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On behalf of the
CCD Health Task Force
CCD Long Term Services and Supports Task Force

Before the Senate Health, Education, Labor and Pensions Committee

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Members of the HELP Committee, thank you very much for this opportunity to tell you about how changes in our health care system could impact people with disabilities. I am Mary Andrus, Assistant Vice President for Government Relations at Easter Seals, and I am here today as a Co-Chair of the Health Care Task Force and a representative of the Long Term Services and Support Task Force of the Consortium for Citizens with Disabilities (CCD), a coalition of national consumer, advocacy, provider and professional organizations who advocate on behalf of people of all ages with physical and mental disabilities and chronic conditions, and their families.

Overview

CCD believes that the goal of health care reform should be to assure that all Americans, including people with disabilities and chronic conditions, have access to high quality, comprehensive, affordable health care and long term services and supports that meets their individual needs and enables them to be healthy, functional, live as independently as possible, and participate in the community.

Insurance Market Reforms

The legislation that the HELP Committee has put forward, the Affordable Choices Act of 2009, contains very constructive changes regarding insurance market reform. These improvements to the private health insurance market have significant positive implications on the ability of all Americans to access affordable health insurance regardless of their health status. Specifically, providing guaranteed issue and guaranteed renewal rules on coverage in the individual and small group market and prohibiting pre-existing health condition exclusions in these markets would immediately widen the opportunity for people with disabilities to obtain and retain quality insurance coverage. To assure that insurance is not just available to people with disabilities and chronic conditions, but to commit to seeing that it is affordable, this legislation initiates restrictions on premium rating practices in these markets to prohibit the use of health status in determining premium rates.

The combination of these modifications to the way business is currently conducted would constitute significant improvements for people with disabilities. But this proposal takes another big step toward protecting people from being overwhelmed by the cost of illness. CCD strongly supports the prohibition of annual and lifetime insurance caps. In addition, we strongly support limits on out-of-pocket spending to meaningfully address either catastrophic medical events or the accumulation of costs over years of living with a disability or chronic condition. It is important for medically necessary prescribed treatments and services that are eligible medical expenses under the IRS rules to be considered out-of-pocket expenses. Many people with disabilities and chronic diseases will be left without protections from catastrophic financial costs for services or treatments that their doctor prescribes but their plan fails to cover.

Benefit Categories

One of the most critical aspects of the health care reform debate for the disability community is the assurance of an appropriate set of benefits to meet the needs of people with disabilities and chronic conditions. This community understands that the benefits package is not defined in the legislative proposal and we enthusiastically support the inclusion of rehabilitation and habilitation services as a category for further definition of what would be covered. Provision of acute and post-acute rehabilitation and habilitation services in multiple settings of care to match the level of intensity of services needed by individuals to return them to their home and community as quickly as possible is key to the goal of overall health care reform.

CCD strongly urges the Committee to include a category that provides a full complement of durable medical equipment (such as wheelchairs), prosthetics, orthotics (DMEPOS) and other assistive devices

and related services. Such devices are critical in enabling people with disabilities to function. Without access to proper and affordable equipment of this nature, people with disabilities and chronic conditions can not have their needs met by private insurance and will, ultimately, be forced to avail themselves of the public programs that do offer such coverage. This result would not look a lot different from the status quo and is not consistent with the goals of this remarkable effort. We can not state strongly enough the importance of the inclusion of coverage of DMEPOS and assistive equipment as a general category in defining the essential health care benefits.

Community Living Assistance Supports and Services Proposal

An essential element of health care reform is ensuring that vulnerable populations have access to coverage that meets their care needs. For persons with disabilities and chronically ill older Americans – arguably the most vulnerable populations in the nation – long term services and supports are their primary unmet care need, and are critical to promoting health and preventing illness. While approximately 45 million Americans do not have medical insurance, over 200 million adult Americans lack any insurance protection against the cost of long term services and supports. The inclusion of the Community Living Assistance Services and Supports (CLASS) language in this proposal is the threshold to meaningful change ensuring that individuals are able to function as independently as possible within their homes, families, and their communities. We strongly support the inclusion of the CLASS proposal. This provision should be retained as the legislative process moves forward.

Many Americans who are born with or develop severe functional impairments can access coverage for the long term services critical to their independence (such as personal assistance, assistive technologies, long term therapies, and training in basic skills) only through the federal/state Medicaid program. The Medicaid program has become the default long term services program and the last resort for millions of individuals and families who have nowhere else to turn to have their long term needs met. Families must impoverish themselves by spending down their life savings before they can access the care they need under Medicaid. To a family struggling to make ends meet, there is no difference between spending $20,000 on hospital care and spending $20,000 on home care or nursing home care. It is still $20,000 coming out of their pockets.

The CLASS provision would create a new national insurance program to help adults who have or develop severe functional impairments to remain independent, employed, and stay a part of their community. To qualify for CLASS benefits, individuals must be at least 18 years old and have contributed to the program for a minimum "vesting" period of 5 years. Eligibility for benefits would be determined by state disability determination centers and will be limited to individuals who are unable to perform two or more activities of daily living (ADL) (e.g. eating, bathing, dressing) or its equivalent.

Financed through modest voluntary payroll deductions (with opt-out enrollment like Medicare Part B), this measure would help remove barriers to choice and independence (e.g., housing modification, assistive technologies, personal assistance services, transportation) that can be overwhelmingly costly, by providing a cash benefit to those individuals who need support for basic functions. The large risk pool to be created by this approach would make added coverage affordable. It would give individuals added choice and access to supports without requiring them to become impoverished to qualify for Medicaid. This should have a significant beneficial impact on the Medicaid program in the future as fewer people find it necessary to spend-down to become Medicaid eligible. Furthermore, many beneficiaries of working age could continue to remain in the workforce. We also believe that individuals could supplement their CLASS coverage through the private insurance market.

We believe that Option A would fail to make any progress in this critical area. While some of the provisions of Option B would be worthwhile in a limited market, it is not comprehensive enough and would do little to increase essential insurance coverage throughout the population.

Medigap Coverage for Medicare Beneficiaries Under 65

People below age 65 become Medicare beneficiaries if they can no longer work due to disability and receive benefits under the Social Security Disability Income (SSDI) program, or if they require kidney dialysis due to end stage renal disease (ESRD). However, these Medicare beneficiaries have no federal right to access supplemental insurance through Medigap as seniors do. The need for this supplemental insurance has been recognized by 27 states which mandate some level of Medigap access to Medicare enrollees under 65.

As Congress considers how to improve the existing health care system, the guaranteed issue of Medigap policies to all Medicare beneficiaries with disabilities and ESRD below the age of 65 to bring access to Medigap policies in line with seniors on Medicare,would provide needed coverage to these individuals. Medigap policies should be accessible and affordable to all Medicare beneficiaries regardless of age or health condition.

Non-Discrimination in Insurance Markets and Products

CCD appreciates the protections in this proposal to prohibit discrimination for insurance eligibility and marketing. We would like to suggest the addition of language that strengthens the protections and prohibits plan coverage designs that would discriminate against people with disabilities and chronic disease. Many people with disabilities and chronic conditions are uninsured and under-insured. With the consideration of this health care proposal, there is the opportunity to better ensure that the design of plans and their benefits (including any formulary and tiered formulary structure) do not substantially discourage enrollment by individuals with disabilities or chronic diseases.

Thank you again for the opportunity to address this Committee and for all the work you are doing to truly make a difference in the way people with disabilities and chronic conditions can live, learn, work and play in their communities.

For additional information, please contact any of the individuals below.

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