/>

Provide multidisciplinary scientific education for health professionals and promote excellence in research and services for the benefit of people with cerebral palsy and childhood-onset disabilities.

American Academy of Developmental Medicine and Dentistry: <http://www.aadmd.org/>

The American Academy of Developmental Medicine and Dentistry (AADMD) was organized in 2002 to provide a forum for healthcare professionals who provide clinical care to people with neurodevelopmental disorders and intellectual disabilities (ND/ID). The mission of the AADMD is to improve the overall health of individuals with ND/ID through patient care, teaching, research and advocacy.

The Arc: <http://www.thearc.org/page.aspx?pid=2530>

The Arc is the premier provider of supports and services for people with intellectual and developmental disabilities and has a demonstrable record of success in achieving the outcomes people want for their lives. The Arc believe that people with intellectual and developmental disabilities are entitled to the rights afforded every American and that they demand to be included and participate as full members of the community. Our chapters are vital in providing the supports and services crucial to achieving these goals.

Autism Speaks: <http://www.autismspeaks.org/index.php>

Autism Speaks was founded in February 2005 by Bob and Suzanne Wright, grandparents of a child with autism. Since then, Autism Speaks has grown into the nation's largest autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. We are proud of what we've been able to accomplish and look forward to continued successes in the years ahead.

Family Village: <http://www.familyvillage.wisc.edu/Specific.htm>

Family Village is a web portal that provides links to condition-specific organizations that provide information on health care for a wide variety of developmental and genetic diagnoses.

United Cerebral Palsy: <http://www.ucp.org/>

One of the largest health nonprofits in the U.S., the UCP mission is to advance the independence, productivity and full citizenship of people with disabilities through an affiliate network. This includes approximately 100 local service providers, known as “affiliates,” reaching more than 176,000 individuals and their families daily in the U.S., Australia, Canada, and the U.K. (Scotland).

LEARNED BEHAVIOR

Center for Effective Collaboration and Practice: <http://cecp.air.org/fba>

The Center for Effective Collaboration and Practice (CECP) offers a complete set of instructions for doing a Functional Behavioral Analysis as well as interview forms that can be used to do an Indirect FBA. This website also has instructions for creating positive behavior plans and supports.

Capacity Works: <http://www.capacityworks.com/about.html>

Through the years, Beth Mount’s artwork, publications, and posters have served to inspire us all to realize that every person with a disability is a valuable and productive member of community life. The impact of Beth’s 30 year body of work has been extensive and is known throughout the world. Her work has been instrumental in helping people to find meaning in supporting people with disabilities to build their lives.

SENSORY ISSUES

National Consortium on Deaf-Blindness: <http://nationaldb.org/>

Excellent resource for information on communication approaches that can be used with people who have sensory impairments and/or who have multiple disabilities.

Sensory Processing Disorder Foundation: <http://www.sinetwork.org/>

SPD Foundation offers an abundance of services and programs for professionals, parents, and anyone interested in knowing more about the sensory challenges that affect children academically, socially, and/or in their emotional development

CHANGE IN ROUTINE

Gray Center Social Stories: <http://thegraycenter.org/social-stories>

A Social Story™ describes a situation, skill, or concept in terms of relevant social cues, perspectives, and common responses in a specifically defined style and format. The goal of a Social Story™ is to share accurate social information in a patient and reassuring manner that is easily understood by its audience. Half of all Social Stories™ developed should affirm something that an individual does well. Although the goal of a Story™ should never be to change the individual’s behavior, that individual’s improved understanding of events and expectations may lead to more effective responses.

INADEQUATE COMMUNICATION

Communication Matrix: <http://www.communicationmatrix.org/>

An easy to use assessment instrument designed for individuals of all ages who function at the earliest stages of communication and who use any form of communication.

National Consortium on Deaf-Blindness: <http://nationaldb.org/>

Excellent resource for information on communication approaches that can be used with people who have sensory impairments and/or who have multiple disabilities.

CAREGIVER STRESS

Parent to Parent of New York State: <http://www.parenttoparentnys.org/>

Parent to Parent of New York State is a place where families of individuals with special needs and the professionals who serve them can meet and share information.

National Alliance for Caregiving: <http://www.caregiving.org/>

Established in 1996, **The National Alliance for Caregiving** is a non-profit coalition of national organizations focusing on issues of family caregiving. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, a government agency, and corporations.

QUALITY OF LIFE

Capacity Works: <http://www.capacityworks.com/about.html>

Through the years, Beth Mount's artwork, publications, and posters have served to inspire us all to realize that every person with a disability is a valuable and productive member of community life. The impact of Beth's 30 year body of work has been extensive and is known throughout the world. Her work has been instrumental in helping people to find meaning in supporting people with disabilities to build their lives.

NYS Inclusive Recreation Resource Center: <http://www.nysirrc.org/about.html>

The mission of the NYS Inclusive Recreation Resource Center is to promote and sustain participation by people with disabilities in inclusive recreation activities and resources throughout the state.

Independent Living Centers: <http://www.acces.nysed.gov/vr/lsn/ilc/about.htm>

Independent Living Centers (ILCs) provide an array of services that assist New Yorkers with disabilities to live integrated and self-directed lives. ILCs assist with living learning and earning remove barriers to full participation in to the local community and beyond. ILCs are private, not-for-profit organizations, governed by a majority of people with disabilities and staffed primarily by people with disabilities. ILCs are resource centers that do not run residential programs or operate places where people live. The philosophy of independent living is to maximize opportunities for choices and growth through peer driven supports and self-help. ILCs are the voice of people with disabilities and the disability rights movement in local communities across New York State. Peer counseling is available at most Independent Living Centers.

Self Advocacy Association of New York State: <http://www.sanys.org/>

SANYS is a grassroots network for people with developmental disabilities that has regional chapters throughout New York State.

MENTAL HEALTH

Textbook of Diagnosis of Mental Disorders in People with Intellectual Disability (DM-ID): <http://www.dmid.org/>

The National Association for the Dually Diagnosed (NADD), in association with the American Psychiatric Association (APA), developed a Manual that is designed to be an adaptation of the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition-Text Revision (DSM-IV-TR). The title of this Manual is the Diagnostic Manual — Intellectual Disability (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability. Grounded in evidence based methods and supported by the expert-consensus model, Diagnostic Manual — Intellectual Disability (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability offers a broad examination of the topic, including a description of each disorder, a summary of the DSM-IV-TR diagnostic criteria, a review of the literature and research and an evaluation of the strength of evidence supporting the literature conclusions, a discussion of the etiology and pathogenesis of the disorders, and adaptations of the diagnostic criteria for the ID population. A shorter volume, Diagnostic Manual — Intellectual Disability (DM-ID): A Clinical Guide for Diagnosis of Mental Disorders in Persons with Intellectual Disability has been abridged for clinical usefulness. It focuses on issues related to diagnosis in people with ID, the limitations in applying DSM-IV-TR criteria to people with ID, and adaptation of the diagnostic criteria.

NADD developmental disability and mental health needs: <http://www.thenadd.org/>.

NADD is the leading North American expert in providing professionals, educators, policy makers, and families with education, training, and information on mental health issues relating to persons with intellectual or developmental disabilities.

NYS Office of Mental Health: <http://www.omh.state.ny.us/>

The New York State Office of Mental Health operates psychiatric centers across the State, and also regulates, certifies and oversees more than 2,500 programs, which are operated by local governments and nonprofit agencies. These programs include various inpatient and outpatient programs, emergency, community support, residential and family care programs.

NYACTS: <http://www.nyacts.org/>

NYACTS is an initiative of the New York State Office for People with Developmental Disabilities (OPWDD) for adults and children on the autism spectrum. The NYACTS website is a portal to help families access services and supports for people with autism throughout the lifespan.

NYS Office of Children and Family Services: <http://198.22.236.25/main/>

The New York State Office of Children and Family Services (OCFS) provides a system of family support, juvenile justice, child care and child welfare services that promote the safety and well-being of children and adults. OCFS is responsible for programs involving foster care, adoption, child protective services, preventative services for children and families, services for pregnant adolescents, and protective programs for vulnerable adults. OCFS is also responsible for the functions performed by the State Commission for the Blind and Visually Handicapped and coordinates state government response to the needs of the Native Americans on reservations and in communities.

NYS Association of Psychiatric Rehabilitation Services: <http://www.nyaprs.org/> NYAPRS

A statewide coalition of people who use and/or provide recovery oriented community based mental services. They value difference and promote cultural competence in all aspects of their work. NYAPRS is dedicated to improving services and social conditions for people with psychiatric disabilities or diagnoses, and those with trauma-related conditions by promoting their recovery, rehabilitation and rights so that all people can participate freely in the opportunities of society.

NYS Chapter of National Alliance on Mental Illness: <http://www.naminys.org/>

NAMI-NYS is the state organization of the National Alliance on Mental Illness, the nation's largest grassroots organization for people with mental illness and their families. NAMI-NYS provides support to family and friends of individuals with mental illness and persons living with mental illnesses through more than 50 affiliates statewide. The website for the National Alliance on Mental Illness is: <http://www.nami.org>

NYS Developmental Disabilities Planning Council: <http://ddpc.ny.gov/>

The New York State Developmental Disabilities Planning Council is a Federally-funded New York State Agency working under the direction of the Governor's Office. The DDPC is responsible for developing new ways to improve the delivery of services and supports to New Yorkers with developmental disabilities and their families. The Council focuses on community involvement, employment, recreation and housing issues faced by New Yorkers with developmental disabilities and their families.

M- A Mental Health Association in NYS: <http://www.mhanys.org/index.php>

MHANYS and its affiliate network work to promote mental health and recovery, encourage empowerment in mental health service recipients, eliminate discrimination, raise public awareness with education, and advocate for equality and opportunity for all. MHANYS works to ensure available and accessible mental health services for all New Yorkers. Website for the national Mental Health Association: <http://www.nmha.org>

NYS Rehabilitation Association: <http://nyrehab.org/Index.cfm>

The mission of the NYS Rehabilitation Association is to provide leadership and advocacy on multiple matters of public policy on behalf of community rehabilitation providers, and to work with individuals with differing abilities and other consumers to improve and enhance rehabilitation and educational services throughout the State; Inform, educate, and support NYSRA members in their efforts to offer a diverse spectrum of services and employment opportunities to consumers; and Support and promote policy and other initiatives that will help integrate and mainstream people with differing abilities into the community.

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