

## **Advocates Seek Disability Focus in National Healthcare Reform Implementation**

*November, 2010*

To: Kathleen Sebelius  
Secretary  
Health and Human Services

Carolyn Clancy  
Agency for Healthcare Research and Quality  
Health and Human Services

We the undersigned disability advocacy groups urge you to move forward with the National Health Care Quality Strategy and Plan. As a disability community, we are stakeholders in the task you will undertake. However, we want to assure that the three pillars, upon which the Framework for Quality Strategy is based – better care, affordable care, and healthy people/healthy communities – includes the more than 54 million children and adults with disabilities in America.

Better care is a laudable goal for all Americans. However, people with disabilities, including children and adults with chronic health conditions, face numerous physical, attitudinal, system, structural, transportation, communication, and other barriers to receipt of even the most basic health care. Basic primary care – let alone quality primary care - is not a guarantee for anyone in the disability community. (Drainoni M, Lee-Hood E, Tobias C, et al., 2006)

Three out of five people with serious mental illness die 25 years earlier than other individuals, from preventable, co-occurring chronic diseases, such as asthma, diabetes, cancer, heart disease and cardiopulmonary conditions. (Colton & Manderscheid, 2006; Manderscheid, Druss, & Freeman, 2007) Inaccessible medical equipment and lack of trained physicians, dentists, and other health professionals prevent individuals with disabilities from receiving the basic primary and preventive care others take for granted, such as getting weighed, preventative dental care, pelvic exams, x-rays, physical examinations, colonoscopies, and vision screenings. (Kirschner, Breslin, & Iezzoni, 2007; Chan, Doctor, MacLehose, et al. (1999); Manderscheid R., Druss B., & Freeman E. 2007).

AHRQ's National Healthcare Quality Report & National Healthcare Disparities Reports must include a robust section on health quality needs of people with disabilities. The current quality initiatives and frameworks must include the quality needs of people with disabilities including those with chronic health conditions. Data collection must be designed to enable the quality of care to increase for everyone – including people with

disabilities. For example, health information technology should be designed to collect data for populations of people with disabilities so that reporting of relevant quality measures can help improve the quality of care of people with disabilities.

We believe the national quality care strategy must include a focus on basic primary care that individuals with physical, mental health, sensory, environmental, cognitive, intellectual, developmental, and other disabilities, including individuals with chronic health conditions, often go without because of a lack of primary care providers trained to treat them. In 2000, *Healthy People 2010*, cautioned that "as a potentially underserved group, people with disabilities would be expected to experience disadvantages in health and well-being compared with the general population." Current data supports that notion.

People who are deaf or experience significant problems hearing report they were three times as likely to report fair or poor health compared with those without hearing impairments. (NCD, 2009). They have difficulty communicating with primary care providers who don't want to pay interpreters or "bother" with a Telecommunication Device for the Deaf (TDD). Children with ADD may have difficulty getting examined by primary care providers untrained to treat them. People with significant vision loss are more likely to have heart disease and hypertension, experience a greater prevalence of obesity, and smoke more than the general population. (NCD, 2009). Further, people who are blind often miss out on the prevention handouts and booklets given to patients by primary care providers. Even providers report they have difficulty communicating with patients who are deaf or have severe visual impairments. (Bachman S., Vedrani, M., Drainoni, M., Tobias, C., & Maisels L., 2006). People with HIV/AIDS often face the prejudice of providers who do not want to treat them. The National Health Quality Strategy and Plan must address these barriers to quality care.

27% of adults with major physical and sensory impairments are obese, compared with 19% among those without major impairments (Iezzoni, 2009).[\[1\]](#) Research shows that individuals with intellectual disabilities must contact 50 physicians before they can find one trained to treat them. (Corbin, Holder, & Engstrom, 2005). The National Health Quality Strategy and Plan must address these barriers to quality care.

According to the National Council on Disability (NCD), 2009 report, *The Current State of Health Care for People with Disabilities*, "[p]eople with disabilities experience significant health disparities and barriers to health care, as compared with people who do not have disabilities." Further, "[t]he absence of professional training on disability competency issues for health care practitioners is one of the most significant barriers

preventing people with disabilities from receiving appropriate and effective health care.” The National Health Quality Strategy and Plan must address these barriers to quality care.

Members of the disability community experience a broad spectrum of functional limitations that result from their disabilities. Many experience secondary chronic conditions. As the recent draft “*A Strategic Framework 2010-2015 – Optimum Health & Quality of Life for Individuals with Multiple Chronic Conditions*” by the HHS Working Group on Multiple Chronic Conditions” (May, 2010) reported, functional limitations can often complicate access to health care and interfere with self-management. The Institute of Medicine noted there is evidence that patients actively receiving care for one chronic condition may *not* receive care for other unrelated conditions. Quality care for people with disabilities means addressing the prevention of secondary conditions and the care of *multiple* chronic conditions and The National Health Quality Strategy and Plan must include this.

The 1997 IOM report *Enabling America* bluntly stated that federal research effort in the area of disability was inadequate. On July 26, 2005, the U.S. Surgeon General issued a *Call to Action* warning that people with disabilities can lack equal access to health care. Though some funds are available for developmental and intellectual disabilities through the CDC, Maternal and Child Health, and the Developmental Disabilities Act, the 2007 IOM report, *The Future of Disability in America* states that research spending on disability is miniscule in relation to current and future needs. In this Report, the IOM also warns that the number of people with disabilities is likely to rise, fueled by aging baby boomers. At the same time, this report articulates the unmet health needs of children with disabilities, including those with chronic health conditions, as they transition into adulthood. More research is needed to improve the quality of care for children and adults with disabilities including healthcare during their transition to adulthood and the National Health Quality Strategy and Plan must address this need.

While the National Health Quality Strategy and Plan includes a focus on comparative effectiveness research, the disability community is concerned that current successful interventions for people with disabilities, such as anti-seizure or anti-spasticity medications *not* fall victim to comparative effectiveness research under the guise of improving quality of care. The National Health Quality Strategy and Plan *should* consider the issue of transportation, a key barrier to people with disabilities who seek quality health care from clinicians equipped to meet their health care needs.

Finally, the National Health Quality Strategy and Plan's third pillar, healthy people/healthy communities must include people with disabilities. People with disabilities are often left out of community health initiatives due to ignorance, or the many physical, attitudinal and other barriers they face in the community. The National Health Quality Strategy and Plan should work collaboratively with states to increase their awareness of the need to integrate people with disabilities into these initiatives.

To improve the quality of care for people with disabilities, we need to assure adequate numbers of primary care providers are trained to treat the population of people with disabilities including those with chronic health conditions; people with disabilities have access to adequate primary care; and funding is available for research and programs to end the health disparities people with disabilities face. The National Health Quality Strategy and Plan can finally address these issues for all people with disabilities.

We urge you to include the improvement of the health of people with disabilities, including those with chronic health conditions, as a major goal in the National Health Quality Strategy and Plan, recognize people with disabilities as major stakeholders in all quality initiatives, and make sure people with disabilities are included in the healthy people/community health initiatives. Our groups are glad to serve as resources for AHQR to better integrate the health care needs of people with disabilities in the National Health Quality Strategy and Plan. Thank you. (References below signatures.)

Sincerely

Access Living of Metropolitan Chicago

ADAPT New York State

ADAPT Montana

Alliance for the Betterment of Citizens with Disabilities

American Association of People With Disabilities

Association of University Centers on Disabilities

American Association on Health and Disability

American Medical Rehabilitation Providers Association

The Arc of the United States

Autistic Self-Advocacy Network

Bazelon Center for Mental Health Law

Brain Injury Association of America

Bronx Independent Living Services

California Foundation Independent Living Centers

Center for Disability Rights (Rochester)  
Center for Independence of the Disabled, NY.  
Center for Self-Determination  
Coalition for Community Integration  
Christopher and Dana Reeve Foundation  
Disabled In Action of Metropolitan New York  
The Disability Network  
Disability Rights Center  
Disability Rights Education and Defense Fund  
Easter Seals  
The Epilepsy Foundation  
Family Voices  
Harlem Independent Living Center  
Harris Family Center for Disability and Health Policy at Western University of Health  
Sciences  
Hearing Loss Association of America  
Institute for Human Centered Design  
Khmer Health Advocates, Inc.  
Little People of America  
National Association of County Behavioral Health and Developmental Disability  
Directors  
National Association of Councils on Developmental Disabilities  
National Association of the Deaf  
National Center for Environmental Health Strategies, Inc.  
National Coalition for Mental Health Recovery  
National Council for Community Behavioral Healthcare  
National Council on Independent Living (NCIL)  
National Down Syndrome Society  
National Organization of Nurses with Disabilities  
National Spinal Cord Injury Association  
National Youth Leadership Network  
New York Association of Psychiatric Rehabilitation Services  
New Yorkers for Accessible Health Coverage  
Not Dead Yet  
Paraquad, St. Louis Center for Independent Living  
Physician-Parent Caregivers  
Regional Center for Independent Living (Rochester, NY)  
Rochester ADAPT

Silicon Valley Independent Living Center  
Special Olympics  
Spina Bifida Association  
Starkloff Disability Institute  
Statewide Independent Living Council of GA, Inc.  
United Cerebral Palsy  
United Spinal Association