

Community Action Network

Frequently Asked Questions About Developmental Disabilities

October 2008



As children with developmental disabilities grow into adults, they and their caregivers face difficult transitions.

Almost half a million Texans are living with developmental disabilities. Support is needed for individuals and families living with these challenges. However, the gap in services is greatest for adults.

Priority Issues:

- Community-based care is less expensive and provides a higher quality of life for people than institutionalized care. Access to community-based care and supports is limited due to a lack of resources.
- As children with developmental disabilities grow into adults, they often lose access to healthcare and other support.
- As family caregivers age, they are less able to care for their grown children who are developmentally disabled.

Questions:

What are Developmental Disabilities?

The federal definition of developmental disabilities covers persons whose disability occurs before age 22 and includes a mental or physical impairment or a combination of both. There must be a substantial limitation in three or more of these major life areas: self-care; expressive or receptive language; learning; mobility; capacity for independent living; economic self-sufficiency; or self-direction.¹ Developmental disabilities usually last throughout a person's lifetime.² Examples of developmental disabilities include mental retardation, seizure disorders, and autism spectrum disorder.

The effects of disabilities vary considerably among people who have them, just as the range of abilities varies considerably among all people. Children may take longer to learn to speak, walk and take care of their personal needs, such as dressing or eating. People may take longer learning in school. As adults, many people could be able to lead independent lives with proper community supports. A small percentage will have serious, lifelong limitations in functioning. People with disabilities often experience feelings of stigmatization, and can be excluded, belittled, and/or isolated.³

What is the best way to care for people with developmental disabilities?

The best way to care for a person with developmental disabilities depends on the person's needs and preferences. The overwhelming majority of Texans with developmental disabilities live independently in their own homes, or under the care of family members or other caregivers.

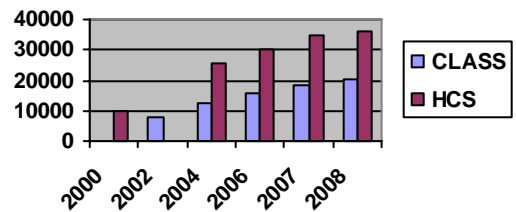
In 2007, 11,504 Texans with developmental disabilities were living in institutions.⁴ A report released by the State Auditor's Office in July 2008 found that state schools were failing to find community-based homes for 70% of the residents who wanted them; the report also found that state schools have hired employees who had previous abuse and neglect records.⁵ Recent statistics show an 80% increase in the number of children enrolled in the state school system. This is contrary to the Texas Legislature's requirement for the state to seek permanent homes for anyone under age 22 who lives in an institution. In 2008, the U.S. Department of Justice launched a formal investigation of civil rights violations in 11 of the 13 state schools in Texas.⁶

Under the Americans with Disabilities Act (ADA) unjustifiable institutionalization of a person with a disability who can live in the community is discrimination. The Olmstead vs. L.C. Supreme Court ruling in 1999 determined that states should provide community-based services as an alternative to institutional services when it is deemed appropriate by professionals, is accepted by the person with a disability, and when accommodations can be reasonably provided.⁷

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Two alternatives to institutionalization are Community Living Assistance and Support Services (CLASS) and Home and Community-Based Services (HCS). CLASS provides services to people with developmental disabilities who live in their homes.⁸ HCS provides individualized services and supports to persons with mental retardation who are living with their family, in their own homes, or in other community settings, such as small group homes.⁹ Care provided under programs like CLASS and HCS, on average, costs 15%-25% less than care provided in institutional settings.¹⁰ The waiting lists for both CLASS and HCS have been steadily growing resulting in approximately 57,000 people needing these services.

of People on Texas Waiting Lists for CLASS and HCS



In April 2008, the average wait time for CLASS placement was 2.4 years and the average wait for HCS was 3.4 years. These results are statewide and may differ by geographical area (Texas Council for Developmental Disabilities, 2008).

What health issues do people with developmental disabilities face?

The major issue is access to care. Most persons with disabilities rely on Medicaid services, but the physician participation rate in Texas ranks last among the states.¹¹ In addition, Texas is one of only six states that does not include adult dental care benefits as a part of Medicaid.¹²

Social and emotional support from others is essential for good mental health.¹³ However, adults with developmental disabilities showed an alarming rate of inadequate emotional support. Twenty-four percent of these adults had no one to talk to about personal issues (compared to 7% of respondents with no disability).¹⁴ They also had no one to talk to about health issues.

They are less likely to have screenings and they may be more prone to preventable illnesses. Lack of access to routine screenings has an impact on their overall health.¹⁵ A 2006 study found that women with a history of multiple developmental disabilities or with mental retardation were significantly more likely than women with no developmental disabilities never to have had a pap smear or pelvic exam.¹⁶

What educational supports are available for people with developmental disabilities?

Children with developmental and other disabilities between the ages of 3 and 21 have a right to free public education.¹⁷ Over the past two decades, many public schools in the United States have begun integrating children with developmental disabilities into regular classroom settings, a trend known as "mainstreaming." The result of this trend has been greater public acceptance of people with disabilities and a greater understanding of what students with disabilities can achieve in terms of academic performance.

Thanks in large part to the determined efforts of advocates for disabled students, several U.S. colleges and universities are implementing programs to offer educational opportunities for secondary-school graduates with developmental disabilities.¹⁸ For example, Austin Community College serves students with developmental disabilities through its Office for Students with Disabilities.



At the age of 21, people with developmental disabilities lose educational services and are at a loss for meaningful daily activities.

Making the transition from full-time education to life as an adult can be difficult for people with developmental disabilities and their families. There are limited opportunities for meaningful daily activity and transition to independent living after 21 when mandated educational supports are gone.



What are the challenges facing families and caregivers?

As family caregivers age, caring for their adult children with developmental disabilities becomes more difficult. Approximately 750,000 people with developmental disabilities in the U.S. lived with aging parents (one of whom is over the age of 65) in 2004.¹⁹ While there has been an increase in funding for family support programs in the last 10 years, these programs represent a small portion of spending for developmental disabilities services, and often target families of young children.

Older family caregivers have concerns about planning for the future when they can no longer provide care to their relatives. Future planning includes issues such as future residential, legal, and financial arrangements, health care, vocational/leisure activities, and community supports.²⁰ The need for such planning has been rising as medical advances have prolonged the lifespan of persons with and without disabilities. People with developmental disabilities, for example, had a life expectancy of only 19 years in the 1930s and by 1993 their life expectancy had increased to 66 years.²¹

What other challenges do people with developmental disabilities face?

Personal Safety: People with disabilities are particularly vulnerable to crimes involving interpersonal violence, such as physical or sexual assault. As a population—regardless of age or gender—they are often the least able to recognize danger, the least able to protect themselves, and the least able to obtain assistance within the criminal justice system.²² A 2006 study found that young adults with a history of mental retardation were seven times more likely to have been attacked or beaten in the past 12 months than young adults without a history of developmental disabilities.²³

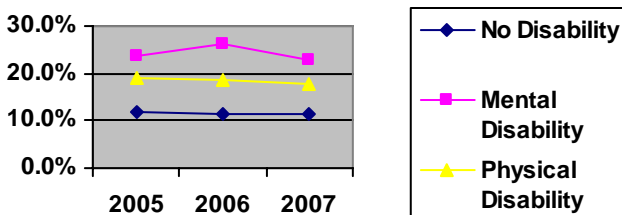
Employment: There is a significant gap in employment between people with disabilities and people without disabilities.²⁴ However, in both the Austin-Round Rock MSA and the City of Austin the employment rates for persons with physical and mental disabilities were higher than both the state and the national rates.²⁵

% Employed in the Austin Round-Rock MSA

	2005	2006	2007
No disability	75%	77%	77%
Physical disability	35%	41%	40%
Mental disability	32%	36%	40%

Note: The above chart shows the % employed. The unemployment rate, which only includes persons that are actively seeking employment, is not reflected in this data.

% Individuals Below the Federal Poverty Line in the Austin-Round Rock MSA by Type of Disability



Poverty: Persons with disabilities are more likely to live in poverty than the general population. The poverty rate for individuals with mental disabilities in the Austin-Round Rock Metropolitan Statistical Area (MSA) is especially high, 23% in 2007.²⁶

Transportation: A 2006 study showed that persons with developmental disabilities relied on walking, local buses, and social service agencies as their primary modes of transportation.

However more than 45% of study participants in all developmental disabilities groups indicated that they had trips they would have liked to make but could not. The same study found that 46% of persons with developmental disabilities had difficulty reading transit schedules, and 49% had difficulty understanding transit schedules.²⁷

What can I do to help?

- Volunteer time and resources to an agency serving persons with developmental disabilities.
- Support legislation to increase services to persons who have developmental disabilities.
- Share this FAQ with people you know.
- Join the Developmental Disabilities Planning Partnership or other local efforts to address these priority issues.
- Visit <http://ilivehereigivehere.org> and donate time or money to local agencies.

Where can I learn more?

The Texas Council on Developmental Disabilities—<http://www.txddc.state.tx.us/index.asp>

Texas Department of Aging and Disability Services—<http://www.dads.state.tx.us/>

Texas Department of Assistive and Rehabilitative Services—<http://www.dars.state.tx.us/>

Developmental Disabilities Planning Partnership—<http://caction.org/mrdd/index.html>

Austin Travis County MHMR Center—<http://www.atcmhmr.com/>

The Developmental Disabilities Planning Partnership is made up of agencies, service providers and interested citizens who want to educate the community about the needs of people with mental retardation and developmental disabilities. Participating agencies include: Arc of the Capital Area, Austin Travis County MHMR Center, Easter Seals Central Texas, Family Eldercare, Marbridge, United Way Capital Area, and Vaughn House.

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CAN Partners: Austin Area Human Services Association • Austin Area Interreligious Ministries • Austin Area Research Organization • Austin Community College • Austin Independent School District • Greater Austin Chamber of Commerce • Austin Travis County MHMR Center • Capital Metro • City of Austin • Community Justice Council • Integrated Care Collaboration • St. David's Community Health Foundation • St. Edward's University • Seton Family of Hospitals • University of Texas at Austin • Travis County • Travis County Healthcare District • United Way Capital Area • Workforce Solutions-Capital Area