

# INTELLECTUAL DISABILITY

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## Introduction

Intellectual disability is not a single, isolated disorder. Intellectual disability is a heterogeneous condition that is defined by significantly sub-average intellectual and adaptive functioning and an onset before 18 years of age (American Academy of Child and Adolescent Psychiatry [AACAP], 1999). The American Association of Intellectual and Developmental Disability (AAIDD, 2007) provides a tri-dimensional definition of intellectual disability which is currently the most widely accepted definition. Intellectual disability is characterized by significant limitations in both intellectual functioning (reasoning, learning, problem solving) and adaptive behavior, which covers a range of everyday social and practical skills (AAIDD). As defined by AACAP, adaptive skill areas include communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. This categorization sub-classifies intellectual disability according to the intensity and nature of needed supports. In addition, it emphasizes the need for detailed assessment in all relevant domains, including psychological and emotional functioning (AACAP).

In recent years, there has been an effort to replace the term “mental retardation” with “intellectual disability” (AAIDD, 2007). The Centers for Disease Control have made this change, as has the American Association on Mental Retardation (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 (President’s Committee for People with Intellectual Disabilities [PCPID], 2007). However, mental retardation is still listed as a diagnosis in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)* (American Psychiatric Association [APA], 2000).

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 (DMHMRSAS). The Board and the Office of the Inspector General were re-named to reflect this change. 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 Department of Behavioral Health and Developmental Services (DBHDS). This measure was adopted to support the Department’s mission and to move away from the stigma

associated with the term “mental retardation.” 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 intellectual disability may also have a diagnosable mental health disorder, also 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 of a mental health disorder and intellectual disability may cause significant clinical impairment and place additional burden upon these children and their families. Unfortunately, it is frequently assumed that behaviors associated with co-occurring mental health 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 and specify that intellectual disability is a developmental disability, not a mental health disorder. Accordingly, this revised section includes additional information about intellectual disability, as well as commonly co-occurring mental health disorders.

## 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 to 3 percent of the population, with doctors finding a specific cause in only 25 percent of cases (Penn State Hershey Children’s Hospital, 2011). For example, when the diagnosis is based on IQ alone, prevalence is estimated at approximately 3 percent, but when the AAIDD’s (2007) tri-dimensional definition is used, the national prevalence rate is estimated at 1 percent (AACAP, 1999). A conservative approximation (using a 1 percent rate) estimates that 73,890 individuals age 6 and over in Virginia have intellectual disability. Intellectual disability is more common in males than females, with a male-to-female ratio of approximately 1.5 to 1 (APA, 2000). Intellectual disability affects about 1 in 10 families in the United States (AAIDD).

The following information is specific to Virginia. Using 2010 Census data and applying national prevalence rates from studies and surveys, the Virginia Department of Behavioral Health and Developmental Services (DBHDS) estimates that approximately 73,890 individuals ages 6 and older in Virginia have an intellectual disability. In Fiscal Year 2011, 14,069 children received developmental services through Infant and Toddler Connection and 6,527 children with intellectual disability received services through Virginia’s Community Services Boards (DBHDS, 2011).

## 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, along with detailed family and medical history evaluation (AACAP, 1999).

The *DSM-IV-TR* provides the standard criteria for a diagnosis of intellectual disability, used in diagnosis of both children and adults (APA, 2000). The disorder is characterized by:

1. significantly subaverage intellectual functioning;
2. significant limitations in adaptive functioning in at least 2 of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety; and
3. 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-IV-TR*, 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 to 75 (APA, 2000). The threshold for intellectual disability is typically set at 70. Experts generally agree that scores of 71 to 75 are consistent with intellectual disability only when significant deficits in adaptive behavior are present and manifested during the developmental period (AACAP). Table 1 outlines the degrees of severity of intellectual disability as set forth by the *DSM-IV-TR* (APA).

Table 1

### Degrees of Severity of Intellectual Disability

Severity	Approximate IQ Range
Mild	55 to approximately 70
Moderate	35-40 to approximately 50-55
Severe	20-25 to approximately 35-40
Profound	Below 20-25

Source: APA, 2000.

#### **Adaptive Functioning**

Adaptive behavior refers to an individual's effectiveness in functioning at an age and culturally appropriate level. With regard to impairments in adaptive functioning, AAIDD (2007) and the *DSM-IV-TR* (APA, 2000) criteria specify that the child or adolescent must demonstrate significant impairments in at least 2 of 10 areas of functioning for a diagnosis of intellectual disability. These include limitations in communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety (APA). There are multiple measures which address these 10 areas of adaptive behavior.

#### **Age of Onset**

The *DSM-IV-TR* also stipulates that the onset of symptoms occur prior to the age of 18 (APA, 2000). 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). Instead, service providers should acknowledge the cognitive or behavioral deficit as a form of developmental disability and leave room for further diagnosis as the child gets older (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. For example, the condition may be treatable and/or preventable, and it may be associated with a particular "behavioral phenotype" or increased risk for a medical disorder. 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). Among the identified causes of intellectual disability, those most frequently cited include prenatal causes, malformations of unknown causation, external prenatal causes, perinatal causes and postnatal causes (AACAP).

### **Intellectual Disability and Co-occurring Mental Health Disorders**

Several well-constructed, community-based population studies suggest that 35 to 40 percent of children and adolescents with intellectual disability are likely to have a diagnosable mental health disorder

as well (Emerson & Hatton, 2007). Children and adults with intellectual disability and mental health disorders may be one of the most underserved populations in the United States (Fletcher, Loschen, Stavrakaki & First, 2007). This can have a significant impact on a child’s coping skills and mental health, and it may be one of the primary factors limiting the functioning, quality of life, and adaptation of intellectual disability to community life (Masi, 1998).

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 & Patton). 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).

The specific levels of intellectual disability appear to be differentially associated with the rates and types of mental health disorders that may be diagnosed. Specifically, psychopathology in individuals diagnosed with mild intellectual disability is associated with psychiatric disorders, while individuals with a profound level of intellectual disability are associated with behavioral issues (Fletcher, Loschen, Stavrakaki, & First, 2007). For individuals with moderate and severe intellectual disability, behavioral and psychiatric disorders are demonstrated to exist at similar rates (Fletcher, Loschen, Stavrakaki & First). Clinicians are faced with certain challenges and acknowledge increased difficulty in diagnosing mental health disorders in individuals with intellectual disability.

Table 2 lists co-occurring mental health disorders and their prevalence rates.

*Table 2*

**Prevalence of Co-occurring Mental Health/Developmental Disorders among Children and Adolescents with or without Intellectual Disability**

Co-occurring Disorder	Point 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	8.3	0.9

Disorder (ADHD)		
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 (AACAP, 1999). 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, review of any 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, review of 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.

A separate diagnostic manual was developed to ensure that individuals with intellectual disabilities who present psychiatric symptoms are accurately diagnosed. In 2007, the National Association for the Dually Diagnosed (NADD) published the *Diagnostic Manual-Intellectual Disability (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability*. The *DM-ID* offers a description of each disorder, a summary of the *DSM-IV-TR* diagnostic criteria, a review of the literature and research, an evaluation of the strength of evidence supporting the literature conclusions, a discussion of the etiology, and adaptations of the diagnostic criteria for the intellectual disability population (Hartwell-Walker, 2012).

There is no single "best" treatment for those youth with a co-occurring mental health disorder (King, State & Maerlender, 2005). An underlying assumption in treating co-occurring disorders in youth with intellectual disability is that most youth experience the same complex interaction of biological, psychological and environmental forces which shape mental health disorders (King, State & Maerlender). It is extremely critical that clinicians serving youth with both an intellectual disability and co-occurring mental health disorder employ 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 paragraphs, 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).

As noted by the NADD, medication is appropriate for many mental health disorders, such as mood disorders and psychotic disorders. Medication treatment should not be a total treatment approach but rather part of a comprehensive bio-psycho-social-developmental treatment approach. 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. Behavior management plans are developed to deal with inappropriate behaviors and to teach adaptive skills. A functional analysis of behavior is conducted to determine the best approaches to use in the behavior plan. Systematic behavior programs may be implemented by individuals in the youth's environment. The dually diagnosed youth may participate in the design of the behavioral program.

Many treatment modalities and interventions have been tried, with varying degrees of effectiveness, with youth with intellectual disability (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.

## Proven Interventions

The following paragraphs highlight guiding principles in service design and provision to children and adolescents with intellectual disability, regardless of whether they are diagnosed with a co-occurring mental health disorder. Services should contribute to improving the quality of life of individuals with intellectual disability. According to the AACAP (1999), interventions for children and adolescents with intellectual disability are based on several guiding principles: person-centered planning, appropriate education, family training, community integration and transition planning for adulthood. With appropriate personalized supports over a sustained period, the life functioning of youth with intellectual disability generally will improve. However, intellectual disability is a life-long disability (DBHDS, 2009).

### ***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 from the time they are born. The requirement for early intervention was enacted in 1986 to ensure that all children with disabilities from birth through the age of two would receive appropriate early intervention services (Infant and Toddler Connection of Virginia, n.d.). This requirement was later incorporated as Part C of IDEA. Early intervention services are based on an evaluation sufficiently comprehensive to identify both the child's disability and educational needs.

In Virginia, the Virginia Department of Behavioral Health and Developmental Services (DBHDS) is the lead agency which 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. 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, case management, and transportation to services (Biasini et al., 1999).

Once the child reaches the age of 3, federal law requires that special education programs established by IDEA be made available for the child and family (National Dissemination Center for Children with Disabilities [NICHCY], 2009). As the child gets older, the emphasis on special education programs shifts to training in daily living skills, as well as academic subjects. Interventions also include medical care for any co-occurring physical conditions, such as seizure disorders, motor handicaps, and sensory impairments, as well as treatment of any co-occurring mental disorders and psychosocial dysfunction.



The services provided through IDEA to preschool children and school-aged children are most often provided as home-based, center-based or in naturally occurring environments. An Individualized Education Program (IEP) is developed based on results of the team evaluation and parental input. This plan describes the objectives for improving the child's skills and may include family or parent-focused activities. These services must also be provided in the least restrictive setting possible, but must include a continuum of placements that includes instruction in regular classes, special classes, special schools, home instruction, and instruction in hospitals and institutions.

### ***Behavioral Techniques***

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, environmentally mediated interventions, and psychotherapy, including individual, group and family-oriented approaches.

Behavioral interventions, including treatments using applied behavior analysis, have a large evidence base (Toth & King, 2010). Behavioral approaches 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., on a fixed time schedule) and extinction are used to reduce challenging behaviors (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.

The information discussed in the following paragraphs is taken from King, State & Maerlender (2005). Research conducted over the past 20 years has supported the effectiveness of behavioral therapies in managing many of the challenges faced by in children and adolescents with intellectual disability. Behavioral treatments are designed to provide alternatives to unwanted behaviors. One such treatment is positive behavior support. Positive behavioral support involves the assessment and reengineering of environments so youth with problem behaviors experience reductions in their problem behaviors while increasing social, personal and professional quality in their lives. Positive behavior support is the application of behavior analysis and systems change perspectives within the context of person-center values to the intensely social problems created by any accompanying undesirable or maladaptive behaviors. Positive behavior support has 3 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.

### ***Pharmacological Interventions***

Certain issues related to pharmacology have been recognized exclusively in individuals with intellectual disability and co-occurring mental health disorders. Reports of the prevalence of psychotropic medication use in both adults and children with intellectual disability show that over 1/3 of this population served in residential settings is receiving one psychotropic drug (Toth & King, 2010). There is also a lack of specificity about which psychotropic medications are utilized as well as an "off-label" use 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 symptoms adequately.

It is 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). The effects of medication on children with intellectual disability are similar to that expected for the general population (King, State & Maerlender, 2005).

While psychotropic drugs are not often used with children with intellectual disability, they are most often prescribed in children or adolescents who exhibit disruptive behavior, including self-injury, stereotyped behaviors (e.g., hand or finger twisting, or complex whole body movements) and aggression (AACAP, 1999). Recent research suggests that atypical antipsychotics may be a better first choice than typical antipsychotics because of the lower risk of side effects (Rifkin, 2004). This must be considered in light of the fact that there are no studies that address the use of antipsychotics in children or adolescents who are aggressive and psychotic (Rifkin). It is important to note that no professional body has published drug guidelines for patients with intellectual disability. Thus, thorough psychosocial assessment is critical for youth with intellectual disability (Rifkin). Moreover, medications should be prescribed as they would be for the general psychiatric population, with special attention paid to possible behavioral effects and to the child or adolescent's ability to reliably report possibly dangerous side effects (Silka & Hauser, 1997).

One area that may be regarded as an exception is the treatment of ADHD. Several investigators have demonstrated that stimulants are efficacious in the treatment of accompanying hyperactivity to a degree that matches youth not diagnosed with intellectual disability (King, State & Maerlender, 2005). However, this has been noted more frequently for youth with mild to moderate impairment, rather than for youth with great cognitive disability (King, State & Maerlender).

### ***Discharge Planning***

As indicated by Silka & Hauser (1997), appropriate discharge planning is crucial for children with intellectual disability and co-occurring mental health disorders receiving 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?

## **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 co-occurring mental health disorders and intellectual disability. In addition, the sociocultural background and native language of the child should be considered in assessing intelligence and level of impairment (AACAP, 1999).

### ***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 and co-occurring mental health disorders. 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. Thus, the knowledge and expertise that families already possess about their child and their child's syndrome 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.

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

The Arc (formerly the Association for Retarded Citizens), a non-profit organization which supports persons with intellectual disability, has reported that approximately 285,034 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, 2010). A report by the DBHDS (2009) shows that service availability for children with intellectual disability is also a serious concern in Virginia. In the 2010-2016 Comprehensive State Plan, the DBHDS reported that 1,564 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. The following information about Virginia's Medicaid Waivers is taken from the Virginia Department of Medical Assistance Services (2010). 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 developed the Intellectual Disability Waiver (formerly the Mental Retardation Waiver) to provide home and community-based services to individuals under 6 years of age who are "at developmental risk," and to individuals above 7 years of age diagnosed with intellectual disability who:

1. qualify for institutional care in an Intermediate Care Facility for Individuals with Mental Retardation (ICF/MR);
2. are at imminent risk of ICF/MR placement, and
3. require home and community-based services to live in the community rather than living in an ICF/MR.

Virginia also administers the Day Support Waiver, which provides services to individuals with intellectual disability who are on the waitlist for the Intellectual Disability Waiver. Services are not as comprehensive as those offered through the Intellectual Disability Waiver in that they provide day support, pre-vocational services and supported employment to recipients on the waitlist.

Unfortunately, for both the Intellectual Disability and Day Support Waivers, there are long waiting lists of persons who have already applied. 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, 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.

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#### **Organizations/Weblinks - National**

##### **American Association of Intellectual and Development Disabilities** (formerly American Association on Mental Retardation)

4444 North Capitol Street, NW. Suite 846 - Washington, DC 22001-1512  
<http://www.aaid.org>

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

Division on Developmental Disabilities  
1110 North Glebe Road, Suite 300 - Arlington, VA 22201-5704  
<http://www.daddcec.org>

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

666 Broadway, Eighth Floor - New York, NY 10012-2317  
<http://www.ndss.org>

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

P.O. Box 190488 - San Francisco, CA 94119  
<http://www.fragilex.org>

**National Dissemination Center for Children and Youth with Disabilities (NICHCY)**

P.O. Box 1492 - Washington, DC 20013  
<http://nichcy.org>

**National Organization on Fetal Alcohol Syndrome**

900 17th Street, NW, Suite 910 - Washington, DC 20006  
<http://www.nofas.org>

**The Arc of the United States** (formerly Association for Retarded Citizens)

1010 Wayne Avenue, Suite 650 - Silver Spring, MD 20910  
<http://www.thearc.org>

**U.S. Department of Education**

U.S. Office of Special Education and Rehabilitative Services  
400 Maryland Ave., S.W. - Washington, DC 20202-7100

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

Regulations, News, Information and Resources  
<http://idea.ed.gov>

**IDEA 2004 Fact Sheet**

<http://ideapartnership.org/topics-database/idea-2004/267-overview-resources/1371-idea-2004-fact-sheets-guides-and-tool-kits.html>

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

Administration for Children and Families  
Administration on Developmental Disabilities  
Mail Stop HHH 300-F - 370 L'Enfant Promenade, SW - Washington, DC 20447

**Virginia Resources**

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

700 East Franklin Street, 10th Floor - Richmond, VA 23284  
<http://www.partnership.vcu.edu>

**Support for Consumer-Run Mental Health Programs in Virginia**

<http://www.vocalvirginia.org/#/about-the-vocal-co-op/4533123887/valinks.htm>

**The ARC of Virginia**

2025 East Main Street, Suite 120 - Richmond, VA 23223  
<http://www.thearcofva.org>

**Virginia Board for People with Disabilities**

Washington Building  
1100 Bank Street, 7th Floor - Richmond, VA 23219  
<http://www.vaboard.org>

**Virginia Department of Behavioral Health and Developmental Services**

Office of Developmental Services  
P.O. Box 1797 - Richmond, VA 23219  
<http://www.dbhds.virginia.gov/ODS-default.htm>

**Virginia Department of Education**

**Office of Special Education**

P.O. Box 2120, Richmond, VA 23218  
[http://www.doe.virginia.gov/special\\_ed/index.shtml](http://www.doe.virginia.gov/special_ed/index.shtml)

**Virginia Office for Protection and Advocacy**

<http://disabilitylawva.org>

Richmond Office

1910 Byrd Avenue, Suite 5 - Richmond, VA 23230

Virginia Beach Office

287 Independence Boulevard - Virginia Beach, VA 23462

**Books/Clinical Guides**

Fletcher, R., Loschen, E., Stavrakaki, C., & First, M. (Eds.). (2007). *Diagnostic Manual -- Intellectual Disability (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability*. Kingston, NY: NADD Press.

Fletcher, R., Loschen, E., Stavrakaki, C., & First, M. (Eds.). (2007). *Diagnostic Manual -- Intellectual Disability (DM-ID): A Clinical Guide for Diagnosis of Mental Disorders in Persons with Intellectual Disability*. Kingston, NY: NADD Press.