INTELLECTUAL DISABILITY

KEY POINTS

- **Characterized by early onset of symptoms in developmental period, below average IQ, and deficits in adaptive functioning.**
- **32 to 40 percent of children with ID also have a co-occurring mental health disorder (known as dual diagnosis).**
- **Effective intervention has the goal of improving 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 functioning and adaptive behaviors. Intellectual functioning—also called intelligence—refers to general mental capacity, such as learning, reasoning, and problem solving. Adaptive behaviors are conceptual, social, and practical skills, such as using concepts like numbers and time, developing interpersonal skills, and managing day-to-day activities. In order for a youth to be diagnosed with an intellectual disability, he or she must have an onset of symptoms during the developmental period, have an IQ significantly below average (usually 70 or below), and have significant deficits in adaptive functioning.

A multidisciplinary team, which may include psychologists, psychiatrists, pediatricians, and clinical geneticists, should conduct the assessment for intellectual disability. Assessments should include standardized testing of intellectual ability, adaptive behavior, and adaptive 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 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 between 32 and 40 percent of all individuals with intellectual disability 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 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. A dual diagnosis may cause significant clinical impairment in youth with intellectual disability 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 intellectual disability. Holding to this assumption can leave mental

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

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 psychiatric disorder	36.0	8.0
Any emotional disorder	12.0	3.7
Any anxiety disorder	11.4	3.2
Any depressive disorder	1.4	0.9
Attention-deficit/hyperactivity disorder (ADHD)	8.3	0.9
Any conduct disorder	20.5	4.3
Autism spectrum disorder	8.0	0.3
Tic disorder	0.8	0.2
Eating disorder	0.2	0.1
Emotional disorder & conduct disorder	4.4	0.8
Conduct disorder & ADHD	5.8	0.6
Emotional disorder & ADHD	1.3	0.1
Emotional disorder & conduct disorder & ADHD	0.8	0.1

Source: Emerson, 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 intellectual disability in a particular case is important because the cause may be associated with a particular "behavioral phenotype" or increased risk for a medical disorder. Doctors can find a specific reason for an intellectual disability in 25 percent of cases. The following are risk factors associated with the development of intellectual disability:

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

INTERVENTIONS

Children with intellectual disability 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 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 intellectual disability. Table 2 summarizes interventions for youth with intellectual disability.

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.
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 intellectual disability into the general public, such as setting boundaries, creating positive reinforcement of desired behaviors, and creating activity schedules.

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 both structured (e.g., classroom) and everyday (e.g., family dinner time) settings and in one-on-one or group instruction. ABA is also used with 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 (before age four) 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 intellectual disability. For this reason, psychotropic drugs should only be used to target co-occurring mental health disorders, and only when therapeutic and social measures do not properly address symptoms.

Reports of the prevalence of psychotropic medication use in both adults and children with intellectual disability show that over one-third of this population served in residential settings is receiving at least one psychotropic drug. 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 disorders, 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-social-developmental treatment approach. In addition, treating ADHD with medication is contraindicated in youth with IQs less than 50, as pharmacological treatment can cause serious side effects such as tics, social withdrawal, irritability, and anxiety. Table 3 outlines some of the different pharmacological approaches and the different comorbid symptoms that each drug treats for individuals with intellectual disability.

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 http://www.psychiatrictimes.com/special-reports/issues-treating-patients-intellectual-disabilities

SPECIAL EDUCATIONAL 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.

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

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

- Has a 25 percent developmental delay in one or more areas of development,
- Has atypical development, or
- Is diagnosed with a physical or mental condition that has a high probability of resulting in a developmental delay.

In Virginia, the Virginia Department of Behavioral Health and Developmental Services (VDBHDS) is the lead agency that administers Part C of IDEA. Virginia's statewide early intervention system is called the Infant & Toddler Connection of Virginia. Infant and toddler services can be home-based, center-based, or a combination. To the maximum extent possible, services are to be provided in the child's natural environment.

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

Pursuant to IDEA, special education is defined as specially designed instruction, offered at no cost to the parent(s), that meets the unique needs of a child with a disability, including instruction conducted in a classroom, in the home, in hospitals, in institutions, and in other settings, and instruction in physical education. According to IDEA, "specially designed instruction" means adapting, as appropriate to the needs of an eligible child, the content, methodology, or delivery of instruction a) to address the unique needs of the child that result from the child's disability; and b) to ensure the child's access to the general curriculum, so the child can meet the educational standards that apply to all children within the jurisdiction of the public school division.

There are numerous students with disabilities who do not require special education services through an Individualized Education Program (IEP) but may need accommodations to be successful. Examples of accommodations include: giving a student preferential seating, allowing more time for tests, having certain tests read aloud, allowing the use of a calculator, and so forth.

These students may be eligible for a 504 plan under Section 4 of the amended Rehabilitation Act of 1973. The 504 plan is generally developed by a committee consisting of the student with the disability, if appropriate; one or more of the student's parents or guardians; one or more of the student's teachers; and the school's 504 coordinator. A 504 plan, which must be updated annually, documents the student's disability, his or her need for accommodations, and the set of specific accommodations that will be provided by the school.

VIRGINIA'S HOME AND COMMUNITY-BASED MEDICAID WAIVERS

In Virginia, individuals with an intellectual disability 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 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)	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 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

Partnership for People with Disabilities at Virginia Commonwealth University
https://partnership.vcu.edu/
Virginia Board for People with Disabilities
https://www.vaboard.org/
Virginia Department of Behavioral Health and Developmental Services (DBHDS)
http://www.dbhds.virginia.gov/
Covered services by waiver type:
https://drive.google.com/file/d/1LrbJAArPyynLT40Wq8hfcllEB1uUHAR_/view
DMAS waiver information:
https://csa.virginia.gov/Content/doc/DMAS_Program_Changes_Learning_the_New_DD_Waivers_and_the_CCC_Plus_Waiver_2018.pdf
Infant and Toddler Connection of VA
https://www.itcva.online/
Virginia Department of Education
Office of Special Education Programs
http://www.doe.virginia.gov/special_ed/index.shtml
Virginia Office for Protection and Advocacy (VOPA)
disAbility Law Center of Virginia (dLCV)
http://dlcv.org/
The Arc of Virginia
https://thearcofva.org/

The Collection of Evidence-based Practices for Children and Adolescents with Mental Health Treatment Needs, 8th Edition

Virginia Commission on Youth, 2021

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