## A RECOMMENDATION REPORT FROM THE HHS ADVISORY COMMITTEE ON MINORITY HEALTH (ACMH)

Assuring Health Equity for Minority Persons with Disabilities

# A Statement of Principles and Recommendations

**Submitted to** 

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Office of Minority Health



## Assuring Health Equity for Minority Persons with Disabilities

# A STATEMENT OF PRINCIPLES AND RECOMMENDATIONS U.S. Department of Health and Human Services Advisory Committee on Minority Health (ACMH)

#### Submitted

Through
Garth Graham, MD, MPH,
Deputy Assistant Secretary for Minority Health
To
Kathleen Sebelius, Secretary,
U.S. Department of Health and Human Services

**July 2011** 

#### **Advisory Committee on Minority Health:**

Section 1707 of the Public Health Service Act, as amended, by the Minority Health and Health Disparities Research and Education Act of 2000 (P. L. 106-525) authorizes the establishment of an Advisory Committee on Minority Health. The Committee also is governed by provisions of Public Law 92-463, as amended (5 U.S.C. Appendix 2), which sets forth standards for the formation and use of advisory committees. The Act directs the Advisory Committee on Minority Health to advise the Department of Health and Human Services, through the Deputy Assistant Secretary for Minority Health, on improving the health of racial and ethnic minorities and on the development of the program activities of the Office of Minority Health.

#### **COMMITTEE MEMBERS:**

#### Chairperson

Rubens J. Pamies, MD, FACP (deceased) Vice Chancellor for Academics Affairs, Dean for Graduate Studies, Professor of Medicine, University of Nebraska Medical Center

Omaha, NE

Term. Date: 02/23/2011

#### **Members**

#### Diana M. Bonta, RN, DrPH

Kaiser Permanente, Vice President, Public Affairs, Southern California Region Pasadena, CA

Term. Date: 11/01/2011

#### Olveen Carrasquillo, MD, MPH

Chief, Division of General Internal Medicine University of Miami Miller School of Medicine

Miami. Florida

Term Date: 02/23/2012

#### **Bettye Davis-Lewis, EdD**

Chief Executive Officer
Diversified Health Care Systems, Inc.

Houston, TX 77004 **Term Date:** 06/01/2010

#### Gayle Dine-Chacon, MD

Associate Vice President for Native American Health, Associate Professor, Clinician Educator, Director, Center for Native American Health, Department of Family and Community Medicine Albuquerque, NM

Term Date: 02/23/2012

#### Bryan Liang, MD, PhD, JD

Executive Director and Professor of Law, Institutes of Health Law Studies; California Western School of Law San Diego, CA

**Term. Date:** 06/01/2010

#### Edward L. Martinez, MS

Senior Consultant, National Association of Public Hospitals and Health Systems Viroqua, WI

Term. Date: 02/23/2012

#### Kelly Moore, MD

Visiting Associate Professor, Colorado School of Public Health, University of Colorado Denver, American Indian and Alaska Native Programs Albuquerque, NM

Term. Date: 02/23/2012

#### Marguerite J. Ro, DrPH

Chief, Assessment Policy Development, and Evaluation Section
Public Health Seattle-King County
Seattle, WA

Term Date: 02/23/2013

#### Oreta Mapu Togafau, DrPA

Senior Policy Advisor to the Governor American Samoa Government Pago Pago, AS

rago rago, AS

Term Date: 02/23/2012

#### **Cara Cowan Watts**

District Seven Representative to the Cherokee Nation Tribal Council District 7 – Will Rogers

Claremore, OK

Term. Date: 11/01/2011

**REPORT WRITING GROUP** Rubens J. Pamies, MD, FACP Diana M. Bonta, RN, DrPH Edward L. Martinez, MS Olveen Carrasquillo, MD., MPH Marguerite J. Ro, DrPH

Contractor: Community Science, TeamPSA Technical Writer

### **Table of Contents**

Introduction and Context for the Report on Minorities with Disabilities7
Health Inequities for Persons with Disabilities7
Lack of Provider Competency in Disabilities as a Barrier to Care10
Minorities with Disabilities: Marginalized, Vulnerable, and Forgotten Populations
11
Limited Data and Research on Health Inequities among People with Disabilities.12
Minorities with Disabilities: Conclusions and Recommendations12
1. Raise awareness about minorities with disabilities13
2. Recognize disability as a fundamental component of cultural competency13
3. Require competency for all health care providers and professionals13
4. Improve research and practice on disabilities in minority populations14
5. Strengthen the health care workforce to ensure high quality care for people
with disabilities15
Concluding Comments15
Endnotes 15

6

#### **Assuring Health Equity for Minority Persons with Disabilities**

#### Introduction and Context for the Report on Minorities with Disabilities

The charge of the Advisory Committee on Minority Health (ACMH) is to advise the Secretary of the Department of Health and Human Services on ways to improve the health of racial and ethnic minority populations and on the development of goals and program activities within the Department. The Committee now faces a major new responsibility: It will have a critical role in ensuring that health care reform, as embodied in H.R. 3950, The Patient Care and Affordable Care Act of 2010 (P. L.111-148), is implemented equitably. This process should be monitored to guarantee that the provisions of the bill adequately respond to the needs of vulnerable populations and propel the nation toward achieving health equity.

With these responsibilities in mind, ACMH's first 2009 report, Ensuring that Health Care Reform Will Meet the Health Care Needs of Minority Communities and Eliminate Health Disparities: A Statement of Principles and Recommendations, proposed 14 Principles for Minority Health Equity in Health Care Reform to ensure that health policy reform will meet the health care needs of minority communities. Recognizing our country's history of health inequities and the need for systematic vigilance, oversight, and corrective action, ACMH proposed the development and establishment of a Federal Health Equity Commission, which would provide oversight and monitoring of health care reform implementation in a manner designed to eliminate health inequities for minority and vulnerable populations. ACMH's second 2009 report, A Federal Health Equity Commission will Promote the Public's Health and Ensure Health Equity in Health Care Reform: A Statement of Principles and Recommendations, which is in the clearance process, describes the ACMH's proposal for this Commission.

Next in its series of reports, ACMH focuses on an especially underserved and vulnerable population: minorities with disabilities. *By every measure, persons with disabilities disproportionately and inequitably experience morbidity and mortality associated with unmet health care needs in every sphere. Minorities with disabilities are doubly burdened by their minority status.* As health care reform proceeds, ACMH believes that the circumstances and needs of this population should be specifically addressed to ensure that the benefits of health care reform are available to all, which is the focus of the current report.

#### **Health Inequities for Persons with Disabilities**

On September 30, 2009, the National Council on Disability (NCD) issued *The Current State of Health Care for People with Disabilities*, a lengthy and extensively documented (i.e., 227 pages, 600 endnotes) report.<sup>3</sup> According to the U.S. Census Bureau, of the 291.1 million people in the U.S. population in 2005, 54.4 million (18.7%) had a disability, and 35.0 million (12.0%) had a severe disability (e.g., used a wheelchair, walker, or cane; were unable to or needed help to perform functional activities, activities of daily living (ADLs), or instrumental activities of daily living (IADLs); had a learning disability or other mental or emotional condition; or had any other mental, emotional, or physical condition that affected their everyday life).<sup>a</sup> Physical disabilities

<sup>&</sup>lt;sup>a</sup>In the American Community Survey, disability is measured by several concepts related to an individual's functional limitations and ability to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Functional activities include seeing, hearing, speaking, lifting, carrying, using stairs,

tend to be more common than are sensory or mental health disabilities. African Americans and Hispanics/Latinos typically experience disability at a higher rate than do Whites/Caucasians.<sup>4</sup> People with disabilities are a large and important group of health consumers in the United States. However, despite the demographic increase in the disability population and the implications for people with disabilities and the broader society, according to the Institute of Medicine, the federal government, legislators, and health care systems have yet to respond.<sup>5</sup>

According to the NCD report, people with disabilities have poorer health and use health care at a significantly higher rate than do people without disabilities. People with disabilities also experience a higher prevalence of secondary conditions (e.g., obesity) and use preventive services at a lower rate than do persons without disabilities. People with disabilities frequently lack health insurance or coverage for necessary services such as specialty care, long-term care, care coordination, prescription medications, durable medical equipment, and assistive technologies. Persons with disabilities often receive care from multiple providers without adequate coordination of services as well. Along with poorer health and higher use of health care, the NCD report documents that barriers to preventive services disproportionately affect people with disabilities: for example, persons with disabilities are less likely to receive counseling for smoking cessation than are persons without disabilities. Other barriers include health care provider stereotypes about disabilities; lack of appropriate provider training; and a lack of accessible medical facilities and examination equipment, sign language interpreters, and individualized accommodation. People with disabilities also experience inequitable treatment in health care settings, racial and ethnic disparities, limited access to health information, and exclusion from health-related research.6

Numerous prior reports have described the particular challenges to health and well-being faced by persons with disabilities. Asserting the principle that good health is necessary for people with disabilities to work, learn, and engage with their families and communities, these reports have placed the health of people with disabilities among the public health issues that should be at the forefront of health care policy research, financing of health care delivery, and training/education of health care providers.<sup>7</sup> The health and wellness of people with disabilities are public policy concerns that should drive the acquisition and use of new knowledge and technologies.

Specific examples of health disparities and unique problems in accessing health care services for people with disabilities include the following:<sup>8</sup>

- Women with disabilities have fewer Papanicolaou smears (Pap tests) and mammograms than
  do women without disabilities. Compared to women without disabilities, women with
  disabilities are less knowledgeable about and aware of risk factors for cardiovascular disease
  and are less likely to participate preventive screening.
- Adults who are deaf or hearing impaired are three times as likely to report fair or poor health
  as compared to those who do not have hearing impairments. American Sign Language (ASL)
  is the primary language for many people who are deaf; however, interpreters often are not
  provided during medical visits.

walking, or grasping small objects. ADLs include getting around inside the home, getting into or out of bed or a chair, bathing, dressing, eating, and toileting. IADLs include going outside the home, keeping track of money and bills, preparing meals, doing light housework, taking prescription medicines, using the telephone, and maintaining employment.

- Adults with developmental disabilities are at increased risk for hearing and vision difficulties, cardiovascular disease, obesity, seizures, mental health and behavioral problems, poor oral health, and poor general fitness. Young adults with developmental disabilities often have difficulty transitioning from coordinated childhood medical care to adult medical services because some providers are not trained to provide needed care and are not adequately reimbursed by insurance companies for care coordination.
- Compared to the general population, people with significant vision loss are more likely to have heart disease and hypertension, to be overweight or obese, and to smoke. Printed health care instructions, educational materials, and information such as directions for taking prescription medications are not always provided in formats accessible to the visually impaired. People with vision impairments often do not receive high-quality diabetes education.
- Persons with intellectual or developmental disabilities (ID or DD) experience disparities in oral health outcomes. According to the Surgeon General's Report on Oral Health in America (2000), oral health is a key factor in the quality of life and life expectancy of people with disabilities.<sup>9</sup>

Disparities in health and health care for people with disabilities often are influenced by social determinants such as education, income and poverty, and the local environment. Policy makers and the current administration have acknowledged the health disparities that people with disabilities experience and the critical need for health care reform to better address the needs of this population. The Patient Protection and Affordable Care Act includes language and/or specific provisions or amendments that:

- (1) prohibit discrimination against people with disabilities;
- (2) seek input from disability organizations on home- and community-based care and treatment:
- (3) collect state level data on community- and home-based care by type of disability; (4) expand state aging and disability centers and increase availability of community based care services:
- (5) reduce the incidence of preventable illness and disability;
- (6) engage Disability Resource Centers to improve access to and use of health risk assessments;
- (7) provide preventive services to reduce physical and mental disability and restore functioning;
- (8) evaluate community intervention programs for Medicaid populations designed to reduce disability;
- (9) develop a national health promotion strategy that includes a focus on disability;
- (10) identify standards for measurement of disability status and ensure collection of data on disability status for all federally funded health care of public health program, activity or survey:
- (11) assess access to care and treatment including the number of providers trained in serving this population;
- (12) increase the disability cultural competency of providers;
- (13) prohibit the practice of reducing the value of the life of persons with disabilities in determining cost effective health care; and
- (14) set standards for determining eligibility for Social Security benefits due to disability. 10

In addition, the health care reform bill calls for the creation of a committee to review and update the criteria and methodology for defining Medically Underserved Populations (MUP) and Primary Care Health Professions Shortage Areas. According to Section 5602, the Negotiated Rulemaking Committee will assess the availability and appropriateness of data used to determine the MUP designation, the impact of this methodology and the designation process on communities and providers, and the extent to which the current methodology accurately reflects barriers to access and care faced by certain populations<sup>11</sup>. This component of the legislation also represents a unique opportunity to facilitate dialogue regarding applying the MUP and Primary Care Health Professions Shortage Areas designations to individuals with disabilities, thereby increasing access to resources to address disparities within this population (M.H., personal communication, June 1, 2010).

#### Lack of Provider Competency in Disabilities as a Barrier to Care

The pervasive absence of professional training and the lack of disability competency and awareness among health care providers are among the most significant and fundamental barriers preventing people with disabilities from receiving quality health care.<sup>12</sup>

Without appropriate training and awareness, health care providers often hold incorrect assumptions and stereotypes about people with various disabilities—assumptions that may result in inadequate care. Research has revealed, for example, that some providers incorrectly assume that people with physical or developmental disabilities (1) do not have a good quality of life; (2) do not feel pain thus do not require anesthesia; (3) have cognitive deficits simply because they may not be fluent in standard English; and (4) do not require reproductive counseling and care because they are not sexually active. In addition to undermining quality of care, interactions that involve these assumptions can damage patient-provider trust and discourage people with disabilities from seeking care.<sup>13</sup>

The ACMH 2008 report *Reducing Health Disparities by Promoting Patient-Centered Culturally and Linguistically Sensitive/Competent Health Care* outlines the critical role that cultural competency can play in eliminating health inequities.<sup>14</sup> The report states that disability should be a basic and critical component of cultural competency training and education for health care providers.<sup>15,16</sup> The ACMH insists that cultural competency be understood as an overarching approach to access and service delivery that benefits all citizens. One objective of *Healthy People 2020* is that graduate students in public health receive training related to persons with disabilities.<sup>17</sup> It recommends that cultural competency that includes disability be required teaching and licensing components of curricula for all medical school and health professional training programs.

The consequences of the absence of disability competency among health care providers are dire. 

It is possible to become a board-certified physician without having hands-on experience with patients with disabilities. Furthermore, many physicians are reluctant, or aversive, to treating patients with complex disabilities, who may also be limited in their ability to communicate their health history or needs. 

As there is no clear line between where disability ends and medical conditions begin, physicians should be able to determine the extent to which a patient's condition is a component, consequence, or coincidence of his or her disability.

#### Minorities with Disabilities: Marginalized, Vulnerable, and Forgotten Populations

While there is a substantial need for increased public awareness about disabilities in general, there is a specific need for data regarding health disparities among minorities with disabilities. It is particularly important to raise awareness about the burden of disability and race/ethnicity vis-à-vis health disparities and inequities. Aside from the public health issues that most racial/ethnic minorities face, minorities with disabilities experience additional disparities in health, prejudice, discrimination, economic barriers, and difficulties accessing care as a result of their disability—in effect, they face a "double burden." For example, Blacks/African Americans with Down syndrome are more than seven times as likely as are Whites/Caucasians to die by age 20. The life expectancy for Whites/Caucasians with Down syndrome is about 55 years compared to 25 years for Blacks/African Americans. Further research is needed to explore health disparities in other racial/ethnic communities (e.g., Asian Americans and Pacific Islanders, Hispanics/Latinos, Native Americans /Alaskan Natives) and other minority groups within the disabled community (e.g., immigrants/refugees, women).

Similar to the concept of double burden, *simultaneous oppression* is defined as "areas in which the experiences of Blacks/African Americans with disabilities result in a distinct form of oppression that entails limited or no individuality and disability identity, resource discrimination, and isolation within the Black/African American community and family."<sup>23</sup> Resources typically are not allocated to devalued individuals. Simultaneous oppression adds "insult to injury" as a result of stereotyping, stigma, psychological discomfort, paternalism, and pity.<sup>24</sup> Whereas simultaneous oppression has often been associated with Blacks/African Americans in the literature, the idea can be applied to the experiences of other minorities with disabilities.<sup>25</sup>

Cultural perceptions of disabilities not only affect the type of treatment that a family seeks or receives but also interact with important and unaddressed aspects of cultural competency. Widespread discrimination against the disabled population, including minorities, has resulted in lack of appropriate health care. Disabilities are often misdiagnosed or overlooked among minority populations. The following examples highlight the intersection of health disparities, minority disability, access to care, and the need for more culturally competent services:

- In 2008, Minnesota public health officials launched a study to investigate autism among Somali children. Findings revealed that rates of Somali children ages three and four participating in autism disorder services through the public school system was significantly higher than were those of any other racial or ethnic group. Given the stigma surrounding autism in the Somali community and reported reluctance to accept the diagnosis of autism or seek care, it is possible that these findings underestimate the problem. Language barriers also present challenges for some Somali parents/families wanting to access services, whereas others opt to seek treatment from traditional healers.<sup>28</sup>
- In general, people who are deaf or hearing impaired face barriers in accessing high- quality care, including difficulty communicating with providers and accessing information. These barriers can lead to misdiagnosis, medical errors, and patient distrust and fear. Such challenges are exacerbated for individuals who are not fluent in English (e.g., immigrants and refugees) or use ASL.<sup>29</sup>

Testimony, presentations, and discussions at an ACMH meeting on January 5, 2010, highlighted several issues that are particularly important for minorities with disabilities: (1) challenges associated with being dually diagnosed (i.e., having a disability as well as a chronic disease); (2) the potential for and risks of polypharmacy<sup>b</sup>; (3) lack of provider expertise when children with disabilities are transitioning to adulthood; (4) lack of adequate behavioral services for persons with ID/DD; (5) lack of provider expertise with assistive technologies to ensure responsiveness to the evolving needs of persons with disabilities; and (6) inability/failure of health care providers to promote healthy behaviors, active living, and the value of wellness among persons with disabilities. Despite the abundance of recommendations, there are limited federal directed resources and collaborative leadership to implement these recommendations.<sup>30</sup>

#### Limited Data and Research on Health Inequities among People with Disabilities

People with disabilities experience significant health disparities compared with people who do not have disabilities, <sup>31</sup> and the consequences of disability vary across the life span. A study of the health status of athletes participating in the Special Olympics provides a clear-cut example: two-thirds of these individuals were overweight or obese; nearly one-half had untreated tooth decay or gait abnormalities; one-third was missing teeth; and one-quarter failed hearing tests.<sup>32</sup> Furthermore, it is critical to understand the unique needs and resources of children with special healthcare needs (i.e., children at increased risk for physical, developmental, behavioral, or emotional conditions who require services beyond that required by children generally)<sup>33</sup> and the impact of disabilities on the children and their families. Despite these disparities, people with disabilities are not included in major federal health disparities research. As a consequence, federally funded health disparities research does not recognize people with disabilities as a population that experiences disparities. This lack of recognition makes it extremely difficult to obtain population-based data related to minorities and disabilities.<sup>34</sup>

Federal policy does not identify people with disabilities or subgroups of people with disabilities, as MUPs.<sup>35</sup> As a result, medical students and residents who are interested in working with these populations are not eligible for federal loan repayment programs. In addition, incentives for research and database development are not readily available.

The NCD report finds that federally conducted or supported disability and health research is poorly integrated into overall health disparities and health promotion research. Two specific structural problems impede the development of a unified, coherent plan for disability and health research and program development: (1) the level of funding is inadequate to establish a clear research strategy that will inform policy and planning; and (2) disability health disparities and health promotion research at the federal level is weak and uncoordinated.<sup>36</sup>

#### Minorities with Disabilities: Conclusions and Recommendations

The ACMH recognizes and understands the consequences of federal and state policymakers as well as other public officials' limited awareness of vulnerable and marginalized population of minorities with disabilities. The charge of the ACMH is to improve the health of racial and ethnic minority populations and raise awareness about issues affecting persons within its constituent communities, who are vulnerable and underserved.<sup>37</sup> To address and overcome the lack of data, knowledge, and culturally competent care specific to minorities with disabilities, the ACMH recommends the following:

July 2011 ACMH Report 12

<sup>&</sup>lt;sup>b</sup> If a person is taking several medications, the risk for drug interactions and side effects increases.

#### 1. Raise awareness about minorities with disabilities.

Multiple strategies should be implemented at the federal, state, and local levels to raise awareness of the health inequities that persons with disabilities experience, especially minorities. The Department of Health and Human Services' (DHHS) Office of Minority Health (OMH) and the Department's Office on Disability (OD) should collaborate to leverage resources for this campaign. DHHS OMH and DHHS OD should widely communicate their support for the NCD 2009 report, *The Current State of Health Care for People with Disabilities,* and use this report to raise awareness about the needs of minorities with disabilities. Furthermore, it is important for agencies to collaborate to develop and operate a platform for the exchange of promising or best practices to eliminate health disparities.

Increased funding is needed to develop strategies that would engage minority communities by providing education on disabilities and resources for advocacy (e.g., providing all families with tools and knowledge that empower them to advocate on behalf of their relatives with disabilities). Strengthening funding and leadership roles of federal groups such as the Interagency Committee on Disability Research (ICDR) of the National Institute on Disability and Rehabilitation Research, as well as funding research on minorities with disabilities that emphasizes a patient-centered approach could further this mission.

#### 2. Recognize disability as a fundamental component of cultural competency.

Health disparities within the disabled community have been attributed in part to a lack of cultural competency among providers. Consideration of culturally specific differences among people with disabilities, and among subgroups of that population, is essential to the provision of effective care and treatment. The lack of understanding of, or limited sensitivity to, the experiences, beliefs, values, and practices of persons with disabilities can have a profound impact on their access to quality care. An individual's cultural identity as both a disabled person and a minority can influence self-perceptions of health and care-seeking behaviors. Providers' misperceptions of patients with disabilities can have a negative impact their ability to provide culturally sensitive and appropriate care. Therefore, in accordance with mandates of health care reform, disability should be considered a fundamental component of cultural competency education for health professionals. Failure to include disability in cultural competency education can result in poor patient-provider communication, mistrust of the provider, inappropriate treatment, and reluctance to seek care.

#### 3. Require competency for all health care providers and professionals.

The Association of American Medical Colleges and the Liaison Committee on Medical Education should establish specific disability competencies required of health care professionals before graduation from medical and residency training programs. They should translate these competencies into specific course recommendations that physician, nursing, pharmacy, and other health profession training programs can adopt.

Disability competency should be a core curriculum component or licensing requirement for (1) accreditation or receipt of federal funding for most medical and dental schools and other professional health care training institutions, (2) hospital participation in federally funded medical student internship and residency programs, (3) applicants who seek a medical or another health care professional license or certification, and (4) continuing education programs. Cultural and linguistic competency training should include mechanisms to address provider challenges such as bias or low expectations and to implement best practices into policy to ensure access to quality healthcare services. Such requirements would ensure that health profession institutions are properly equipped to train future health professionals and health organizations and institutions have protocols in place to provide care and services to patients with disabilities. Teaching, research, and practice organizations should collaborate to develop cultural competency practice guidelines that account for the range of disabilities and diversity of ethnicities.

#### 4. Improve research and practice on disabilities in minority populations.

Congress should increase funding for the ICDR of the National Institute on Disability and Rehabilitation Research to (1) vest it with sufficient resources and authority to fulfill its mandated research coordination role and (2) expand its role to include collaboration with other agencies such as the Centers for Disease Control and Prevention (CDC), the Agency for Healthcare Research and Quality (AHRQ), and DHHS OD, to identify areas for joint health and health disparities research. More funding should be allocated for improved data collection design to support data-based reporting and analyses on inequities regarding morbidity and mortality among minorities with disabilities. For instance, federal support can help states, counties, and cities collect local health data and connect their data to other public databases.

DHHS OMH and OD should review and synthesize the above-referenced major reports on minorities with disabilities and the health disparities and inequities they experience. DHHS OMH and OD should provide leadership by highlighting the need for action based on the recommendations from these reports. This work also will provide DHHS OMH and OD leaders an opportunity to advocate for increased funding for (1) research focused on disabilities in minority populations, and (2) improved data collection on minorities with disabilities throughout relevant federal agencies.

The Federal Collaboration on Health Disparities Research (FCHDR), a collaboration of federal agencies working to find solutions to eliminate health disparities through research, began operations in 2006 to explore, coordinate, and support innovative health disparities research and identify priorities for cross-agency collaboration. Because the research on health and health disparities that government agencies conduct is not coordinated, it is unclear how much research is currently aimed at addressing health disparities and promoting health and wellness for the people with disabilities. ACMH urges continued FCHDR leadership with strong support from DHHS OMH and OD to (1), synthesize and coordinate federal data collection and research; (2) identify or create opportunities for joint health and healthcare disparities research, particularly on minorities with disabilities; (3) promote community based participatory research to strengthen the impact of healthcare delivery systems on healthcare disparities, and (4) support research evaluating the implementation of evidence-based clinical practices.

## 5. Strengthen the health care workforce to ensure high quality care for people with disabilities.

ACMH urges HRSA, the Centers for Medicare & Medicaid Services (CMS), and other agencies with influence on health care providers to examine strategies that ensure a workforce that provides appropriate, high quality, culturally competent care for people with disabilities. These strategies may include, but are not limited to, applying a Health Professional Shortage Area (HPSA) designation based upon the availability of providers for the disabled population, especially minorities with disabilities. Such a designation would enable physicians, physician assistants, advanced practice nurses, and dentists who choose to provide health care services for a significant number of patients with disabilities to be eligible for the National Health Service Corps (NHSC). The NHSC provides loan repayment in exchange for a service commitment to designated underserved populations. HRSA and other agencies such as CMS and DHHS OD should identify and implement strategies that will encourage providers to serve the people with disabilities.

#### **Concluding Comments**

As people with disabilities and people of racial/ethnic minority status face health and healthcare disparities that put them at disadvantage in their quality of life compared to their counterparts, the health and wellness of these populations are public policy concerns that warrant increased attention and action. It is particularly important to raise awareness about the dual burden of inequities that minorities with disabilities face. To improve knowledge, understanding, and care for people with disabilities in general and minorities with disabilities in particular, increased federal support and resources are needed to raise awareness; improve research, practice, and data; and prepare the health care workforce to provide equitable and quality care. Addressing the aforementioned issues and recommended strategies will further movement toward health equity for vulnerable populations and ultimately all people.

#### **Endnotes**

<sup>&</sup>lt;sup>1</sup> US Department of Health and Human Services Advisory Committee on Minority Health. Ensuring that Health Care Reform Will Meet the Health Care Needs of Minority Communities and Eliminate Health Disparities. A Statement of Principles and Recommendations. July 2009. Available at <a href="http://minorityhealth.hhs.gov/Assets/pdf/Checked/1/ACMH">http://minorityhealth.hhs.gov/Assets/pdf/Checked/1/ACMH</a> HealthcareAccessReport.pdf

<sup>&</sup>lt;sup>2</sup> US Department of Health and Human Services Advisory Committee on Minority Health. A Federal Health Equity Commission Will Promote the Public's Health and Ensure Health Equity in Health Care Reform. A Statement of Principles and Recommendations. Submitted to US DHHS OMH, Washington, DC, December 2009.

<sup>&</sup>lt;sup>3</sup> National Council on Disability. *The Current State of Health Care for People with Disabilities*. September 30, 2009. Available at <a href="http://www.ncd.gov/publications/2009/Sept302009">http://www.ncd.gov/publications/2009/Sept302009</a>

<sup>&</sup>lt;sup>4</sup> Ibid., Note 3.

<sup>&</sup>lt;sup>5</sup> Institute of Medicine. *The Future of Disability in America* (Washington, DC: National Academies Press, 2007); Institute of Medicine. *Disability in America: Toward a National Agenda for Prevention* (Washington, DC: National Academies Press, 1991); Surgeon General of the United States. *Call to Action to Improve the Health and Wellness of People with Disabilities* (Washington, DC: Government Printing Office, 2005); DHHS Office on Disability. *Breaking Down Barriers to Health Care for Women with Disabilities: A White Paper from a National Summit* (Washington, DC: Department of Health and Human Services, Office of Women's Health, 2004).

<sup>&</sup>lt;sup>6</sup> Ibid., Note 3

<sup>&</sup>lt;sup>7</sup> National Council on Disability. Meeting the Unique Needs of Minorities with Disabilities: A Report to the President and the Congress, April 26, 1993; DHHS Office of Minority Health. Improving the Quality of Life for Minorities with Disabilities, Closing the Gap, October/November 1999; DHHS Office of Minority Health. Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation, 2002; US Department of Health and Human Services, *Report of the Surgeon General's Conference on Health Disparities and Mental Retardation*, US Department of Health and Human Services, 2002; First National Child Health and Child Welfare Conference. *Closing the* Disparity Gap for Racial and Ethnic Minority Children: An Investment in Our Future, October 2004; Advisory Committee on Training in Primary Care Medicine and Dentistry. 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, November 2005.

<sup>&</sup>lt;sup>8</sup> Ibid., Note 3.

<sup>&</sup>lt;sup>9</sup> Surgeon General of the United States. *Oral Health in America: A Report of the Surgeon General.* May 2000 (Washington, DC: US Department of Health and Human Services); Discussion and presentations at ACMH Meeting January 5-6, 2010.

<sup>&</sup>lt;sup>10</sup> Surgeon General of the United States. *Oral Health in America: A Report of the Surgeon General.* May 2000 (Washington, DC: US Department of Health and Human Services); Discussion and presentations at ACMH Meeting January 5-6, 2010.

<sup>&</sup>lt;sup>11</sup> Ibid, Note 10

<sup>&</sup>lt;sup>12</sup> Ibid., Note 3.

<sup>&</sup>lt;sup>13</sup> Ibid., Note 3.

<sup>&</sup>lt;sup>14</sup> US Department of Health and Human Services Advisory Committee on Minority Health. *Reducing Health Disparities by Promoting Patient-Centered Culturally and Linguistically Sensitive/Competent Health Care*, submitted to US DHHS OMH, Washington, DC, September 8, 2008.

<sup>&</sup>lt;sup>15</sup> Lewis, Allen. Disability disparities: A beginning model. (2009). *Disability & Rehabilitation* 31(14):1136-1143. Available at <a href="http://www.ingentaconnect.com/content/apl/tids/2009/0000031/00000014/art00004">http://www.ingentaconnect.com/content/apl/tids/2009/00000031/00000014/art00004</a>.

<sup>&</sup>lt;sup>16</sup> Eddey, G.E, and K.L. Robey. (2005). Considering the culture of disability in cultural competence education. Academic Medicine 80(7):706-712.

<sup>&</sup>lt;sup>17</sup> U.S. Department of Health and Human Services. Healthy People 2020 Public Meetings: 2009 Draft Objectives. Available at: http://www.healthypeople.gov/HP2020/Objectives/files/Draft2009Objectives.pdf, Accessed 5/6/10.

<sup>&</sup>lt;sup>18</sup> Ibid. Note 3

<sup>&</sup>lt;sup>19</sup> Ibid., Note 3.

Rader, Rick. "Add This to the Pile: The Simultaneous Oppression of Minorities with Disabilities Seeking Health July 2011 ACMH Report

Care Justice." Presentation to the Advisory Committee on Minority Health, January 5, 2010. <sup>21</sup> Ibid., Note 20. <sup>22</sup> Ibid., Note 20. <sup>23</sup> Ibid., Note 20. <sup>24</sup> Ibid., Note 20. <sup>25</sup> Vernon, Ayesha. (1997). Fighting two different battles: Unity is preferable to enmity. In L. Barton & M. Oliver (Eds.), Disability studies: Past, present, and future (pp. 255-262). Leeds: The Disability Press. <sup>26</sup> Corbin, Stephen B. "To Live Well with a Disability – A Report Card of 'Ds' Won't Pass." Presentation to the Advisory Committee on Minority Health, January 5, 2010. <sup>27</sup> Ibid., Note 20. <sup>28</sup> Minnesota Department of Health. March 2009. Autism Spectrum Disorders among Preschool Children Participating in the Minneapolis Public Schools Early Childhood Special Education Programs. St. Paul, MN. <sup>29</sup> lezzoni, L., B.L. O'Day, M. Kileen, and H. Harker (2004). Communicating about health care: Observations from persons who are deaf or hard of hearing. *Annals of Internal Medicine* 140:356-362. <sup>30</sup> Correa-de-Araujo, Rosaly. "US DHHS Office on Disabilities Overview." Presentation to Advisory Committee on Minority Health, January 5, 2010. <sup>31</sup> Ibid., Note 3. NCD urges that Congress amend the Minority Health and Health Disparities Research and Education Act of 2000 to broaden the definition of "health disparity population" found in 42 U.S.C. § 287c-31(d) to encompass "populations for which there is a significant disparity in the quality, outcomes, cost, or use of health care services or access to or satisfaction with such services as compared to the general population," as specified in 42 U.S.C. § 299a-1(d). This would enable people with disabilities to be included in the health and health care disparities research, program development, professional training, health promotion, and clinical interventions conducted and supported by the National Center on Minority Health and Health Disparities, as well as by other federal agencies engaged in health disparities research and activities on behalf of racial and ethnic minorities and other geographic and population groups. <sup>32</sup> Ibid., Note 20. <sup>33</sup> McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102(1, pt 1):137-140. <sup>34</sup> Ibid., Note 14. <sup>35</sup> Ibid., Note 20. <sup>36</sup> Ibid., Note 3. <sup>37</sup> Ibid., Note 8. <sup>38</sup> Ibid., Note 14.

**ACMH Report** 

17

<sup>39</sup> Ibid., Note 14 July 2011