



Office of Developmental Primary Care

Improving outcomes for people with developmental disabilities

Background

In the late 1960's, only four percent of people with developmental disabilities (DD) lived in the community. Today, most individuals with DD have never been in an institution. The life expectancy of people with DD has increased dramatically. It approaches that of the general population. In addition to their disability, as they age, adults with DD typically acquire multiple, chronic medical conditions. Approximately 30% have associated mental illness. We have yet to develop the consult, assessment, and enhanced primary care services necessary to serve this new population of people with complex needs.

The Office of Developmental Primary Care was developed to build the health care system's capacity to serve adults with developmental disabilities through clinical services, advocacy, research, training and technical assistance.

Vision

Transition age youth and adults with developmental disabilities (DD) have access to health care 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

Challenges

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

- **Opportunities for the self-advocacy community** to engage policy makers
- **Special medical services and medical experts** for patients with DD
- **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
- **Accountability for Health Plans** to provide access to effective, respectful, competent, timely care
- **Data on the health status and health care utilization** of the population
- **Support for clinical and health services research**

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:

- Special primary care services for those with intensive, interdisciplinary needs
- Access to specialized mental health services for those with intellectual and communication disabilities
- Access to special needs dentistry
- Regular, independent health assessment and advocacy
- Support and training for direct care personnel and family caregivers
- Data and monitoring of access to care, health outcomes and health status
- Stable funding to develop and maintain an expert health professional workforce

The CART Model

The long-term strategic plan begins with building a program 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 Office of Developmental Primary Care was established in the University of California, San Francisco, Department of Family and Community Medicine. The Office of Developmental Primary Care has provided training to over 3,100 health professionals; established a website with practical clinical resources; engaged policy makers; and established a research program to study our clinical innovation. The goal of the project is to evolve into a UCSF Center for Excellence in Developmental Medicine to support the CART Model:

- **C**linical services in university and community settings
- **A**dvocacy to influence policy and support patients
- **R**esearch programs in health services and education to rigorously study the cost effectiveness of our clinical and training innovations
- **T**raining and technical assistance for medical professionals, self-advocates and caregivers

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