

# Health Care Reform for Transition Age Youth and Adults with Developmental Disabilities (CA)

Bruce is a 30 year old man with autism with a mental age of 2 years old. He is six foot tall, 260 pounds and terrified of needles. Now he has diabetes. What would it take for Bruce to get good medical care?

**Vision.** Transition age youth and adults with developmental disabilities (DD) have access to health services that maximize their wellness and function. Health care for transition age youth and adults with DD is interdisciplinary team-based care with patients and caregivers at the center of the team.

**Definition.** Developmental disabilities (DD):

- originate before age 18
- are expected to continue indefinitely
- constitute significant functional limitations in at least three or more areas such as capacity for self-care, learning, language and mobility
- include autism, cerebral palsy, epilepsy and intellectual disability

**In addition to their disability, most people with developmental disabilities have chronic medical conditions and approximately 30% have associated mental illness.**

**The Challenges.** The longevity of people with DD now approaches that of the general population. Resources provided within the State of California's integrated systems of care for children with DD are relatively more robust and better funded than transition age youth and adult systems.

When transition age youth with DD reach adulthood, experienced physicians and other trained health care providers are typically no longer part of the picture. Health care needs continue beyond childhood, but the mandate for a wraparound, comprehensive support system does not.

*Resources for adults are insufficient and poorly integrated. There is a lack of:*

- **Certified medical experts** for patients with DD
- **Special medical services**
- **Support for clinical and health services research**
- **Training programs** for medical personnel and caregivers who manage complex medical and behavioral conditions.
- **Reimbursement** for the extra time involved in care coordination, prevention and treatment.
- **Physicians who accept the low reimbursements** for patients dependent on public health insurance.

*Lack of parent support.* Unlike their younger counterparts, this population lacks parent support.

- An estimated 30,000-77,000 people with DD in California are **currently living with caregivers over age 60**. As parents age along with their children, eventually, they can no longer provide advocacy and care.
- Many adults with DD have **no family advocates or caregivers**.
- This lack of support is an issue because **health problems generally become more complex** as people with developmental disabilities age.

*Policy gaps.* Since the 1970's, many thousands of adults with disabilities have moved from institutions into the community. However, current policy and funding are not sufficient to protect them from neglect, much less to provide them with health care. Without appropriate oversight and comprehensive services, adults easily fall through the cracks.

The most important policy gaps include pragmatic approaches to:

- Maintaining, organizing and facilitating access to confidential information
- Obtaining informed consent
- Enabling the use of brief medical stabilization for procedures
- Providing independent advocacy
- Clarity on which agency is responsible for developing and funding behavioral services

**The Solutions.** About two years ago, a group of stakeholders convened to plan a pilot for a model of health care reform. Remarkable progress has been made in developing new funding, partnerships, and in expanding dialogue to include state and national leaders, researchers, and clinicians. The leadership includes:

- The Arc of San Francisco
- Faculty from the University of California, San Francisco
- Golden Gate Regional Center
- Health Plan of San Mateo/San Mateo County Medical Center
- San Francisco Department of Public Health
- University of the Pacific School of Dentistry

**The CART Model.** The long-term strategic plan begins with building an academic unit within the Department of Family and Community Medicine at UCSF to provide clinical leadership and establish working relationships between the medical and developmental service providers. The Arc of San Francisco will lead an advocacy and policy campaign to develop resources for reform and will deliver health advocacy services. Health Plan of San Mateo is leading an effort to develop a multidisciplinary clinic. These projects will form a first-in-the-country pilot to serve an entire community. A goal of the project is to evolve into a UCSF Center for Excellence in Developmental Medicine to support the CART Model:

- Clinical services in university and community settings
- Advocacy to influence policy
- Research programs in health services and education to rigorously study the cost effectiveness of our clinical and training innovations
- Training and technical assistance for medical professionals and caregivers