

Previously referred to as mental retardation, intellectual or developmental disability (IDD) is “a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18” (American Association on Intellectual and Developmental Disabilities [AAIDD], 2019). Mental retardation was replaced in federal law with the term “intellectual disability” as a result of President Obama’s signing of Rosa’s Law (2010). The term *intellectual disability* still refers to the same population as did mental retardation.

ADVANCES IN INTELLECTUAL DISABILITY RESEARCH

The early 19th century work of Jean-Marc-Gaspard Itard, Jean-Étienne-Dominique Esquirol, and Edouard Séguin resulted in a new method of treatment for people with intellectual disabilities, based upon the then-revolutionary view that people with intellectual disabilities did not have diseased or abnormal brains, but rather suffered from abnormal mental development before, during, or after birth. Séguin opened the world’s first school for those with severe intellectual disabilities, and in 1876, he founded what would eventually become the American Association on Intellectual and Developmental Disabilities (Encyclopaedia Britannica, n.d.). In the late 19th century, Theodore Simon and Alfred Binet developed what became known as the Binet-Simon Scale: a test to roughly estimate the intellectual development of children aged three to twelve years old (Human Intelligence, 2018).

Current research on intellectual disability seeks to understand the etiology of IDD, understand the complexity of comorbid symptoms, improve screening and early diagnosis, develop early interventions and treatments, and develop appropriate, valid biomarkers (National Institutes of Health [NIH], 2019).

DIAGNOSING INTELLECTUAL DISABILITY

Universal biomarkers identifying intellectual disability do not exist, therefore a clinical evaluation is necessary to diagnose intellectual disability. A diagnosis occurs when an individual possesses significant deficits in both intellectual functioning and adaptive behavior (Tasse, 2016).

Adaptive behaviors are the conceptual, social, and practical skills necessary for normal, age-appropriate daily living. Without such skills, a person may need extra support to succeed in school, work, and/or daily life. Deficits in adaptive functioning are measured using standardized, culturally appropriate tests (MentalHelp.net, 2019a).

EXAMPLES OF ADAPTIVE SKILLS

<u>Conceptual Skills</u>	<u>Practical Skills</u>
Reading	Self-Care
Expressive Language	Mobility
Money, time and number concepts	Self-Direction
	Independent Living
<u>Social Skills</u>	
Self-esteem	Interpersonal skills
Responsibility	Ability to follow rules
Obey laws to avoid being victimized	

(AAIDD, 2019)

The American Psychological Association (APA) and the AAIDD both use adaptive functioning to determine the severity of IDD Intellectual, but the severity codes used by each organization differ. The APA's severity codes include:

- **Mild intellectual disability** (85% of intellectually disabled): Individuals at this level often become self-supportive, as they have the ability to adapt to social norms. Many individuals within this group can achieve some level of academic success.
- **Moderate intellectual disability** (10% of intellectually disabled): Individuals at this level can achieve independent employment that involves limited conceptual or social skills. They may require guidance during stressful life situations. Most self-care activities can be performed independently with occasional support.
- **Severe intellectual disability** (3%-4% of intellectually disabled): These individuals have minimal communication skills, although they typically can learn a few self-help skills. They can take minimal care of themselves and require complete supervision.
- **Profound intellectual disability** (1%-2% of intellectually disabled): Individuals at this level experience little cognitive or motor ability and often require 24-hour care and support.

(MentalHelp.net, 2019b)

The AAIDD base their severity codes on level of support needed:

- **Intermittent support**: Individuals at this level only require support during times of stress, uncertainty, and/or transition; they do not need regular support.
- **Limited support**: Individuals at this level can learn to improve their conceptual, social, and practical skills needed to increase adaptive functioning, but they may require support to navigate everyday situations.
- **Extensive support**: Individuals at this level can complete some self-care tasks and have basic communication skills but require daily support.

- **Pervasive support**: Individuals at this level require daily interventions to help them function in every aspect of his or her life. Supervision is required to ensure the health and safety of the individual.

(MentalHelp.net, 2019b)

Some professionals advocate for a continuum approach when determining the severity of adaptive functioning rather than a categorical approach, as a categorical approach does not account for the varying types and intensities of support needed by individuals within the same level of severity. Individuals have different needs. The benefit of these codes, however, is their simplicity (MentalHelp.net, 2019b).

CAUSES OF INTELLECTUAL DISABILITY

The myriad of underlying causes of intellectual disability include genetic conditions, complications during pregnancy and/or birth, infections and diseases, environmental, toxic exposure and nutrition (Medline Plus, 2019).

Genetics

Genetic intellectual disability occurs when inherited genes are abnormal, when genes develop inappropriately due to infections in the mother, or due to high exposure to x-rays. More than 800 genes are known to be involved in intellectual or developmental disability (Chiurazzi & Pirozzi, 2016). Common genetic disorders include:

Single Gene Disorders

Phenylketonuria (PKU)

In the United States, PKU affects approximately 1 in 10,000 to 15,000 newborns. A gene mutation reduces or eliminates the functioning of the amino acid phenylalanine, necessary for appropriate brain function. Too much phenylalanine damages the brain's nerve cells, resulting in brain damage. Blood tests, currently given to every American child at birth, diagnose this condition. If diagnosed early, intellectual disability can be slowed or eliminated through the use of specialized diets (Genetics Home Reference, 2019b).

Chromosomal Disorders

Down syndrome

Affecting approximately 200,000 people in the United States, Down syndrome occurs in 1 out of every 800 newborns (Genetics Home Reference, 2019a). The incidence of Down syndrome increases with a mother’s age. Down syndrome occurs when an individual has a full or partial extra copy of chromosome 21. Three types of Down syndrome exist: trisomy 21 (95% of cases), translocation (4% of cases), and mosaicism (1% of cases). This additional genetic material alters development. People with Down syndrome have an increased risk for other medical conditions, and all individuals with Down syndrome experience mild to moderate cognitive delays; however, these effects do not stop individuals with Down syndrome from attending work, school, having relationships, voting, and being contributing members of society (National Down Syndrome Society, n.d.).

Fragile X Syndrome

Fragile X syndrome occurs in 1 in 4,000 male babies and 1 in 6,000 female babies. This syndrome arises when a mutation on the X chromosome prohibits the gene from producing a necessary protein. One in 259 women and 1 in 800 men carry a “pre-mutation” of this gene. Though they have no symptoms of Fragile X, they can potentially pass the full mutation of the disease and its symptoms to their children. “Fragile X syndrome is the most common inherited cause of intellectual disabilities and the most common known cause of autism” (FRAXA Research Foundation, 2019).

Pregnancy/Birth

During pregnancy, alcohol use can result in Fetal Alcohol Syndrome, a leading preventable cause of intellectual disability during pregnancy. Smoking also increases the risk of intellectual disability. Malnutrition, illnesses, and environmental factors such as exposure to lead and cat feces may also contribute to the development of intellectual disability. During birth, lack of oxygen and other birth injuries can lead to intellectual disability. Premature birth and low-birth weight can predict serious

problems (Centers for Disease Control and Prevention [CDC], 2019; Medline Plus, 2019).

Early Childhood

Children growing up in poverty appear to be at greater risk for intellectual disability because of untreated childhood diseases, environmental toxins, and malnutrition. Certain infectious diseases, such as rubella, can cause brain damage. High quantities of lead and mercury in the environment also negatively affect the brain. Finally, accidents involving head trauma or temporary deprivation of oxygen can also lead to intellectual disability (Medline Plus, 2019).

PREVALENCE OF INTELLECTUAL DISABILITY

In the United States, approximately 5.1% of the population is diagnosed with an intellectual/developmental disability (U.S. Census Bureau, n.d.). The table below provides the most recent data available of intellectual (cognitive) disability rates in Texas and the KCF counties of interest.

PREVALENCE ESTIMATES FOR PERSONS WITH COGNITIVE DISABILITY (2013-2017)			
County	Total Population	Population with IDD	
Texas	26,943,687	1,148,929	4.6%
Bandera	21,125	1,460	7.2%
Bexar	1,861,276	102,302	5.9%
Comal	127,955	5,907	4.9%
Kendall	39,829	2,022	5.4%
(U.S. Census Bureau, n.d.)			

SUPPORTING PERSONS WITH INTELLECTUAL DISABILITY

People with intellectual disability are offered legal protection in educational and work settings. The Individuals with Disabilities Education Act (IDEA) provides “free public education to eligible children with disabilities throughout the nation and ensures special education and related services to those children” (Individuals with Disabilities Education Act, n.d.). People with intellectual disabilities are also among the protected classes described in the 1990 Americans with Disabilities Act (ADA), which grants equal opportunity for employment and reasonable accommodations in the workplace (U.S. Equal Employment Opportunity Commission, n.d.).

LOCAL INTELLECTUAL DISABILITY RESOURCES

The Alamo Area Council of Governments (AACOG) was designated as the Alamo Local Authority for Intellectual & Developmental Disabilities in Bexar County. It is responsible for local planning, policy development, resource allocation, and oversight of services as well as screening and eligibility and coordination of services. Services provided include: eligibility determination, consumer benefits support, behavioral supports, community supports services, day habilitation, employment assistance, respite services, specialized therapies and supported employment (AACOG, n.d.).

Unicorn Center provides vocational training and job placement for adults with IDD. The programs offered include life skills training, job placement with job coaching and long-term follow-up, and a day activity center. It serves 300 individuals daily, ranging in age from 18 to 80 years old. Unicorn Center is an agency of Mission Road Developmental Center (n.d.b).

Every Moment Matters Agency provides a variety of services to individuals with IDD and their families including a home-living program, home and community-based services and a general revenue program. Clients must meet eligibility requirements for Medicaid services and must live in their own or their family's home (Every Moment Matters Agency, 2019).

Reaching Maximum Independence (RMI) is a San Antonio non-profit organization that provides residential and vocational options for people with IDD and other disabilities. Currently serving 90 individuals with disabilities, RMI provides group homes, semi-independent apartments, foster homes, and weekday Life Enrichment programs (Reaching Maximum Independence, n.d.).

The Arc of San Antonio was founded in 1954 to "offer one of the largest continuum of services for children and adults with a broad range of

developmental abilities" (The Arc, 2019). Serving over 200 individuals a day, The Arc provides social, motor and vocational skills in its various programs including adult life enrichment, health matters, community living assistance and support services, community services case management, and family support services. Their goal is to "enhance the lives of people with intellectual and developmental disabilities and their families" (The Arc, 2019).

Mission Road Developmental Center offers a variety of day and residential programs for both adults and children with IDD. Children's programs include a boarding school, custodial residential and emergency shelter services, respite care, and a summer camp. Adult programs include residential care and day services as well as vocational training and in-home and family support services (Mission Road Developmental Center, n.d.a).

Hill Country Mental Health & Developmental Disabilities Centers serves individuals with a variety of mental health challenges within nineteen counties, including Bandera, Comal and Kendall counties. Its IDD services focus on providing day programs, residential services, supported home living, foster care, and companion care. Vocational services, service coordination, and respite care are also available (Hill Country Mental Health & Developmental Disabilities Centers, 2019).

The Texas Department of Aging and Disability Services (DADS) provides an online search engine for intermediate care facilities for individuals with an intellectual disability or related condition which listed 92 facilities in Bexar County as of October 2019. Of these facilities, there were only 83 vacancies, 39 of which were at the San Antonio State Supported Living Center. There were seven listings in Comal County with 51 vacancies, however there were no listings for Bandera and Kendall counties as of October 2019 (Texas Department of Aging and Disability Services, 2019).

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