

June 9, 2010

To:

Kathleen Sebelius  
Secretary  
Health and Human Services

Mary Wakefield  
Administrator  
Health Resources and Services Administration

Pam Hyde, JD  
Administrator  
Substance Abuse and Mental Health Administration

We the undersigned disability advocacy groups urge you to include representation of the ***cross-disability community*** on the Negotiated Rulemaking Committee (NR) that will establish a comprehensive methodology and criteria for designation of “Medically Underserved Populations” (MUPS) and Primary Care Health Professions Shortage Areas. As a cross-disability community, we are stakeholders in the task you will undertake. However, we do not fit within the geographic census tract data that has been used in the past to designate medically underserved populations. More than 54 million Americans with disabilities, including individuals with physical, mental health, sensory, environmental, cognitive, intellectual, and developmental disabilities experience inadequate health care 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." They have and the data is startling.

Basic 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).

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)

27% of adults with major physical and sensory impairments are obese, compared with 19% among those without major impairments (Jezzoni, 2009).<sup>1</sup> Research shows that individuals with intellectual disabilities must contact 50 physicians before they can find one trained to treat them. (Corbin, Holder, & Engstrom, 2005)

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.”

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.

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.

We need to assure adequate numbers of primary care providers are trained to treat the population of people with disabilities; people with disabilities from across the disability community have access to adequate primary care; and funding is available for research and programs to end the health disparities people with disabilities face. With the passage of health care reform and the formation of the NR Committee to redefine “medically underserved populations,” HRSA can finally work to rectify the problem for all people with disabilities. Collectively, we are an underserved population and we are not adequately represented on the proposed NR Committee. We urge you to appoint someone to represent the cross-disability community, recognize people with disabilities as a constituency stakeholder within the definition of medically underserved populations, and include subject matter experts who represent the

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<sup>1</sup> The *Future of Disability in America* (IOM, 2007) includes a very comprehensive review of the literature of the health status of the people with various disabilities.

health care needs of the cross-disability community. Our groups are glad to serve as resources for HRSA. Thank you. (References below signatures.)

Sincerely

Access Living  
ADAPT  
ADAPT Montana  
Alpha-1 Association  
Alpha-1 Foundation  
American Association of People With Disabilities  
American Association on Health and Disability  
Amputee Coalition of America  
American Medical Rehabilitation Providers Association  
American Network of Community Options and Resources  
American Speech-Language-Hearing Association  
The Arc of the United States  
Association of Maternal & Child Health Programs  
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  
Center for Women's Health Research at UNC  
CHADD – Children and Adults with Attention-Deficit/Hyperactivity Disorder  
COPD Foundation  
Council for Exceptional Children  
Disability Health Coalition  
The Disability Network  
Easter Seals  
The Epilepsy Foundation  
First Signs  
Hearing Loss Association of America  
Life Skills Institute and Life Skills, Inc  
Little People of America  
Mental Health America  
National Association of County Behavioral Health and Developmental Disability Directors  
National Association of Head Injury Administrators  
National Association of Councils on Developmental Disabilities  
Khmer Health Advocates, Inc.  
National Coalition for Mental Health Recovery

National Council on Independent Living (NCIL)  
National Down Syndrome Society  
National Organization of Nurses with Disabilities  
National Association of Private Special Education Centers  
National Association of the Deaf  
National Center for Environmental Health Strategies, Inc.  
National Multiple Sclerosis Society  
National Spinal Cord Injury Association  
New York Association of Psychiatric Rehabilitation Services  
Not Dead Yet  
Physician-Parent Caregivers  
Regional Center for Independent Living (Rochester, NY)  
Rochester ADAPT  
Spina Bifida Association  
Statewide Independent Living Council of GA, Inc.  
Stop CMV - The CMV Action Network  
Substance Abuse Resources and Disabilities Issues Program (SARDI), Boonshoft School of  
Medicine  
TASH  
Tourette Syndrome Association  
Tuberous Sclerosis Alliance  
Master of Public Health Program, Tufts University School of Medicine  
United Cerebral Palsy  
United Spinal Association  
Center on Independent Living, University of Kansas

### References:

- Bachman S., Vedrani, M., Drainoni, M., Tobias, C., Maisels L., , Provider Perceptions of Their Capacity to Offer Accessible Health Care for People With Disabilities *J Disabil Policy Stud.*; Winter 2006; 17, 3; 130-136
- Chan L, Doctor JN., MacLehose RF., et al. (1999) Do Medicare patients with disabilities receive preventive services? *Arch Phys Med Rehabil.* 80:642-646
- Colton CW., Manderscheid RW.. (2006, April). Congruencies in increased mortality rates, years of potential life lost, and causes of death among public mental health clients in eight states. *Preventing Chronic Disease: Public Health Research, Practice and Policy.* 3(2), 1-14. Available at [www.pubmedcentral.nih.gov/articlerender.fcgi?tool=pubmed&pubmedid=16539783](http://www.pubmedcentral.nih.gov/articlerender.fcgi?tool=pubmed&pubmedid=16539783).
- Corbin S., Holder M., Engstrom K. (2005) *Changing attitudes, changing the world: the health and health care of people with intellectual disabilities.* Washington, D.C.: Special Olympics International.
- Drainoni M, Lee-Hood E, Tobias C, Bachman S, Andrew J, Maisels L. (2006) Cross-disability experiences of barriers to health-care access. *J Disabil Policy Stud.* 17:101-115.
- HHS Working Group on Multiple Chronic Conditions. (2010, May) Strategic Framework 2010-2015 – Optimum Health & Quality of Life for Individuals with Multiple Chronic Conditions.

(Draft) Available online at:

- Iezzoni, L.I., (2009, January 27) Testimony before the Senate Health, Education, Labor, and Pensions Committee, by Lisa I. Iezzoni, MD, Professor of Medicine, Harvard Medical School and Associate Director, Institute for Health Policy, Massachusetts General Hospital, Boston, MA.
- Iezzoni LI, McCarthy EP, Davis RB, Siebens H. Mobility impairments and use of screening and preventive services. *Am J Public Health*. 2000;90:955-961.
- Institute of Medicine, (1997) *Enabling America*, National Academies Press, Washington, DC
- Institute of Medicine, (2007) *The future of disability in America*. National Academies Press, Washington, DC.
- Kirschner K.L., Breslin, ML., Iezzoni, LI., (2007, March 14) Structural impairments that limit access to health care for patients with disabilities. *JAMA*., 297:10:1121-1125
- Manderscheid R., Druss B., Freeman E . (2007, August 15). *Data to manage the mortality crisis: Recommendations to the Substance Abuse and Mental Health Services Administration*. Washington, D.C.
- National Council on Disability (NCD), (2009) *The Current State of Health Care for People with Disabilities*. Available online at: [www.hhs.gov/ohps/initiatives/mcc/federal-register051410.pdf](http://www.hhs.gov/ohps/initiatives/mcc/federal-register051410.pdf)
- US. Department of Health and Human Services. Health People 2010. 2nd ed. With Understanding and Improving Health, and Objectives for Improving Health. 2 Vols. Washington, DC: U.S. Government Printing Office, November 2000