



*Improving outcomes for people  
with developmental disabilities*

## ❖ History of the Office of Developmental Primary Care

In the 1970's, institutions for people with developmental disabilities (DD) started to close. A health care system was developed to support children and their families. However, at the time, there weren't that many adults with DD living in the community. Therefore, the focus was on developing systems for children. The hope was that adults could access the mainstream health care system. Over the past 40 years this system has largely worked for children, but has not worked as well for adults. Special health care needs continue as people with DD age. However, access to specialized health care services ends abruptly at adulthood. Today, people with DD live in the community, yet adequate health care services are not yet widely available.

There are over 220,000 Californians with DD living in the community. They have significant limitations in self-care, language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. By definition, they don't have the capacity to access mainstream healthcare without support. Government does not guarantee an independent advocate. Over 90,000 of these individuals are adults. Adults with DD are living longer and their parents are aging. Many adults have no family support. They can easily fall through the cracks. This has led to health care disparities. When children with special health care needs grow up, there is no integrated health care system into which they can transition. Health care providers simply don't yet have the training and resources to develop the services that are needed. These problems have been identified in many policy papers. However, little progress has been made.

In 1999, Dr. Clarissa Kripke joined the clinical faculty in the UCSF Department of Family and Community Medicine. At the time, medically fragile adults with DD were coming to her practice. The office-based model was difficult for her patients. To address this challenge, she developed a home-based model of care. To develop her service, she looked for other models of care across the country. She found very few pioneers working in the field of Developmental Medicine.

In 2006, a group of leaders from agencies in San Francisco and San Mateo came together. They committed to developing a model health care system for adolescents and adults with DD. Faculty from UCSF partnered with The Arc of San Francisco, Golden Gate Regional Center, San Francisco Department of Public Health and Health Plan of San Mateo to develop a health care reform initiative. In 2008, the UCSF Department of Family and Community Medicine was awarded a grant to develop a curriculum in DD. The Office of Developmental Primary Care was established through this grant. Leaders from other departments and schools are doing excellent work to serve and study this population. The Office of Developmental Primary care seeks to provide resources to those who are working on this issue. Faculty have begun to discuss integrating programs into a more coordinated effort. The goal is to improve the health of individuals with DD.