

Previously referred to as mental retardation, intellectual disability is “is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior” (American Association on Intellectual and Developmental Disabilities [AAIDD], 2017). In October 2010, President Obama signed Rosa’s Law in which the term mental retardation was deemed unacceptable and the term Intellectual disability took its place (S. Res. 2781, 2010). However, the term *Intellectual disability* still refers to the same population as did mental retardation.

ADVANCES IN INTELLECTUAL DISABILITY RESEARCH

The 19th century work of French physicians Jean-Marc-Gaspard Itard and Edouard Seguin resulted in a curriculum of sensory, self-care, and vocational skills for intellectually disabled, “feeble-minded,” people. Aspects of this “Physiological Method” are still utilized today. In 1876, Seguin founded what would eventually become the American Association on Intellectual and Developmental Disabilities (AAIDD). The development of intelligence testing by Theodore Simon and Alfred Binet in the late 20th century allowed for clinical definitions of intellectual disability. Scientific advances during this time also increased understanding of the causes and prevention of intellectual disability (Harbour & Maulik, 2010).

Current research on intellectual disability seeks to improve newborn and population screening, identify and treat: genetic disorders such as Fragile X syndrome and Down syndrome; disorders that involve biochemical processes and metabolic issues related to brain

functioning, brain injury, or long-term consequences to the brain (including hypoxia, prenatal malnutrition, low birth weight, and PKU); and mechanisms that cause behavioral problems. As well as to improve screening and early diagnosis and develop early interventions and treatments; “evidence is needed to demonstrate that early screening and intervention can improve outcomes in IDD” (National Institutes of Health [NIH], n.d.b).

DIAGNOSING INTELLECTUAL DISABILITY

A diagnosis of intellectual disability is accomplished using these three diagnostic criteria; deficits in intellectual functions, deficits in adaptive functioning and the set of these two occurring during the developmental period (childhood or adolescence) (American Psychiatric Association, 2016).

Adaptive behaviors are the conceptual, social, and practical skills necessary for normal daily living. Deficits in adaptive functioning are measured using standardized, age and culturally appropriate tests (Reynolds, Zupanick, & Dombeck, 2013a).

EXAMPLES OF ADAPTIVE SKILLS

Conceptual Skills

Reading
Expressive Language
Money, time and number concepts

Practical Skills

Self-Care
Mobility
Self-Direction
Independent Living

Social Skills

Self-esteem
Responsibility

Interpersonal skills
Ability to follow rules/
Obey laws and to avoid
Being victimized

(AAIDD, 2017)

Severity of Intellectual Function

Intellectual functioning is also known as cognitive ability. Intellect is defined as "the ability to reason, plan, think, and communicate" (Reynolds, et al., 2013c). Those with intellectual disability require various levels of support from families, teachers, and doctors. Often, people with intellectual disability also require treatment for other physical disabilities, personality disorders, and mental illnesses. Levels of support needed or adaptive functioning 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. They often will learn to the 6th grade level as well as develop normal social skills.
- ***Moderate intellectual disability*** (10% of intellectually disabled): Individuals at this level can often conduct unskilled or semi-skilled work with supervision, but require guidance during stressful life situations. They often learn at an elementary school level and develop some social skills.
- ***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 continual nursing care.

(Reynolds, et al., 2013b)

CAUSES OF INTELLECTUAL DISABILITY

The myriad of underlying causes of intellectual disability include genetic conditions, problems during pregnancy and birth, and issues such as disease or poverty that occur during early childhood (The Arc, 2011). The common link between all the factors is the result; lack of normal growth and development within the brain.

Genetics

Genetic intellectual disability occurs when inherited genes are abnormal, when genes develop inappropriately due to infections in the mother, or with high exposure to x-rays. Genetic conditions appear to contribute to around 40-60% of severe cases of intellectual disability. Over 500 genetic disorders have been shown to correlate with intellectual disability and occur in two types: single gene or chromosomal disorders (Ainsworth and Baker, 2004, p4-9). 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, 2017).

Chromosomal Disorders

Down syndrome

Affecting more than 250,000 people in the United States, Down syndrome occurs in 1 out of every 700 newborns (National Down Syndrome Society, n.d.). The incidence of Down syndrome increases with the mother's age. This syndrome evolves when *some* or *all* of the cells carry extra copies of chromosome 21. More than ninety five percent of children with Down syndrome are diagnosed with Trisomy 21, or 47 chromosomes instead of 46 in *all* of their cells (Mayo Clinic, 2014).

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, 2017). The University of Texas Southwestern Medical Center in Dallas is one of only three universities nationwide that houses a Fragile X Syndrome Research Center (NIH, n.d.a.).

Pregnancy/Birth

Events that occur during pregnancy and birth explain roughly 11% of severe cases of intellectual disability (Ainsworth & Baker, 2004, p4). During pregnancy, alcohol use can result in Fetal Alcohol Syndrome, the leading preventable cause of intellectual disability during pregnancy. Malnutrition, illnesses such as rubella and syphilis, and environmental factors may also contribute to the development of intellectual disability. During birth, lack of oxygen and other birth injuries can lead to intellectual disability. Other risk factors include premature birth and low-birth weight (The Arc, 2011).

Early Childhood

Factors during childhood, specifically certain childhood diseases, environmental issues, and accidents, contribute to approximately 3% to 12% of cases of severe intellectual disability (Ainsworth & Baker, 2004, p5). For example, untreated cases of chicken pox, measles, and Hib disease (a bacterial infection) can evolve into meningitis or encephalitis, which may cause brain damage. High quantities of lead and mercury in the environment also negatively affect the brain. Finally, accidents involving head trauma or lack of oxygen can also lead to intellectual disability. Children growing up in poverty appear to be at greater risk for intellectual disability because of untreated childhood diseases, environmental toxins, and malnutrition (The Arc, 2011).

PREVALENCE OF INTELLECTUAL DISABILITY

In the United States, approximately 5.0% of the population is diagnosed with intellectual disability (U.S. Census Bureau, n.d.). The table

below provides the most recent data available (from the 2011-2015 American Community Survey 5-year estimates) of intellectual (cognitive) disability rates in Texas and the KCF counties of interest.

PREVALENCE ESTIMATES FOR PERSONS WITH COGNITIVE DISABILITY			
County	Total Population	Population with ID	
	#	#	%
Texas	26,062,431	1,115,138	4.6%
Bandera	20,602	1,502	7.6%
Bexar	1,793,642	96,924	5.8%
Comal	118,666	5,634	5.0%
Kendall	36,902	2,054	5.9%

(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) ensures an “appropriate education” for children with intellectual disability until the age of 22 in most states (The Arc, 2016). People with intellectual disability 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 Centers, Inc., founded in 1984 and located in San Antonio, provides vocational training and job placement for adults with

intellectual disability. The programs offered include supported employment for about 90 adults in businesses throughout San Antonio, extended employment at the Unicorn's Sheltered Workshop, site-based habilitation that provides social, recreational and educational activities and group projects with customers that serve the community (Mission Road Ministries, n.d.b).

Providence Place's Center for Higher Independence provides vocational and life skills training to young adults with disabilities, including intellectual disabilities. Independent living is reinforced through supervised residential dormitory living, comprehensive vocational/life skill assessment and individualized training plans. Job readiness and community job placement are complemented by follow-up job coaching with weekly evaluations that include the student's immediate supervisor. Opportunities for social activities and social skill development are incorporated into daily training schedules (Providence Place, 2017).

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

The Arc of San Antonio also provides direct care services for those that have intellectual disability and other developmental disabilities (I/DD). The direct care services include life enrichment programs for children and teens, day habilitation and vocational training for I/DD

adults, as well as case management services to help families find other resources. The Arc of San Antonio also has a fully-accessible swimming pool available for swimming and aquatic therapy with a separated pool specifically designed for children and adults who wear diapers (The Arc of San Antonio, 2017).

Mission Road Developmental Center offers a variety of programs (both day and residential) for both adults and children with I/DD. 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 Ministries, n.d.a.).

Hill Country Community MHDD Centers serves individuals with I/DD in a 19 county area, which includes Bandera, Comal and Kendall counties. It focuses 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 Community MHDD Centers, n.d.).

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 conditions which listed 88 facilities in Bexar County as of January 2017.

Unfortunately, there were only 56 vacancies, 29 of which were at the San Antonio State School. There were seven listings in Comal County (with 29 vacancies) and no listings for Bandera and Kendall counties (DADS, 2017).

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