A significant number of individuals engage in problem behaviors that are not linked to social or environmental functions. When a teacher fails to identify clear signs that environmental variables are influencing problem behavior, it is possible that biological factors may play a part in the occurrence of problem behavior. This article will:

- Provide an introduction to the ways in which biologically-based issues affect problem behavior;
- Explain the difficulties involved in the diagnosis of mental illness in individuals with developmental disabilities;
- Discuss important issues related to psychotropic medications;
- Describe how interdisciplinary teams work together to conduct a functional assessment and develop intervention strategies.

**Major Theories Explaining Physiologically Maintained Problem Behavior**

Physiological factors can change the way an individual responds to his or her environment. How internal events increase and decrease behavior can be explained in a variety of ways. In some situations, physiological events increase the likelihood that a person will engage in problem behavior.

*Setting Events*. When an event temporarily changes the effectiveness of a reinforcer or a punisher, it is referred to as a setting event. Unpleasant physiological states such as headaches or allergies can change the way an individual responds to his work. When a person is feeling well, activities at work are enjoyable and requests are completed cheerfully. When feeling unwell, however, an individual may respond to his work by losing his temper or leaving the workplace. Clearly, physiological setting events can have an impact on a person’s behavior.

*Antecedents*. In other situations, increases in biological responses or physiological arousal may be an antecedent event that immediately precedes the occurrence of problem behavior. Highly anxious individuals may be more likely to engage in aggression or self-injury when their heart rate and breath rate have increased. In addition, increases in physiological arousal levels can be associated with certain situations or settings. An environmental event paired with a physiological reflex response can result in respondent learning or conditioning.

**Example**

A woman with developmental disabilities has had a humiliating experience riding the bus on the way to work. Several children teased the woman because of the way she looks. Her emotional response during this interaction resulted in an increase in heart rate, sweating, and strong feelings of anger and embarrassment. The next day when the woman approached the bus, she immediately experienced the same physiological responses of increased heart rate and sweating,
even though the children weren’t present.

An emotional response to a significant event or one that occurs repeatedly can result in just the presence of stimuli associated with the event (in this example the bus) producing the emotional response. This pairing is known as respondent learning (also known as classical conditioning). This emotional response is often associated with problem behavior and may affect how a person responds down the road when a similar situation or event occurs or stimuli that were paired with the previous event are present (e.g. the bus).

Three additional theories explain how physiology and problem behavior may be related. These theories are often discussed in the context of self-injurious and stereotypic behavior.

Sensory stimulation. The first theory refers to behaviors that are maintained by sensory stimulation. For instance, some individuals frequently press or obstruct a main blood vessel in the neck because of the resulting pleasurable sensation. A visually impaired individual may press on or poke his eyeball, which results in internal visual sensations. Other examples include rubbing, twirling, or mouthing objects. Some individuals may regurgitate food (referred to as rumination). Any repetitive behavior that occurs often enough can result in physical injury, and thus become self-injurious behaviors.

Homeostatic theory. Some experts believe that self-injury and other repetitive behaviors increase when a student experiences either very low or very high levels of stimulation in an environment. Homeostatic theory proposes that a certain level of stimulation may be optimal for an individual. Stereotypic behaviors may provide an individual with a way to compensate for under or over stimulating environments and maintain a certain level of internal stimulation or homeostasis. Environments that do not give individuals the opportunity to engage in social interactions or other types of engaging activities may result in the person increasing the frequency of stereotypic behavior. On the other hand, loud or stressful settings could increase self-injurious or stereotypic behavior if the person is trying to reduce the degree of stressfulness of the environment.

Organically influenced. Other biological factors can also affect problem behavior. Research on self-injurious behavior has focused on the release of endogenous opiates, a natural morphine-like substance that the body manufactures. Endogenous opiates are often described by athletes as a "runner's high" since endogenous opiates are released during intense exercise. Some research suggests that individuals who engage in self-injury may be experiencing a release of endogenous opiates. One way that this has been studied is to administer a drug that blocks the release of endogenous opiates (e.g., naltrexone) and observing any subsequent changes in self-injurious behavior.

Organic factors also include medical syndromes involving genetic disorders. Lesch-Nyhan, Rett, and Cornelia de Lange syndromes are often associated with severe self-injury. Individuals diagnosed with Prader-Willi syndrome have insatiable feelings of hunger that in extreme
situations can result in a ruptured stomach due to overeating. For many people with this syndrome, problem behavior can occur when access to food is blocked. If the team suspects a previously undiagnosed genetic syndrome is associated with problem behavior, a referral for a medical evaluation may be warranted.

Physical Health Issues and Problem Behavior

A routine physical examination is an important first step in the functional assessment process if an individual has not recently been to a physician or if you suspect there may be an undiagnosed medical issue. Assessing the status of an individual's physical health before conducting functional assessment and behavior intervention plan can decrease the need for more intensive intervention approaches when problem behaviors are related to pain or discomfort due to an acute or chronic medical condition. Problem behaviors can be influenced by many types of acute or chronic illnesses that result in pain or discomfort.

Common Acute & Chronic Medical Issues Associated with Problem Behavior:

- Allergies
- Illness
- Sore throat
- Pain
- Medications
- Urinary tract infection,
- Sinus problems
- Otitis media (middle ear infection)
- Constipation
- Injuries
- Gastrointestinal problems
- Menstrual cycle

For instance, a number of research studies have reported that middle-ear infections, also referred to as otitis media, are correlated with self-injury. Self injurious behavior such as head banging or ear poking may reduce or displace the pain associated with a middle-ear infection. This has been observed in both individuals with developmental disabilities as well as typically developing young children. Urinary tract infections, sinus problems, allergies, or sore throats are just a few examples of infections that may be associated with problem behavior. Painful internal experiences can be related, not just to self-injury, but to aggression and other problem behaviors as well.

Problem behaviors that increase and decrease in a cyclical manner may be maintained by underlying physiological factors. One of the more common examples of this cyclical pattern is related to the menstrual cycle.
Carr and his colleagues (1996) systematically investigated the daily frequency of aggression of several women during a set time period each morning. They found that in one case, demand statements preceded 98% of aggressive episodes. In other words, painful menstruation was a setting event that increased the probability of an antecedent (demand statements) resulting in problem behavior. 


Sleep deprivation is another factor often associated with increases in problem behavior. Research reports that 35% of individuals with developmental disabilities experience sleep disorder compared to 12% experienced by individuals without disabilities. Twenty to thirty percent of children of all abilities from ages one to four years old experience sleep disturbances.

Over the counter and prescription drugs can have an impact on behavior by temporarily changing the reinforcing value of everyday activities. Individuals taking medications for health or psychiatric reasons often experience side effects such as drowsiness, nausea, constipation, dizziness, stomach problems, and other unpleasant physiological events. These adverse effects of medication can become more intense due to improper dosage administration, interaction effects with other drugs, and changes in diet.

Dietary intake is an important consideration when an individual is taking medication for any reason. Poor nutrition changes how the body responds to or metabolizes medication by increasing side effects or negative drug interactions. Certain types of medications compromise the body’s ability to utilize nutrients. Stimulants such as methylphenidate (Ritalin®) and d-amphetamine (Dexedrine®) decrease appetite or change the way some foods taste. Being aware of issues related to medication and diet during the functional assessment may alert you to these types of issues and result in interventions that will increase the quality of life for the person you are supporting. More information about prescribed medication and its management will be presented in detail later in this module.

The last issue to consider when discussing health issues related to problem behavior is addiction to legal and illegal drugs. Addiction to both legal and illegal drugs changes an individual's physiological state and can be related to problem behavior. Unpleasant internal sensations due to the withdrawal of an addictive drug such as caffeine or nicotine can be setting events for problem behavior. In one research study, the amount of caffeine ingested by individuals with disabilities was documented and the frequency of problem aggression was observed. There was a correlation between the amount of coffee ingested and an increased frequency in problem behavior. As a result of this finding, regular coffee was replaced with a decaffeinated brand. The study reported a decrease in aggressive behavior when the decaffeinated coffee was introduced.
Diagnosing Psychiatric Disorders in Individuals with Developmental Disabilities

In the past, when a person had the diagnosis of a developmental disability and a psychiatric disorder, they were labeled as "dually diagnosed." This term is not used as much anymore because it implies that the two are separate, unrelated disorders, when in fact there may be a great degree of overlap. One thing is clear, however, people with developmental disabilities are subject to the same mental health problems as other typically developing individuals, including major depressive disorder, anxiety disorders, and schizophrenia. There is evidence that the occurrence of depression, eating disorders, and psychosis are about the same in both typical and developmentally disabled individuals. In fact, it may be true that there is a higher incidence of certain psychiatric disorders in individuals with developmental disabilities than in the population at large. For example, children and adolescents with developmental disabilities are more likely to be diagnosed with conduct disorder, anxiety disorder, and pervasive developmental disorders than typically developing children.

Physicians and psychiatrists often use the same diagnostic procedures and instruments with individuals with mild cognitive impairments as they do with typically developing individuals. The interview process or the questionnaires sometimes need to be adapted, but individuals with mild cognitive limitations often can accurately describe their feelings, concerns, and physical ailments. It is important to remember, however, that with this group of individuals as with children or other vulnerable populations, it is important to corroborate verbal reports with other behaviors or observations. For example, a child may find the attention from the doctor or school counselor reinforcing and may "enhance" his report of feeling depressed to obtain extra attention. In this situation, it may be important to look for other symptoms of depression such as a change in diet or sleeping habits to help determine whether the child has depression or not.

Diagnosing psychiatric disorders can be even more difficult when working with individuals with more severe cognitive impairments. How do you determine whether a person with mental retardation has a psychiatric disorder if you are not able to measure symptoms that are based on reliable verbal report? In addition, are the criteria described in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) published by the American Psychological Association (1994) directly applicable to individuals with developmental disabilities? There are several important issues to sort out when diagnosing psychiatric disorders that may need to be considered.

First, there are issues related to the behavior problems themselves that may make diagnosis difficult. For example, a person who is able to provide some information about the way he or she is feeling, both physically and mentally, may be unwilling to do so. If a person is unwilling to answer questions or give personal information, does this mean that he or she has Oppositional Defiant Disorder? More importantly, what would those symptoms tell you about other, possibly unrelated disorders? For example, a person who experiences hallucinations or is suffering from paranoia may not want to give the doctor information about their symptoms for fear that they
will be hospitalized or given unwanted medical interventions.

Second, many physicians, particularly those less familiar with individuals with developmental disabilities, may attribute certain behaviors exhibited by the person to his or her disability. In other words, the diagnosis of mental retardation may overshadow and preclude any psychiatric diagnosis (this has been referred to as diagnostic overshadowing). Lack of social skills, repetitive behaviors, odd mannerisms, and other problems may be attributed to the person having a diagnosis of mental retardation or autism rather than to physical ailment or psychiatric disorder.

**Example**

Mei-Shya, a teenager with profoundly mental retardation, has significant limitations in social and communication skills. She often spends her time alone and engages in some stereotypic play with toys or school materials such as twirling pencils and twisting string. Mei-Shya was recently diagnosed as having autism and she was prescribed haloperidol (Haldol®) because her physician had read that Haldol can increase cognitive functioning in some people. Over the next few weeks, Mei-Shya hands began to tremble and shake, and she began flapping her hands frequently. In addition, Mei-Shya started pacing in her classroom and became even more withdrawn from her classmates. When her mother took her back to the psychiatrist for her three month follow up appointment, the resident who was working with the doctor had little experience working with individuals with developmentally disabled and attributed her pacing and hand flapping to autism. Mei-Shya's mother was not so sure she agreed because it seemed like these problems had increased over the past several months since starting the medication. She took Mei-Shya to a second doctor with more experience with developmental disabilities who was immediately concerned that the medication may have been causing some of the recent problems that Mei-Shya was experiencing and switched her to another type of medication. The akathisia (pacing) and tremor in her hands disappeared when the new medication was started.

Obtaining reliable information for diagnostic purposes can be challenging when supporting an individual with disabilities. In fact, it can be difficult and embarrassing for many individuals to express how they are feeling inside to authority figures, especially if they do not know the person well. In addition, communication impairments can make it difficult for an individual to adequately describe or label what he or she is experiencing. For individuals who have extremely limited verbal or communication skills due to age or disability, it may be impossible to rely on self-report information.

For many reasons, doctors, nurses, psychologists, and other providers must rely to a great degree on the report of caregivers to provide information on behavioral and health issues. Unfortunately, caregivers are not always able to provide extensive histories or provide reliable reports. Staff people who have not known the person for a long time and noncustodial parents may not be aware of recent changes in health or mental status. Sometimes an individual's parents have cognitive or psychiatric impairments making it difficult to obtain information for the same
reasons listed previously.

In order to increase the accuracy of information shared with medical personnel, it is critical to look at a variety of indicators besides verbal report to diagnose psychiatric disorders. Recent changes in eating and sleeping patterns, mood changes, changes in appearance, or other medical problems (e.g., gastrointestinal conditions, diabetes, or thyroid problems) can serve as indicators for changes in mental status. As noted previously, however, it is important to ascertain whether psychiatric disorders result in behavioral changes or whether changes in behavior are related to another source.

**Example**

Donna has been under a lot of stress at work. She's been expected to take on some additional responsibilities at work that she is not sure she is capable of doing. In addition, a co-worker quit so that Donna now has to do her colleague's work as well. Finally, Donna has been fighting with her boyfriend nearly every night and thinks he may be seeing someone else. Donna's friends at work notice that she has circles under her eyes and she reports that she hasn't been sleeping well. In addition, she's lost her taste for many of the foods she used to like and doesn't want to eat much any more. Donna's supervisor thinks that she is depressed and recommends that she see her doctor so that she can be referred to a therapist or psychiatrist for treatment for depression. Donna's physician recommends some additional tests to make sure there isn't any medical problems contributing to Donna's emotional state. The doctor discovers that Donna is suffering from gastrointestinal reflux with a secondary condition of stomach ulcers. Once Donna is treated with antibiotics, heartburn medication, and has made some changes in her eating habits, she feels much better and her mood significantly improves.

In this example, there is a combination of possible mental health problems that mesh with physical problems. We all feel depressed or low when we are sick, so it is important to distinguish between an acute medical problem and a long term, chronic disorder.

Clearly, it requires an enormous degree of skill, clinical experience, and knowledge regarding medications and their effects to accurately diagnose psychiatric disorders in individuals with developmentally disabilities. In the next lesson, we will focus on how mental health issues can directly affect problem behavior.

**Mental Health Issues and Problem Behavior**

It is critical to distinguish between problem behavior that occurs for environmental reasons (e.g., to escape from a difficult task) and those behavior problems that occur as a result of a psychiatric disorder. For example, some individuals may engage in stereotypic hand flapping when they are excited about something or when they are playing with certain toys. A child with Tourette syndrome may also flap her hands, but this behavior may be more likely due to her tic disorder rather than to the toys with which she is playing. Increased aggression and irritability could be a
sign of depression, but also could in fact be due to a change in staffing arrangements.

It can be difficult to determine whether problem behavior is the direct or indirect effect of a psychiatric disorder. Sometimes making this determination requires looking at what an individual has done over time. For example, if a seasonal disorder is identified in a child, you would expect certain behaviors to occur over and over again in a pattern across the year. The same is true with most cyclical disorders. But that is not to say that new behaviors can’t emerge over time when a person has a psychiatric disorder. To make matters more complicated, it may also be the case that behavior problems occur according to certain patterns or cycles that may or may not be associated with the disorder. In the following example, you will read the case of child who appears to have cyclical behavioral pattern, but it is unclear to what this pattern can be attributed.

**Example**

Ryan is a 10-year-old with Attention Deficit Disorder. His parents have noticed a fairly consistent pattern for Ryan across the school year that has been occurring since kindergarten. When the school year starts, Ryan has very few behavior problems and works very hard to stay on task across the school day. As the Thanksgiving holidays approach, Ryan's teacher notes that he has to frequently remind Ryan to stay focused and act impulsively. In addition, Ryan's fidgeting increases and he has to move to the front of the class so that his teacher can keep a closer eye on him. Ryan's problems worsen further between Thanksgiving and the winter break. In January, there is an initial improvement in Ryan's behavior, but by Spring Break he has often deteriorated to the point where a parent conference is called and an explicit behavior plan must be developed to address his disruptive behavior. This plan and increased attention usually help see Ryan through the rest of the school year, but again both Ryan and his teacher are relieved when the summer break comes.

In this example, is it the case that the symptoms of Ryan's ADD are cyclical? Does the fact that he gets worse during the winter months and later in the school year mean that his disorder has worsened? Or is it the case that environmental factors including boredom with his new class and teacher, lack of outdoor exercise during winter months, or increasingly complex classwork are the variables that are truly affecting his behavior? It is difficult to single out what behaviors are being affected by biology and what are being affected by environment in this example.

It has been suggested that the relationship between problem behavior and psychiatric disorder may be conceptualized as primary, secondary, or consequential. An example of a primary relation would be that the problem behavior is a sign or symptom of the psychiatric disorder such as a person with obsessive-compulsive disorder who repeatedly washes his hands. An example of a secondary relation would be having a panic attack, which occurs in response to a difficult situation and results in the person trying to leave that situation. When his teacher tries to stop the person from leaving the room, the person may become aggressive which is a secondary effect but related to having the panic attack. Finally, in a consequential relationship, problem behavior may
occur as a symptom, but gets inadvertently reinforced and is then shaped over time into an operant behavior. For example, a person with a seizure disorder may start "faking" seizures because he gets a lot of attention from it and gets to escape from doing things he doesn't like. Unfortunately, it is very difficult to distinguish whether any given occurrence of problem behavior is primary, secondary, or consequential.

This goes back to the issue about whether it is possible to accurately diagnose psychiatric disorders in individuals with developmental disabilities, whether they experience them in the same way that individuals without disabilities do, or whether it is possible that disorders are manifested differently in people with developmental disabilities than in typically developing individuals.

It is important to consider the possibility that people with developmental disabilities who have a mental illness may not necessarily exhibit the same symptoms as non-disabled individuals. In addition, the diagnostic signs that suggest a psychiatric disorder may not necessarily indicate the presence of mental illness. If a person also engages in problem behavior, then there is the danger that the occurrence of problem behavior will lead to a psychiatric diagnosis (e.g., depression) when none exists. This (mis)diagnosis may then be used to justify medication interventions that are neither necessary nor effective. On the other hand, a psychiatric disorder may be present, but go unrecognized because the symptoms, including problem behavior, are not consistent with the DSM-IV criteria. The symptoms might be incorrectly attributed to developmental disability rather than the underlying psychiatric disorder. You will be learning more about how to work within an interdisciplinary team context to ensure your team gathers information that improves decision-making and support for individuals with complex physiological issues later in this module.

Psychotropic Medications and Problem Behavior

In this section, we are going to discuss how psychotropic medications are used with individuals who have both developmental disabilities and psychiatric diagnoses. As noted earlier in this article, when a person has been diagnosed with a psychiatric disorder such as a mood disorder and mental retardation, they are sometimes referred to as having a dual diagnosis. For many of these individuals, psychotropic medications are prescribed in an attempt to decrease symptoms related to the psychiatric disorder. Medications are typically classified as antipsychotic, antianxiety, antidepressant, antimania, stimulant, or sedative-hypnotic. In addition, other medications or herbal supplements may be classified as a psychotropic medication when it is prescribed with the goal to improve mood, mental status, or behavior, such as when antiseizure medications are given to treat aggression.

One of the most common reasons that psychotropic medications are prescribed, however, is to reduce the occurrence of problem behavior. The difficulties for treatment are especially problematic because our understanding of behavior disorders and psychiatric disorders are imprecise, which can result in applying the same treatments to problem behaviors that outwardly
appear similar to psychiatric symptoms, but in fact, are not related.

The focus of positive behavior support is to teach individuals social and functional skills to replace problem behavior and to modify environmental events making problem behavior irrelevant. Many of the most difficult to treat problem behaviors, however, can be regulated by factors in both the person's social environment as well as by biological or biochemical factors. Because of this dual control, our assessment and intervention efforts need to consider the possibility of both behavioral and biomedical interventions. In this section, issues related to the use of psychotropic medication when treating problem behavior will be discussed in the context of environmental factors. One of the best ways to stay informed about medications is to refer to the Physician’s Desk Reference or use Internet websites such as Medscape to research any new medications you are unfamiliar with.

There is clearly enough medical evidence to indicate that using medications for the treatment of medical problems (e.g., diabetes, glaucoma, heart conditions, thyroid disorders, gastrointestinal reflux) is warranted. It is less accepted in our communities, however, to use psychotropic medications to treat mental health problems, particularly with vulnerable populations such as children and individuals with developmental disabilities. Nonetheless, the prescriptions for these individuals has continued to grow, perhaps because the use of medication has become more socially acceptable or because pharmaceutical companies are developing newer, safer, and more effective medications. Each one of us can think of a person for whom psychotropic medication was extremely effective and resulted in improved quality of life and another person for whom medication was completely ineffective or worse, resulted in serious side effects. As a result, we often have mixed opinions about the use of medications and understandably, some suspicion regarding the frequent use of psychotropic medications with the people that we support.

A very common mistake in using psychotropic medications is to assume a medication is used to treat a simple underlying psychopathological disorder that is responsible for the symptoms the person is experiencing. For example, it would not be possible to identify a medication to "treat autism." Instead, medications are selected to treat specific symptoms such as repetitive, ritualistic or compulsive behavior. There is so much variability among individuals with specific conditions such as autism that it is impossible to identify a single intervention that works for everyone. In short, there is no "best" medication to treat problem behaviors, whether these medications are associated with certain diagnoses or not.

When people with developmental disabilities exhibit problem behavior, there is often no generally recognized way of identifying underlying psychopathology or biological factors affecting the behavior. Indeed, in many instances there may be no underlying psychopathology at all. Instead, the problem behavior may be controlled by environmental factors such as limited communication skills or inadvertent reinforcement with attention. A systematic approach is needed to identify likely environmental contributions (or rule them out), and to investigate possible biological mechanisms that may contribute to problem behavior.
At the same time, medications can affect problem behavior by causing certain side effects that may in turn serve as a setting event for problem behavior. Medications that make a person drowsy or sedated can increase the likelihood that an antecedent event such as the presentation of a nonpreferred task will trigger problem behavior maintained by escape. Medications that stimulate a person's appetite make food even more inviting or reinforcing. Weight gain caused by this medication can be embarrassing for an individual and result in an increase in problem behavior maintained by escape from social interactions or physical activities that were once rewarding.

Medications have also been known to cause paradoxical effects in some people. For example, some selective serotonin reuptake inhibitors (SSRIs) like Prozac® can actually increase anxiety rather than decrease it. Antipsychotic medications may make some people feel jittery and restless or cause akathisia, previously defined in S1. These side effects are temporary for many individuals, but for others they are long-lasting and often result in the alteration of the medication regime. Finally, certain medications have been reported to cause behavioral disinhibition. This means that while on the medication, the person's behavior changes for the worse, primarily the person becomes more irritable and even more verbally or physically aggressive. As a result, his or her behavior problems actually increase from before the medication was started. It is possible that the person, who had previously been able to keep their behavior problems "in check" to some degree were now no longer able to when taking the medication.

**Considerations for Using Psychotropic Medications**

There are governmental and international agencies that have developed procedures for evaluating prescription medications through established testing procedures before a medication can be prescribed to the general public. The World Health Organization Essential Drugs and Medicines (EDM) (http://www.who.int/medicines/en/) agency coordinates medication evaluation and monitoring procedures throughout the world. In the United States, a four stage Food and Drug Administration (FDA) (http://www.fda.gov) approval process assures that medications that are sold are safe, at least during short-term treatment. In the first phase, a small sample of typical volunteers are given the medication under laboratory conditions and physiological and biochemical measures are taken to assure safety of the drug. In the second phase, a small sample of the large population (e.g., people with heart disease) are given low to moderate dosages of the medication under carefully controlled conditions, and possible side effects and basic pharmacological actions closely monitored for safety and efficacy. In the third phase, a large random sample of the target population and a matched control group are given the medication or placebo under typical clinical circumstances and the effectiveness and safety monitored over a longer period (for example, 8 weeks). Not knowing whether the person is taking the active medication or the placebo is called keeping the person blind to the test group he or she is in. This controls for any hopes or beliefs a person may have about the medication's effects, which may prejudice their ratings. Only after passing these three phases is the medication approved for use.
in the general population.

Unfortunately, it often takes much longer for medications to be tested with vulnerable populations such as children, the elderly, and individuals with developmental disabilities. For example, some of the most common medications used in the treatment of problem behavior fall in the category of antipsychotics or neuroleptics. Once these medications have been FDA approved, psychiatrists and physicians may begin to prescribe it as they see fit. It often takes several years more, however, before the medication has been tested adequately with individuals with developmentally disabilities.

Example

One of the most common prescribed medications for individuals with developmental disabilities and problem behavior is an atypical antipsychotic called risperidone (Risperdal®). The medication was initially only approved for use with severe, psychotic symptoms associated with schizophrenia. Over the next several years, however, it became widely used and recommended for individuals with developmental disabilities with severe behavior problems such as physical aggression and self-injury. It was also thought to be somewhat effective in reducing stereotypic and other repetitive behavior, motor tics, and obsessive-compulsive symptoms associated with autism (see reference section for recent studies in this area). Given that it is probably one of the most common medications used with developmentally disabled individuals, it is surprising that to this day, it has yet to be approved by the FDA for use with this population. There are some behaviors that it would be impractical or unsafe to use direct behavioral observational methods to measure intervention effects such as fire setting, sexual assault, or severe self-injury. There may be circumstances under which the behavior of concern cannot be observed for ethical reasons, such as intimate sexual interactions, personal hygiene activities, illicit drug use, or confidential conversations. Some behaviors, such as theft, are surreptitious and fleeting and therefore do not lend themselves to direct observational assessment methods. Behavior that is infrequent, but very serious (e.g., suicide attempts), are not appropriate for measurement and evaluation using direct behavioral observational methods.

Other psychological events cannot be directly observed, but behavior associated with those processes may be observable at times. Hallucinations of an individual with schizophrenia are not observable, but the person with schizophrenia who is seen talking to someone when no one else is present, or who is seen picking insects off a wall that are not visible are examples of possible corollary behaviors to the target behavior (i.e., hallucinations) that may be observable and could be recorded. Similarly, delusional thinking cannot be directly observed, but delusional statements (e.g., "The aliens are watching me") can be observed and recorded. Affect or mood is also difficult to observe but behavior associated with those states can be, such as crying, making self-deprecating or depressed statements, and sighing repeatedly. Hand wringing, skin picking, twirling hair, jiggling one's knee in an agitated fashion, pacing, and spontaneous self-statements about "feeling nervous" or "worried," can all be recorded as behavioral measures correlated with the presumed mood state of anxiety and could be used as a directly observable behavior even
though they perhaps indirectly measure the behavior of interest (e.g., a person's mood).

Many medications take some time to approach a level that is effective for a particular individual, so often there is a period when the medication is titrated, which means that the dose of the medication is gradually increased to a certain level. Guidelines for selecting doses are rather inconsistent and vary with: the type of medication, how long it has been available for use, the training and experience of the medical professional prescribing it, and finally the clinical studies that have been done to date. Other considerations such as the age and weight of the individual, medical diagnoses, and other medications currently being taken also have an impact on the dose selected.

Unfortunately, clinical experience is more likely to be the basis for medication type and dose selection, rather than research studies because there is often a delay between when a medication has been FDA approved and the time it takes for a study to be completed and published. Word of mouth between medical professionals and reports from caregivers regarding the effectiveness of medications with certain types of patients is largely what a physician relies on when deciding what medication and dose to use. It is this unscientific approach to prescription practices that is often frustrating for parents, teachers, and other professionals. They feel that they are participating in a trial and error process regarding prescription practices. As noted above, studies are not often conducted with individuals who have disabilities, primarily because it is so difficult to get approval and conduct studies using this population as a test group. Consequently, there is little data or empirical research upon which medical professionals can rely.

An important final consideration when evaluating medication effects is to determine whether there were other interventions or environmental factors that may have changed at the same time the medication was started, a dose changed, or the therapeutic level reached. If possible, any other interventions should remain constant during the period a medication is being evaluated so that the true effect of the medication can be determined.

**How Psychotropic Medication Affects Problem Behavior**

There are many theories that biological or biochemical factors may be implicated in severe problem behavior. Most medications are aimed at changing a specific neurotransmitter system by either blocking or stopping the neurotransmitter from being absorbed or by increasing the cell's ability to absorb the neurotransmitter. The most common neurotransmitter system affected by psychotropic medications are the dopamine, serotonin, and/or neuropeptide opioid systems because imbalances in these systems are the most likely to affect behavior. But these neurotransmitters are also likely to affect other biochemical processes. For example, too much serotonin can result in an increased need for sleep. That is why medications that affect serotonin often also have the side effect of making a person sleepy or lethargic. The dopamine system has a big impact on movements and who well our muscles work, therefore medications that affect
dopamine levels may cause involuntary movement side effects such as hand tremor.

Most medications are designed in an effort to correct imbalances in these receptor systems. For example, people with Lesch-Nyhan syndrome often exhibit very severe self-mutilation and have markedly lower levels of dopamine in the central nervous system than people without the syndrome. It appears that these reduced levels of the neurotransmitter dopamine have a direct effect on increasing the occurrence of self-injury in people with this syndrome. Thus, taking a medication that increases dopamine may decrease self-injury. Self-injury may also be more likely to occur because when a person bangs their head or hits themselves, their body releases naturally occurring substances referred to as opioids. We spoke of this earlier as referring to a "runner's high." Self-injurious behavior becomes repetitive and self-reinforcing either by altering normal pain sensation or because of the rewarding effects of the opioids. Medications that block that sensation may be effective in reducing self-injury.

It is clear that there are many neurochemical mechanisms that may affect behavior and it is difficult to determine what to attribute changes in behavior to - medication or environmental variables. Usually, we have thought of biological variables as having separate effects from environmental influences, but there may be a greater degree of overlap than previously thought.

Medications not only affect problem behavior, but they can also have an impact on how effective certain types of reinforcement are for an individual. For example, it has been demonstrated that methylphenidate (Ritalin®) can reduce a person's sensitivity to reinforcement or reduce the strength of reinforcement. In other words, a person taking methylphenidate may find that something that was once reinforcing has now lost its appeal. Antipsychotics or neuroleptics can reduce the effects of aversive stimuli, such as punishers, by making them less effective or aversive. As a result, a person may be better able to tolerate a change in the routine, a difficult task, or frustration with communication problems when they are taking the medication. This biobehavioral relationship which was discussed earlier describes how biological factors play a role in behavioral issues.

Medical professionals who prescribe psychotrope medications to decrease problem behavior seldom consider these biobehavioral relationships. Practitioners and family members are often under the misconception that medications alter brain chemical or physiological processes and cause behavior to change independent of the environmental circumstances within which the person functions. In some circumstances, a medication may have one kind of behavioral effect, whereas under different circumstances the same medication may have different results. To better understand the neurobehavioral mechanisms of psychotrop medications in persons with developmental disabilities, we must understand the individual's behavioral and medical history as well as the current circumstances influencing his or her behavior (e.g., whether the problem behavior is maintained by positive or negative reinforcement). By approaching medication evaluations from a functional assessment perspective, it will easier to understand how medications affect behavior.
If behavioral interventions are chosen based on a functional assessment of the environmental conditions controlling behavior problems, a similar approach could also be adopted to select appropriate medication therapies. Few physicians would prescribe a medication for an inflamed throat without first measuring body temperature, looking for signs of enlarged and tender lymph glands, examining the eardrum, obtaining a white blood count, and taking an appropriate personal history. Yet, psychotropic medications are routinely prescribed to treat the problem behavior for people with developmental disabilities without the information required for an adequate "functional" diagnosis. By adopting a functional assessment approach, influential environmental factors are identified, and a medication can be selected which will improve the person's ability to function independently. The goal is to treat the underlying behavioral and biological mechanisms, not just the problem behavior.

### Working with an Interdisciplinary Team

Medical and behavioral issues have traditionally been addressed by different types of professionals each of whom addressed problem behavior from a different perspective. Behavior consultants are called in to support an individual engaging in problem behavior, while psychiatrists and medical professionals address issues related to mental health and mental illness. There are now growing examples of mental health professionals and behavioral specialists working together to support individuals who engage in problem behavior. **Interdisciplinary teams** can be challenging since each field develops terminology and conceptual models that guide decision making. Sometimes misunderstandings occur because a term used by a mental health professional means something entirely different to an individual with training in positive behavior support.

Before an interdisciplinary team begins to collaborate, it can be useful to start by defining key terms as a group to ensure everyone is communicating effectively. For instance, creating a group definition for the term setting event, which is sometimes defined differently in other fields, will ensure the planning process goes smoothly. For instance, if two individuals on the team are in disagreement with each other about the types of interventions that may best support a person, it may be useful to spend time asking both individuals to describe how their opinions are related to their training background. With further dialogue it may become clear that both individuals agree on many aspects of the intervention but differences in language and terminology have created confusion.

Recently, a group of mental health professionals both with and without training in positive behavior support met at a national positive behavior support conference to discuss the barriers that frequently disrupt team collaboration. This group believed many of the problems that are encountered in teams are due to diverse training backgrounds and that professionals have different assumptions about the definition of certain terms (e.g. dual diagnosis, setting event, etc.). In addition, many individuals use "short cuts" in their terms such as acronyms or jargon,
which can be misleading for professionals unfamiliar with these words.

Many of the ideas generated by the group emphasized the importance of building strong team training and facilitation:

**Building Strong Interdisciplinary Teams**

- Create group definitions for terms before beginning team problem solving.
- Redefine terms as a group and neutralize "turf issues."
- In some cases, it may be necessary to avoid the use of certain terms when collaborating with a particular team.
- Identify the different models that professionals follow and make sure everyone is familiar with these models (e.g., medical model, applied behavior analysis).
- Pay attention to relationships while engaging in the team process.
- Foster a positive team atmosphere that emphasizes common values and respect for individual team member's strengths at the local level.
- Make sure teams have learned good team facilitation and meeting skills.
- Teach team members to focus on needs and to avoid getting into arguments or taking "positions."
- Ensure there is supervisor support and encourage the team to work from the approach of focusing on strengths (e.g., a strengths-based model).
- Be flexible when working with physicians and be sensitive to their time limitations by being creative about sharing information.
- Encourage early identification of medical and physiological issues in the PBS process.

By taking into account these important issues, an interdisciplinary team can work together effectively. It is often difficult to overcome some of these barriers, probably due to time constraints or limited opportunities to interact as a team.

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**How the Functional Assessment Process Applies to Biological Issues**

The functional assessment process can be more difficult when biological factors are related to an individual's problem behavior. Unexpected increases or the sudden appearance of problem behaviors might signal the need to investigate whether an individual has underlying health problems. In other situations, a person's behavior may increase and decrease in a cyclical pattern. Collecting data over time can assist the team in investigating the nature of these patterns.

Ongoing functional assessment is important even when problem behaviors are clearly maintained by physiological factors. As we discussed previously, problem behavior initially maintained by physiological influences can later become reinforced by social outcomes.
Example

Desiree is a young child with a disability who bangs her head against chair or other hard surfaces to obtain sensory stimulation. Desiree noticed that whenever she began banging her head, her preschool teacher would quickly walk over to her, provide comforting attention, and offer to read a book in an effort to redirect Desiree. Although Desiree still engages in head banging to obtain sensory stimulation when she is alone, she has learned that this behavior can also serve a useful social function: obtaining attention and preferred activities.

Information collected during the functional assessment is even more important when multiple functions are suspected to be maintaining problem behavior. Observations should be conducted across many different situations to clearly identify the functions maintaining an individual's problem behavior in each routine or activity. Plotting suspected physiological setting events on the same tracking form that problem behaviors are recorded can assist the team in confirming this hypothesis.

It is common to assume that if an individual's behavior has a physiological cause, the only effective approach is medical in nature. For instance, some problem behaviors may increase when an individual is alone with no opportunities to engage in stimulating activities. Creating opportunities to interact socially within the environment and redirecting individuals to activities that are incompatible with stereotypic behavior are important interventions that increase a person’s quality of life. Designing settings that include plenty of games, toys, or activities may naturally decrease stereotypy and other problem behaviors. In addition, studies have shown that not only making stimulating activities available but also prompting individuals to engage in them and demonstrating how they work can decrease stereotypic behavior.

Environmental interventions are often used when an individual compulsively ingests nonedible objects, a behavior that is referred to as pica. Interventions for pica may include removing paperclips or other small objects that are easily swallowed from an individual's environment. Providing the individual with edible items that are similar in size or shape may also deter a person from eating the inedible items. Other environmental interventions include ensuring that food is not left unattended when supporting an individual with Prader-Willi syndrome.

Social skills education can provide alternatives for reducing increases in emotional and physiological arousal that trigger problem behavior. Teaching anger management, effective problem-solving skills, and conflict resolution strategies introduce new options for an individual to decrease the stress that comes from not knowing what to do when an emotional situation arises. Relaxation as an intervention strategy for decreasing problem behavior has not been validated in the research literature. However, the addition of procedures including both relaxation and biofeedback for stress reduction are used by many people both with and without disabilities. In some situations, increasing exercise can reduce the likelihood of problem behavior. A number of research studies have reported that problem behavior decreases when
individuals with disabilities have a chance to exercise on a regular basis.

Environmental interventions are common when supporting children with sleeping problems. These strategies include interventions during bedtime and morning routines to encourage regular sleeping patterns and systems for communicating with schools when a child has slept poorly the night before so that setting event interventions can be implemented during the day.

**Example**

Durand and his colleagues (1996) demonstrated the effectiveness of sleep interventions with four children who either woke frequently during the night or engaged in problem behavior at bedtime. Previously, interactions in the night included reasoning, offering snacks, or climbing into bed with the child. Part of the intervention was to establish a consistent bedtime while gradually increasing the length of time before parental attention was given to the child during night awakenings. This was done by waiting three minutes before responding to a child's request for attention in a neutral tone of voice. In the study, the child's parent provided reassurance and quietly told the child to go back to bed. If the child continued to cry, his mother would wait an additional three minutes before responding again. The neutral tone of voice during intervention was intended to decrease the reinforcing value of parental interaction. Each night, the parent increased the time before responding to the child by two minutes. This type of intervention has been successful in supporting children both with and without disabilities (Durand et al., 1996).


Communication logs between parents and teachers, or between home and work settings can be used to make sure everyone is aware when an individual sleeps poorly the night before. Setting event interventions vary depending on the unique information from each functional assessment encountered, however, environmental interventions could include letting a child take a nap at the nurses office or encouraging an individual to stay awake throughout the day to reset his or her sleeping patterns. In other situations, the number of antecedent events associated with problem behavior can be reduced when an individual has slept poorly. Starting work with a more preferred task before moving to activities that are more difficult is another strategy employed when this type of setting event occurs.

Measuring how the physiological effects of medications change problem behavior can be done in a variety of ways. In the next part of the lesson, we will discuss some tools that can be used to measure the effects of medication and how they can be integrated into the positive behavior support process.

**Tools for Measuring Medication Effects**

In many clinical settings, medication effects are monitored and documented via clinical notes...
and medical reports made by the medical professionals who are overseeing the individual's clinical care. Unfortunately, most medical records are inconsistent with regard to their content as medical notes are taken for a variety of reasons not just to document medication response. Therefore, using subjective clinical notes or nursing reports may not be the most effective way of measuring medication effects.

One way to measure the effects of a medication can be to use rating scales. Many scales have been developed to collect information on the frequency and/or severity of problem behavior, and can be used to evaluate medication effects over time. One of the important things to remember when using a rating scale, however, is to obtain a rating before starting the medication and then at some regular interval after the medication has begun. Using a rating scale can provide valuable information, because many of these tools have been standardized with various groups of individuals (e.g. typically developing children, adult psychiatric patients) so that norms have been developed that can be used for comparison purposes. These ratings can be useful because they will show how the responses of the person you are monitoring differ from a reference group.

One of the most common rating scales used to measure medication effects in developmentally disabled individuals is the Aberrant Behavior Checklist (ABC). The ABC is a 58-item standardized rating scale developed to measure the effects of medication on problem behavior in individuals with developmental disabilities. Given its widespread use and acceptance, it is considered one of the "best" measures of medication effects with people with developmental disabilities. Other measures of problem behavior include:

- the Emotional Problems Scales: Behavior Rating Scales (BRS) and Self-Report Inventory (SRI),
- the Reiss Screen for Maladaptive Behavior,
- the Nisonger Child Behavior Rating Form (NCBRF), and
- the Self-Injurious Behavior Questionnaire (SIBQ).

Each scale has had varying degrees of psychometric standardization, but all have been used with people with developmental disabilities to address a variety of problem behaviors. They have also been used to measure behavior in a wide range of individuals at varying functioning levels and may be useful in settings where it is difficult to collect data based on direct observation. See the reference list for this section for more information about these scales.

There have also been many rating scales developed to measure the side effects of medications. Some of these scales have been adequately standardized and some have not. Most of the scales depend on the type of medication, and the side effects expected. For example, the Neuroleptic Side Effects Checklist has been used with neuroleptics or antipsychotic medication because it lists the 30 most common side effects associated with this class of medications. One of the most
common side effects of neuroleptic medications, particularly ones that have been developed more than twenty years ago (i.e., "typical" or "classical" neuroleptics such as Haldol, thoridazine, chlorpromazine), is tardive dyskinesia, which is a movement disorder that usually affects the head, trunk, or limbs and causes involuntary movements. Several scales have been developed to evaluate tardive dyskinesia, which is most likely to occur when a neuroleptics medication is started or when it is withdrawn after long term use. The Diskinesia Identification System - Condensed User Scale (DISCUS), the Abnormal Involuntary Movement Scale (AIMS), and other scales have been used to observe whether dyskinisias or other extrapyramidal side effects result when starting or stopping an antipsychotic. Recently, "atypical" antipsychotics were developed to address this side effect and are categorized as either typical or atypical based on the medications tendency to cause movement side effects.

These rating scales should not be used in place of medical supervision, however. Regular monitor of pulse, blood pressure, weight, and blood samples can also help in identifying possible side effects of medication. In very rare circumstances, antipsychotic medications may cause a fatal syndrome known neuroleptic malignant syndrome, which requires immediate hospitalization for treatment.

There are several things to consider when using rating scales, however. First, rating scales are usually not used often enough to provide a comprehensive impression of how a person is doing. A rating that is completed once a month may not be very meaningful or representative of the person's behavior over the previous 30 days, even if the person is instructed to think about an individual's progress over the past 30 days. Completing the rating scale more often may not be the answer, however, because there is evidence that people become careless if they have to complete a scale too often. In addition, raters sometimes are not able to detect subtle differences that may have occurred over the previous interval because they are simply filling out the questionnaire by rote or on "automatic pilot". Finally, other errors in rating may occur because of recency effects, or behaviors that occur shortly before a scale is completed which influence the overall ratings. An especially severe instance of self-injury observed at the end of the day just before the rating scale is completed can lead to an overall higher rating for the entire period, even if the person has been doing well otherwise.

Sometimes it is better to use other measures of medication effects that don't rely on a person making a subjective rating about the frequency or severity of the behavior over time. In this case, direct measures of the behavior can be collected. In the next lesson, the ways in which measures can be made will be discussed.

### Direct Measures for Evaluating Medication Effects

There are a variety of ways that people can collect information about how effective a medication is that rely on more direct measures of behavior. For example, the number of incident reports made at work, the number of office referrals at school, or the number of times a supervisor is
contacted, may be collected as information against which the effects of medication can be evaluated. Using these measures alone, however, can be problematic because there are many different variables that can affect these types of reports. Some teachers are more likely to send children to the office, a new staff person may assume that incident reports must be made each and every time a behavior occurs, and each supported employment professional tends to communicate with his or her supervisor differently. All of the variability associated with these types of examples can affect the frequency of reports. Therefore, it may be better to use a more objective measure of problem behavior to use as a yardstick against which to measure medication effects.

At times, it may be best to use some important biological measures to evaluate the effectiveness of a medication. For example, there are therapeutic levels of some medications that can be evaluated in a blood or urine sample. If the medication is within a known therapeutic range, then it is being adequately absorbed and metabolized. If the medication is above the therapeutic level, than there may be issues related to overdose or toxicity that could be dangerous for the individuals and require immediate reductions in dose or discontinuation of the medication entirely. This is primarily true of many of the "older" medications such as lithium, haloperidol (or Haldol), tricyclics, or MAO inhibitors that aren't often used anymore. Many of the newer medications are developed so that overdose is much less likely.

In addition to blood levels, there are other laboratory measures that may be useful to monitor physiological side effects, such as red and white blood cell counts, thyroid levels, and measures of endocrine function. Getting these blood levels evaluated every 3-6 months, depending on the medication, is often recommended. For some individuals, who aren't able to describe side effects such as gastrointestinal upset, dry mouth, or dizziness, using laboratory blood levels may be an important measure to evaluate these biological effects.

Another strategy for objectively measuring medication effects is to conduct observations of the individual's behavior in the settings where the behavior is most likely to occur. In many cases, simply tracking the frequency of problem behavior across the day or for specific period of times can be useful to monitor the effects of a medication. Counting the number of times a person checks the stove or windows before and after a medication has been started allows the team to determine how effective the medication has been on those compulsive behaviors.

Functional assessment measures can be used to monitor how environmental factors may interact with medication changes. Comparing these measures before the medication has started, once it has begun, and when dosages have been changed can assist teams in developing a hypothesis regarding the function of the behavior and in monitoring the behavioral effects of medication. For example, several studies with children with ADD taking methylphenidate (Ritalin®) have shown that while the methylphenidate reduces off-task, disruptive, and fidgety behavior overall, there are certain environmental situations that may actually override the medication effects. The situations where environmental events still occurred included times when the teacher was absent from the room, when a child was sitting in timeout, or when a problem behavior resulted in
attention from peers. Even though a medication reduces problem behavior in many situations, there may still be instances where the effects of the medication can be "overpowered" by reinforcers in the environment.

Choosing the best way to measure medication effects can be difficult. There are many considerations including the frequency, the severity, and the topography of the behavior or other behaviors in the response class. It may be very difficult to measure medication effects on a behavior that occurs only once a week. Some behaviors occur in bouts or episodes sporadically across the day. Thus, observations of an individual who self-injures 10-20 times per day but in only two or three episodes may not provide a very accurate picture of the behavior if the person is only observed 4 times a day for 10 minutes per observation.

Physicians and psychiatrists often have time limitations that make it impossible to participate in the interdisciplinary team process on an ongoing basis. Creating communication systems that summarize important information can be an invaluable tool for collaborating with medical professionals. One way to improve communication is to develop a medical book that includes all of the information about an individual's health, history, and background. This type of notebook is often used in situations where more than one individual is supporting a person with a disability.

**Medication & Communication Notebook**

- Changes in student's physiological state throughout the day
- Medication administration
- Medication history
- Medical and health related history
- Family medical history
- Positive behavior support plan and evaluation data

A medication and communication notebook is a tool that can be easy to transport to and from medical appointments. Sometimes a photograph is placed on the inside of the notebook to ensure that the right information is being shared with medical personnel when there are a number of individuals living in a home. Family members or staff bring the book to each medical appointment to provide a psychiatrist or physician with information about how an individual is responding to new medications, share medical histories and family health backgrounds, and to summarize current PBS plans. Combining data collected at home, school, and other settings into one notebook provides a complete view of how an individual is responding to medical treatment.