

# INTELLECTUAL DISABILITY

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## Introduction

Intellectual disability is defined as any disorder with an onset during the developmental period that limits both the intellectual and adaptive functioning of a child (American Association on Intellectual and Developmental Disability [AAIDD], 2013). Adaptive functioning includes the conceptual, social, and practical domains of a child's development (American Psychiatric Association [APA], 2013). A limit to adaptive functioning can be any deficit wherein a youth has difficulty adjusting to different environments or specific tasks compared to their peers (AAIDD). Deficits in any of the following could be present:

- Conceptual skills: language, reading, writing, math, memory, reasoning, and knowledge
- Social skills: empathy, social judgment, interpersonal communication skills, ability to make and keep friends
- Practical skills: self-management (job responsibilities, money management, personal care, and school tasks) (APA, 2013b)

In recent years, there has been an effort to replace the term “mental retardation” with the term “intellectual disability” (AAIDD, 2007). The Centers for Disease Control has made this change, as has the AAIDD. In addition, the President's Committee on Mental Retardation has also adopted the change and renamed the committee the President's Committee for People with Intellectual Disabilities (PCPID). The *DSM-5* also reflects the change by using the term intellectual disability instead of mental retardation (APA, 2013a).

Virginia has also taken steps to replace the term mental retardation with intellectual disability. In 2008, the Virginia General Assembly passed legislation to rename Virginia's Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) to the Virginia Department of Behavioral Health and Developmental Services (VDBHDS). The final version of the bill required that it also be passed by the 2009 General Assembly before becoming effective. The 2009 General Assembly unanimously approved the new name. The Board of VDBHDS and the Office of the Inspector General were re-named to reflect this change. This measure was adopted to support the Department's mission and to move away from the stigma associated with the term mental retardation. To this end, in 2012, the Virginia General Assembly passed legislation (House Bill 552, Garrett; Senate Bill 387, Martin) eliminating the term mental retardation in the *Code of Virginia* and replacing it with intellectual disability.

Children with an intellectual disability may also have a diagnosable mental health disorder. This is known as a dual diagnosis. While most professionals understand dual diagnosis to describe those who suffer from both mental health disorders and substance abuse, the term is also used for those with the double challenge of intellectual disability and a mental health disorder (Hartwell-Walker, 2012). A dual diagnosis may cause significant clinical impairment in youth with intellectual disability and place additional burden upon these youth and their families. Unfortunately, it is frequently assumed that behaviors associated with co-occurring disorders are related to the intellectual disability. Holding to this assumption can leave mental health issues untreated and exacerbate symptoms.

At its November 9, 2011, meeting, the Commission on Youth recommended that the *Collection's* section on Intellectual Disability be revised to include discussion of co-occurring mental health disorders. Accordingly, this revised section includes additional information about intellectual disability, as well as commonly co-occurring mental health disorders.

### **Recent Changes from the DSM-IV to the DSM-5**

In 2013, the American Psychiatric Association released the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. Several key changes were made to the intellectual disability category. The *DSM-5* is a manual for assessment and diagnosis of mental health disorders and does not include information for treatment of any disorder (APA, 2013a).

As noted previously, the *DSM-5* replaces the term "mental retardation" (which was used in the *DSM-IV*) with the term "intellectual disability." Intellectual disability is now the accepted term in medical, educational, and other professional realms (APA, 2013a). The *DSM-5* also outlines new diagnostic criteria for clinicians. Adaptive functioning assessments must be used in conjunction with intelligence quotient (IQ) scores instead of using IQ scores as the sole determinant of intellectual disabilities, and severity must be determined through adaptive functioning assessments alone, instead of IQ scores (APA). By removing IQ scores from the severity portion of diagnosis, an overemphasis on scores is eliminated and the individual's overall functioning level is emphasized. IQ scores are still to be used in the assessment for intellectual disabilities. Intellectual disability is considered anything two standard deviations or more below the mean of the population; which is the equivalent of an IQ score of about a 70 or below (APA 2013b).

In the future, more evidence supporting treatments of disorders with *DSM-5* classifications will be available as clinical studies utilizing *DSM-5* criteria are conducted. As a result, this *Collection* will reference studies that utilize *DSM-IV* diagnostic criteria to explain symptoms and treatments.

### **Prevalence**

Estimates of the prevalence of intellectual disability vary, depending on a number of factors including diagnostic criteria, study design, and methods of ascertainment. Intellectual disability affects about 1.5 to 2.5 percent of the population (Bethesda Institute, 2012) and about 1 in 10 families in the United States

(AAIDD, 2007). Cases of severe intellectual disability occur in less than one percent of the general population (APA, 2013a).

The following information is specific to Virginia. Using national prevalence rates from studies and surveys, VDBHDS estimates that in 2012 approximately 76,763 individuals six years old and older in Virginia had an intellectual disability and 15,626 children received developmental services through Infant and Toddler Connection (VDBHDS, 2013).

### Assessment and Diagnosis

A multidisciplinary team, which may include psychologists, psychiatrists, pediatricians, and clinical geneticists, typically conducts the assessment for intellectual disability. All assessments should be comprehensive and should include standardized testing of intellectual ability, adaptive behavior, adaptive function, and detailed family and medical history evaluation (AACAP, 1999; APA, 2013a).

The *DSM-5* provides the standard criteria for a diagnosis of intellectual disability used in diagnosis of both children and adults (APA, 2013a). The disorder is characterized by:

- Deficits in intellectual functioning;
- Significant limitations in adaptive functioning; and
- Onset before the age of 18 (APA).

### Intellectual Functioning

Intellectual functioning is typically measured by individually administered cognitive assessment instruments (AACAP, 1999; AAIDD, 2007). According to the AACAP and the *DSM-5*, clinicians must consider the socio-cultural background and native language of the youth when choosing a cognitive assessment instrument. Ignoring these variables may lead to a falsely positive diagnosis of intellectual disability in youth of linguistic and cultural minorities. For a diagnosis of intellectual disability, the youth must have an IQ that falls below 70, or two standard deviations below the mean of the population (APA, 2013b).

### Adaptive Functioning

Adaptive behavior refers to an individual’s effectiveness in functioning at an age and culturally appropriate level compared to his or her peers (APA, 2013a). The *DSM-5* uses adaptive functioning assessments to determine the severity of intellectual disability instead of IQ scores. This change bolsters the importance of careful assessment in this criterion. Table 1 lists the three domains of adaptive functioning as discussed in the *DSM-5*.

**Table 1**  
**Adaptive Functioning Domains**

Domain	Life Skills Affecting Adaptive Functioning
Conceptual	Comprises academic competencies, including language, memory, reading and writing, math, practical skills and problem solving, and judgment in new situations and around others
Social	Emphasizes skills including awareness of the thoughts and feelings of others, empathy, interpersonal communication, friendship, and social judgment
Practical	Life skills like practicality, managing oneself, personal care, job expectations, managing money, recreation, and school organization

Source: APA, 2013a.

A youth must have significant deficits in one of three domains that are so great they require ongoing support and care in order for the child to go to school or to be a contributing member of society. While these deficits are within the realm of adaptive functioning, they must be paired with intellectual functioning deficits to be considered a true intellectual disability (APA, 2013a). Table 2 outlines the varying degrees of severity for intellectual disability.

**Table 2**  
**Intellectual Disability Severity**

Severity	Description
Mild	<ul style="list-style-type: none"> <li>Majority of individuals with intellectual disability</li> <li>Able to achieve nominal academic gains</li> <li>Mostly self-sufficient</li> </ul>
Moderate	<ul style="list-style-type: none"> <li>Around 10 percent of intellectual disability population</li> <li>Adequate, but limited, communication skills</li> <li>Self-care possible with assistance or extensive instruction</li> <li>Independence possible with support system</li> </ul>
Severe	<ul style="list-style-type: none"> <li>Around 3 to 4 percent of the intellectual disability population</li> <li>Basic communication skills</li> <li>Require safety supervision and supportive assistance</li> </ul>
Profound	<ul style="list-style-type: none"> <li>Around 1 to 2 percent of intellectual disability population</li> <li>24-hour care and support</li> <li>Co-occurring sensory/ physical limitations</li> </ul>

Source: Reynolds, Zupanick, & Dombeck, n.d.

### **Age of Onset**

The *DSM-5* also stipulates that the onset of symptoms occur during the developmental period (APA, 2013a). This does not prohibit diagnosis of a person after the age of 18. Rather, there must be documented evidence that the onset of symptoms occurred prior to the age of 18. It is important to note, however, that children under age 2 should not be given a diagnosis of intellectual disability unless the deficits are relatively severe and/or the child has a condition that is highly correlated with intellectual disability, such as Down syndrome (APA). Prior to age two, service providers should acknowledge any cognitive or behavioral deficit as a form of developmental disability and leave room for further diagnosis as the child gets older, unless the deficits are relatively severe (Biasini, Grupe, Huffman & Bray, 1992).

### **Causes and Risk Factors**

Knowledge of the causes of intellectual disability in a particular case is important for a number of reasons because the cause may be associated with a particular “behavioral phenotype” or increased risk for a medical disorder. In the general population, doctors can find a specific reason for an intellectual disability in 25 percent of cases (National Library of Medicine [NLM], 2015). However, in 58 to 78 percent of youth with mild intellectual disability, and in 23 to 43 percent of youth with severe intellectual disability, no causation is ascertained with current diagnostic techniques (AACAP, 1999). In other cases, numerous causes of intellectual disability have been identified. In general, the milder the severity of intellectual disability, the more difficult it is to identify the etiology (Jellinek, Patel & Froehle, 2002). The following are risk factors associated with the development of intellectual disability:

- Infections (present before or shortly after birth)
- Chromosomal abnormalities (e.g. Down syndrome)
- Environmental factors
- Nutritional (e.g. malnutrition)
- Toxic exposure (exposure to alcohol, cocaine, amphetamines, and other drugs)
- Trauma (present before or shortly after birth) (NLM)

## Intellectual Disability and Co-occurring Mental Health Disorders

Youth with intellectual disability are significantly more likely to be diagnosed with a comorbid disorder (APA, 2013a). It is estimated that between 32 and 40 percent of all individuals with intellectual disability also have another serious mental health disorder. Specific disorders include attention-deficit/hyperactivity disorder (ADHD), major depressive disorder, autism spectrum disorder, schizophrenia, bipolar disorder, and anxiety disorders (Aggarwal, Guanci, & Appareddy, 2013). Furthermore, assessment for these comorbid disorders is extremely difficult due to the preexisting intellectual disability. Assessments may have to be altered in order to properly overcome communication barriers and motor/sensory deficits (APA). Clinicians note that these challenges make it difficult to diagnose mental health disorders in individuals with intellectual disability.

Specifically regarding youth, a study was conducted with a large, nationally representative sample of British children with and without intellectual disability to ascertain the relationship between mental health disorders and intellectual disability (Emerson & Hatton, 2007). The results of the study indicated that the prevalence of a wide range of mental health disorders was significantly higher among children with intellectual disability. This study was conducted on a combined sample of 18,415 children and revealed that the prevalence of psychiatric disorders was 36 percent among children with intellectual disability versus 8 percent among children without (Emerson & Hatton). This study found the prevalence rates of psychiatric disorders for children and adolescents with intellectual disabilities to be higher among children with intellectual disabilities for 27 of 28 comparisons and statistically significantly elevated for 20 of the 28 comparisons. Additionally, increased prevalence rates were marked for ADHD and conduct disorders, with the latter accounting for approximately two-thirds of all diagnoses among children with intellectual disability. The study also noted that there was a cumulative risk of exposure to social disadvantage with increased prevalence rates for any mental health disorder, including any conduct disorder and ADHD, for children with and without intellectual disability. Social disadvantage may include the adverse impact on education, employment, earnings, and increased expenditures related to disability (World Health Organization, 2011). Children with intellectual disability were at significantly greater risk of exposure to all forms of social disadvantage that were examined.

This study contradicts the previously held belief among physicians that ADHD did not occur in children with intellectual disability. As a result of this belief, treatments for ADHD, including stimulant medications, were rarely used to treat children with intellectual disability and ADHD. However, recent research reveals that as many as 25 to 40 percent of children with intellectual disability also have ADHD, significantly more than in the general population (American Academy of Pediatrics, 2012).

According to the *DSM-5*, the most prevalent co-occurring disorders are ADHD, depressive and bipolar disorders, anxiety disorders, and autism spectrum disorder. The *DSM-5* classifies ADHD and autism spectrum disorder as neurodevelopmental disorders due to the fact that these disorders typically manifest early in development and are characterized by developmental deficits that impair personal, social, academic, or occupational functioning (APA, 2013a). Major depressive disorder may occur in a wide range of individuals with intellectual disability. Furthermore, individuals with severe intellectual disability are more likely to exhibit aggression and disruptive behaviors (e.g., harm to self and others or property destruction) (APA). Table 3 lists co-occurring mental health disorders and their prevalence rates.

**Table 3**  
**Prevalence of Co-occurring Mental Health/Neurodevelopmental Disorders Among Children and Adolescents with or without Intellectual Disability**

Co-occurring Disorder	Prevalence Rates by Percentage (Percentage children/adolescents with the disability or disorder at a particular time)	
	With Intellectual Disability	Without Intellectual Disability
Any psychiatric disorder	36.0	8.0
Any emotional disorder	12.0	3.7
Any anxiety disorder	11.4	3.2
Any depressive disorder	1.4	0.9
Attention-deficit/hyperactivity disorder (ADHD)	8.3	0.9
Any conduct disorder	20.5	4.3
Autism spectrum disorder	8.0	0.3
Tic disorder	0.8	0.2
Eating disorder	0.2	0.1
Emotional disorder & conduct disorder	4.4	0.8
Conduct disorder & ADHD	5.8	0.6
Emotional disorder & ADHD	1.3	0.1
Emotional disorder & conduct disorder & ADHD	0.8	0.1

Source: Emerson & Hatton, 2007.

An accurate psychiatric diagnostic evaluation and diagnosis provide the foundation for effective treatment planning (Aggarwal, Guanci, & Appareddy, 2013). Such a psychiatric diagnostic evaluation would be sufficiently comprehensive to identify the child’s disabilities and educational needs. Clinicians diagnosing co-occurring mental health disorders in children and adolescents with a severe intellectual disability may have to rely more on information obtained from family and other caregivers, including direct behavioral observations of the child in various settings. In general, the assessment of co-occurring mental health disorders in youth with intellectual disability should include the following, as adapted from AACAP:

1. Comprehensive history obtained from child, parents, teachers, and other caregivers across different settings (e.g., home and school). Such a comprehensive history must include information about: presenting symptoms with concrete behavioral examples, psychiatric symptoms (e.g., premorbid and current behavioral and personality patterns), adaptive functioning, self-care, communication, social functioning, past psychiatric diagnoses and treatment history, past and current educational and rehabilitative programs history, past and current cognitive assessment results, and multiple perspectives on the child’s presenting concerns.
2. Interview of the child that is tailored to the youth’s needs and ability levels.
3. Medical review, including developmental and medical history, past treatments, and coexisting general medical conditions and their treatment and/or prognosis.

4. Diagnostic formulation that takes into account the youth’s developmental level, communication skills, associated impairments, familial and socio-cultural factors, and possible abuse.

Many treatment modalities and interventions have been tried, with varying degrees of effectiveness, with youth with intellectual disability and co-occurring mental health disorders (NADD, n.d.). It is considered best practice to use evidence-based treatments. Please refer to the appropriate sections of the *Collection* for additional information on evidence-based and promising treatments for the mental health disorders discussed in this section.

**Interventions**

An array of therapeutic techniques can be employed to treat mental health disorders in youth with intellectual disability. Of these, the most widely utilized and investigated have been behavioral interventions, psychopharmacological interventions, and environmentally mediated interventions, which include developmental and educational services. Individual, group, and/or family psychotherapy may also be included in the treatment plan. Verbal psychotherapies are most appropriate for persons with mild to moderate intellectual disability.

Effective interventions for children and adolescents with intellectual disability should contribute to improving quality of life. According to the AACAP (1999), these interventions are based on several guiding principles: person-centered planning, appropriate education, family training, community integration, and transition planning for adulthood.

Table 4 summarizes interventions for youth with intellectual disability.

**Table 4  
Summary of Interventions for Youth with Intellectual Disability**

<b>What Works</b>	
Behavioral interventions, such as positive behavior support (PBS)	Behavioral interventions analyze the cause of a negative behavior and how it is being reinforced, and then offer techniques targeted to promoting positive behaviors.
<b>What Seems to Work</b>	
Psychotropic medication for co-occurring mental health disorders	Prescribed to treat comorbid disorders such as anxiety disorders, ADHD, and so forth. Because these medications have not been studied in ID populations, they should only be used when therapeutic and social measures do not properly address symptoms and in conjunction with appropriate behavioral interventions.
<b>Not Adequately Tested</b>	
Psychotropic medications to treat challenging behaviors	Psychotropic medications are sometimes used “off label” to treat challenging behaviors such as aggression. These medications should be used with caution and only when necessary. They should never be used for the convenience of caregivers.

### **Behavioral Interventions**

Research conducted over the past 20 years has supported the effectiveness of behavioral interventions, including interventions using applied behavior analysis, in managing many of the challenges faced by children and adolescents with intellectual disability (King, State & Maerlender, 2005). Behavioral interventions are designed to provide alternatives to unwanted behaviors. These interventions analyze the cause of the behavior (antecedent) and how it is being reinforced. Techniques such as functional communication training (e.g., learning how to request breaks), noncontingent reinforcement (i.e., reinforcement delivered on a fixed time schedule), and extinction are used to reduce challenging behaviors (e.g., aggression, self-injury, task-avoidance) and to promote positive behaviors. Behavioral techniques target skills, deficits, and modifications to the individual's environment and are most effective if applied across multiple settings to promote generalization of skills.

There are many simple behavioral techniques that can be helpful in attempting to ease the transition of an individual with intellectual disability into the general public. The following are just a few examples:

- Setting boundaries
- Positive reinforcement of desired behaviors
- Activity schedules
- Task correspondence training (Aggarwal, Guanci, & Appareddy, 2013)

One behavioral intervention frequently used with youth with intellectual disability is positive behavior support (PBS). PBS is an approach to developing effective and individualized interventions for children with severe challenging behavior. PBS is a process for understanding and resolving the problem behavior of youth that was developed both from the science of applied behavior analysis and the values of child-centered approaches to learning (Fox & Duda, 2011). It offers an approach for developing an understanding of why the child engages in problem behavior and strategies for preventing the occurrence of problem behavior while teaching the child new skills. PBS considers all factors that impact a child and the child's behavior and can be used to address problem behaviors that range from aggression, tantrums, and property destruction to social withdrawal (Fox & Duda). It has three primary features: functional (behavioral) assessment, comprehensive intervention, and lifestyle enhancement. A functional literature review found that positive behavior support appeared to be effective in a majority of cases studied, although no long-term quality of life outcomes were reported.

### **Behavioral Interventions in Dual Diagnosis**

There is no single "best" treatment for youth with a co-occurring mental health disorder (King, State & Maerlender, 2005). Multimodal approaches seem to be the most effective form of treatment as they treat symptoms or the root problem in different ways (Aggarwal, Guanci, & Appareddy, 2013). An underlying assumption in treating co-occurring disorders in youth with intellectual disability is that most youth experience the same complex interaction of biological, mental health, and environmental forces that shape mental health disorders (King, State & Maerlender). It is critical that clinicians serving youth with both intellectual disability and co-occurring mental health disorder use a comprehensive, multidimensional, and multidisciplinary approach.

Most service providers agree that treatment of dual disorders must include a comprehensive plan comprised of four components (National Association of the Dually Diagnosed [NADD], n.d.). The first component includes interdisciplinary evaluation of the youth, as noted in previous sections, in order to obtain an accurate diagnosis and to establish habilitation and treatment needs. The second is a thorough medical and neurological evaluation to identify acute or chronic conditions that need attention. The third component consists of a psychiatric evaluation to determine if medication is appropriate. Finally, follow-



up interviews are crucial to help monitor the youth's response to the selected treatment approaches (NADD).

Functional behavioral assessments and positive behavior support (PBS) are widely considered best practices when teaching individuals with intellectual disabilities (Hansen, Wills, & Kamps, 2014). A functional behavioral assessment looks beyond the behavior itself and identifies specific social, affective, cognitive, and/or environmental factors associated with specific behaviors to offer a better understanding of the function or purpose behind student behavior (Center for Effective Collaboration and Practice, 2001). PBS is frequently used with children who persist in challenging behavior and do not respond to general child guidance procedures (Center on the Social and Emotional Foundations for Early Learning [CSEFEL], n.d.). In PBS, interventions are designed based on understanding the purpose of the challenging behavior. The positive strategies used to change behavior include teaching new skills, preventing the occurrence of challenging behavior, and supporting the child in achieving meaningful, long-term outcomes.

### ***Pharmacological Interventions***

There are no pharmacological treatments available for intellectual disability (Zeldin et al., 2016). For this reason, psychotropic drugs should only be used to target co-occurring mental health disorders, and only when therapeutic and social measures do not properly address symptoms (Zeldin et al.; Aggarwal, Guanci, & Appareddy, 2013).

Reports of the prevalence of psychotropic medication use in both adults and children with intellectual disability show that over one-third of this population served in residential settings is receiving at least one psychotropic drug (Toth & King, 2010). Psychotropic medications are also used “off-label” for the treatment of challenging behaviors, such as aggression and behavioral disturbance (Toth & King). Clinicians have found that medication is often prescribed to children with intellectual disability for symptom suppression without being integrated into the overall plan (AACAP, 1999). The literature repeatedly advises that medication should not be used for the convenience of caregivers or as a substitute for appropriate services. An additional concern is that follow-up behavioral data is infrequently collected and providers often fail to monitor for side effects. This is especially important in children and adolescents with intellectual disability, because these patients may be unable to report side effect symptoms adequately.

### ***Pharmacological Interventions in Dual Diagnosis***

As noted by the National Association of the Dually Diagnosed (NADD), in people with intellectual disabilities, medication is appropriate when there is a dual diagnosis for many psychiatric disorders, such as mood disorders and psychotic disorders. Medication treatment should not be a total treatment approach but rather be part of a comprehensive bio-psycho-social-developmental treatment approach. It is also important to note that the same rules for utilizing pharmacological interventions for children with a diagnosed mental health disorder apply to youth with intellectual disability (Toth & King, 2010).

In general, the effects of medication on children with intellectual disability are similar to that expected for the general population (King, State & Maerlender, 2005). However, treating ADHD with medication is contraindicated in youth with IQs less than 50, as pharmacological treatment can cause serious side effects such as tics, social withdrawal, irritability, and anxiety (Aggarwal, Guanci, & Appareddy, 2013).

Psychotropic drugs are also sometimes prescribed off label to treat children or adolescents who exhibit behavioral disturbances, including self-injury, stereotyped behaviors (e.g., hand or finger twisting, or complex whole body movements) and aggression (AACAP, 1999; Aggarwal, Guanci, & Appareddy, 2013). A 2015 meta-analysis of 14 studies of the effects of antipsychotic medication in reducing challenging behavior among children with intellectual disabilities found that they appeared to be effective

in the short term; however, the authors caution that further long-term, high-quality research on the safety and efficacy of these treatments is needed (McQuire et al., 2015). There has also been much debate about whether medications such as antipsychotics should be used to treat these behaviors (Maston, 2009; Sheehan et al., 2015). In addition, concerns have been raised about the safety of the use of antipsychotic medications in young people (Sheehan et al.). Although evidence exists for using psychotropic medication to treat challenging behaviors, careful monitoring of effectiveness and side effects is recommended (Edelsohn et al., 2014). For these reasons, clinicians should be cautious about prescribing medication off label to treat challenging behaviors in individuals in youth with intellectual disability and should give proper consideration to behavioral intervention alternatives (Edelsohn et al.; McQuire et al.).

When psychotropic medications are prescribed for co-occurring disorders or challenging behaviors, special attention must be paid to possible behavioral effects and to the child or adolescent’s ability to reliably report possibly dangerous side effects (Silka & Hauser, 1997). Table 5 outlines some of the different pharmacological approaches and the different comorbid symptoms that each drug treats for individuals with intellectual disability.

**Table 5**  
**Pharmacological Treatments and Their Side Effects**

<b>Drug</b>	<b>Targeted Symptoms</b>	<b>Potential Side Effects</b>
Risperidone	Hyperactivity, irritability, aggression, and impulsivity	Hyperprolactinemia, weight gain, somnolence, and headaches
Quetiapine	Aggression and hyperactivity	Sedation, weight gain, and paradoxical agitation
Ziprasidone	Aggression and irritability	Dizziness, fever, and fast/uneven heartbeat
Stimulants and nonstimulant atomoxetine	Symptoms of ADHD	In persons with an IQ less than 50, can cause tics, social withdrawal, irritability, anxiety, and anorexia
Fluoxetine	Stereotypic and self-injurious behaviors	Restlessness, hyperactivity, agitation, decreased appetite, insomnia
Valproic acid	Aggression and self-injurious behavior	Hepatic failure, pancreatitis, thrombocytopenia, development of ovarian cysts, obesity, irregular menses, increased hair growth, sedation, GI upset, tremor, alopecia

Source: Aggarwal, Guanci, & Appareddy, 2013.

### **Discharge Planning**

As indicated by Silka & Hauser (1997), appropriate discharge planning is crucial for children with intellectual disability and co-occurring mental health disorders who have received acute or short-term inpatient treatment. Ideally, discharge planning, including plans for outpatient follow-up and the provision of any additional services, should commence early in the process. Early and continual contact with all community supports, including family, school personnel, and outpatient therapists, is imperative.

Silka & Hauser (1997) outline three questions to be addressed by the treatment team:

1. What are the objectives?
2. Who is responsible for which service (case manager, family, agency, client, and others)?
3. What are the minimal discharge criteria?

### **Developmental and Educational Services**

The Individuals with Disabilities in Education Act (IDEA) (Public Law 94-142, Public Law 99-457, and Public Law 102-119) requires that children with intellectual disability or related developmental disorders receive a free and appropriate education (FAPE). The requirement for FAPE only applies to Part B educational services available from ages two to 22.

In Virginia, Part B preschool services are available to eligible children with disabilities from age two to age five (Virginia Board for People with Disabilities, 2014). While IDEA mandates that such services be available starting at age three, Virginia parents have the option of either IDEA Part B preschool or IDEA Part C early intervention services for their child between the ages of two and three. A separate eligibility determination is required for Part B services from that required for Part C.

Early intervention services under Part C are based on a multi-disciplinary evaluation and each state develops its own definition of eligibility. In Virginia, children from birth to age three are eligible for Part C early intervention services if the child:

- Has a 25 percent developmental delay in one or more areas of development,
- Has atypical development, or
- Is diagnosed with a physical or mental condition that has a high probability of resulting in a developmental delay (Virginia Board for People with Disabilities, 2014).

In Virginia, the Virginia Department of Behavioral Health and Developmental Services (VDBHDS) is the lead agency that administers Part C of IDEA. Virginia's statewide early intervention system is called the Infant & Toddler Connection of Virginia. Infant and toddler services can be home-based, center-based, or a combination. To the maximum extent possible, early intervention services are to be provided in the child's natural environment. The nature of the services is determined based on an assessment of the child and the family priorities. The services that are provided in response to this plan may include the identification of appropriate assistive technology, intervention for sensory impairments, family counseling, parent training, health services, language services, health intervention, occupational therapy, physical therapy, speech therapy, case management, and transportation to services (Biasini et al., 1999).

*The following information is taken from the Virginia Board for People with Disabilities (2014).* Pursuant to IDEA, special education is defined as specially designed instruction, offered at no cost to the parent(s), that meets the unique needs of a child with a disability, including instruction conducted in a classroom, in the home, in hospitals, in institutions, and in other settings, and instruction in physical education. According to IDEA, "specially designed instruction" means adapting, as appropriate to the needs of an eligible child, the content, methodology, or delivery of instruction a) to address the unique needs of the child that result from the child's disability; and b) to ensure the child's access to the general curriculum, so the child can meet the educational standards that apply to all children within the jurisdiction of the public school division. There are numerous students with disabilities who do not require special education services through an Individualized Education Program (IEP) but may need accommodations to be successful. Examples of accommodations include: giving a student preferential seating, allowing more time for tests, having certain tests read aloud, allowing the use of a calculator, and so forth. These students may be eligible for a 504 plan under Section 4 of the amended Rehabilitation Act of 1973. The 504 plan is generally developed by a committee consisting of the student with the disability, if appropriate; one or more of the student's parents or guardians; one or more of the student's teachers; and

the school's 504 coordinator. A 504 plan, which must be updated annually, documents the student's disability, his or her need for accommodations, and the set of specific accommodations that will be provided by the school.

## **Other Elements for Consideration**

### ***Cultural Factors***

Any assessment of adaptive behavior focuses on how well children can function and maintain themselves independently and how well they meet the personal and social demands outlined for them by their cultures. Because various cultures may hold their own views regarding the level of functioning/skills expected of children of certain ages, clinicians must be culturally sensitive in diagnosing children with intellectual disability, with or without co-occurring mental health disorders. In addition, the sociocultural background and native language of the child should be considered in assessing intelligence and level of impairment (AACAP, 1999; Colorado Board of Education, 2013).

### ***Family Involvement***

Service providers must make every effort to include the family in all aspects of planning and service delivery for children and adolescents with intellectual disability with or without co-occurring mental health disorders (Aggarwal, Guanci, & Appareddy, 2013). They must consider the level of knowledge and understanding of the family regarding the disability of the child, and they must also be sure that the family is sufficiently informed of all service options. If professionals fail to acknowledge parents as partners in the process, they run the risk of alienating them, resulting in a lack of interest or participation in necessary services (NLM, 2015). Thus, the knowledge and expertise that families already possess about their child and their child's strengths should be valued (Hodapp, DesJardin & Ricci, 2003). Families of children with less common genetic syndromes become the experts on their child's disorder, frequently being the only ones with experience or knowledge of a particular syndrome (Fidler & Hatton, as cited by Hodapp, DesJardin & Ricci).

### ***Peer Interaction***

Successful peer interactions can have significant benefits for youth with intellectual disability. Through social interactions, children and adolescents can learn and practice social skills, develop peer relationships, and receive needed support. Research has shown that increased social competence can positively affect academic achievement and quality of life (Carter & Hughs, 2005; Goldstein et al., 2002; Hartup, 1999, as cited by Toth & King, 2010). A recommended approach for youth with an intellectual disability combines such support-based approaches with skills-based strategies.

### ***Lifestyle Considerations***

Pain caused by dental, dietary-related, or muscle soreness issues may be common in children with intellectual disability (Zeldin, et al., 2016). Parents, guardians, and family members can help physicians determine the source of pain and ensure proper pain management treatment.

### ***Availability of Community Services and Supports***

The Arc, a non-profit organization that supports persons with intellectual disability, has reported that over 300,000 children and adults nationwide are on waiting lists for such essential supports and services as service coordination, housing, employment, in-home supports, early intervention, transportation, and respite care (The Arc, 2017). A report by the VDBHDS (2013) shows that service availability for children with intellectual disability is also a serious concern in Virginia. In the *2014 – 2020 Comprehensive State Plan*, VDBHDS reported that 611 children and adolescents were on the waiting list for intellectual disability services.

In Virginia, individuals with an intellectual disability may be eligible to receive services from Virginia's Medicaid Waivers. Medicaid Waivers are partnerships between the family support system and Medicaid providers to provide services that allow individuals with intellectual disability to live in their communities rather than reside and receive services in an institution. Virginia has six approved Waivers. Three of these Waivers, the Intellectual Disability (ID) Waiver, the Day Support for Persons with Intellectual Disabilities (DS) Waiver, and the Individual and Family Developmental Disabilities Support (DD) Waiver provide community based supports to individuals with intellectual disabilities.

Virginia's ID Waiver serves children and adults with an intellectual disability diagnosis and provides a variety of services. To be eligible for the ID Waiver, an individual must be six years of age or older and must have a psychological evaluation completed by a licensed professional that states a diagnosis of intellectual disability and reflects the individual's current level of functioning (VDBHDS & Virginia Department of Medical Assistance Services [VDMAS], 2015). The DD Waiver serves adults and children six years of age and up with developmental disability diagnosis who require home and community-based services to live in the community. Group residential services are not provided through this Waiver. Virginia also administers the Day Support Waiver, which provides services to individuals with intellectual disability who are on the waitlist for the ID Waiver. Services are not as comprehensive as those offered through the ID Waiver but day support, pre-vocational services, and supported employment service are provided to recipients on the waitlist. Unfortunately, for both the ID and DS Waivers, there are waiting lists. As with all Medicaid-funded services, there are also financial eligibility criteria.

Research indicates that lack of services can exacerbate the problems of youth with intellectual disability, as it may allow for an increase in the severity of the disability or learning delays (The Arc, 2010). Furthermore, lack of services may also lead to greater dependence and isolation, and a decrease in self-esteem and productivity. Consequently, providers and policy makers must make every effort to identify these children and provide them with necessary services to ensure that they become productive members of society.

## **Overview for Families**

The term "mental retardation" has been replaced with "intellectual disability" (APA, 2013a). Furthermore, the determinant for assessing the severity of an intellectual disability has transitioned from solely IQ scores to an adaptive functioning assessment. In order for a youth to be diagnosed with intellectual disability, he or she must have an onset of symptoms during the developmental period, have an IQ significantly below average (usually 70 or below), and have significant deficits in adaptive functioning (APA).

A large percentage of children with intellectual disability have the ability to lead productive lives if proper treatment and care are given. These children do not require long term hospitalization/institutionalization and can be members of their respective communities. For best results, a physician should evaluate a youth's overall physical and intellectual strengths and weaknesses and create a tailored plan to help with a successful integration at home, school, and the community. The following areas should be the focus of a physician's evaluation:

- Neurology
- Psychology/Psychiatry
- Educational needs
- Hearing, speech, and vision
- Physical therapy (AACAP, 2012)

Youth with intellectual disability are often aware that they are educationally behind their peers. This can cause withdrawal, anger, nervousness, or behavioral challenges. Older children may experience

depression; however, some may lack the communication skills to express their feelings and therefore may not receive the help they need (AACAP, 2012). Early diagnosis and intervention are crucial to successful treatment of intellectual disabilities and any comorbid mental health disorders. Dual diagnosis treatment serves as the best tool for comorbid conditions because all symptomology is treated (Aggarwal, Guanci, & Appareddy, 2013).

Regardless of whether there are co-occurring mental health disorders in a child with an intellectual disability, the family is encouraged to meet with a child psychologist, who can set reasonable expectations for development, create a plan offering opportunities for success, and offer useful information to the youth and parents about the stresses of growing up with intellectual disability (AACAP).

### **Resources and Organizations**

#### **American Association of Intellectual and Developmental Disabilities**

(formerly the American Association on Mental Retardation)

<http://aaidd.org/>

#### **Center for Parent Information and Resources**

<http://www.parentcenterhub.org/>

#### **Council for Exceptional Children**

Division on Developmental Disabilities

<http://www.dddcec.org/>

#### **Individuals with Disabilities Education Act (IDEA)**

<http://idea.ed.gov/>

#### **National Down Syndrome Society (NDSS)**

<http://www.ndss.org/>

#### **National Fragile X Foundation**

<https://fragilex.org/>

#### **National Organization on Fetal Alcohol Syndrome**

<https://www.nofas.org/>

#### **U.S. Department of Education**

Office of Special Education and Rehabilitative Services

<https://www2.ed.gov/about/offices/list/osers/index.html?exp=5>

#### **U.S. Department of Health and Human Services**

Administration for Children and Families

<https://www.acf.hhs.gov/>

#### **U.S. Department of Health and Human Services**

Administration for Community Living

<https://www.acl.gov/news-and-events/latest-news/administration-intellectual-and-developmental-disabilities-announces>

#### **The Arc of the United States**

(formerly the Association for Retarded Citizens)

<http://www.thearc.org/>

### **Virginia Resources and Organizations**

#### **Partnership for People with Disabilities at Virginia Commonwealth University**

<https://partnership.vcu.edu/>

#### **Virginia Board for People with Disabilities**

<https://www.vaboard.org/>

#### **Virginia Department of Behavioral Health and Developmental Services (VDBHS)**

<http://www.dbhds.virginia.gov/>

#### **Virginia Department of Education**

Office of Special Education

[http://www.doe.virginia.gov/special\\_ed/index.shtml](http://www.doe.virginia.gov/special_ed/index.shtml)

#### **Virginia Office for Protection and Advocacy**

disABILITY Law Center

<http://dlev.org/>

#### **The ARC of Virginia**

<https://thearcofva.org/>

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#### **DISCLOSURE STATEMENT**

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