



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

October , 2009

The Honorable Harry Reid
Majority Leader
U.S. Senate
Washington, DC 20510

The Honorable Tom Harkin
HELP Committee Chairman
U.S. Senate
Washington, DC 20510

The Honorable Max Baucus
Finance Committee Chairman
U.S. Senate
Washington, DC 20510

The Honorable Chris Dodd
Senator
U.S. Senate
Washington, DC 20510

RE: Critical Issues for People with Disabilities in Health Care Reform

Dear Senators Reid, Baucus, Harkin and Dodd:

The undersigned members of the Consortium for Citizens with Disabilities (CCD)*, as well as disability organizations that are not CCD members, sincerely thank you and express our appreciation for your tireless efforts to bring about comprehensive health care reform that ensures all Americans, including individuals with disabilities and chronic conditions, have access to high quality, comprehensive, affordable health care that meets their individual needs and enables them to be healthy, functional, live as independently as possible, and participate in the community.

We believe that a bill that meets the needs of persons with disabilities and chronic conditions will truly meet the needs of all Americans. As you merge the HELP and Finance Committee bills, we urge you to include in the leadership bill that goes to the Senate floor the following provisions.

Private Market Reforms

1. All private insurance market reforms should apply to as many health plans as possible as fast as possible, within and outside the exchange, including all employer-based plans. Market reforms of particular importance to the disability community include:
 - a. the elimination of discrimination based on health status and disability;
 - b. prohibitions on pre-existing condition exclusions;
 - c. guaranteed issue and renewal requirements;

- d. elimination of experience rating;
 - e. elimination of annual and lifetime caps in benefits; and,
 - f. parity in benefits requirements.
2. The benefit package must include “rehabilitative and habilitative services and devices,” such as durable medical equipment, prosthetics, orthotics, and related supplies (DMEPOS). This language appears in the HELP Committee bill. Clarification that “behavioral health services” are covered as “mental health and substance abuse services” is also very important. This language appears in the Finance Committee package. Coverage of these benefits by private health plans is absolutely critical to meeting the needs of people with disabilities and chronic conditions.
 3. For purposes of defining health care terms for ease in comparing benefits between health plans, the term “durable medical equipment” (DME) should be clarified in the statute so the Secretary does not adopt the misguided and inappropriate “in the home” restriction used under the Medicare program. The term “DME” should be defined to include wheelchairs and other mobility devices that are used outside, as well as inside, the person’s home to enable community participation. The term “prosthetics and orthotics” should be defined separately by the Secretary so there is no confusion that these are two separate and distinct benefits.
 4. Private coverage must be truly affordable, especially for individuals with disabilities and chronic conditions, and their families. Subsidies to purchase coverage through the Health Insurance Exchange as well as out-of-pocket limits for low income individuals and families must be adequate to meaningfully subsidize coverage.
 5. The final bill should offer immediate access to state high risk pools for people who cannot otherwise access private insurance while the Health Insurance Exchanges are being established.
 6. Preemption of state benefit mandates should be minimized when pooling risk across state lines or if national plans are permitted.

Medicaid and Long-Term Services and Supports

1. Medicaid eligibility should be expanded to cover individuals and families up to 133 percent of the Federal Poverty Level (FPL). This represents a major public investment in health care that will benefit low income individuals with disabilities and their families.
2. The Community First Choice Option must be included in the bill to finally address the institutional bias in Medicaid. This new state option would provide individuals with disabilities who are eligible for nursing homes and other institutional settings with options to receive community-based services and supports.

3. Inclusion of the “CLASS Act” is also critical to the needs of people with functional limitations that place them at risk of needing long term care. The CLASS Act would create a voluntary insurance program to assist in providing people with functional disabilities access to long term services and supports necessary to remain independent. The program will be solvent, affordable, and save Medicaid money.
4. The “free rider” employer fee exemption for individuals on Medicaid must be included in the final bill in order to eliminate financial disincentives to hire Medicaid beneficiaries.

The Medicare Program

1. The Senate should reject proposals that bundle post-acute care (PAC) services with acute care hospital services, and show restraint when considering proposals that bundle post acute care in a variety of settings. Any provisions relating to PAC bundling should require CMS to conduct rigorous demonstration projects to test PAC bundling before widespread implementation; require strong consumer protections and validated measurement tools; and exempt from the bundled payment specialty, low prevalence treatments (e.g., traumatic brain injury) and highly customized or relatively expensive items (e.g., limb prosthetics, custom orthotics, complex rehab mobility devices). In the context of pilot programs, the Senate bill should include consideration of the Continuing Care Hospital (CCH) concept, where PAC bundling would be directed by those with PAC experience, not acute care hospital providers.
2. Medicare beneficiaries with disabilities below age 65 and those with end stage renal disease (ESRD) should have access to guaranteed issue and renewability of Medigap supplemental policies, the same way that seniors on Medicare do today. To limit out-of-pocket costs, ESRD beneficiaries should also have a choice to join Medicare Advantage plans. S. 1669, the Equal Access to Medicare Options Act of 2009, a bill introduced by Senator Kerry, would accomplish both of these goals and we urge inclusion of these provisions in the health reform bill. It makes little sense to prohibit discrimination based on health status in the private insurance market and then permit such discrimination to continue to occur in the Medigap market.
3. The outpatient therapy caps exceptions process should be extended for two years to ensure that beneficiaries who need rehabilitation therapy the most receive it.
4. To preserve access to physicians and therapists for individuals with disabilities and chronic conditions, adequate and appropriate payment levels for physicians and therapists should be maintained.

Prevention, Effectiveness Research and Other Policies

1. The prevention provisions in the Senate bill should include prevention of secondary conditions, strategies to prevent injuries, and the collection of scientifically verifiable

data concerning effective interventions that will prevent secondary conditions and maintain function for persons with disabilities and chronic conditions.

2. Comparative effectiveness research (CER) should be an important tool in helping distinguish between the effectiveness of both existing and emerging treatment options. However, CER should not lead to inappropriate restrictions in coverage of and access to therapies, treatments, medications, and devices for persons with disabilities and chronic conditions. Outcomes of CER should not be a substitute for the clinical judgment of the physician or health care professional in consultation with the patient.
3. “Disability” should be recognized as a demographically identifiable category for purposes of research and included in reporting and other requirements related to health care disparities along with other categories such as race, gender, and socioeconomic status. CMS should survey providers to determine where people with disabilities receive treatment, where the providers are located, whether their facilities and equipment are accessible, and whether their employees have received disability awareness training.
4. Diagnostic and treatment equipment must be accessible to those with disabling impairments. Accessibility guidelines for such equipment should be developed by the Access Board and then adopted as standards by applicable federal agencies.
5. A Patient-Centered Outcomes Research Institute should be established with governance derived from the input of patients, providers, government officials and other stakeholders to focus primarily on clinical effectiveness rather than cost-effectiveness. With a patient-centered process, there is a greater opportunity to provide assurance that this important research will lead to improved patient care and not reduced cost through restrictions in coverage and access to treatment options.

Again, we thank you for your extraordinary leadership to bring about comprehensive healthcare reform which ensures that individuals with disabilities and chronic conditions have access to high quality, comprehensive, affordable health care. We look forward to working with you to enact legislation that not only meets needs of people with disabilities and chronic conditions, but of all Americans.

If you have any questions, please contact the CCD Co-Chairs listed below.

Sincerely,

CCD Members and other National, State and Local Organizations:

CCD Health Task Force Co-chairs:

Peter Thomas, Brain Injury Association of America

Mary Andrus, Easter Seals

Liz Savage, The Arc and United Cerebral Palsy Disability Policy Collaboration

Angela Ostrom, Epilepsy Foundation

Tim Nanof, American Occupational Therapy Association

CCD Long Term Services and Supports Task Force Co-Chairs:

Marty Ford, The Arc and United Cerebral Palsy Disability Policy Collaboration

Suellen Galbraith, American Network of Community Options and Resources

Lee Page, Paralyzed Veterans of America

Andrew Morris, United Spinal Association