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June 9, 2010

Health Resources and Services Administration
Department of Health and Human Services
Attention: HRSA Regulations Officer
Parklawn Building, Room 14A-11
5600 Fishers Lane
Rockville, MD 20857

Re: #HRSA-1

To Whom It May Concern,

We strongly urge you to appoint several individuals with broad knowledge and awareness of health and health care disparities, barriers to care, and health outcomes experienced by individuals with diverse disabilities to the Negotiated Rulemaking Committee (NR) that will establish a comprehensive methodology and criteria for designation of Medically Underserved Populations (MUPS) and Health Professions Shortage Areas (HPSA).

We also specifically support the recommendations of Dr. Matt Holder and others who have called for identification of individuals with neurodevelopment disorders as a Medically Underserved Population and the call by the Justice for All Action Network (JFAAA), Schwab Rehabilitation Hospital and Access Living (Chicago, Illinois), and others for recognition of disability status as the basis for inclusion in the MUPS and HPSA designation.

According to HRSA's sixth annual report on training primary care physicians, "Vulnerable individuals and populations often have a greater risk for poor health outcomes than the general population because of the interplay of disparate health care access; health care quality; and genetic, personal, behavioral, environmental, socioeconomic, and community risk factors." [1] For people with disabilities, these interrelated and crosscutting determinants of health are especially relevant.

Disability status, although not yet recognized by HRSA as a MUP or HPSA, is nevertheless pervasive among underserved populations that are defined by race, poverty and age. While individuals with disabilities are already de facto members of these populations, Federal agencies concerned with health, health care and related research have devoted little attention to addressing the specific health care inequities and barriers to care people with disabilities face, so practically speaking, they remain not only underserved, but also invisible.

In the United States an estimated 54.4 million (18.7 percent) people have some level of disability, and 35.0 million (12.0 percent) have a severe disability.[2] The incidence of disability is significantly higher among working-age African Americans (17 percent) and among Native Americans (22.5 percent) as compared with 12.6 percent among whites. [3]

Rates of disability also increase with age; 41.9 percent of individuals over the age of 65 report disability, compared with18.6 percent of people who are younger. [4] More than two thirds of adults who have vision impairments are over age 65, and the leading causes of vision impairment in the United States are age-related. [5] Among adults over 65, 11.1 percent report deafness or a lot of trouble hearing. [6] Disability affects women more significantly as they age. Among women aged 16 to 64, a little over 17 percent have one or more disabilities, compared with 43 percent of women who are 65 or older. [7]

Poverty and Disability

The impact of poverty on health has been well documented. Disability status is both a cause and an outcome of poverty, thus disability and poverty in the United States are inextricably entwined. For people with disabilities, the rate of poverty is between two to three times the rate for people who do not have disabilities. About half of all working-age adults who experience poverty have a disability. Moreover, almost two-thirds of adults experiencing long-term poverty also have a disability. [8]

Poverty limits access to adequate and effective health care and disease prevention services, and increases the probability of living in neighborhoods that contribute to poor health or of being homeless. [9] The US health care system further exacerbates the connection between poverty and disability. [10] For example, recent research indicates that rates of uninsurance can be as high as 28 percent for people with certain conditions such as mental health disabilities. [11] Moreover, according to a recent report, “People with disabilities account for a larger share of those experiencing income poverty than people in any single minority or ethnic group (or, in fact, all minority, ethnic and racial groups combined)…” [12] Disability, along with poverty, therefore are overlapping identities for underserved individuals who experience systemic health and health care inequality.

Health Disparities and Barriers to Care

The impact of various interrelated and crosscutting determinants of heath affect people with specific impairments differently, yet virtually every group experiences barriers to care and health disparities that affect health status and health outcomes. Barriers to care can include limited medical facility accessibility; lack of accommodations such as Sign Language Interpreters and print materials in formats that are accessible to people who are blind or have vision impairments; and lack of accessible diagnostic and exam equipment.

Identified by the Institute of Medicine, one of the most significant barriers to care is lack of provider education and disability awareness needed to counter disability stereotypes and misconceptions held by health care providers. [13] Other barriers include lack of insurance or insurance coverage limits, and lack of care coordination.

The Current State of Health Care for People with Disabilities, published in 2009 by the National Council on Disability, reports the following examples of health disparities, barriers to care, and health status for specific groups:

- People who are deaf or experience significant problems hearing report a higher prevalence of “fair” or “poor” health status, and hypertension and diabetes is more prevalent than among people who do not have hearing difficulties. Communication barriers compromise care for people who are deaf or hard-of-hearing and inadequate communication can cause reluctance on the part of the person to seek care, medication errors, misdiagnoses, and a significant danger before and after anesthesia and surgery.

- Income, education, and membership in certain racial and ethnic minority groups are significantly associated with vision impairment. For example, 16 percent of adults in poor families had vision difficulties, compared with 9 percent of adults in families that were not poor. People who are Hispanic have higher rates of vision impairment than people who are African American, and both groups have higher rates than those for people who are white. Approximately 30 percent of people over age 18 who have vision impairments rate their overall health status as either “fair” or “poor,” compared with 8 percent of the population that does not have vision impairments. They also experience a greater prevalence of obesity.

- Women with disabilities experience poorer health than women who do not have disabilities, despite the fact that both groups report the same types of health problems. Nearly a third of women with extensive functional limitations rate their overall health as poor compared with less than 1 percent of women with no limitations. Women with disabilities are also less likely to receive mammography services and pap tests than women without disabilities.[14]

As a practical matter, health care clinics and offices that serve primarily low income individuals have significant budget constraints that make it difficult for them to take proactive steps to accommodate patients with diverse disabilities by removing architectural barriers, providing Sign Language interpreters, providing additional exam time for people with cognitive or speech disabilities, and acquiring accessible examination and diagnostic equipment. The lack of such accommodations therefore profoundly influences the quality of care individuals with various disabilities receive in the forums where they are most likely to seek care and contributes to their underserved status.

A growing body of research by renowned health policy experts including the Institute of Medicine, the Surgeon General of the United States, the National Council on Disability, the Centers for Disease Control and Prevention, and by leading public health research centers and institutions indicates that people with disabilities are both underserved and poorly served by the current health care system and that medical professionals, especially primary care practitioners, lack even basic training and disability awareness required to provide culturally appropriate care.

HRSA’s proposed interest groups and categories from which the NR Committee will be composed do not possess knowledge and expertise about the healthcare gaps and barriers people with disabilities face or the extent to which such individuals meet existing criteria for MUPS designation. Consequently, they cannot be expected to adequately represent these important, and thus far unrepresented issues, during the NR deliberations. Since one of the foundational purposes of the committee“…is to determine whether the proposed rule might significantly affect additional interests not adequately represented by the list of proposed participants," representatives from these possible additional affected interests must be selected. Therefore, we reiterate our strong recommendation that several experts with cross-disability experience in the diverse field of health and disability be appointed to the NR Committee that will establish criteria for both MUPS and HPSA. In light of the small size of the final committee, we also recognize that one individual may be called on to represent a variety of interests. As an alternative, we recommend that at least one expert and an alternate, each of whom represents groups with closely associated cross-cutting and cross-disability perspectives, be appointed.

Thank you for your consideration.

Sincerely,

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Endnotes

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[1] The Role of Title VII, Section 747 in Preparing Primary Care Practitioners to Care for the Underserved and Other High-Risk Groups and Vulnerable Populations. Sixth Annual Report of the HRSA Advisory Committee on Training in Primary Care Medicine and Dentistry. (Rockville, MD, March 2008), 80 pp.

[2] Matthew Brault, “Americans with Disabilities: 2005,” *Current Population Reports* (Washington, DC: U.S. Census Bureau, 2008), p. 3.

[3] J. Waldrop and S. M. Stern, *Disability Status: 2000—Census 2000 Brief* (Washington, DC: U.S. Bureau of the Census), p. 2.

[4] C. Boult, M. Altmann, D. Gilbertson, C. Yu, and R. L. Kane, “Decreasing Disability in the 21st Century: The Future Effect of Controlling Six Fatal and Nonfatal Conditions,” *American Journal of Public Health* 86, no.10 (1996), pp. 1388–1393.

[5] Anthony F. Di Stefano et al., “Community Services, Needs, and Resources in Visual Impairment: A 21st Century Public Health Perspective,” *Journal of Visual Impairment and Blindness, Vision Loss and Public Health Supplement 100 (2006)*.

[6] C. A. Schoenborn and K. Heyman, “Health Disparities Among Adults with Hearing Loss in the United States, 2000–2006,” National Center for Health Statistics.

[7] U.S. Census Bureau. *Characteristics of the Civilian Non-institutionalized Population by Age, Disability Status, and Type of Disability 2000*. (Washington, DC: 2003).

[8] Shawn Fremsted, “Half in Ten: Why Taking Disability into Account is Essential to Reducing Income Poverty and Expanding Economic Inclusion,” Center for Economic and Policy Research, (2009), p. 3.

[9] Fremsted, “Half in Ten.”

[10] Pokempner and Roberts, *Ohio State Law Journal.*

[11] National Council on Disability, *The Current State of Health Care for People with Disabilities*, (Washington, DC: NCD, September 30, 2009), p. 40.

[12] Fremsted, “Half in Ten.”

[13] Institute of Medicine (IOM), *The Future of Disability in America* (Washington, DC: National Academies Press, 2007), p. 153.

[14] National Council on Disability, *The Current State of Health Care for People with Disabilities*, p. 41, 53, 61, 73.