



**CONSORTIUM FOR CITIZENS  
WITH DISABILITIES**

January 8, 2010

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

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

The Honorable Tom Harkin  
Chair  
HELP Committee  
U.S. Senate  
Washington, D.C. 20510

The Honorable Chris Dodd  
U.S. Senate  
Washington, D.C. 20510

The Honorable Nancy Pelosi  
Speaker  
U.S. House of Representatives  
Washington, DC 20515

The Honorable Henry Waxman  
Chair  
Energy and Commerce Committee  
U.S. House of Representatives  
Washington, D.C. 20515

The Honorable Charles Rangel  
Chair  
Ways and Means Committee  
U.S. House of Representatives  
Washington, D.C. 20515

The Honorable George Miller  
Chair  
Education and Labor Committee  
U.S. House of Representatives  
Washington, D.C. 20515

Re: **Disability Community's Recommendations to House-Senate Conference on Health Reform**

Dear Members of Congress:

On behalf of the Consortium for Citizens with Disabilities (CCD), we are writing to express our deep gratitude and strong support for critical elements of H.R. 3962, the Affordable Health Care for America Act and H.R. 3590, the Patient Protection and Affordable Care Act. CCD, a coalition of national consumer, service provider, and professional organizations, advocates on behalf of persons with disabilities and chronic conditions and their families.

We believe 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 that meets their individual needs and enables them to be healthy, functional, live as independently

as possible, and participate in the community. The House and Senate bills go a long way toward meeting that goal.

Below are our recommendations for reconciling the differences between the two bills, from the perspective of persons with disabilities and chronic conditions. Our recommendations address the following key components of the bill:

- Immediate health insurance reforms (page 2)
- Health insurance market reforms (page 3)
- Long term services and supports (page 8)
- Medicaid reforms (page 9)
- Medicare reforms (page 9)
- Civil rights protections (page 11)
- Health disparities, data collection, and training (page 12)

We look forward to working with all of you to ensure that the final bill sent to the President best reflects the needs of all Americans, including individuals with disabilities and chronic conditions.

## **I. IMMEDIATE HEALTH INSURANCE REFORMS**

### **1. Prohibit Lifetime and Annual Limits on Coverage**

Both bills include provisions to limit or prohibit the use of lifetime and annual coverage caps by insurance plans. We believe that healthcare reform should eliminate such caps to the maximum extent possible, and as soon as feasible. **Toward that end, we believe the final bill should implement the following policies:**

- Prohibit all qualified health plans from placing annual or lifetime limits on covered benefits and services (Sec. 221 and 222 of the House bill);
- Immediately prohibit group and individual plans from lifetime limits on essential benefits and restrict annual limits; once the exchange is operational, prohibit both lifetime and annual limits of any kind (Sec. 10101 of the Senate bill); and
- Immediately prohibit all plans from placing lifetime aggregate limits on covered benefits (Sec. 109 of the House bill).

Historically, lifetime and annual caps have had a significant discriminatory impact on persons with disabilities and chronic conditions by forcing them into financial hardship due to their medical conditions. Caps on coverage eliminate access to care when people who believe they are insured need health care services the most.

### **2. Ensure Affordable and Speedy Access to Temporary High Risk Pool**

Both the Senate and House bills create a temporary high risk pool to help provide immediate essential coverage for individuals with preexisting conditions. It is imperative to the disability community that access to this pool is affordable and timely for vulnerable individuals previously denied insurance

coverage because of preexisting conditions. **We urge Congressional leaders to implement the following policies in the final bill:**

- Allow access into the pool for individuals that have been denied coverage outright, or have been offered limited or unaffordable coverage as a result of a preexisting condition (Sec. 101 of the House bill)
- Allow access for individuals that have an eligible medical condition as defined by the Secretary (Sec. 101 of the House bill and Sec. 1101 of the Senate bill)
- Allow access for the spouses and dependents of eligible individuals (Sec. 101 of the House bill)
- Provide premium and cost-sharing protections to the greatest extent possible, including limits to the amount a premium can vary based on age (Sec. 101 of the House bill)
- Prohibit annual and lifetime coverage limits, as well as preexisting condition exclusion periods, within the risk pool (Sec. 101 of the House bill)
- Prohibit all preexisting condition exclusions in the high risk pool (Senate bill Sec. 1101)

Of the two versions of the temporary high risk pool, the House version defined in Section 101 makes the temporary high risk pool more affordable and accessible for those likely to have been previously denied coverage for pre-existing conditions, including people with disabilities and chronic conditions.

### **3. Implement Immediate Restrictions on a Private Plan's Ability to Impose Preexisting Condition Limits and Exclusions on an Individual's Coverage**

Both bills propose immediate limits to a plan's ability to limit or deny coverage based on preexisting conditions. Because we consider the immediate elimination of this discriminatory practice a top priority, **we propose the final bill include the following policies:**

- Implement an immediate ban on the use of any preexisting condition exclusions by all health plans for people younger than 19 years of age. (Sec. 10103 of the Senate bill)
- Implement immediate reductions to the time a group plan may "look back" for preexisting conditions and a group plan's preexisting condition limitation period (Sec. 106 of the House bill)
- Require group health plans that provide coverage for surgical benefits to cover the outpatient and inpatient diagnosis and treatment of a minor child's congenital or developmental deformity, disease or injury. (Sec. 108 of the House bill)

## **II. HEALTH INSURANCE MARKET REFORMS**

In general, all private market insurance reforms that benefit consumers (i.e. standards and requirements that would eliminate pre-existing condition exclusions, guarantee availability and renewability, limit premium rating, establish a comprehensive essential benefits package and prohibit caps on coverage) must be applied to all plans and in all markets to the maximum extent possible and as soon as possible. Below we have highlighted just a few of these important provisions.

### **1. Prohibit Discrimination Based on Health Status in the Individual and Group Markets**

Both the House and Senate bills include provisions to address discrimination against individual participants and beneficiaries based on, among other things, health and disability status and genetic

information. Ending such discrimination is the cornerstone of the disability community's priorities for healthcare reform, and **we therefore propose adoption of the following policies:**

- Expand HIPAA protections that prohibit discrimination based on health status into the individual insurance market (Sec. 1201 of the Senate bill, which adds Sec. 2705 (a) to the Public Health Service Act.)
- Prohibit all qualified health benefit plans from imposing any preexisting condition exclusion, limit or condition as soon as feasible (Sec. 211 of the House bill, Sec. 1201 of Senate bill, which adds sec. 2704 to the Public Health Service Act)

**Wellness Program Financial Incentives:** The disability community has growing concerns that wellness programs administered so that financial incentives and penalties are tied to health status, as opposed to participation in wellness programs, can and are being used to discriminate against individuals with disabilities and chronic conditions. To ensure that wellness programs cannot undermine attempts to prohibit discriminatory practices by health insurance plans, **we strongly recommend the final bill include the following policies:**

- Authorize funding for research and demonstration projects designed to provide an evidence base for effective wellness programs and identify best practices; and
- Define with specificity the characteristics of a qualified wellness program e.g., certified by the Secretary and include multiple evidence-based strategies, strategies that focus on prevention and support for employee populations that are at risk of poor health outcomes, and supportive environment components. (See sections 112 and 3143 of the House Bill and sections 4303 and 10408 of the Senate bill)

These provisions achieve two major reform goals for the disability community: increased protections from discrimination based on health status and funding of research on wellness programs to build an evidence base for wellness programs that will actually help participants achieve better health outcomes.

At the same time, we strongly oppose wellness programs that are not evidence based and utilize methods that could be used as a back door to discriminate against employees based on disability, genetic information, and health status. These programs also may subject individuals with disabilities to undue burdens with respect to the divulging of highly sensitive, medical information. **For these reasons, we request the final bill:**

- Exclude the Senate bill's provisions providing an exception for wellness programs that utilize incentives or penalties from the non-discriminatory requirements detailed in HIPAA (See section 1201 of the Senate bill which adds section 2705 (j) – (m) to the Public Health Service Act): and
- Include a construction clause that explicitly clarifies that no financial incentive for wellness programs may have the purpose or effect of violating the Americans with Disabilities Act, the Genetic Information Nondiscrimination Act, or similar laws.

## **2. Benefits Package that Includes Services and Protections for Individuals with Disabilities**

Both the House and Senate bills include categories of benefits in the standard benefit package that are of particular importance to people with disabilities and chronic conditions. **We support the inclusion of**

**the following essential health benefits which are of particular importance to people with disabilities and chronic conditions:**

- Rehabilitative and habilitative services and devices (Senate bill: Section 1302) *including durable medical equipment, prosthetics, orthotics and related supplies* (See House bill: Section 222)
- Mental health and substance disorder services, including behavioral health treatment (House bill: Section 222 and Senate bill: Section 1302)
- Oral health, vision, and hearing services, equipment, and supplies for children under 21 years of age (House bill: Section 222)
- Preventive and wellness services and chronic disease management (Senate bill: Section 1302)

These provisions will ensure that healthcare reform truly meets the individual needs of person with disabilities and chronic conditions by optimizing their health and functioning, maintaining functioning and preventing further deterioration and thus enabling them to be healthy, functional, and live as independently as possible, and participate in the community.

In defining the categories of essential health benefits, we support provisions that require the Secretary to include protections for individuals with disabilities and chronic conditions. **We recommend the final bill include the following policies:**

- Ensure that such benefits reflect an appropriate balance among the categories so that benefits are not unduly weighted toward any category;
- Not make coverage decisions, determine reimbursement rates, establish incentive programs, or design benefits in ways that discriminate against individuals because of their age, disability, or expected length of life;
- Take into account the health care needs of diverse segments of the population, including women, children, *persons with disabilities*, and other groups;
- Ensure that essential benefits not be subject to denial on the basis of the individual's present or predicted disability, degree of medical dependency, or quality of life; and
- Prevent the narrowing of benefits within the essential benefits package and allowing health plans to offer more generous benefits than the essential package (See section 1302 of the Senate bill)
- Require parity in mental health and substance abuse disorder benefits (See section 214(b) of the House bill)

These are strong patient protections that will help ensure that the essential health benefits package—that must be offered by all health plans that participate in the new Health Insurance Exchanges—will take into account the needs of people with disabilities and chronic conditions and not impose value judgments about disability and quality of life. This legislative language makes clear that Congress understands the subtle discrimination that can occur against people with disabilities in the area of benefit design.

**Standard Definitions of Benefits:** In addition, Section 1001 of the Senate bill requires the HHS Secretary to develop, through regulation, standard definitions of many terms including "durable medical equipment" (DME) for purposes of comparing benefit categories from one private health plan to another. Defining DME according to the Medicare definition would expand the problematic "in the

home” restriction to all private plans, which would represent a major step backward for people with disabilities. In addition, a definition of “DME” alone would not comport with the House’s language in Section 222 specifically delineating between coverage of “DME” and “prosthetics, orthotics and related supplies.” **We therefore recommend the final bill:**

- Explicitly state that HHS is not to define DME for purposes of “in home” use only
- Add “prosthetics, orthotics, and related supplies” to the list of benefit terms in the Senate bill (Section 1001) to be defined separately from DME and consistent with the benefit categories listed in Section 222 of the House bill.

### **3. Impact of Health Care Choice “Compacts” on State Benefit Laws**

CCD is concerned that a provision in both the House and Senate health reform bills (Sections 309 and 1333 respectively) creating *Health Care Choice Compacts*—allowing insurance companies to sell insurance products across State lines—would lead to a serious erosion of state-based coverage requirements that state legislatures have enacted over the years. Many of these state benefit laws are critical in providing benefits to people with disabilities and chronic conditions. CCD believes that, under this provision, insurance companies will rush to “house” themselves in the state with the least regulations, resulting in a race to the bottom for consumer protections. The new federal standards are meant to act as a floor—not as a ceiling—for essential benefits, giving room for plans within states to offer more generous coverage to their constituents.

Given the potential ramifications of this policy on consumer protections and access to benefits, **CCD strongly recommends the following policy be included in the final bill:**

- Require that all state benefit and consumer protection laws be accorded full force and effect when multi-state compacts organize under one state’s laws but sell insurance across state lines.

### **4. Protect Individuals with Disabilities when Developing Related Regulations**

We also support the following provisions that protect against potential restrictions in access to certain benefits or settings of care. **We recommend the final bill include Section 1554 of the Senate bill, which specifies that the Secretary shall not promulgate any regulation that:**

- Creates any unreasonable barriers to the ability of individuals to obtain appropriate medical care
- Impedes timely access to health care services
- Interferes with communications regarding the treatment options between the patient and provider
- Restricts the ability of health care providers to provide full disclosure of all relevant information to patients making health care decisions
- Violates the principles of informed consent and the ethical standards of health care professionals
- Limits the availability of health care treatment for the full duration of the patient’s medical needs. [See section 1554 of the Senate bill]

### **5. Nondiscrimination in Medigap Coverage**

Guaranteeing issue and prohibiting discrimination based on health status in the private insurance market is the hallmark of the healthcare reform bill. For seniors on Medicare who purchase private Medigap

policies to assist with Medicare copayments and deductibles, federal law similarly guarantees issue, but Medicare beneficiaries below age 65 (i.e., Medicare beneficiaries with disabilities or end stage renal disease (ESRD)) do not have this same right. In fact, 29 states have passed state laws permitting Medicare beneficiaries below age 65 access to the Medigap market, but this right is not guaranteed in federal law. It makes little sense to guarantee issue in the private insurance market but then permit this same discriminatory treatment to continue in the Medigap supplemental insurance market.

Last year, Senator Kerry introduced the Equal Access to Medicare Options Act of 2009, S.1669, in an effort to correct this problem. The bill would permit all Medicare beneficiaries with disabilities and ESRD to purchase Medigap supplemental policies. It would also permit ESRD beneficiaries to join Medicare Advantage plans to reduce their cost sharing, as an alternative to purchasing a Medigap policy. **CCD recommends that Congressional leaders include in the final healthcare reform bill the following policies:**

- Guaranteed issue of Medigap policies for Medicare beneficiaries under age 65
- Elimination of the prohibition of ESRD beneficiaries to join Medicare Advantage plans

## **6. Ensure an Adequate Network of Providers**

We believe that healthcare reform should ensure that critical services and devices will be available from a full continuum of accredited programs and treatment settings at a level of intensity that is consistent with the needs of the patient. For people with disabilities and chronic conditions, timely access to specialty services, including access to specialists as care coordinators, is essential. **For these reasons, we recommend adoption of the following policies in the final bill:**

- Require plans to permit patients to choose their participating primary care provider (Senate Manager's Amendment Section 2719A)
- Improve access to emergency and ambulance services; access to specialized primary care services for women and children; and internal and external appeals processes when treatments are denied. (See Sen. Manager's Amendment Sec. 2719A and Sec. 2719)
- Require the access to specialty care provisions of Senator Cardin's Patient Rights Amendment, including the right of an enrollee with a chronic condition or disability to select a specialist as a care coordinator (See Sections 1611 and 1613 of Cardin Amendment)
- Require adequate provider networks to ensure enrollee access to essential benefits (See section 215(a) of the House bill)
- Specify that for health plans to be considered "qualified" by the Secretary, the plans must ensure "a sufficient choice of providers (in a manner consistent with applicable network adequacy provisions under section 2702(c) of the Public Health Services Act) and provide information to enrollees and prospective enrollees on the availability of in-network and out-of-network providers" in order to ensure enrollee access to covered benefits, treatments and services under a qualified health benefits plan. (See section 1311 of the Senate bill)
- Prohibit a group health plan and a health insurance issuer from discriminating with respect to participation in the group or individual health insurance plan or coverage against any health care provider who is acting within the scope of that provider's license or certification under applicable state law (See Section 2706 of the Senate bill)

## **7. Restrict the Operation of Individual Market Health Insurance Outside of the Exchange**

**We recommend the following policy be adopted in the final bill:**

- Prevent non-grandfathered individual health insurance coverage from operating outside of the exchange. (Section 202(c)(1) of the House bill)
- Require grandfathered plans outside of the exchange to meet the standards for qualified health benefits plans

If individual plans are allowed to operate outside of the exchange with no limitations or standards, there will be widespread unfair competition in the marketplace. This will inevitably result in relatively young and healthy individuals purchasing coverage outside of the exchange, causing adverse selection within the exchange. The premiums for those within the exchange—which would likely include many individuals with disabilities and chronic conditions—would continue to rise and the exchange(s) would lose their advantage to pool risk over a broad and diverse population.

### **III. LONG TERM SERVICES AND SUPPORTS**

#### **1. Implement the CLASS Act**

**We recommend adoption of the following policy:**

- Implement a new actuarially-sound, premium-based, voluntary, national long term services and supports insurance program that provides a cash benefit to help eligible adults with severe functional impairments remain independent, employed, and a part of their communities, as an alternative to having to become impoverished and enroll in Medicaid. (Sec. 8002 of the Sen. bill)

Section 2581 of the House bill also implements the CLASS Act, but the Senate's provisions provide more specificity with respect to fiscal solvency of the program. For example, the Senate bill requires the Secretary to regularly consult with the Board of Trustees and the Advisory Council to ensure that enrollee premiums are adequate to ensure the financial solvency of the CLASS program. For this reason, we prefer the Senate language. However, both the House and Senate bills could be improved with respect to automatic enrollment of employees, whereupon employees choosing not to participate could opt out of the program. **We therefore recommend adoption of the following policy:**

- Expand automatic enrollment to all employers so that all employees would have a meaningful opportunity to choose whether to participate in the program and, thereby, further protect the solvency of the program.

#### **2. Promote the Use of Home and Community Based Services (HCBS) under Medicaid**

Both bills include key provisions to increase the number of people with disabilities able to live in the community rather than institutions. **We recommend the adoption of the following policies:**

- Include in the bill the Community First Choice Option. (Section 2401 of the Senate bill)
- Remove barriers to providing home and community based services (Sec. 2402 of the Senate bill)
- Extend the "Money Follows the Person Rebalancing Demonstration" (Sec. 2403 of the Sen. bill)



- Protection for recipients of home and community-based services against spousal impoverishment (See section 2404 of the Senate bill)
- Offer incentives for states to offer home and community-based services as a long-term care alternative to nursing homes. This provision provides FMAP increases to states to rebalance their spending between HCBS and institutionally-based services (nursing homes and intermediate care facilities for people with intellectual disabilities/mental retardation and related conditions) (See section 10202 of the Senate bill)

#### **IV. ADDITIONAL IMPORTANT MEDICAID REFORMS**

One of the CCD’s main principles is to achieve access to affordable and comprehensive insurance through healthcare reform. An expansion of Medicaid eligibility will help to meet these goals for individuals with chronic conditions and disabilities who are also low income. Medicaid beneficiaries with disabilities and chronic conditions in many states experience significant barriers in accessing primary care services because of low provider reimbursement rates. When these beneficiaries cannot access primary care services they either use more costly emergency rooms or delay care. Such delays often result in costly hospitalizations. Therefore, it is critical to increase Medicaid reimbursement rates in order to assist states. **CCD supports inclusion of the following policies in the final bill:**

- Expand Medicaid eligibility to 150 percent of the poverty line to Medicaid eligible categories, including those traditionally eligible (Section 1701 of the House bill)
- Raise Medicaid reimbursement rates for primary care services to Medicare rates to ensure provider participation and access to care (Section 1721 of the House bill)
- Guarantee newly eligible Medicaid beneficiaries the full range of essential benefits (Section 1703(c) of the House bill), rather than requiring states to provide these new beneficiaries scaled-back “benchmark benefits” as in the Senate bill
- Eliminate the use of the asset test when determining income for certain eligible Medicaid beneficiaries (Section 1703 of House bill)
- Include Medicaid and other public programs as “acceptable coverage” for purposes of compliance with the requirement to have health insurance (See Section 501 of the House bill)

Inclusion of these provisions in the final bill will go a long way toward improving access to higher quality care for Medicaid beneficiaries with disabilities and chronic conditions.

#### **V. MEDICARE REFORMS**

##### **1. Patient Protections in Bundling Demonstrations, Pilots, and Plans**

“Bundling” of payments is of concern to the disability community, especially when post-acute care is part of the set of bundled services. Both the House and Senate bills make significant efforts to protect patients from being under-served in bundled payment models and mandate pilot testing of post-acute care bundling through the Continuing Care Hospital (CCH) concept. The Senate bill is more explicit in this regard and for this reason, CCD supports this provision in the Senate bill. (See Sec. 10308)

Despite CCD’s support for the more explicit language of the Senate bill, CCD believes that patients are best protected when the authority to expand the bundling pilot into permanent Medicare policy rests with Congress, not the HHS Secretary. Section 1152 of the House bill accomplishes this by calling

explicitly for a comprehensive study of post-acute care bundling before widespread implementation. The study must identify, among other things, the nature of protections needed for individuals under a system of bundled payments as well as the types of conditions to which bundling should or should not apply.

Knowing how poorly specialized devices such as prosthetic limbs and complex conditions such as brain and spinal cord injuries have fared under capitated payment methodologies in the past, this study may provide valuable insight that could help protect the kind of rehabilitation needed by these and other patient subpopulations. For this reason, CCD urges a very deliberate, evidence-based approach to bundling of post-acute care.

**CCD recommends including the following policy in the final bill:**

- Implement a very deliberate, evidence-based approach to bundling of post-acute care, which includes a requirement that the Secretary conduct the Continuing Care Hospital (CCH) pilot. (Section 1152 of the House bill, Section 10308 of the Senate bill)

**2. Protect the First Month Purchase Option for Power Wheelchairs**

The “first month purchase option” under Medicare allows individuals in need of power wheelchairs or other mobility devices the right to purchase the device up front in the first month of need, or rent the device over a 13-month period. It is the beneficiary’s choice. Most beneficiaries choose to purchase the device up front and pay a one-time, 20% copayment. This allows the beneficiary to take title to the device immediately and customize the wheelchair accordingly. The House and Senate bills propose to eliminate patient choice by forcing beneficiaries to rent their mobility device for thirteen months before they can own the device, except for complex rehab power wheelchairs.

We appreciate the House and Senate’s decision to exempt complex rehab power wheelchairs from this policy and strongly support that policy. However, we remain concerned that eliminating the first month purchase option for all other power wheelchair users will restrict access as suppliers begin to assess patients based more on their prognosis and ability to use the device for 13 full months rather than on their true mobility needs. We are also concerned that small or rural suppliers will be unable to finance for 13 months the purchase of power wheelchairs from manufacturers, contributing to a loss of patient access to appropriate mobility.

**We therefore recommend adoption of the following policy in the final bill:**

- Adopt the exemption of this policy for complex rehab power wheelchairs. In addition, we support an additional proposal that allows a beneficiary to purchase a wheelchair up front if a physician certifies that the beneficiary will likely require the power wheelchair for at least 13 months. If the patient were to no longer need the power wheelchair within the first 13-month period, the supplier would have to refund the Medicare program the difference between the 13-month rental period and the purchase amount.

Senator Specter introduced this Amendment during the Senate debate but it was not acted upon. Under this proposal, all parties are protected. Patients receive the appropriate wheelchair to meet their needs, the government recovers payments made for power wheelchairs that are no longer needed by

beneficiaries who were expected to use them for at least 13 months, and suppliers are not exposed to the burden of financing the purchase power wheelchairs from manufacturers, only to be paid by Medicare and the beneficiary over a 13-month period. We recommend adoption of this proposal or an alternative that will achieve savings while preserving access.

### **3. Protect Access to Rehab Therapies for People with Disabilities and Chronic Conditions**

Both the House and Senate bills extend the Medicare outpatient therapy caps exceptions process, with the only difference being the time of the extension. The exceptions process is critical to meeting the rehabilitation therapy needs of Medicare beneficiaries with disabilities and chronic conditions, at the very time these beneficiaries need these services the most. **We recommend adoption of the following policy in the final bill:**

- Extend the therapy caps exceptions process until December 31, 2011, or longer (Section 1231 of the House bill)

The related section (Section 3103) in the Senate bill only extends the process for one year.

### **4. Consumer Choice of Home Health Care Professionals**

CCD believes it is best to have the type of professional who will be ultimately providing services to a patient perform that patient's initial evaluation. **For this reason, CCD supports inclusion of the following policy in the final bill:**

- Allow home health agencies the flexibility to use occupational therapists to open Medicare home health cases and conduct the initial visit. (Sec. 1155B of the House bill)

This provision scores for no significant cost or savings, even over a ten-year budget window, and has no opposition. The provision would benefit Medicare beneficiaries by allowing the most clinically appropriate service provider to conduct the initial visit and could reduce waiting times for cases to open by allowing home health agencies to use their skilled staff more flexibly.

## **VI. CIVIL RIGHTS PROTECTIONS**

### **1. Applicability of Section 504 of the Rehabilitation Act and Other Civil Rights Laws**

With significant federal dollars flowing to states, businesses, health plans, and individuals, it is critical that the final bill explicitly clarify that long-standing disability nondiscrimination law applies to these recipients of federal financial assistance. **We therefore recommend including the following policy in the final bill:**

- Prohibit discrimination in violation of Section 504 of the Rehabilitation Act that would result in the exclusion from participation in, or denial of benefits under, any health program or activities any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, or under any program or activity that is administered by an Executive Agency or any entity established under the bill. (See section 1557 of the Senate bill)

## **2. Ensure Medical Diagnostic Equipment Accessibility and Adherence to the ADA**

**We recommend adoption of the following policies:**

- Require the Access Board to establish guidelines (and review and amend such guidelines) setting forth the minimum technical criteria for medical diagnostic equipment and the promulgation of related regulations by appropriate agencies. (Sec. 2592 of the House bill)
- Ensure that providers and plans covered by the bill meet the requirements of the Americans with Disabilities Act and the requirements of section 504 of the Rehab Act, including provisions ensuring that individuals with disabilities receive equal access to all aspects of the health care delivery system. (Section 2592 of the House bill)

Section 4203 of the Senate bill also requires accessibility standards, but omits the language on the ADA. Section 2592 of the House bill also fully conforms to existing practice whereby the Access Board establishes guidelines and the administering agencies (e.g., the Justice Department) establish standards and are responsible for oversight and enforcement.

## **VII. HEALTH DISPARITIES, DATA COLLECTION, AND TRAINING FOR HEALTH CARE PROFESSIONALS AND OTHER REFORMS**

### **1. Specify Disability as a Health Disparity Category**

Individuals with disabilities have faced significant health disparities according to the limited available health indicators. Health reform legislation aimed at reducing health disparities should include the population of individuals with disabilities so that data can be collected to help identify areas in need of improvement. **CCD strongly supports inclusion of the following policies in the final bill:**

- Establish disability as a distinct health disparity population (Section 2301 of the House bill)
- Implement a rich data collection program integrated with quality reporting requirements and programs to collect and evaluate data on disparities in health care services and performance for persons with disabilities and other populations. (Section 4302 in the Senate bill)

Section 931 of the Senate bill incorporates Section 485E of the Public Health Service Act to define “Health Disparity Populations.” Section 485E does not specifically include individuals with disabilities and, therefore, we do not support it.

### **2. Provide Disability Training for Health Professionals**

To reduce health disparities and improve the health of individuals with disabilities, CCD believes we must increase the number of health professionals trained to meet their healthcare needs. **Therefore, CCD supports inclusion of the following policies in the final bill:**

- Establish the National Health Care Workforce Commission to review, among other topics, the health care workforce needs of special populations, specifically including individuals with disabilities. (Section 5101 of the Senate bill)
- Authorize grants that would be used for the development of research, demonstration projects and model curricula for cultural competency, prevention, public health proficiency, reducing health

disparities, and aptitude for working with individuals with disabilities, training in health professions schools, and continuing education programs (Section 5307 of Senate bill)

- When providing grants to increase the number of primary healthcare providers, give entities grant priority if they provide training in the care of vulnerable populations, including individuals with disabilities as a vulnerable population. (Section 5301s and 5303 of the Senate bill)

The related House provisions do not specify the needs of individuals with disabilities (compare Sections 2113, 2115 and 2251 of the House bill).

### **3. Limit Out-of-Pocket Costs by Extending the Medical Expense Deductibility Waiver for Seniors to People with Disabilities**

CCD appreciates that everyone must share responsibility in financing comprehensive healthcare reform. Section 9013(a) of the Senate health reform bill increases the threshold for medical deductions from 7.5% to 10% annually. Section 9013(b) creates a temporary waiver of this increased threshold for tax years 2013 through 2017 for taxpayers or their spouses who have attained age 65. There is no similar provision in the Senate bill for people with disabilities who are covered under the Social Security Disability Insurance (SSDI) program and, as a result of their SSDI status, also receive Medicare coverage.

Persons with disabilities and parents of children with disabilities already incur significantly more than average costs to pay for medical expenses, prescription drugs, therapy visits, assistive technologies and related equipment necessitated by various disabilities. Medicare recipients under age 65 do not have a federal right—like seniors on Medicare do—to purchase Medigap supplemental coverage to assist with reducing their out-of-pocket medical costs. CCD proposes that Congress extend this same waiver provided to seniors (from the increased 2.5% threshold) to SSDI recipients. **Therefore, CCD recommends that the final health reform bill:**

- Extend the waiver from the increase in the medical deductibility threshold from seniors only, to people with disabilities on Social Security Disability Insurance (SSDI) who also receive Medicare coverage.

### **4. Prevention and Wellness Funding**

CCD appreciates and commends Congress for including provisions in the healthcare bills that provide strong federal support for services and practices that will help to alleviate health problems faced by many Americans, including individuals with disabilities and chronic conditions, that could be prevented or eliminated through early intervention and treatment. **CCD recommends the final bill:**

- Authorize and appropriate funding to the maximum extent possible to provide for an expanded and sustained national investment in public health infrastructure and activities to promote prevention and wellness. (House bill, Sec. 2301 and Senate bill, Sec. 4002)

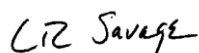
## **VIII. CONCLUSION**

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,

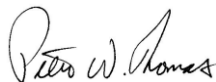
comprehensive, affordable health care. We also realize that during the hard work of negotiating and enacting legislation to reach reform that compromises must be made on key issues. We respectfully request that as you decide what will remain in the final bill, that you give serious consideration to the important disability-related provisions in this letter. If you have any questions, please contact the CCD Co-Chairs listed below.

Sincerely,

Co-chairs of the CCD Health and Long Term Services and Supports Task Forces:



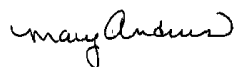
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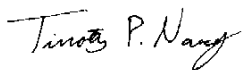
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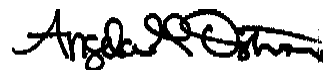
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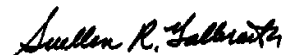
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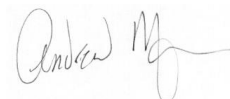
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