INTELLECTUAL DISABILITY

KEY POINTS

- **Characterized by early onset of symptoms in developmental period, below average IQ, and deficits in adaptive functioning.**
- **About one-third of children with ID also have a co-occurring mental health disorder (known as dual diagnosis).**
- **Effective intervention has the goal of improving adaptive functioning and the quality of life.**
- **Behavioral interventions have the most evidence-based support.**

OVERVIEW

Intellectual disability (ID) is a neurodevelopmental disorder characterized by significant limitations in both intellectual and adaptive functioning. Intellectual functioning—also called intelligence—refers to general mental capacity, including, but not limited to, such abilities as learning, reasoning, and problem solving. Adaptive behaviors are conceptual, social, and practical skills, such as, but not limited to, using concepts like numbers and time, developing interpersonal skills, and managing day-to-day activities. For a youth to be diagnosed with ID, he or she must have an onset of symptoms during the developmental period, have an IQ significantly below average (usually around 70 or below), and have significant deficits in adaptive functioning.

A multidisciplinary team, which may include psychologists, psychiatrists, pediatricians, and clinical geneticists, should conduct the assessment for ID. Assessments should include standardized testing of intellectual ability (generally called an IQ test), adaptive behavior and function, and a detailed family and medical history evaluation. In addition, the team should evaluate a youth's overall physical and intellectual strengths and weaknesses and create a tailored person-centered plan to help the child be fully included in all facets of community life.

Intellectual Disability and Co-occurring Mental Health Disorders (Dual Diagnosis)

It is estimated that one-third of all individuals with ID also have a diagnosable mental health disorder.[1] This is known as a dual diagnosis. While most professionals understand dual diagnosis to describe those who are living with mental health disorders and substance abuse, the term is also used for individuals who have a diagnosis of ID and a mental health disorder. A dual diagnosis may cause significant clinical impairment in youth with ID and result in additional challenges for these youth and their families. Unfortunately, it is frequently assumed that behaviors associated with co-occurring disorders are related to the ID. Holding to this assumption can leave

[1] Aggarwal, R., Guanci, N., & Appareddy, V. L. (2013). Issues in treating patients with intellectual disabilities. *Psychiatric Times.* Retrieved from https://www.psychiatrictimes.com/view/issues-treating-patients-intellectual-disabilities.

mental health issues untreated and exacerbate symptoms. Table 1 lists mental health disorders that commonly co-occur with ID and their prevalence rates.

Table 1
Prevalence of Co-occurring Mental Health/Neurodevelopmental Disorders Among Children and Adolescents with and without Intellectual Disability

Co-occurring Disorder	Prevalence Rates by Percentage	
	With Intellectual Disability	Without Intellectual Disability
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, E., & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *The British Journal of Psychiatry, 191*, 493-499.

CAUSES AND RISK FACTORS

Knowledge of the causes of ID in a particular case is important because the cause may be associated with a particular “behavioral phenotype,” the cognitive and behavioral characteristics associated with a genetic syndrome. Understanding the cause can lead to a better understanding of expected difficulties, life course, risk factors, and helpful interventions. Doctors can find a specific reason for an ID in 25 percent of cases. The following are risk factors associated with the development of ID:

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

INTERVENTIONS

Children with ID have the ability to lead meaningful lives if they are provided the education and supports needed to be successful. Effective interventions should contribute to improving day-to day adaptive functioning and overall quality of life. The most widely utilized and investigated interventions are 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 intervention plan. Verbal psychotherapies are most appropriate for persons with mild to moderate ID. Table 2 summarizes interventions for youth with ID.

Table 2
Summary of Interventions for Youth with Intellectual Disability

What Works	
Behavioral interventions	Behavioral interventions analyze the cause of a negative behavior and how it is being reinforced and then offer techniques targeted to promoting positive behaviors. They may also involve modified teaching approaches to assist in the development of social skills, emotion regulation, and functional skills.
Applied behavioral analysis (ABA)	A type of behavioral intervention that uses principles of learning theory to bring about meaningful and positive change in behavior. ABA techniques have been used to help build a variety of skills (e.g., communication, social skills, self-control, and self-monitoring) and help generalize these skills to other situations.
Functional communication training (FCT)	An example of a behavioral intervention program that combines the assessment of the communicative functions of problem behavior with ABA procedures to teach alternative responses. Problem behaviors can be eliminated through extinction and replaced with alternate, more appropriate forms of communicating needs or wants.
What Seems to Work	
Psychotropic medications for co-occurring mental health disorders	Prescribed to treat co-occurring disorders such as anxiety disorders and ADHD. 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.
Not Adequately Tested	
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

Behavioral interventions are designed to provide alternatives to unwanted behaviors. These interventions analyze the cause of the behavior 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 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 ID into the general public, such as setting boundaries, creating positive reinforcement of desired behaviors, and creating activity schedules. The overall goal of behavioral intervention is to increase the quality of life.

Applied Behavioral Analysis (ABA)

Also known as *early intensive behavioral intervention* and *comprehensive behavioral treatment for young children*, applied behavioral analysis is a type of behavioral intervention that uses principles of learning theory to bring about meaningful and positive change in behavior. ABA techniques have been used to help build a variety of skills (e.g., communication, social skills, self-control, and self-monitoring) and help generalize these skills to other situations. The techniques can be used in structured (e.g., classroom), everyday (e.g., family dinner time), and in one-on-one or group instruction settings. ABA is also used for individuals with ID who have autism spectrum disorder. Intervention is customized based on the individual's needs, interests, and family situation. ABA techniques are often used in intensive, early intervention programs to address a full range of life skills.

Functional Communication Training (FCT)

FCT is one example of a behavioral intervention program that combines the assessment of the communicative functions of problem behavior with ABA procedures to teach alternative responses. Problem behaviors can be eliminated through extinction and replaced with alternate, more appropriate forms of communicating needs or wants. FCT can be used across a range of ages and regardless of cognitive level or expressive communication abilities.

Pharmacological Interventions

There are no pharmacological treatments available for ID. For this reason, psychotropic drugs (chemical drugs that alter perception, mood, consciousness, or behavior in the nervous system) should only be used to target co-occurring mental health disorders, and only when therapeutic and social measures do not properly address symptoms.

Reports of the prevalence of psychotropic medication use in both adults and children with ID show that over one-third of this population served in residential settings is receiving at least one psychotropic drug. Psychotropic medications are also used "off-label" for the treatment of challenging behaviors, such as

aggression and behavioral disturbance. The literature repeatedly advises that medication should not be used for the convenience of caregivers or as a substitute for appropriate services.

Pharmacological Interventions in Dual Diagnosis

For people with intellectual disabilities, medication is appropriate when there is a dual diagnosis of a psychiatric disorder, such as a mood disorder or a psychotic disorder. Medication treatment should not be a total treatment approach but rather be part of a comprehensive bio-psycho-socio-developmental treatment approach. In addition, treating ADHD with medication is not recommended in youth with IQs less than 50, as pharmacological treatment can cause serious side effects such as tics, social withdrawal, irritability, and anxiety. Table 3 outlines some of the different pharmacological approaches and the different comorbid symptoms that each drug treats for individuals with ID.

Table 3
Pharmacological Treatments and Their Side Effects

Drug	Targeted Symptoms	Potential Side Effects
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, R., Guanci, N., & Appareddy, V. L. (2013). Issues in treating patients with intellectual disabilities. *Psychiatric Times.* Retrieved from https://www.psychiatrictimes.com/view/issues-treating-patients-intellectual-disabilities.

SPECIAL EDUCATION SERVICES IN VIRGINIA

The Individuals with Disabilities in Education Act (IDEA), Part B, requires that eligible children with disabilities receive a free and appropriate education (FAPE) from ages 2-22.

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 to a) address the unique needs of the child that result from the child's disability; and b) 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.

In Virginia, IDEA Part B preschool services are available to eligible children with disabilities from age two to age five. Virginia parents also have the option of IDEA Part C early intervention services for their child before age three. A separate eligibility determination is required for Part B services and Part C services.

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.

In Virginia, the Virginia Department of Behavioral Health and Developmental Services (DBHDS) 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, services are to be provided in the child's natural environment.

The nature of the services is based on two components: an assessment of the child and the priorities of the family. The services that are provided in response to this plan are the identification of appropriate assistive technology, intervention for sensory impairments, family counseling, parent training, health services and intervention, language services, occupational therapy, physical therapy, speech therapy, case management, and transportation to services. Part C services are provided on a sliding fee scale (adjusted for income).

Other Accommodations

There are numerous students with disabilities who do not require special education services through an Individualized Education Program (IEP), but who 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 developed by a committee generally consisting of the student with the disability (if appropriate), at least one of the student's parents or guardians, at least one of the student's teachers, and the school's 504 coordinator. A 504 plan, which must be updated annually, documents the student's disability, their need for accommodations, and the set of specific accommodations that will be provided by the school.

VIRGINIA'S HOME AND COMMUNITY-BASED MEDICAID WAIVERS

In Virginia, individuals with an ID may be eligible to receive services from Virginia's Home and Community-Based (HCBS) Medicaid Waivers. Medicaid HCBS waivers provide opportunities for individuals eligible for an

institutional level of care to receive services in their own home or community rather than in an institutional setting. Eligible individuals are screened for the waiver by their local community services board. If the child is found eligible for the waiver, the parent would "waive" the child's right to receive services in an institution and choose instead to receive services in the community. Virginia's four HCBS Waiver programs are described in Table 4. More information about Developmental Disability (DD) Waivers can be found on the DBHDS website.

Table 4
Medicaid Waiver Program in Virginia

Waiver	Description
Developmental Disability (DD) Waivers	
Community Living Waiver (formerly ID Waiver)	Includes residential supports and a full array of medical, behavioral, and non-medical supports; available to adults and children; may include 24/7 supports for individuals with complex medical and/or behavioral support needs through licensed services.
Family & Individual Supports Waiver (formerly DD Waiver)	Provides supports for individuals living with their families, friends, or in their own homes, including supports for those with some medical or behavioral needs; available to both children and adults.
Building Independence Waiver (formerly Day Support Waiver)	Supports adults (18+) to live independently in the community; individuals own, lease, or control their own living arrangements and supports are complemented by nonwaiver-funded rent subsidies.
CCC Plus Waiver (formerly EDCD Waiver/Tech Waiver) Is transitioning to Cardinal Care	CCC Plus is a new statewide Medicaid managed care program. The CCC Plus Waiver is the community alternative to a nursing facility placement. Individuals on a DD Waiver receive their acute and primary care medical services through CCC Plus. CCC Plus Waiver service may be used while on a wait list for a DD Waiver.

Source: Virginia Department of Behavioral Health and Developmental Services.

RESOURCES AND ORGANIZATIONS

American Academy of Child and Adolescent Psychiatry (AACAP) Practice Parameter
https://www.jaacap.org/article/S0890-8567(19)32223-3/pdf

American Association of Intellectual and Development Disabilities
http://aaidd.org/
Behavioral Supports
https://aaidd.org/news-policy/policy/position-statements/behavioral-supports

American Psychiatric Association
https://www.psychiatry.org/patients-families/intellectual-disability/what-is-intellectual-disability

American Speech-Language-Hearing Association
Intellectual Disability
https://www.asha.org/Practice-Portal/Clinical-Topics/Intellectual-Disability/

Center for Excellence in Developmental Disabilities
https://health.ucdavis.edu/mindinstitute/centers/cedd.html

Center for Parent Information and Resources
http://www.parentcenterhub.org/

Council for Exceptional Children
Division on Autism and Developmental Disabilities
http://www.daddcec.org/

Individuals with Disabilities Education Act (IDEA)
https://sites.ed.gov/idea/

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/

Society of Clinical Child and Adolescent Psychology
https://sccap53.org/

U.S. Department of Education
Office of Special Education and Rehabilitative Services (OSERS)
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

The Arc of the United States
http://www.thearc.org/

Webinar: Effective Behavior Strategies for Children with Intellectual/Developmental Disabilities
https://www.aucd.org/docs/webinars/Aug22MHWebinar.pdf

VIRGINIA RESOURCES AND ORGANIZATIONS

The Arc of Virginia
https://thearcofva.org/

Infant and Toddler Connection of VA
https://www.itcva.online/

Partnership for People with Disabilities at Virginia Commonwealth University
https://partnership.vcu.edu/

Virginia Board for People with Disabilities
https://www.vbpd.virginia.gov/

Virginia Department of Behavioral Health and Developmental Services (DBHDS)
http://www.dbhds.virginia.gov/

Covered services by waiver type:
https://drive.google.com/file/d/1LrbJAArPyynLT40Wq8hfcllEB1uUHAR_/view

Virginia Department of Education
Office of Special Education Programs
https://www.doe.virginia.gov/programs-services/special-education

Virginia Department of Medical Assistance Services (DMAS)
https://www.dmas.virginia.gov/

Cardinal Care Virginia Medicaid Program
https://www.dmas.virginia.gov/for-providers/cardinal-care-transition/

Disability Law Center of Virginia (DLCV)
http://dlcv.org/

The Collection of Evidence-based Practices for Children and Adolescents with Mental Health Treatment Needs, 9th Edition
Virginia Commission on Youth, 2023

The information contained herein is strictly for informational and educational purposes only and is not designed to replace the advice and counsel of a physician, mental health provider, or other medical professional. If you require such advice or counsel, you should seek the services of a licensed mental health provider, physician, or other medical professional. The Virginia Commission on Youth is not rendering professional advice and makes no representations regarding the suitability of the information contained herein for any purpose.