

May 2009

A substantial change occurred in the field of mental retardation/intellectual disability in the United States on July 25, 2003 when, by executive order, President George W. Bush changed the name of the President’s Committee on Mental Retardation to the President’s Committee on Intellectual Disability, in part to distinguish between the terms mental illness and mental retardation (U.S. Department of Health & Human Services Administration for Children & Families [ACF], 2003). In January 2007, the world’s oldest organization on mental retardation/intellectual disability officially changed its name from American Association on Mental Retardation (AAMR) to the American Association on Intellectual and Developmental Disabilities (AAIDD). The name change was prompted by many factors including establishing a new standard in disability terminology, introducing a more socially-acceptable way to address people with intellectual disabilities, moving away from a term that has become offensive to people with disabilities, and being more consistent with terminology currently used in Europe and Canada (American Association on Intellectual and Developmental Disabilities (AAIDD), 2006). The term *intellectual disability* still covers 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 people. Aspects of this “Physiological Method” are utilized today. In 1876, Seguin founded what would eventually become the AAIDD. The development of intelligence testing by Theodore Simon and Alfred Binet and adaptive skill testing by Richard Doll 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, with early work by Wilhelm Griesinger, John L. H. Down, and Asbjorn Folling (Ainsworth & Baker, 2004).

Current research on intellectual disability seeks to improve newborn screening, treat Fragile X syndrome, and reverse brain damage in babies deprived of oxygen (National Institutes of Health, n.d.).

Diagnosing Intellectual Disability

Intellectual disability is defined by the AAIDD as a disability originating before the age of 18, “characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills” (AAIDD, n.d.). A diagnosis of intellectual disability is accomplished using the three methods described in the AAIDD definition: age of the person (below 18 years), scores on intelligence tests, and assessment of adaptive behaviors.

Intellectual Testing

The presence and severity of intellectual disability is first determined based on the score achieved on an IQ test, such as the Stanford-Binet or Wechsler Intelligence scale tests (Ainsworth & Baker, 2004). While a person with average intelligence scores 100 on an IQ test, those diagnosed with intellectual disability receive a score below 70. Approximately 2.7% of the Texas population has IQ scores below 70 (Texas Department of Aging and Disability Services [DADS], 2009).

Levels of Intellectual Disability	
Level	<i>IQ Range</i>
Mild	52-69
Moderate	36-51
Severe	20-35
Profound	19 or less

(Sulkes, 2006)

Adaptive Behavior

The Vineland Social Maturity Scale (Ainsworth & Baker, 2004) is often utilized to diagnose limits in adaptive behaviors for those with intellectual disability. Adaptive behaviors are the conceptual, social, and practical skills necessary for normal daily living. Typically, difficulties with at least two behaviors combined with the results of IQ testing will result in a medical diagnosis of intellectual disability.

Examples of Adaptive SkillsConceptual Skills

Reading

Expressive Language

Social Skills

Self-esteem

Responsibility

(AAIDD, n.d.)

Practical Skills

Self-Care

Mobility

Self-Direction

Independent Living

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 (Association of Retarded Citizens (ARC), 2005). 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 (Ainsworth & Baker, 2004). Common genetic disorders include:

Single Gene Disorders*Phenylketonuria (PKU)*

In the United States, PKU affects approximately 1 in 10,000 to 15,000 children. 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, 2008).

Chromosomal Disorders*Down syndrome*

Affecting more than 400,000 people in the United States, Down syndrome occurs in 1 out of every 733 newborns (National Down Syndrome Society, n.d.). In Texas from 1999-2005 there were 3,296 recorded cases of Down syndrome births – a prevalence of 12.7 cases per 10,000 births (Texas Department of State Health Services, 2009). 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 percent of children with Down syndrome are diagnosed with Trisomy 21, or 47 chromosomes instead of 46 in *all* of their cells (MayoClinic.com, 2009).

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 (The Fragile X Research Foundation (FRAXA), 2008). The Baylor College of Medicine in Houston, TX is one of only three universities nationwide that hosts a Fragile X Syndrome Research Center (NICHD, 2005).

Pregnancy/Birth

Events that occur during pregnancy and birth explain roughly 11% of severe cases of intellectual disability (Ainsworth & Baker, 2004). 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 (ARC, 2005).

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). 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 (ARC, 2005).

Prevalence of Intellectual Disability

In the United States, approximately 1-3% of the population is diagnosed with intellectual disability (Penn State Hershey Children’s Hospital, 2007). The charts below provide recent estimates of intellectual disability rates in Texas, and San Antonio and its surrounding region.

2005 Prevalence Estimates for Persons with Intellectual Disability (ID)			
County	Total Population*	Population with ID	
	#	#	%
Texas	22,489,182	613,955	2.7
Bandera	19,419	530	2.7
Bexar	1,473,582	40,229	2.7
Comal	87,430	2,387	2.7
Kendall	26,356	720	2.7

*Census estimate
(Texas Department of Mental Health and Mental Retardation (Texas MHMR), 2003)

Estimated Degree of Intellectual Disability (ID) within 2005 Total ID population				
County	Pop. with ID	Mild	Moderate	Severe and Profound
Texas	613,955	524,010	67,474	22,471
Bandera	530	452	58	19
Bexar	40,229	34,335	4,421	1,472
Comal	2,387	2,037	262	87
Kendall	720	614	79	26

(Texas MHMR, 2003)

Supporting Persons with Intellectual Disability

<u>Levels of Support</u>
Intermittent = Occasional
Limited = Day Program
Extensive = Ongoing, Daily Support
Pervasive = All Daily Activities, often nursing care
(ARC, 2009; Sulkes, 2006)

Those with intellectual disability require various levels of support from their families, teachers, and doctors. Often, people with intellectual disability also require treatment for other physical disabilities, personality disorders, and mental illnesses. People diagnosed with mild intellectual disability often become self-supportive, though they require

support during times of significant social or economic stress. They often will learn to the 6th grade level as well as develop normal social skills. Those with moderate intellectual disability 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. People with severe intellectual disability have minimal communication skills, though they typically can learn a few self-help skills. They can take minimal care of themselves and require complete supervision. Those with profound intellectual disability experience little cognitive or motor ability and often require continual nursing care (Sulkes, 2006).

People with intellectual disability are offered legal protection in educational and work settings. The 2004 Individuals with Disabilities Education Act (IDEA) ensures an “appropriate education” for children with intellectual disability until the age of 21 (ARC, 2006). 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, 2008).

Local Intellectual Disability Resources

The Alamo Area Council of Governments (AACOG) was designated as the Mental Retardation Authority for Bexar County in September 2006. it has responsibility 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, 2009).

Unicorn Centers, Inc., founded in 1984 and located in San Antonio, provides vocational training and job placement for adults with intellectual disability. About 200 adults (“customers”) are served daily by its various programs. The programs offered include supported employment for about 60 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 (Unicorn Centers, Inc., n.d.).

