

## **Public Comments in Support of Including the Population of Adults with Complex Disabilities as a Medically Underserved Population**

A 30 year old with autism is 6'5", 210 lbs, has a severe intellectual disability and is afraid of needles?

A 40 year old who lives in a private home and is dependent on a ventilator to breath and a gastrostomy tube to eat.

A person with an intellectual disability is diagnosed with diabetes and lives in a group home where nobody is licensed or trained to check a blood sugar.

Current policy is to serve people with complex disabilities in the community--not in institutions. People with complex disabilities living in the community is a new. There is no federal funding source to develop a medical infrastructure to meet their medical needs.

### **Definition of Health Disparity in Disability**

A health care disparity is a population with a difference in health status not directly attributable to the condition leading to or associated with the disability.

**Underservice for people with disabilities is closely related to functional status.** The more complex the disability and the lower the cognitive and functional status, the more need for special funding and service delivery models. It is FUNCTIONAL status rather than (or in addition to) health status that creates the dramatically increased work and complex logistics for clinicians, service agencies, patients and caregivers. Also, people with lower functional status are supported by large and complex teams with members from a variety of agencies who do not share funding, eligibility, information systems, or service area. They all need to be coordinated. (e.g. caregivers, specialists, agencies, funders, service providers, conservators, therapists, DME suppliers, teachers, vocational rehabilitation specialists, etc.).

**The assumption that all people require similar level of primary care service cannot be applied to adults with disabilities.** Individuals with complex disabilities require intensive primary care services including visits, interagency collaboration, and care coordination that are not possible in mainstream primary care practice. Having a "usual source of care" or "insurance" doesn't mean that there is access to care because the doctor may not be set up for complex care with funding for very specialized consultation services, small panel size, trained personnel and physical, financial and programmatic accessibility.

### **Disability should not be defined by specific condition but shouldn't be too broad.**

Too broad a definition will allow grant review committees to define what a MUP means for disability. This will disadvantage the most needy groups of people with individuals who have few advocates, little capacity for self-advocacy, little political power, few experts to put together proposals, and little data to support their proposals.

**Effective health service delivery for people with complex disabilities requires interagency and multidisciplinary collaboration.** People with complex disabilities often have very unique needs that can only be met by regional services. Service areas and eligibility should match service areas and eligibility for other services patients may need to access. Direct patient support, care coordination, and health care need to be integrated. Agencies that share responsibility need to be able to work together effectively. We need more consolidation so we can identify a defined population to develop an organized system of care around them that includes different agencies and systems (e.g. social service, care coordination, medical, dental, mental health, employment, education). To enable organized systems of care with integrated medical and long term-care services, the MUP definition for disabilities should focus on existing service populations such as:

**\*Dual eligibles (medicaid/medicare)**

**\*Departments of Developmental Service**

**\* Medicaid Home and Community Based Waiver programs.**

**MUP status would be valuable for people with disabilities because it would open access to funding for:**

1. Training funds for health care providers. The lack of a trained workforce is a huge barrier to care.
2. Funding for special clinical services.
3. Funding for health services, health policy and clinical research.

### **Data Needs for Future**

People with intellectual disabilities have been systematically excluded from national health surveillance, and we cannot report on their health status. Survey data is problematic for folks who have cognitive problems since neither they nor caregivers are very accurate reporters of health status and they are very difficult to reach. We need to track outcomes and utilization patterns.

**Clarissa Kripke, MD, FAAFP**

**Associate Clinical Professor**

**Director, Office of Developmental Primary Care**

**Chair, Chancellor's Advisory Committee on Disability Issues**

**Associate Editor, *American Family Physician***

**Office of Developmental Primary Care:**

**Department of Family and Community Medicine**

**University of California, San Francisco**

**500 Parnassus Ave. MU318E, Box 0900**

**San Francisco, CA 94143-0900**

**Program Coordinator: Pat Mejia**

**(415) 476-4641**

**(415) 683-8792 cell**

**(415) 476-6051 fax**

**<http://DevelopmentalMedicine.ucsf.edu>**

Dr. Kripke is a Family Physician on the clinical faculty of the University of California, San Francisco and a parent of a child with autism. She provides primary care for medically fragile adults with developmental disabilities.