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We, the undersigned self-advocacy and disability advocacy groups write to you to support the HHS Office of Minority Health (OMH)'s enhancement initiative to ensure that the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health Care remain current and appropriate. We understand that according to its website, OMH's primary responsibility is to improve health and healthcare outcomes for racial and ethnic minority communities by developing or advancing policies, programs, and practices that address health, social, economic, environmental and other factors which impact health. This creates a problem since individuals with disabilities are not officially within the purview of OMH. However, to reflect the mandates in the Affordable Care Act and Healthy People 2020, which both treat people with disabilities in parity with individuals who are members of racial and ethnic minorities in terms of health disparities (See, e.g., ACA §4302), the CLAS standards must also address the issue of culturally and linguistically competent care and treatment of individuals with disabilities to remain current and appropriate.

Like members of racial and ethnic minorities, people with disabilities experience significant health disparities and different treatment in the health care system. 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." 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).

Research shows that members of racial and ethnic minorities and poor people are overrepresented among people with disabilities. (Fujiura, Yamaki, & Czechowicz, 1998). According to *The 2005 Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities: Calling You to Action* over 50 million Americans with disabilities in the United States face health care disparities because of their disabilities; Over 7.3 million are members of ethnic minorities (ages 15-64). Overall, Asian Americans and whites, 5 years of age

or older, have lower rates of disability than other racial and ethnic groups. American Indian and Alaska Native and Black or African-American populations experience the highest rates, five percent above rates of disability among white populations. (U.S. Department of Health and Human Services, 2005)

People who both have disabilities *and* are people of color report even greater health disparities than their non-disabled counterparts. US National Health Interview Survey data shows that persons with both mobility limitations *and* minority status experienced greater health disparities than adults with minority status *or* mobility limitations alone in most outcomes measured. Among the measures with the greatest disparities were worsening health, depressive symptoms, diabetes, stroke, visual impairment, difficulty with activities of daily living, obesity, physical activity and low workforce participation. (Jones GC & Sinclair LB, 2008). Further, according to a CDC report, (Wolf, LA, Armour, BS, Campbell, VA, 2008) analysis of the Behavioral Risk Factor Surveillance System (BRFSS) surveys show that 33% more black respondents with disabilities than black respondents without disabilities report fair or poor health as do 38% more disabled American Indian/Alaskan Natives than those without disabilities.

Other disparities between members of racial and ethnic minorities with disabilities and whites with disabilities are profound. For example, the CDC reported (Friedman, JM, 2001) that whites with Down syndrome in the United States had a median death age of 50 in 1997, while the median age was 25 for blacks, and just 11 for people of other races. When compared to whites who exhibit the same symptoms, African Americans tend to be diagnosed more frequently with schizophrenia and less frequently with affective disorders. Further, 27% of blacks compared to 44% of whites received antidepressant medication when first diagnosed with depression. (U.S. Department of Health and Human Services, 2001)

The CLAS Standards provide a powerful tool for decreasing health disparities for all people with disabilities - those who are members of racial and ethnic minorities, and those who are not. The CLAS Standards must include deaf individuals who are not native English speakers and are in need of sign language interpreters as well as people with hearing loss - a growing segment of our aging population - who may use auxiliary aids, such as assistive listening devices or CART. Individuals whose disabilities interfere with their ability to speak often use augmentative communication devices and these must fall under the CLAS Standards. The CLAS Standards must require providers to ensure that patients with intellectual disabilities comprehend all communications – verbal and written - regarding their health care. The CLAS Standards must also cover written communication for blind individuals and those with low vision so that alternative formats for prevention and health information materials are available in the health care setting. Finally, the CLAS Standards must cover the attitudinal barriers and other barriers to care that are rooted in the lived experience of people with disabilities. See e.g. *Tugg v. Towey*, 864 F. Supp. 1201 (S.D. Fla. 1994)

Since OMH is the "keeper of " the CLAS Standards, it is critical that OMH commit to include cultural and linguistic needs of individuals with disabilities in the CLAS Standards to remain current and appropriate and reflect the intent of the Affordable Care Act and Healthy People 2020. Our organizations are glad to serve as resources should you need assistance in integrating people with disabilities into the CLASS Standards.

Sincerely,

Access Living of Metropolitan Chicago
ADAPT Montana
All About You Home Care
American Association of People With Disabilities
American Association on Health and Disability
Association of University Centers on Disabilities
ATAP - The Association of Assistive Technology Act Programs
Autistic Self-Advocacy Network
Boston Center for Independent Living
California Foundation Independent Living Centers
Center for Disability Rights (Rochester)
Center for Independence of the Disabled, NY.
Center for Self-Determination
Center for the Advancement of Rehabilitation & Disability Services
Disabled In Action of Metropolitan New York
Disability Rights Center
Family Voices
504 Democratic Club
Greater Boston Legal Services
Hearing Loss Association of America
Institute for Human Centered Design
Institute of Social Medicine & Community Health
Khmer Health Advocates, Inc.
Little People of America
National Association of County Behavioral Health and Developmental Disability Directors
National Association of State Head Injury Administrators
National Association of the Deaf
National Center for Environmental Health Strategies, Inc.
National Council on Independent Living (NCIL)
National Organization of Nurses with Disabilities (NOND)
National Spinal Cord Injury Association
New York Association of Psychiatric Rehabilitation Services
New Yorkers for Accessible Health Coverage
Not Dead Yet
The Ohio State University Nisonger Center
Regional Center for Independent Living (Rochester, NY)
Special Olympics
Starkloff Disability Institute
Statewide Independent Living Council of GA, Inc.
Texas State Independent Living Council
United Spinal Association
Women with Disabilities Health Equity Coalition (WowDHEC)

References:

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.

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.

Friedman, JM, (2001, June 08). Racial disparities in median age at death of persons with Down syndrome --- United States, 1968—1997. *MMWR Weekly*. CDC. 50(22);463-5.

Fujiura, G. T., Yamaki, K., & Czechowicz, S. (1998). Disability among ethnic and racial minorities in the United States. *Journal of Disability Policy Studies, 9*, 111-130.

Jones GC, Sinclair LB. (2008) Multiple health disparities among minority adults with mobility limitations: san application of the ICF framework and codes. *Disability and Rehabilitation*. 30(12-13):901-15.

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/ophs/initiatives/mcc/federal-register051410.pdf

U.S. Department of Health and Human Services. Health People 2020. (2010). Improving the Health of Americans. http://www.healthypeople.gov/2020/topicsobjectives2020/default.aspx

U.S. Department of Health and Human Services. (2001). *Mental Health: Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.

U.S. Department of Health and Human Services. (2005) *The 2005 Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities: Calling You to Action.* U.S. Department of Health and Human Services, Office of the Surgeon General.

Wolf, LA, Armour, BS, Campbell, VA, (2008, October 03) Racial/Ethnic disparities in self-rated health status among adults With and Without Disabilities -- United States, 2004 – 2006**.** *MMWR Weekly*. 57(39):1069-1073.