



CAROLINA
Health & Transition
PROGRAM

CHAT: Fact Sheet on Developmental Disabilities

More than 6 million individuals in the United States have developmental disabilities. A **developmental disability**, according to the Developmental Disabilities Assistance and Bill of Rights Act, is defined as a severe, chronic disability which:

- originated at birth or during childhood,
- is expected to continue indefinitely, and
- substantially restricts the individual's functioning in several major life activities.

More specifically, a developmental disability is a severe, chronic disability which:

- is attributable to a mental or physical impairment or a combination of mental and physical impairments;
- is manifested before the person attains age 22;
- results in substantial functional limitations in three or more of the following areas of major life activity:
 - self-care
 - receptive and expressive language
 - learning
 - mobility
 - self-direction
 - capacity for independent living, and
 - economic self-sufficiency;
- reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated;
- when applied to infants and young children, means individuals from birth to age five, who have substantial developmental delay or specific congenital conditions. If services are not provided to children birth to age 5 with acquired conditions, there is a high probability of resulting developmental disabilities.¹

Examples of developmental disabilities include:

- Autism
- Brain injury
- Cerebral palsy
- Down syndrome / Trisomy 21
- Fetal alcohol syndrome
- Fragile x
- Spina bifida

¹Institute on Community Integration, University of Minnesota. (2009). About Developmental Disabilities. Retrieved November 24, 2009, from

<http://ici.umn.edu/relatedresources/definition.html><http://ici.umn.edu/relatedresources/definition.html>

Terminology

An *intellectual disability* is a disability characterized by significant limitations both in **intellectual functioning** (reasoning, learning, problem solving) and in **adaptive behavior**, which covers a range of everyday social and practical skills.² The cause and level of disability generally are identified in childhood. An exception is traumatic brain injury (TBI) and acquired brain injury (ABI) which may occur at any time. TBI is the result of a traumatic event involving head injury, such as a motor vehicle accident or a shaken baby incident. ABI is the result of illness or a non-traumatic insult to the brain, such as encephalitis, inhaled or ingested toxins, and the like.

A *developmental disability* (DD), while encompassing intellectual disabilities as an umbrella term, is not limited to cognitive function. Developmental disabilities include a host of other physical disabilities and limitations and may be strictly physical, such as blindness from birth. Some individuals have both physical and intellectual disabilities stemming from genetic or other physical causes (e.g., Down Syndrome, fetal alcohol syndrome).³

The designation *mental retardation* (MR) is considered offensive by most people. Mental retardation and intellectual disability are terms for the same thing, but intellectual disability is gaining currency as the preferred term. In fact, the American Association on Mental Retardation (AAMR) changed its name in 2007 to the American Association on Intellectual and Developmental Disabilities (AAIDD).

The AAIDD notes, “It is crucial that ‘mental retardation’ and ‘intellectual disability’ should be precisely synonymous in definition and in all related classification because current federal and state laws contain the term ‘mental retardation’. That is the term used in law and public policy to determine eligibility for state and federal programs, including the Individuals With Disabilities Education Act—IDEA (2004), Social Security Disability Insurance, and Medicaid Home and Community Based Waiver. Also, the term ‘mental retardation’ is used for citizenship and legal status, civil and criminal justice, early care and education, training and employment, income support, health care, and housing and zoning.”⁴

Primary Care Services

While many of the preventative and primary care services recommended for persons with intellectual disabilities are the same as those recommended for the general population, there are some clinical areas that warrant greater primary care oversight and additional research. Studies indicate that persons with intellectual and developmental disabilities experience a higher prevalence of several other health risks, including seizure disorders, gastric disorders, hypothyroidism, premature aging, and a higher risk of respiratory infection. There is, for example, a demonstrated risk of early onset osteoporosis among those with developmental disabilities—a result of several factors which may impact bone health (e.g. long-term medication use, non-ambulatory status, and the attendant lack of weight bearing exercise and low absorption of vitamin D due to little time spent outdoors).

²American Association on Intellectual and Developmental Disabilities, http://www.aaidd.org/content_104.cfm Accessed 11/24/09.

³Ibid.

⁴Ibid.

⁵http://mikulski.senate.gov/_pdfs/Press/Organizations.pdfm Accessed November 24, 2009.

At issue is the perception by many physicians and other providers that they are not adequately trained to provide optimum care for persons with developmental disabilities. Compounding the difficulty is a general lack of evidence-based guidelines specific to patients with developmental disabilities. There are a number of individual schools of medicine that have begun to embed some DD-specific clinical experience into their training programs, but at present, there is no broad-based consensus on what specific training regarding developmental disabilities physicians in the U.S. should receive in their pre- and post-doctoral education.

North Carolina

In a report requested by the North Carolina General Assembly, the North Carolina Institute of Medicine (NC IOM) called for increased training of health professionals in providing care for persons with intellectual and developmental disabilities (I/DD). Among the recommendations were:

- Training for health care professionals (including physicians, dentists, nurses, allied health personnel and other health providers) to provide better health care service for persons with I/DD;
- Establishment of medical homes for persons with I/DD;
- Transition of youth with I/DD from pediatric to adult medical care providers and self-management;
- Training of psychiatrists, counselors and other health professionals to meet the mental health needs of persons with I/DD;
- Education for health care providers on the broader I/DD supports system and coordination of services;
- Internships and residency rotations in settings that routinely provide services to persons with I/DD;
- Support for continuation and expansion of mini-fellowships in developmental medicine;
- Appropriations to the state AHEC system to support these educational efforts.⁶

Additional Resources

Medical Care for Children and Adults with Developmental Disabilities, 2nd Edition, Rubin and Crocker. Paul H. Brookes Publishing Co., Baltimore, MD, © 2006.

Intellectual Disabilities at Your Fingertips: A Health Care Resource, Tyler and Baker. High Tide Press, New Lenox, IL, © 2009.

American Academy for Cerebral Palsy and Developmental Medicine. www.aacpdm.org/index

American Academy of Developmental Medicine and Dentistry. www.aadmd.org/

American Association on Intellectual and Developmental Disabilities. www.aaid.org/

Developmental Disabilities Nurses Association. www.ddna.org

North Carolina Council on Developmental Disabilities. www.nccdd.org

⁶Successful Transitions: A Report of the NCIOM Task Force on Transitions for People with Developmental Disabilities, North Carolina Institute of Medicine, May 2009.

CHAT is funded by the New Freedom Initiative: State Implementation Grants for Integrated Services for CSHCN (D70MC6894-03-01) from the Integrated Services Branch, Division of Services for Children with Special Health Needs (DSCSHN) in the Federal Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS).

