Introduction to Intellectual and Developmental Disabilities

By: The Arc

What are intellectual and developmental disabilities?

An individual is considered to have intellectual and developmental disabilities based on the following three criteria: intellectual functioning level (IQ) is below 70-75; significant limitations exist in two or more adaptive skill areas; and the condition is present from childhood (defined as age 18 or less) (AAMR, 1992).

What are the adaptive skills essential for daily functioning?

Adaptive skill areas are those daily living skills needed to live, work and play in the community. They include communication, self-care, home living, social skills, leisure, health and safety, self-direction, functional academics (reading, writing, basic math), community use and work. Adaptive skills are assessed in the person's typical environment across all aspects of an individual's life. A person with limits in intellectual functioning who does not have limits in adaptive skill areas may not be diagnosed as having intellectual and developmental disabilities.

How many people are affected by intellectual and developmental disabilities?

The Arc reviewed a number of prevalence studies in the early 1980s and concluded that 2.5 to 3 percent of the general population have intellectual and developmental disabilities (The Arc, 1982). Based on the 1990 census, an estimated 6.2 to 7.5 million people have intellectual and developmental disabilities. Intellectual and developmental disabilities are 10 times more common than cerebral palsy and 28 times more prevalent than neural tube defects such as spina bifida. It affects 25 times as many people as blindness (Batshaw, 1997).
Intellectual and developmental disabilities cut across the lines of racial, ethnic, educational, social and economic backgrounds. It can occur in any family. One out of ten American families is directly affected by intellectual and developmental disabilities.

How do intellectual and developmental disabilities affect individuals?

The effects of intellectual and developmental disabilities vary considerably among people, just as the range of abilities varies considerably among people who do not have intellectual and developmental disabilities. About 87 percent will be mildly affected and will be only a little slower than average in learning new information and skills. As children, their intellectual and developmental disabilities are not readily apparent and may not be identified until they enter school. As adults, many will be able to lead independent lives in the community and will no longer be viewed as having intellectual and developmental disabilities.
The remaining 13 percent of people with intellectual and developmental disabilities, those with IQs under 50, will have serious limitations in functioning. However, with early intervention, a functional education and appropriate supports as an adult, all can lead satisfying lives in the community.

How are intellectual and developmental disabilities diagnosed?

The AAMR process for diagnosing and classifying a person as having intellectual and developmental disabilities contains three steps and describes the system of supports a person needs to overcome limits in adaptive skills.
The first step in diagnosis is to have a qualified person give one or more standardized intelligence tests and a standardized adaptive skills test, on an individual basis.

The second step is to describe the person's strengths and weaknesses across four dimensions. The four dimensions are:

1. Intellectual and adaptive behavior skills
2. Psychological/emotional considerations
3. Physical/health/etiological considerations
4. Environmental considerations

Strengths and weaknesses may be determined by formal testing, observations, interviewing key people in the individual's life, interviewing the individual, interacting with the person in his or her daily life or a combination of these approaches.
The third step requires an interdisciplinary team to determine needed supports across the four dimensions. Each support identified is assigned one of four levels of intensity - intermittent, limited, extensive, pervasive.

Intermittent support refers to support on an "as needed basis." An example would be support that is needed in order for a person to find a new job in the event of a job loss. Intermittent support may be needed occasionally by an individual over the lifespan, but not on a continuous daily basis.

Limited support may occur over a limited time span such as during transition from school to work or in time-limited job training. This type of support has a limit on the time that is needed to provide appropriate support for an individual.

Extensive support in a life area is assistance that an individual needs on a daily basis that is not limited by time. This may involve support in the home and/or support in work. Intermittent, limited and extensive supports may not be needed in all life areas for an individual.
Pervasive support refers to constant support across environments and life areas and may include life-sustaining measures. A person requiring pervasive support will need assistance on a daily basis across all life areas.

What does the term "mental age" mean when used to describe the person's functioning?

The term mental age is used in intelligence testing. It means that the individual received the same number of correct responses on a standardized IQ test as the average person of that age in the sample population.

Saying that an older person with intellectual and developmental disabilities is like a person of a younger age or has the "mind" or "understanding" of a younger person is incorrect usage of the term. The mental age only refers to the intelligence test score. It does not describe the level and nature of the person's experience and functioning in aspects of community life.

What are the causes of intellectual and developmental disabilities?

Intellectual and developmental disabilities can be caused by any condition which impairs development of the brain before birth, during birth or in the childhood years. Several hundred causes have been discovered, but in about one-third of the people affected, the cause remains

unknown. The three major known causes of intellectual and developmental disabilities are Down syndrome, fetal alcohol syndrome and fragile X.

The causes can be categorized as follows:

• Genetic conditions - These result from abnormality of genes inherited from parents, errors when genes combine, or from other disorders of the genes caused during pregnancy by infections, overexposure to x-rays and other factors. More than 500 genetic diseases are associated with intellectual and developmental disabilities. Some examples include PKU (phenylketonuria), a single gene disorder also referred to as an inborn error of metabolism because it is caused by a defective enzyme. Down syndrome is an example of a chromosomal disorder. Chromosomal disorders happen sporadically and are caused by too many or too few chromosomes, or by a change in structure of a chromosome. Fragile X syndrome is a single gene disorder located on the X chromosome and is the leading inherited cause of intellectual and developmental disabilities.

• Problems during pregnancy - Use of alcohol or drugs by the pregnant mother can cause intellectual and developmental disabilities. Recent research has implicated smoking in increasing the risk of intellectual and developmental disabilities. Other risks include malnutrition, certain environmental contaminants, and illnesses of the mother during pregnancy, such as toxoplasmosis, cytomegalovirus, rubella and syphillis. Pregnant women who are infected with HIV may pass the virus to their child, leading to future neurological damage.

• Problems at birth - Although any birth condition of unusual stress may injure the infant's brain, prematurity and low birth weight predict serious problems more often than any other conditions.

• Problems after birth - Childhood diseases such as whooping cough, chicken pox, measles, and Hib disease which may lead to meningitis and encephalitis can damage the brain, as can accidents such as a blow to the head or near drowning. Lead, mercury and other environmental toxins can cause irreparable damage to the brain and nervous system.

• Poverty and cultural deprivation - Children in poor families may become mentally retarded because of malnutrition, disease-producing conditions, inadequate medical care and environmental health hazards. Also, children in disadvantaged areas may be deprived of many common cultural and day-to-day experiences provided to other youngsters. Research suggests that such under-stimulation can result in irreversible damage and can serve as a cause of intellectual and developmental disabilities.

Can intellectual and developmental disabilities be prevented?

During the past 30 years, significant advances in research have prevented many cases of intellectual and developmental disabilities. For example, every year in the United States, we prevent:

• 250 cases of intellectual and developmental disabilities due to phenylketonuria (PKU) by newborn screening and dietary treatment;

• 1,000 cases of intellectual and developmental disabilities due to congenital hypothyroidism thanks to newborn screening and thyroid hormone replacement therapy;

• 1,000 cases of intellectual and developmental disabilities by use of anti-Rh immune globulin to prevent Rh disease and severe jaundice in newborn infants;

• 5,000 cases of intellectual and developmental disabilities caused by Hib diseases by using the Hib vaccine;

• 4,000 cases of intellectual and developmental disabilities due to measles encephalitis thanks to measles vaccine; and

• untold numbers of cases of intellectual and developmental disabilities caused by rubella during pregnancy thanks to rubella vaccine (Alexander, 1998).

Other interventions have reduced the chance of intellectual and developmental disabilities. Removing lead from the environment reduces brain damage in children. Preventive interventions such as child safety seats and bicycle helmets reduce head trauma. Early intervention programs with high-risk infants and children have shown remarkable results in reducing the predicted incidence of subnormal intellectual functioning.

Finally, early comprehensive prenatal care and preventive measures prior to and during pregnancy increase a woman's chances of preventing intellectual and developmental disabilities. Pediatric AIDS is being reduced by AZT treatment of the mother during pregnancy, and dietary supplementation with folic acid reduces the risk of neural tube defects.

Research continues on new ways to prevent intellectual and developmental disabilities, including research on the development and function of the nervous system, a wide variety of fetal treatments, and gene therapy to correct the abnormality produced by defective genes.

References

American Association on Mental Retardation. (1992). Mental Retardation: Definition, Classification, and Systems of Supports, 9th Edition. Washington, DC.

Alexander, D. (1998). Prevention of Mental Retardation: Four Decades of Research. Mental Retardation and Developmental Disabilities Research Reviews. 4: 50-58
Batshaw, M. (1997). Children With Disabilities. Baltimore: Paul H. Brookes Publishing Co.

The Arc. (1982). The Prevalence of Mental Retardation. (out-of-print).

Where can I go for more information?

You will find a wide variety of information on The Arc's home page on the World Wide Web: http://www.thearc.org/. You can also contact staff at the national headquarters for more information. Or, call your local chapter of The Arc.

The Arc
National Headquarters
1010 Wayne Ave. Suite 650
Silver Spring, MD 20910
301/565-3842
301/565-5342 (fax)
info@thearc.org (e-mail)