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Improving Health and Access to Health Care for People with Disabilities

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According to the US Census Bureau, in 2005, 54.4 million people (18.7 percent) in the US non-institutionalized population had some level of disability, and 35.0 million (12.0 percent) had a severe disability.¹ Rates of disability also increase with age, and by 2030, the number of people aged 65 years and older will likely rise to 69.4 million, up from 34.7 million in 2000. The Institute of Medicine and other research bodies have observed that people with disabilities comprise the largest and most important health care consumer group in the United States, yet the health care system has failed to respond to their current and growing needs.²

The current Congressional efforts to reform health care afford a unique opportunity to incorporate policies that will begin to address the most pressing issues for people with disabilities related to health disparities and access to health care. Our recommendations are provided against this backdrop and focus specifically on:

- Enhancing implementation of federal disability rights laws as they relate to health care systems, facilities, services, and programs, including disease prevention, health promotion, and cultural competency
- Improving data collection on the health and health care experiences of people with disabilities in order to develop appropriate responses to widespread health disparities among this population

Background

For people with disabilities, access to health care includes critical dimensions in addition to health care insurance and payment for services. While coverage is one fundamental component of access, another dimension has to do with barriers people with disabilities encounter when they seek health care services and the capacity of health care systems to ensure accessibility and provide accommodations that constitute essential elements of culturally competent care. Research suggests that problems such as poor architectural accessibility, lack of accessible examination equipment, limited accommodations, and poor cultural competency deter some people from seeking services and can result in inadequate and ineffective care that undermines health and even endangers lives. The following examples illustrate some of the problems people with disabilities encounter when they seek health care:

- A woman who uses a wheelchair was having trouble breathing. She needed an echocardiogram, which was performed while she sat in her wheelchair [rather than lying in the supine position—the standard of care for this test]. As a result, the echocardiogram was of poor technical quality and yielded little information.³

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- A woman who is deaf needed a tonsillectomy. Although she was frightened, she went to the hospital anyway. She recounts her experience: “I was sedated and anesthetized, and I woke up afterwards, scared and crying. I didn’t know what to expect or what was going on with the swelling. There was no [Sign Language] Interpreter there.”⁴
- While diabetes is the leading cause of vision loss, some diabetes educators recommend that patients who have vision impairments, rather than learn self-care for their diabetes, should get help from a sighted person. Furthermore, research suggests that health care providers are generally unaware of speech-output devices that enable people who have vision impairments to measure their blood sugar and blood pressure independently.⁵
- A man with a spinal cord injury who used a wheelchair developed serious pressure ulcers because his health care provider did not have a height-adjustable exam table and refused to assist him on to the standard-height table where he could have received a thorough examination. Because of the lack of early detection and treatment, his condition required surgery and a lengthy hospital stay.⁶
- A nurse for a woman with developmental disabilities who had difficulty undergoing gynecological exams reported that the woman’s doctor downplayed the importance of such exams for the woman, ostensibly because the doctor assumed she was not sexually active.⁷

Federal Disability Rights Laws and Health Care

Federal programs including Medicare, Medicaid, SCHIP, and Title V of the Social Security Act that provide health care and prevention services for people with disabilities serve as a critically important health safety net. However, little attention has been given to the role that federal agencies overseeing these programs—such as the Department of Health and Human Services (HHS), the Centers for Medicare and Medicaid Services (CMS), and the Health Resources Services Administration (HRSA)—should be playing to ensure that the federally supported health care is provided by culturally competent providers, that facilities are accessible, and that providers have the capacity to provide appropriate accommodations when they are required.

Section 504 of the 1973 Rehabilitation Act prohibits discrimination on the basis of disability by recipients of federal financial assistance. The law also requires recipients to evaluate their programs and services to ensure that people with disabilities have adequate access and receive appropriate accommodations so they can participate in and benefit from the program or service. Yet the largest federal programs that either provide health insurance or pay for health care services for people with disabilities through transfer of funds to the states have done little to ensure that states, managed care organizations, health plans, and health care providers take steps to ensure that health care facilities, programs, and services are architecturally and programmatically accessible.

Federal health care agencies do not require that states, managed care organizations, health plans, and health care providers establish mechanisms to collect information that would reveal the

extent of Section 504 compliance throughout the systems that provide care. Furthermore, in the absence of such federal requirements as a condition of receiving funds, states simply pass on their obligation to ensure architectural and programmatic accessibility in contracts with HMOs, health plans, and health provider organizations. In turn, these organizations pass on the same obligations to the health providers with whom they contract for services. Nowhere along this funding and administrative chain is a recipient of federal funds required to report to the funding entity on the extent of accessibility of health provider facilities or the managed care organization (MCO), health plan, or provider capacity to accommodate patients with disabilities. Without such a monitoring mechanism, each recipient of federal funds along the chain not only may be unaware of what is required, they may also have little motivation to take steps to ensure that they or the providers with whom they contract are taking appropriate steps to remove barriers and provide accommodations.⁸

Dual Components of Health Care Access: Implications for People with Disabilities

For some people with disabilities, the dual components of health care access—affordable and adequate insurance coverage and benefits, and health care facility and programmatic accessibility—are inextricably entwined. Yet weak federal oversight of physical and programmatic accessibility has received little public attention and does not appear to be a priority of any federal agency that has a substantial role in researching, assessing, or directly providing health care.⁹ Therefore, we recommend that:

- Congress direct the Department of Health and Human Services to identify disability performance standards that must be included as a condition of receiving federal financial assistance. Standards are needed to ensure that states, health plans, managed care organizations, and health care providers who receive federal health care funds ensure that health facilities and services are architecturally and programmatically accessible for people with disabilities, and that they meet the minimum requirements of Section 504 and any applicable provisions of the Americans with Disabilities Act (ADA).

Language Access

Hearing impairment is the sixth most common chronic condition in the civilian population.¹⁰ Among adults in the US who are over age 18, research suggests that about 3.3 percent experience deafness or have significant difficulty hearing.¹¹ Members of the deaf community who use American Sign Language (ASL) as their primary language belong to a distinct linguistic and cultural group that is entitled to the same recognition that society affords to other groups with distinct languages and cultures. ASL is recognized as a distinct language with its own grammar and syntax that is separate from English. Yet Deaf people report problems communicating with health care personnel because ASL interpreters are often not provided. The availability of Sign Language Interpreters is especially important in the health care context to ensure effective communication, as is availability of interpreters for other languages. Therefore, we recommend that:

- Congress direct the Centers for Medicare and Medicaid Services (CMS) to pay for American Sign Language Interpreters (ASL) when they are required in order to ensure that people who are deaf or hard-of-hearing and whose primary language is Sign Language receive effective care from federally funded health care services.
- Congress direct HHS to amend the standards for delivery of culturally and linguistically appropriate health care services (CLAS) issued by the HHS Office of Minority Health to include ASL Interpreters, and to require any proposals that would extend the 75 percent matching rate for translation services to all Medicaid beneficiaries for whom English is not the primary language to explicitly include such coverage for ASL Interpreters.
 - CLAS standards for private insurers in Congressional proposals to establish a Health Insurance Exchange should also explicitly include ASL Interpreters and should require that insurers who participate in the Exchange pay for ASL Interpreters as a necessary cost of providing effective medical care for people who are deaf or hard-of-hearing.
 - Any grants established for outreach and enrollment efforts, multi-lingual help lines, and data collection efforts should recognize and include the specific communication requirements of people who are deaf, and include provision of Sign Language Interpreters when they are required for effective communication.

Access to Disease Prevention and Health Promotion Programs and Services

Recent research has shown that people with disabilities participate less in prevention programs than those without disabilities.¹² But lack of participation is not solely a matter of personal choice or preference. It also stems from barriers that include lack of provider training and awareness; limited information about methods to accommodate people with various disabilities and facilitate their participation; and architectural, policy, and other barriers that must be removed through proactive efforts by health care provider organizations.

Other recognized barriers to participation by people with disabilities in certain prevention programs include policies such as mandatory exercise required as part of a weight loss program that result in exclusion of people with specific disabilities; fitness and exercise equipment that is inaccessible to people with mobility impairments or that does not provide tactile markings or speech output devices on the control panels for people who are blind or have vision impairments; and lack of effective communication, including availability of Sign Language Interpreters for people who are deaf or hard-of-hearing, during patient education and other related classes. Consequently, legislation addressing disease prevention and health promotion for the general population must include mechanisms to ensure that people with disabilities are included. Therefore, we recommend that:

- Any legislation that establishes incentives for Medicare or Medicaid beneficiaries who participate in prevention programs must include a directive from the Secretary of the Department of Health and Human Services (HHS) to states and health plans that

discriminatory policies must be changed and physical accessibility and programmatic accommodations must be provided for individuals with disabilities who need them. Such steps are required to ensure that they have an equal opportunity to participate in the programs that will qualify them for refunds or other incentives.

- Any national commission or advisory board focusing on public health, wellness, prevention, early intervention, and health system reform must include individuals with expertise in health, disability, and chronic conditions.
- Congress ensure that programs and funding are adequate to develop effective curricula, provide technical assistance, and ensure adequate training of health care providers, especially related to disability awareness and the specific knowledge necessary to treat individuals with disabilities.

Health Disparities and Data Collection

The US Surgeon General's report, "Call to Action to Improve the Health and Wellness of Persons with Disabilities," and Focus Area 6 of *Healthy People 2010* both define disability as a demographic characteristic for the first time in the language of public health. Yet federal health research remains focused on disability and disease prevention rather than on improving access to, and the quality of, health care for people with disabilities.

Federal research agencies collect a broad range of data to measure disparities in the quality of and access to health care for racial and ethnic groups, yet even when sponsoring agency surveys contain questions to identify disabilities, there is no regular reporting on topics such as access to care and health disparities for people with disabilities. To remedy this information gap, we recommend that:

- Congress direct federal agencies responsible for conducting population surveys not only to collect data on people with disabilities sufficient to generate statistically reliable estimates in studies comparing health disparities populations, but also produce regular reports that use the data.
- Congress direct the US Social Security Administration (SSA) to include the capability to collect disability data on Medicare enrollees along with data on race, ethnicity, and language as upgrades are made to the agency's computer data collection system. This information is essential so that researchers can have access to data at a scale that enables them to investigate the reasons for health disparities experienced by people with disabilities and produce meaningful results that will establish a rationale for policies that address the problems.

¹ M. Brault, “Americans with Disabilities: 2005,” *Current Population Reports* (Washington, DC: US Census Bureau, 2008).

² Institute of Medicine, *The Future of Disability in America*, Ch. 10, <http://books.nap.edu/openbook.php?record_id=11898&page=310>.

³ K. L. Kirschner, M. L. Breslin, and L. I. Iezzoni, “Structural Impairments that Limit Access to Health Care for Patients with Disabilities,” *Journal of the American Medical Association* 297 (2007), pp. 1121-1125.

⁴ M. L. Drainoni et al., “Cross-Disability Experiences of Barriers of Health-Care Access,” *Journal of Disability Policy Studies* 17, no. 2 (2006).

⁵ T. Duncan and D. Burton, “Diabetes Management and Visual Impairment: Are People Aware of Accessible Home Blood Pressure Monitors?,” *Access World* 6, no. 1 (January 2005).

⁶ J. Panko Reis, M.L. Breslin, L. I. Iezzoni, and K. Kirscher, *It Takes More than Ramps to Solve the Healthcare Crisis for People with Disabilities* (Chicago: Rehabilitation Institute of Chicago, 2004).

⁷ Drainoni et al., “Cross-Disability Experiences of Barriers of Health-Care Access.”

⁸ S. Yee, Position Paper on Medicaid Healthcare Accessibility for People with Disabilities, Disability Rights Education and Defense Fund, Berkeley, California, 2006.

⁹ Recognizing the role states should play in ensuring that managed care organizations can serve people with disabilities, the Center for Disability Issues in the Health Professions, the Center for Health Care Strategies, and the Lewin Group convened stakeholder and other groups in 2005 to develop “Performance Standards for Medi-Cal Managed Care Organizations Serving People with Disabilities and Chronic Conditions.” The “Medi-Cal Health Plan Readiness Assessment Tool,” released in 2008, reflects the recommendations of the 2005 California HealthCare Foundation report and helps determine whether a plan is prepared to enroll and serve additional beneficiaries with disabilities. See <<http://www.chcf.org/topics/medi-cal/index.cfm?itemID=113558>>.

¹⁰ S. Barnett and P. Franks, “Healthcare Utilization and Adults Who Are Deaf: Relationship with Age at Onset of Deafness,” *Health Services Research* 37, no. 1 (2002).

¹¹ C.A. Schoenborn and K. Heyman, *Health Disparities among Adults with Hearing Loss in the United States, 2000-2006*, (Hyattsville, MD: National Center for Health Statistics, 2008).

¹² B. Altman and A. Bernstein, *Disability and Health in the United States, 2001–2005* (Hyattsville, MD: National Center for Health Statistics, 2008).