

INTELLECTUAL DISABILITY

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Introduction

Intellectual disability is not a single, isolated disorder. The American Association of Intellectual and Developmental Disability (AAIDD) provides a tri-dimensional definition of intellectual disability which is currently the most widely accepted. Intellectual disability, which originates before the age of 18, is a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior (AAIDD, 2007). As defined by the American Academy of Child & Adolescent Psychiatry (AACAP), adaptive behavior covers a range of everyday social and practical skills in 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, 1999).

In recent years, there has been a widespread effort to replace the term “mental retardation” with “intellectual disability” (AAIDD, 2007). Both the Centers for Disease Control and Prevention (CDC) and the American Association on Mental Retardation (AAIDD) have adopted the new terminology. The President’s Committee on Mental Retardation has also adopted the change and renamed itself the President’s Committee for People with Intellectual Disabilities (PCPID, 2007). “Mental retardation” is still used, however, in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)* (American Psychiatric Association, 2000).

Virginia has recently adopted the current terminology. In 2008, the Virginia General Assembly passed legislation to rename the state’s Department of Mental Health, Mental Retardation and Substance Abuse Services as the Department of Behavioral Health and Developmental Services (DBHDS). The Board and the Office of the Inspector General would also be renamed to reflect the change. The final version of the 2008 bill required that, before taking effect, it also be passed by the 2009 General Assembly. The bill passed unanimously, thus supporting the Department’s mission under a new name and moving away from the stigma associated with the term “mental retardation.”

Prevalence

Intellectual disability affects about one in ten families in the United States (AAIDD, 2007). Estimates of the disorder’s prevalence vary, depending on diagnostic criteria, study design, and methods of ascertainment. For example, when diagnosis is based on IQ alone, prevalence is estimated at approximately 3% but, when the AAIDD’s tri-dimensional definition is used (AAIDD), the national prevalence rate is estimated at 1% (AACAP, 1999). Intellectual disability is more common in males than in females, with a male-to-female ratio of approximately 1.5 to 1 (APA, 2000).

The following information is specific to Virginia and was obtained from the DBHDS. In 2008, the Department estimated that approximately 71,526 individuals (ages six and older) had an intellectual disability. Approximately 18,495 infants, toddlers, and young children (birth through age 5) had developmental delays requiring early intervention services. In 2008, data from Virginia's community services boards indicated that 11,135 children between the ages of 0 to 17 had a diagnosis of intellectual disability and were being served (DBHDS, 2009).

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 include standardized testing of intellectual ability, adaptive behavior and a detailed family and medical history evaluation (AACAP, 1999).

The *DSM-IV-TR* provides the standard criteria for a diagnosis of intellectual disability; these are used in the diagnosis of children, as well as adults (APA, 2000). The disorder is characterized by "significantly subaverage intellectual functioning," which must be supported by three factors:

1. significant intellectual impairment;
2. significant limitations in adaptive functioning in at least two 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 Impairment

Intellectual impairment is typically measured by individually administered cognitive assessment instruments (AACAP, 1999; AAIDD, 2007). According to the AACAP and the *DSM-IV-TR*, when choosing a cognitive assessment instrument, the youth's socio-cultural background and native language must be considered, since ignoring these variables may lead to a false 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 the 70 to 75 range (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).

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 two of ten 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 ten areas of adaptive behavior.

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.

Age of Onset

The *DSM-IV-TR* also stipulates that the onset of symptoms occurs prior to the age of 18 (APA, 2000). This does not prohibit diagnosis after age 18, but there must be documented evidence that the onset of symptoms occurred prior to that age. Children under age two, however, should not be given a diagnosis of intellectual disability unless the deficits are relatively severe and/or the child has a condition 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 (AACAP, 1999). However, in 58 to 78% of youth with mild intellectual disability, and in 23 to 43% of youth with severe intellectual disability, no causation has been ascertained with current diagnostic techniques (AACAP, 1999). In other cases, numerous causes of intellectual disability have been identified. Table 2 outlines causes, examples and estimated frequency.

Table 2

Examples of Intellectual Disability Types

Causes	Examples	Estimated Frequency
Prenatal causes, e.g., genetic disorders, monogenic mutations	Down Syndrome, Fragile X Syndrome	32%
Malformations of unknown causation, e.g., malformation of the central nervous system	Neural tube defects, Cornelia de Lange Syndrome	8%
External prenatal causes, e.g., maternal infections, toxins	HIV, Fetal Alcohol Syndrome	12%
Perinatal causes, e.g., infections, delivery problems	Encephalitis, Neonatal asphyxia	11%
Postnatal causes, e.g., infections, toxins, psychosocial	Lead poisoning, deprivation, tumor	8%
Unknown causes		25%

Source: AACAP, 1999.

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 are prenatal causes, malformations of unknown causation, external prenatal causes, perinatal causes and postnatal causes (AACAP, 1999).

Comorbidity

According to the AACAP (1999), intellectual disability frequently co-occurs with other mental health disorders, with most prevalence estimates ranging from 30 to 70%. Clinicians and researchers have explained this high prevalence of comorbidity as the result of the psychological vulnerability of children with intellectual disability. 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).

An accurate psychiatric diagnostic evaluation and diagnosis provide the foundation for treatment planning (AACAP, 1999). Such a psychiatric diagnostic evaluation would be sufficiently comprehensive to identify the child’s disabilities and educational needs. Clinicians diagnosing comorbid psychiatric illnesses in youth with a “severe” intellectual disability may have to rely on information obtained from family and other caregivers, including direct behavioral observations of the youth in various settings. In general, the assessment of comorbid illnesses 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, school, hospital). 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 in to account the youth's developmental level, communication skills, associated impairments, and familial and socio-cultural factors. In addition, the possibility of sexual or other abuse that the patient may not be able to report must be considered before a diagnosis based on the *DSM-IV* criteria is reached.

Table 3 lists the most commonly occurring comorbid conditions and their estimated comorbidity rates.

Just as for youth not diagnosed with an intellectual disorder, there is no single "best" treatment for those youth with a comorbid mental health disorder (King, State & Maerlender, 2005). An underlying assumption in treating comorbid disorders in youth with intellectual disabilities 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 comorbid mental health disorder employ a comprehensive, multidimensional and multidisciplinary approach.

Table 3

Intellectual Disability Comorbid Disorders

Comorbid Disorders	Estimated Rate of Occurrence with Intellectual Disability (ID)	References
Autism Spectrum Disorders	75%	Fombonne, 1997
Attention Deficit Hyperactivity Disorder	4 to 11%	Feinstein & Reiss, 1996
Disruptive Behavior	33%	Richardson, Koller & Katz, 1985
Habit Disorders, Stereotypic Movement Disorder, and Self-injurious Behaviors	Self-injurious behaviors are particularly common in certain IDs, such as Prader-Willi, an abnormality on the 15th chromosome which causes low muscle tone, short stature, incomplete sexual development and a chronic feeling of hunger that can lead to excessive eating and life-threatening obesity (Prader-Willi Association, 2010).	Masi, 1998; AACAP, 1999
Mental Disorders due to General Medical Conditions	Seizure Disorder – 15 to 30% Motor impairments – 20 to 30% Sensory Impairments – 10 to 20%	AACAP, 1999
Schizophrenia	Similar rates in persons with and without ID	Reid, 1993
Mood Disorders, e.g., Depression	Underdiagnosed in persons with intellectual disability; estimated to occur at a rate equal to or greater than those without ID	AACAP, 1999; Reiss & Benson, 1985
Anxiety Disorders	25% in outpatient samples	Feinstein & Reiss, 1996
Posttraumatic Stress Disorder	Significantly underdiagnosed in youth with ID	AACAP, 1999
Obsessive-compulsive Disorders	Occurs but difficult to differentiate from self-injurious, self-stimulatory, or stereotypic behaviors	AACAP, 1999
Eating Disorders	ID is a predisposing factor for eating disorders such as Pica, especially in the more "severe" ranges.	AACAP, 1999

Sources: Commission on Youth Graphic of references provided in table.

Treatments

According to the AACAP (1999), the treatment of youth with intellectual disability is based on several guiding principles: person-centered planning, appropriate education, family training, community integration and transition planning for adulthood. A child or adolescent with intellectual disability will improve with adequate supports (Jellinek, Patel & Froehle, 2002). The concept of community-based integration calls for the treatment and integration of children with intellectual disability into the community to the greatest possible extent. No more than 10% of persons with intellectual disability in the United States have ever lived in institutional settings, and most can be found either living with their families or in community-based, out-of-home placements, such as foster care, group homes and independent living programs (AACAP). Although intellectual disability is a life-long disability (DBHDS, 2009), with proper services and interventions, the majority of youth with intellectual disability do well in the community and can participate in employment opportunities. With appropriate personalized supports over a sustained period, the life functioning of youth with intellectual disability generally will improve.

AACAP (1999) cites five different levels or steps as interventions for youth with intellectual disability:

1. **Primary prevention:** The goal of primary prevention is to prevent any conditions that might result in intellectual disability. Primary prevention methods include, during pregnancy, using folic acid supplementation to prevent neural tube defects and abstaining from alcohol and other substances. Another primary prevention method is using properly-installed infant car seats.
2. **Secondary prevention:** Secondary prevention is the specific treatment of underlying conditions, if known, to prevent or minimize brain injuries that might result in intellectual disability. Shunting in the case of hydrocephaly (the abnormal buildup of cerebrospinal fluid in the brain ventricles) or eating specialized diets for a condition such as phenylketonuria (a genetic disorder in which the body cannot metabolize that protein) are examples of secondary prevention strategies.
3. **Tertiary prevention:** Provision of early intervention, education, habilitation and ancillary therapies (e.g., physical, occupational, language therapies), family support and other services as needed in order to minimize functional impairment and maximize the child or adolescent's abilities would constitute tertiary prevention strategies.
4. **Medical care:** The goal of this level of treatment is to usually treat and/or prevent general medical conditions, such as deafness or seizures in children with Down syndrome, which complicate certain intellectual disability syndromes and lower a child or adolescent's functioning.
5. **Treatment and prevention of psychosocial dysfunction:** The goal of this approach is to prevent and reduce maladaptive behaviors and increase the independent functioning of youth with intellectual disability who are diagnosed with, or at risk for, mental health disorders.

Several factors may influence the choice of treatment methods in children with intellectual disability. First, the child's level of cognitive and communication skills may require the service provider to adapt the method of treatment. For example, a child who lacks communication skills would be unable to benefit from traditional verbally-based treatment such as psychotherapy. Explicit instruction in expected behaviors, rehearsal and opportunities for practice in real situations is most effective. It is also important that clinicians first determine how a particular symptom or pattern of behavior compares to what is expected from a child or adolescent of a given developmental age (King, State & Maerlender, 2005). The general principles of treatment are the same as those for children with other mental disorders. However, treatment techniques should be modified in order to adapt to the child's developmental level, particularly regarding communication skills. Another consideration is the impact of any concurrent general medical disorders. An effective treatment plan should be developed to include significant people in the youth's life and natural supports in their daily settings (AACAP, 1999).

The methods and intensity of treatment are adapted as the child progresses in age. In infants, early intervention and parent training are used to provide sensory and motor stimulation and enhance development (Gale Research, 1998). Furthermore, the site of treatment may impact the methodology used. In most cases, outpatient settings are appropriate. Great care and planning is needed for placing children with intellectual disability in inpatient treatment facilities as they are most often not equipped to provide these children with appropriate therapy, habilitative or recreational programs, and other necessary services (AACAP, 1999).

An additional factor that can have a significant impact on treatment efforts is the willingness of the child and family members to participate and comply with the therapeutic plan. Education and on-going support are essential. Detailed explanations must be given to family members to ensure that they understand all of

the behavioral and pharmacological interventions that are being used to treat the child and the treatment plan objectives.

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 & 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 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 some combination of the two. 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, Grupe, Huffman & Bray, 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 changes to training in daily living skills, as well as academic subjects. Treatment efforts will also include medical care for any comorbid physical conditions, such as seizure disorders, motor handicaps, and sensory impairments, as well as treatment of any psychosocial dysfunction and comorbid mental disorders.

The services provided through IDEA to both preschool 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 (Biasini, Grupe, Huffman & Bray, 1999).

Behavioral Techniques

An array of therapeutic techniques has been employed to treat mental disorders in youth with intellectual disability. Of these, the most widely utilized and investigated have been behavioral treatments, 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 promote positive behaviors and reduce challenging behaviors (e.g., aggression, self-injury, task-avoidance). Behavioral techniques target skills, deficits and modifications to the individual's environment and are most effective when applied across multiple settings to promote generalization of skills.

The information discussed in the following paragraph is derived from King, State & Maerlender (2005). Behavioral treatments are aimed at providing children and adolescents with intellectual disability with alternatives to unwanted behaviors. One treatment with demonstrated success in managing difficult behaviors in youth with intellectual disability is positive behavior support. Positive behavior support involves the assessment and reengineering of environments. In this way, youth with problem behaviors are able to reduce them, 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 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 one-half to two-thirds of cases studied, although no long-term quality of life outcomes were reported.

Pharmacological Treatment

Certain issues related to pharmacology have been recognized exclusively in individuals with intellectual disability. Reports of the prevalence of psychotropic medication use in both adults and children with intellectual disability show that over one-third of the population being 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 treatment 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. The same rules for utilizing pharmacological treatments for youth with a diagnosed mental health disorder apply to youth with intellectual disability (Toth & King). The effects of medication on youth with intellectual disability are similar to those 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 youth 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 youth 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 and treatment are important in the treatment of youth with intellectual disability, whether or not they receive drug treatment (Rifkin). Moreover, medications should be prescribed as they would be for the general psychiatric population, with special attention being paid to possible behavioral effects and the youth’s ability to reliably report possibly dangerous side effects (Silka & Hauser, 1997).

The treatment of attention deficit hyperactivity disorder (ADHD) may be regarded as an exception. Several investigators have demonstrated that stimulants are efficacious in the treatment of accompanying hyperactivity to a degree that matches youth not diagnosed with an 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 who may be placed in acute or short-term inpatient treatment. Ideally, discharge planning—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 treatment objectives?
2. Who is responsible for which service (case manager, family, agency, client, and others)?
3. What are the minimal discharge criteria?

Unproven Treatments

According to the AACAP (1999) guidelines, the effectiveness of dietary restrictions in individuals with intellectual disability is generally not supported by research. This type of treatment includes vitamin and mineral supplements and various dietary restrictions, such as yeast and gluten-free regimens.

Other Important Treatment Elements

There are other factors which clinicians consider in determining appropriate treatment; these are discussed in the paragraphs which follow.

Cultural Considerations

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 unique views regarding the level of functioning/skills expected of children of certain ages, clinicians must be culturally sensitive in diagnosing children with developmental delays 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 treatment and planning. 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 and treatment options. If professionals fail to acknowledge parents as partners in the process, they run the risk of alienating them in the process. This can result 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 disorder should be valued (Hodapp, DesJardin & Ricci, 2003). Families of children with less common genetic disorders become the experts on their child's disorder, frequently being the only ones with experience or knowledge of a particular disorder (Fidler & Hatton, as cited by Hodapp, DesJardin & Ricci).

Peer Interaction

Successful peer interactions can have significant benefits for youth with intellectual disabilities. 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 treatment 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 2010-2014 Comprehensive State Plan, DBHDS reported that 1,564 children and adolescents are currently on the waiting list for intellectual disability services.

In Virginia, individuals with an intellectual disability may be eligible to receive services from two of Virginia's seven Medicaid Waivers. The following information about Virginia's Medicaid Waivers is taken from the Virginia Department of Medical Assistance Services (DMAS) (2010). Medicaid Waivers are partnerships between the family support system and Medicaid providers to provide services that allow individuals with an 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 six years of age who are "at developmental risk," and to individuals above seven years of age diagnosed with an 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 an 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 individuals who have already applied. As of February 2010, there were 8,162 Intellectual Disability Waiver slots, with a waitlist of 5,156. Individuals are selected for available Waiver slots based on their urgent needs ranking. There are 300 Day Support Waiver slots with a wait list of 5,156 (the same as the Intellectual Disability Waiver). As with all Medicaid-funded services, there are also financial eligibility criteria.

Research indicates that lack of services can exacerbate the problems of individuals 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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National Organizations

American Association of Intellectual and Development Disabilities (NAIDD) (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 (CEC)

2900 Crystal Drive, Suite 1000 — Arlington, VA 22202-3557
<http://www.cec.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 Information Center for Children and Youth with Disabilities (NICHCY)

P.O. Box 1492 — Washington, DC 20013

<http://www.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 Avenue, SW — Washington, DC 20202-7100

Individuals with Disabilities Education Act (IDEA)

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

IDEA 2004 Fact Sheet: <http://www.ed.gov/admins/lead/speced/ideafactsheet.html>

U.S. Department of Health and Human Services**Administration for Children & Families**

<http://www.acf.hhs.gov/index.html>

National Institutes of Health (NIH)**National Institute of Child Health & Human Development**

Eunice Shriver Kennedy Administration on Developmental Disabilities

<http://www.nichd.nih.gov>

National Institute on Deafness and Other Communication Disorders

<http://www.nidcd.nih.gov>

National Institute of Mental Health (NIMH)

<http://www.nimh.nih.gov>

Substance Abuse and Mental Health Services Administration (SAMHSA)

National Mental Health Information Center

Child, Adolescent and Family Branch, Center for Mental Health Services

<http://www.mentalhealth.samhsa.gov/child>

National Registry of Evidence-based Programs and Practices

<http://www.nrepp.samhsa.gov>

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

700 East Franklin Street, 10th Floor — Richmond, VA 23284

<http://www.vcu.edu/partnership>

The ARC of Virginia

2025 East Main Street, Suite 120 — Richmond, VA 23223

<http://www.arcofva.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 (DBHDS)

Office of Developmental Services

P.O. Box 1797 — Richmond, VA 23219

<http://www.dbhds.virginia.gov/ODS-default.htm>

Virginia Department of Education (DOE)

Office of Special Education

P.O. Box 2120 — Richmond, VA 23218

http://www.doe.virginia.gov/special_ed/index.shtml

Virginia Office for Protection and Advocacy

<http://www.vopa.state.va.us>

Richmond Office

1910 Byrd Avenue, Suite 5 — Richmond, VA 23230

Virginia Beach Office

287 Independence Boulevard — Virginia Beach, VA 23462