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May 22, 2009

The Honorable Senator Max S. Baucus  
Chairman, Senate Finance Committee  
511 Hart Senate Office Building  
Washington, DC 20510

The Honorable Senator Chuck Grassley  
Ranking Member, Senate Finance Committee  
135 Hart Senate Office Building  
Washington, DC 20510

Comments in response to “Description of Policy Options, Expanding Health Care Coverage: Proposals to Provide Affordable Coverage to All Americans,” Senate Finance Committee, May 14, 2009

Dear Chairman Baucus and Ranking Member Grassley:

The Disability Rights Education and Defense Fund wishes to commend you and the Members of the Senate Finance Committee for setting forth a variety of policy options in the May 14, 2009 document, referenced above, intended to address some of the most intransigent health and health care issues facing the nation. We appreciate the recommendations regarding individual and small group market reform, which will improve health care affordability regardless of health status, and policy options regarding Medicaid that would move toward eliminating the institutional bias and providing greater support for home and community-based services. We also support the proposed option to establish uniform categories for collecting data on access and treatment for people with disabilities, where they receive primary care, the number of providers with accessible facilities and equipment, and inclusion of provisions to collect data on patients with disabilities by type of disability in quality reporting requirements.

However, other policy options presented in the document either omit or do not adequately address a variety of health and health care concerns of people with disabilities. Many critical issues, including the need for additional reforms to address the long-standing and unmet need for long-term care services and supports, will be addressed in detail by others. Therefore, we focus on specific benefit options, the Medicare waiting period, prevention incentives, data collection, and language access. We respectfully urge you to adopt the recommendations set out here as the health care reform process moves forward.

According to the US Census Bureau, in 2005, 54.4 million (18.7 %) people in the U.S. non-institutionalized population had some level of disability and 35.0 million (12.0 %) had a severe disability. 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 from 34.7 million in 2000. The Institute of Medicine and others 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. Our recommendations are provided against this backdrop.

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## **SECTION II: MAKING COVERAGE AFFORDABLE**

### **Benefit Options – Recommendation**

We strongly urge you to specifically include physical medicine and rehabilitation therapies and related services, vision rehabilitation, prosthetics, orthotics, assistive devices including hearing and vision aids, and other durable medical equipment (DME) to the list of benefits required under coverage for non-group and small group markets. Furthermore, these items and services should also be included in the categories of benefits to which parity for cost-sharing is applied.

Whether one is born with or acquires a health condition later in life, there are many reasons why someone might need any of these items or services to help maintain or regain basic functions such as breathing, hearing the spoken word, using the bathroom, getting around, accessing print information, or learning to function at home or in the community. When we pay health insurance premiums, we expect that if we or our children need vision rehabilitation, acute inpatient or outpatient physical rehabilitation and related services, and such items as crutches, oxygen devices, wheelchairs, braces, artificial limbs, blood glucose monitors, hospital beds, hearing aids, walkers, and other assistive and medical equipment, our insurance will provide coverage for them.

However, certain rehabilitation services, devices, and technologies are not covered at all by current health plans. Furthermore, items that have been covered historically are increasingly subject to sometimes insurmountable benefit limits. For example, up to 90 % of California's private group health insurance plans now have annual DME benefit limits of around \$2,000, and the coverage cannot be carried forward from one year to the next. This coverage is wholly inadequate to pay for items such as motorized wheelchairs, or a combination of equipment and devices that might be required in a given year. Research supports that such restrictions create significant hardships for people with disabilities who rely on private health coverage. A 2003 national survey revealed that many working-age adults with disabilities have serious problems paying for needed equipment, and close to half reported going without necessary equipment because of cost.<sup>1</sup> Rehabilitation services, equipment, and devices are as essential for the health of people with disabilities as are open heart surgery, cancer care, and immunizations for everyone.

### **Medicare Coverage: Reduce or Phase-Out the Medicare Disability Waiting Period – Recommendation**

We strongly urge you to lift the 24-month Medicare eligibility waiting period immediately or, at a minimum, to ensure that people with disabilities who are eligible for Medicare under the Social Security Disability Insurance program have access to equivalent coverage at the same cost as Medicare during any waiting period that remains in force. The waiting period has been demonstrated to pose a significant hardship for people who have not yet reached retirement age and who find themselves with significantly reduced income along with the added burden of paying high-cost health insurance premiums. Many go without coverage because of cost, or are unable to acquire coverage because of pre-existing conditions. Expediting Medicare coverage or assuring coverage at the same cost as Medicare during the transition period are the only fair and equitable solutions to a problem that has been well known for many years.

### **Incentives to Utilize Preventive Services and Engage in Healthy Behaviors – Recommendation**

Recent research has shown that people with disabilities participate less in prevention programs than those without disabilities.<sup>2</sup> 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.

Consequently, legislation addressing disease prevention and health promotion for the general population must include mechanisms to ensure that people with disabilities are included. For example, 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 should ensure that programs and funding are sufficient 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.

Other recognized barriers to participation in certain prevention programs by people with disabilities include inaccessible facilities; policies such as mandatory exercise that is 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.

Therefore, any legislation that establishes refunds or 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 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.

## **SECTION VIII: OPTIONS TO ADDRESS HEALTH DISPARITIES**

### **Required Collection of Data – Recommendation**

Upgrades to the US Social Security Administration (SSA) computer collection system should include the capability to collect disability data on Medicare enrollees along with data on race, ethnicity, and language. 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 — the pool of potential Medicare data therefore represents an invaluable resource. Moreover, SSA computer upgrades should include the capacity to generate print information in accessible formats for SSA beneficiaries with vision impairments or who have other print access disabilities.

### **Data Collection Methods – Recommendation**

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, federally funded population surveys must not only collect sufficient data on people with disabilities to generate statistically reliable estimates in studies comparing health disparities populations, but also produce regular reports that use the data.

### **Standardized Categories for Data**

Current Proposed Option: *“Additionally, this proposal would require the collection of access and treatment data for people with disabilities. The Centers for Medicare and Medicaid Services (CMS) would be required to determine where people with disabilities access primary care and the number of providers with accessible facilities and equipment to meet the needs of the disabled. Access to intensive care units would also be evaluated. Quality reporting requirements would include provisions to collect data on patients with disabilities by type of disability.”*

### **Data Categories Recommendation**

We applaud the above recommendation as an essential and long-overdue first step in collecting information that, for the first time in federal research, will reveal the extent to which physical and programmatic barriers exist that deter or prevent people with disabilities from accessing health care facilities and services. In light of the fact that the 1990 Americans with Disabilities Act (ADA) calls for methods for effective communication, auxiliary aids and services, and modification of policies and practices<sup>3</sup> to ensure that people with disabilities have access to health care services, we urge the Committee also to call for the acquisition of information about the frequency with which health care providers make available Sign Language Interpreters when they are required for effective communication with people who are deaf or hard-of hearing. Data should also be collected to determine the extent to which health care providers make available print materials such as health care instructions and educational materials in alternative, accessible formats for people who are blind or have vision impairments. Other methods for ensuring access to health care, such as extended visit times that people with intellectual and developmental disabilities might require, should also be measured.

### **Public Reporting, Transparency, and Education – Recommendation**

As required by statute, the Center for Medicare and Medicaid Services (CMS) must report on its website individual hospital performance on specific quality measures and on certain conditions. However, not only is this information not stratified by race, ethnicity, or gender, it is also not available according to disability status. Health care quality data should be published by race, ethnicity, and gender, and also by disability status, to the extent that it is available. Those who participated in various recent qualitative studies report a wide range of experiences with hospital care. They run the gamut from insensitive and inappropriate remarks about a disabling condition, to stereotypes about disability and the absence of accommodations, to egregious failures to provide culturally and medically competent care.<sup>4</sup> Collecting such data is particularly important because quantitative data is needed to understand more about the hospital experiences of people with disabilities, and the reasons that underlie problems related to care.

### **Language Access – Recommendation**

Hearing impairment is the sixth most common chronic condition in the civilian population.<sup>5</sup> Among adults in the US who are over age 18, research suggests that about 3.3 percent experience deafness or have significant difficulty hearing.<sup>6</sup> Members of the deaf community who use American Sign Language (ASL) as their primary language belong to a distinct linguistic and cultural group who are 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, yet ASL Interpreters are not explicitly included in standards for delivery of culturally and linguistically appropriate health care services (CLAS) issued by the HHS Office of Minority Health.

HHS should amend the CLAS standards to include ASL Interpreters, and the proposal to extend the 75 percent matching rate for translation services to all Medicaid beneficiaries for whom English is not the primary language should explicitly include such coverage for ASL Interpreters. CLAS standards for private insurers in the 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.

Thank you for the opportunity to provide this information.

Best regards,



Susan Henderson  
Executive Director

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<sup>1</sup> The Kaiser Family Foundation sponsored a 2003 national survey of adults with disabilities aged 18-64, and 21% of those who use equipment reported having serious difficulties paying for the equipment, while 46% reported going without necessary equipment and eyeglasses because of cost.

<sup>2</sup> B. Altman and A. Bernstein, *Disability and Health in the United States, 2001–2005*, (Hyattsville, MD: National Center for Health Statistics, 2008).

<sup>3</sup> 42 U.S.C. §12104(1)(A)-(D) (1990); 42 U.S.C. §12188(a)(2), (b)(2)(A)(ii).

<sup>4</sup> Mari-Lynn Drainoni et al., "Cross-Disability Experiences of Barriers of Health-Care Access," *Journal of Disability Policy Studies* 17, no. 2 (2006).

<sup>5</sup> 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).

<sup>6</sup> 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).