

A Hole in the Safety Net: Health Care for Transition Age Youth and Adults with Developmental Disabilities

Transition age youth and adults with developmental disabilities (DD) are a vulnerable population. They represent some of the highest needs and highest costs to the state and to the MediCal and Medicare systems.

Definition of Developmental Disability

Developmental disabilities are complex disabilities that begin during childhood, are expected to continue indefinitely and constitute significant functional limitations in three or more areas of major life function including:

1. capacity for self-care
2. capacity for self-direction
3. capacity for economic self-sufficiency
4. capacity for independent living
5. learning
6. receptive or expressive language
7. mobility

Developmental disabilities include conditions such as intellectual disability (formerly mental retardation), autism, cerebral palsy and epilepsy.^{1,2} Most people with DD have multiple chronic medical problems apart from their disability. About 20% are on medications for behavior.^{3,4,5}

Historical Background

Forty years ago, virtually all individuals with DD resided in state institutions where their life expectancies were limited. As a result of policy changes in the 1970's, legislators started to close institutions and support people in family or group homes.⁶ Due to advances in medicine and improvements in the conditions in which people with DD live, their life expectancies now approach that of the general population.⁷ Today, less than 2 percent of people with DD in California live in developmental centers.⁸ The law and service systems are struggling to catch up to this new reality.

¹ US Code Title 42 chapter 144 subchapter 1 part A section 15002; Welfare and Institutions 4.1 section 4512 (a) (l)

² W and I 4.1 section 4512

³ Department of Developmental Services Client Characteristics Report December 2007.
<http://www.dds.ca.gov/FactsStats/QuarterlyReports.cfm>.

⁴ Long T, Kavarian S. Aging with developmental disabilities: an overview. *Top Geriatri Rehabil.* 2008;24(1):2-11.

⁵ Van Schrojenstein Lantman-de Valk HM, Walsh PN. Managing health problems in people with intellectual disabilities. *BMJ.* 2008. 337:a3507.

⁶ Odom SL, Horner RH, Snell ME, Blacher J. *Handbook of Developmental Disabilities.* New York: The Guilford Press; 2007.

⁷ Janicki MP, Dalton AJ, Henderson CM, Davidson PW. Mortality and morbidity among older adults with intellectual disability: health services considerations. *Disabil Rehabil.* 1999;21(5/6):284-94.

⁸ Department of Developmental Services Fact Book, 11th ed. (October 2008). Sacramento, CA.
http://www.dds.ca.gov/FactsStats/docs/factbook_11th.pdf. Accessed 11/1/09.

Because the state of California has a very narrow definition of DD, there are some individuals with DD who are served by MediCal, but who are not eligible for or served by the regional center system. Also, because the regional center system was established in the 1970's, there are adults who are eligible for regional center services, but who were not identified as children, and it is now difficult to prove eligibility for this entitlement program. Still, they need health care.

Description of the Population

There are approximately 225,000 individuals served by the Department of Developmental Services (DDS) through the regional center system. About 40% of DDS clients are Caucasian, 33% Hispanic, 10% Black and 6% Asian. Approximately half of adults live with their families, 20% in community care homes (group homes), 17% in their own homes with supports and 2% live in developmental centers (state institutions). These living situations are funded by the state through the Department of Developmental Services. About 7% live in skilled nursing homes or intermediate care facilities (group homes with nursing) funded by MediCal. Over the past ten years, despite narrowing the definition of DD, there has been a significant increase in the numbers of people with DD in California. From 1997-2007 the rate of people with autism served by DDS grew 321 percent. Since not all people on the autism spectrum are eligible for regional center services, other systems such as the mental health system are also struggling to develop effective systems of care.⁹

Data on Health Care Utilization and Needs

Another reason that the health care needs of youth and adults with DD have not been addressed is because they are not well-identified in administrative databases. Due to variations in the definition of DD and methodological challenges, there is very little health surveillance on this population. This population is not included in the federal definition of medically underserved populations. Because they tend to be lumped with much larger populations such as the elderly and people with disabilities, their unique needs are not recognized. This population is largely invisible to policy makers. (see attachments).

Challenges for Health Care Service Delivery

Youth and adults with developmental disabilities rely on a complex array of public programs for their long-term care, health care, education, vocation, recreation and other support. The systems are poorly coordinated and communication between them is poor.

By definition, people with developmental disabilities have significant functional limitations in multiple areas of major life function. Without support, they do not have the capacity to meet the complex responsibilities of being a patient such as providing a medical history, making informed consent decisions, and following through on medical recommendations. Their functional limitations greatly impact their activities of daily living. They have the type of needs that typically require institutional levels of care. However, they live in community settings and try to access medical care in primary care

⁹ Department of Developmental Services Fact Book, 11th ed. October 2008.
http://www.dds.ca.gov/FactsStats/docs/factbook_11th.pdf

practices which are not designed or resourced to provide this type of care. This has led to significant health disparities. When people with DD do not get adequate health care, their illnesses may be addressed at advanced stages and they may require increased support from the state for their long-term care.

Also, adults with DD have some of the greatest challenges in accessing family and informal support. People with DD, especially those with intellectual disabilities, communication challenges and autism, can have difficulty developing relationships with non-disabled people even when they have high levels of participation in community activities¹⁰. The primary source of family support comes from aging parents. There are an estimated 77,000 Californians with developmental disabilities living with parents over age 60.¹¹ As the population of people with developmental disabilities ages, this source of support dwindles and we do not have adequate alternatives.

Unique Needs

The general elderly and disabled populations share some of the same challenges as people with DD. However, unlike the elderly, most adults with developmental disabilities did not acquire their limitations as a result of progressive medical illness. Most are not in the process of dying. Most are expected to live with their disabilities for many decades. Also, the public funds almost all of the care for adults with DD and assumes liability for failures of those systems. When costs are transferred from one agency to another or are placed back on patients or caregivers, and when bureaucratic barriers to access are placed in the way of timely care, it may not save taxpayers money. In some cases it can increase overall costs to the state.

The nature of the cognitive disabilities of people with DD is also unique. Compared to the elderly, people with intellectual disabilities tend to have better rehabilitation and habilitation potential. Dementia in the elderly primarily affects short-term memory which makes it difficult for them to retain new lessons. People with intellectual disabilities develop their disabilities at young ages and are not necessarily in a state of decline. They may learn slowly, but they do make progress.¹² When people with DD learn, it can increase their function and independence and has the potential to reduce overall costs of long-term care.

The larger population of people with disabilities share some of the challenges with access to care that people with DD face. For example, they share challenges with physical accessibility of health care facilities and equipment. However, the needs of people who have functional limitations in a single area of major life function or who acquire their disability later in life are significantly different.

¹⁰ Lippold T, Burns J. Social support and intellectual disabilities: a comparison between social networks of adults with intellectual disability and those with physical disability. *J of Intel Dis Res.* 2009. 53(5):463-73.

¹¹ Braddock D, Hemp R, Rizzolo MK. State of the State in Developmental Disabilities (2008) American Association of Developmental and Intellectual Disabilities: Washington DC.

¹² Perkins EA, Small BJ. Aspects of cognitive functioning in adults with intellectual disabilities. *J of Pol and Pract in Intel. Dis.* 2006; 3(3):181-194.