



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

May 22, 2009

The Honorable Max Baucus
Chairman
Committee on Finance
United States Senate
Washington, D.C. 20510

The Honorable Charles E. Grassley
Ranking Member
Committee on Finance
United States Senate
Washington, D.C. 20510

RE: Response to Affordable Care Coverage Recommendations

Dear Chairman Baucus and Ranking Member Grassley:

The Consortium for Citizens with Disabilities (CCD) Health and Long Term Services and Supports Task Forces are pleased to submit written comments on the Senate Finance Committee's set of recommendations regarding policy options for health care coverage contained in the document *Expanding Health Care Coverage: Proposals to Provide Affordable Coverage to All Americans*, dated May 14, 2009. CCD, a coalition of national consumer, service provider and professional organizations, advocates on behalf of persons with disabilities and chronic conditions and their families. 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 that meets their individual needs and enables them to be healthy, functional, live as independently as possible, and participate in the community.

In summary, CCD is particularly supportive of the recommendations regarding individual and small group 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. We are also encouraged by the recommendations regarding Medicaid, including recommendations that serve to eliminate the institutional bias and provide greater support for home and community based services; recommendations regarding long-term care services; and inclusion of disability status as a category for purposes of measuring health disparities.

CCD is deeply concerned, however, with the limited scope of the benefit package that would be available under the Health Insurance Exchange. Based on the document released by the Committee, there is a complete absence of any benefits related to rehabilitation therapies and related services (in both the inpatient and outpatient settings) as well as durable medical equipment, orthotics, prosthetics (DMEPOS) and other assistive devices. These benefits are not luxuries or convenience items. They are basic elements of health care coverage for people with disabilities and chronic conditions. This apparent lack of coverage would have devastating consequences for individuals in need of this care to facilitate their recovery and restore their ability to function and live as independently as possible. These benefits are no less important than antibiotics to a person with an infection, open heart surgery to an individual with coronary artery disease, or setting a limb that has been broken. Congress must explicitly require coverage of these two categories of benefits (i.e., rehabilitation therapies and DMEPOS) in all insurance plans offered under the Exchange and must do so in statute.

CCD commends the committee for including policy options for long term services and supports, and we appreciate the committee's recognition of the hundreds of millions of Americans that lack any insurance coverage for long-term services. We believe that long term services and supports should be consistent with the principles of self-determination and that individuals should be able to choose consumer-managed and directed supports that provide increased decision-making authority to people with disabilities, with support of their family and friends. Towards that end, we have included specific recommendations that would help ensure healthcare reform legislation adopts a two pronged approach to long –term services and supports: 1) establish a national program to finance long term services and supports consistent with the CLASS Act and 2) make improvements to strengthen long term services and supports in Medicaid.

Following are our detailed responses to specific recommendations presented in the Finance Committee document that are of particular significance to persons with disabilities and chronic conditions.

I. Insurance Market Reforms.

CCD supports the following reforms included in the proposal:

- Imposing guaranteed issue and guaranteed renewal rules on coverage in the individual and small group markets.
- Prohibiting pre-existing health condition exclusions in these same markets.
- Restricting premium rating practices in these markets to prohibit the use of health status in determining premium rates.
- Establishing a single “Health Insurance Exchange” for all insurers in the small and individual market; or establishing multiple competing exchanges in addition to the national exchange.

CCD believes that these insurance market reforms would constitute significant improvements to the insurance market for people with disabilities and chronic conditions. These reforms alone would have a major impact on the ability of individuals with health conditions to access affordable private insurance. Of course, whether this coverage will ultimately meet

the needs of people with disabilities is dependent on the benefits that are actually covered under these private insurance plans. CCD also recognizes that these market reforms will not work well if people are able to opt out of the system and only purchase private coverage when they need it. CCD, therefore, supports requirements for health care coverage on as many Americans as possible to ensure that these market reforms succeed in leveling the playing field for people with disabilities and chronic conditions. In addition, CCD believes that health care reform must meaningfully address catastrophic medical events through restrictions on annual or lifetime limits so that individuals and families are not exposed to unlimited out-of-pocket expenses.

II. Minimum benefit package, subsidy and tax credit options.

For the individual and small group markets, the proposal suggests the establishment of a minimum benefit requirement that covers preventive and primary care, emergency services, hospitalization, physician's services, outpatient services, day surgery and related anesthesia, diagnostic imaging and screenings, medical/surgical care, prescription drugs, radiation and chemotherapy, and mental health and substance abuse services.

The proposal also suggests a requirement that each plan apply "parity" for cost-sharing treatment of conditions within each of the following categories: inpatient hospital, outpatient hospital, physician services and other items and services, including mental health services.

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. CCD is seriously concerned that the proposed benefit package fails to specifically include coverage of rehabilitation services (in the inpatient and outpatient settings) and durable medical equipment, prosthetics, orthotics (DMEPOS) and other assistive devices. For people with disabilities and chronic conditions, rehabilitation services and devices are a necessity to maintain and improve function. Acute and post-acute rehabilitation services should be covered in multiple settings of care to match the level of intensity of rehabilitation needed by the patient, including inpatient hospital rehabilitation—where the focus is on intensive, short term rehabilitation in order to return the patient to their home and community as quickly as possible—throughout the continuum of care.

It is imperative that a basic benefit package recognize the value of improving functional status, not simply meeting the acute care needs of people with illnesses or injuries. For instance, a basic benefit package must cover:

- Intensive medical rehabilitation services provided in the inpatient setting;
- Mental health and addiction services including community based and inpatient services provided in compliance with the recently enacted mental health parity law (PL:110-460);
- Post-acute care in a variety of settings to ensure the most appropriate rehabilitation;
- Outpatient therapies that will restore, improve, and maintain function, as well as such services to prevent the further deterioration of functional status;
- Vision rehabilitation services to ensure that individuals can regain functional independence;

- Medically appropriate prescription drugs and therapies that meet the individualized needs of people with disabilities and chronic conditions;
- A full complement of durable medical equipment, orthotics, prosthetics, and medical supplies, without arbitrary and unreasonable dollar limits or exclusions;
- Benefits that address major omissions in contemporary benefits packages to meet the needs of specific subpopulations (e.g., tests and behavioral therapies to address autism spectrum disorder; cognitive therapies for people with traumatic brain injury, etc.); and
- Long term services and supports that ensure continuous coverage of services for individuals with disabilities, with an emphasis on keeping individuals functioning in their homes and communities.

Without access to these types of benefits, people with disabilities and chronic conditions will not have their needs met by private insurance and will, ultimately, be forced to avail themselves to the public programs that do offer such coverage. This result is little different from the current situation for these populations. A reformed health care system must do better.

III. Public Health Insurance Options.

The proposal includes three approaches to a public plan as well as the option of proceeding with health care reform without a public plan option.

CCD recognizes that whether the final health care reform package will contain a public plan option has quickly become the flash point in the healthcare debate. CCD believes there are strong arguments in favor of a public plan, mainly to act as a competing plan to all private health plans in the Exchange, thereby putting pressure on private insurers to offer attractive benefit packages with reasonable premiums. There are many ways to structure a public plan option that would not lead to a government “take-over” of health care in this country and CCD is open to further discussions on a variety of methods by which this could be accomplished.

IV. Role of Public Programs.

Medicaid/SCHIP:

CCD believes that there are many positive features in this section of the policy options, including:

- Providing an automatic increase in the Medicaid Federal Medical Assistance Percentage (FMAP) formula during an economic recession;
- A strengthened benefit package for children so that *all* children in public coverage (Medicaid and CHIP) have access to the full range of treatment necessary to attain and maintain their optimal health and development;
- Extension of new quality provisions that the Children’s Health Insurance Program Reauthorization Act (CHIPRA) applied to children in Medicaid and CHIP to all Medicaid beneficiaries, including people with disabilities;

- In two of the three approaches to Medicaid coverage, providing Medicaid coverage to adults without children between the ages of 19 and 64 who do not meet the strict criteria for coverage as a person with a disability. (Many individuals in this group have chronic physical and mental health conditions.)
- Recognition of the need for increased provider payments to ensure access to services, although we suggest consideration of alternatives to an across-the-board increase that may be more effective in matching higher payments to health care services where access problems have been reported.

We applaud the inclusion of significant improvements in the process for approving waivers and certain state plan amendments, which increase the opportunity for public input and make the approval process more transparent at both the state and federal levels. However we recommend that the Committee also include the same statutory requirements for Section 1915(c) home and community-based waivers to ensure parallel transparency and public involvement when states develop and seek approval for HCBS waiver services. We believe that the 1915(c) waiver process should include the same requirements for public notice and involvement of the state’s medical advisory board, publishing of written comments, posting the waiver proposal on state’s website; open meetings to discuss proposed, and the additional requirements on the Secretary of HHS to ensure transparency and public input at the federal level.

Most of our comments relate to the three approaches for Medicaid coverage. Our preference would be for Option 1, which would use the current Medicaid structure to cover parents, pregnant women, and children with incomes up to 150 percent of the poverty line and adults without children with incomes up to 115 percent of the poverty line. As explained in a recent report from the Kaiser Commission on Medicaid and the Uninsured building on Medicaid makes sense. Medicaid currently provides affordable and comprehensive coverage that is well-suited to low-income and high-need populations in an efficient and cost-effective manner. In addition, Medicaid already has an administrative structure in every state that is ready to assume new groups of beneficiaries.¹

We appreciate that Approach #2 would allow people with disabilities to remain in state Medicaid programs. We are still concerned, however, that putting all other beneficiaries in plans in the exchange would disrupt health care services for these groups. In particular, some children with special health care needs, who do not meet the criteria for coverage under a disability category, could end up in exchange plans. While they would be entitled to services not covered by the exchange plans through a wrap-around EPSDT benefit, a bifurcated benefit package would present challenges for families who would have to know where to go for various services and what to do if the plan refuses services the child needs. It would also be hard for states and providers to understand what the plans should provide and what the state should provide as a wrap-around benefit given that different plans in the exchange will provide different benefit packages.

Our other concern is that states could end up spending more on beneficiaries in the exchange under Approach #2 than in the current Medicaid programs. States would have to pay premiums to the plans in the exchange, fill in cost-sharing charges that beneficiaries

¹ Kaiser Commission on Medicaid and the Uninsured, “Medicaid as a Platform for Broader Health Reform: Supporting High-Need and Low-Income Populations,” May 2009.

would otherwise pay in the exchange plans and provide wrap-around benefits. Due to these increased costs, states could end up reducing benefits and/or provider payments for people with disabilities and older adults who would remain in traditional Medicaid programs.

Approach #3 would keep all current groups of beneficiaries in Medicaid, which we think is preferable to the second approach. However, there is a danger that some people with disabilities could lose out if they are treated as childless adults who would get a voucher allowing them to enroll in Medicaid or the exchange. Those at risk would be people with incomes above the mandatory coverage level for people with disabilities, which is tied to Supplemental Security Income (SSI) eligibility and is about 74 percent of the poverty line, but below the new 115 percent of poverty coverage standard for childless adults. Many people with disabilities are now covered as optional beneficiaries. If states discontinued optional coverage (or never provided this coverage in the first place), these individuals would get a voucher. If they enrolled in Medicaid, they would get the same benefits as parents, which could be less than traditional Medicaid. To avoid this result, we suggest that all people with income below 115 percent of the poverty line who could be covered in a Medicaid disability category be enrolled in traditional Medicaid coverage. Otherwise they could lose access to key benefits such as rehabilitative services, durable medical equipment, and some behavioral health services.

We also think there would need to be significant protections for vulnerable people, such as individuals with mental illness, who are in the childless adult category. The policy options paper states that exchange plans enrolling very low-income adults without children should have provider networks that include community health centers and other safety net providers which is a good first step. These individuals will also need special help understanding the choices they have for coverage. To the extent these individuals end up in exchange plans, they also may need care management services to help them navigate the new health care system.

Medicare Coverage:

CCD applauds the Finance Committee for including options to reduce or phase-out the Two-Year Medicare Disability Waiting Period. This policy has not only been a significant barrier to health care for almost 2 million people with significant disabilities but ultimately increases costs to the Medicare program due to delayed medical treatment. We hope that the Finance Committee will be able to totally eliminate the two-year waiting period immediately. However, if the Committee elects to phase in an elimination we recommend, in order of preference:

- Approach 3, which would reduce the waiting period in six month increments, with complete elimination after one-and-a-half years;
- Approach 2, which would phase-out the waiting period by 2015;
- Approach 4, which would maintain the waiting period for people with access to private insurance that meets or exceeds an actuarial standard. However, we are concerned that an actuarial standard does not guarantee that coverage will be affordable or that out-of-pocket costs will be limited. Moreover, as underscored above, we are very concerned that the benefit package will be very limited and may fail to include access to critical services (i.e. rehabilitation, therapies, durable medical

- equipment, and orthotics and prosthetics) that allow people with significant disabilities to function;
- Approach 1, which would reduce the waiting period to 12 months.

In addition, CCD supports the proposed temporary Medicare buy-in for individuals between the ages of 55 and 64. This population is vulnerable to disability and access to health insurance coverage may prevent the onset of chronic conditions and disabilities.

Furthermore, Congress should finally address the Centers for Medicare and Medicaid Services' (CMS) restrictive interpretation of the Medicare "In-the-Home" rule which limits access to appropriate mobility devices for beneficiaries with disabilities and chronic conditions. A modification of this rule is necessary to permit beneficiaries with mobility disabilities from being trapped within the four walls of their homes.

VI. Prevention and Wellness.

CCD believes that prevention must include services that limit the negative progression of disabling conditions and prevent conditions that are secondary to disabilities and chronic conditions. CCD supports many of the options presented in the paper, including:

- a. Authorizing a personalized prevention plan for Medicare beneficiaries once every five years;
- b. Removing or limiting beneficiary cost-sharing for Medicare and Medicaid preventive services and providing incentives for behavior modification programs;
- c. Providing a 1 percent increase in FMAP to states that provide coverage for all approved preventive services and immunizations;
- d. Funding annual state grants to provide access to specified evidence-based services to help prevent chronic disease; and
- e. Establishing a competitive grant program to promote health and human services program integration and improve care coordination and access to preventive services and treatments.

Prevention legislation must require that any national commission or advisory board focusing on public health, wellness, prevention, early intervention, and health system reform include mental, behavioral, and physical health experts with expertise in disability and chronic conditions. Congress should ensure programs and funding are sufficient to develop effective curriculums, provide technical assistance, and ensure adequate diversity training of health care providers, especially training related to disability awareness and the specific knowledge base necessary to treat individuals with disabilities.

VII. Long Term Care Services and Supports

We commend the Committee for including discussion of and policy options regarding *Long Term Services and Supports* (long term care). We appreciate the Committee's recognition that while approximately 46 million Americans do not have medical insurance, over 200 million Americans lack any insurance protection for the costs of long-term services – such as personal assistance with daily activities, assistive technology, and other supportive services.

Long-term services and supports are essential to sustaining a productive life in the community, maintaining function, preventing the development of secondary conditions, and promoting the health and well-being of Americans with disabilities of all ages. In fact, in order to provide real health security, long-term services and supports must be included in health care reform. We thank the Committee for doing so.

Nearly half of all funding for long-term services is provided through Medicaid which requires individuals to impoverish themselves to receive supports. There is an institutional bias within Medicaid that denies people an equal choice for home and community services. However, over 85% of all long-term services are delivered informally and only 3% of adults have long-term care insurance. We also believe that long-term services and supports should be consistent with principles of self-determination and that individuals should be able to choose consumer-managed and directed supports that provide increased decision-making authority to people with disabilities, with support of their family and friends.

While our comments below reference the policy options highlighted in the paper, we urge that final health care reform legislation adopt a two pronged approach to long-term services and supports: 1) Establish a national program to finance long-term services and supports consistent with the Community Living Assistance Services and Supports (CLASS) Act (S. 697); and 2) Make improvements to strengthen long-term services and supports within Medicaid. Establishment of the CLASS Act would help address growing needs of individuals and families for long-term services as the U.S. population ages. It would relieve pressure on the Medicaid program and allow for much needed improvements, many of which are highlighted below. In addition, we also urge the Committee to include the Community Choice Act (S. 683), which is a longstanding goal of the disability community.

Medicaid Home and Community Based Services (HCBS) Waivers and the Medicaid HCBS State Plan Option (pages 49-50)

We strongly support allowing states to seek approval from the Secretary to offer additional services under the 1915(i) Medicaid HCBS State Plan Option. This will encourage additional states to take up the HCBS State Plan Option and benefit more individuals with disabilities. We also support allowing individuals to simultaneously enroll in more than one Medicaid waiver.

Eligibility for HCBS Services (pages 50-51)

We support the proposal to decouple institutional level of care with eligibility for 1915(c) HCBS waiver services. The policy options paper references replacing level of care requirements for waivers with less restrictive requirements, but we urge the committee to ensure that states also have the option to make their institutional level of care requirements more restrictive, or to do both. This would allow states to restrict access to institutional services while permitting them to serve individuals who, because they did not meet institutional level of care, were denied HCBS services. This would have a significant, positive impact on states' attempts to rebalance their systems and reduce waiting lists for HCBS services.

We support the proposed option to eliminate the prohibition against providing section 1915(i) services to people with incomes above 150 percent of poverty and to allow states the option of conferring eligibility for Section 1915(i) HCBS services as well as full Medicaid benefits

to individuals with income up to a specified level established by the state, but no greater than 300 percent of the maximum federal SSI payment. This provision would close a gap in eligibility between institutional services and Section 1915(i) HCBS services, ensuring that people would not fall through the gap between 150 percent of poverty in the community and the institutional level chosen by the state up to 300 percent of the maximum federal SSI benefit level. By leveling the playing field for this aspect of financial eligibility, this provision helps to eliminate an institutional bias in the Medicaid long term services program for those people qualifying at modestly higher income levels.

In addition, we support ensuring that people with Miller Trusts (Section 1917(d)(4)(B)) can qualify for Section 1915(i) and other Medicaid benefits through the special income rule eligibility pathway. However, we are concerned about possible future misinterpretations and we urge the Committee to ensure that the language could not inadvertently disadvantage people using the other two trusts: individual trusts (Section 1917(d)(4)(A)) and the pooled trusts (Section 1917(d)(4)(C)). It is our understanding that persons using those trusts are eligible for full Medicaid benefits, including HCBS services. We want to ensure that the reference to the Miller Trusts cannot be interpreted to exclude people who use the individual or pooled trusts from eligibility for full Medicaid benefits, including HCBS services. We recognize that Miller Trusts are composed of only pension, Social Security, and other income, and that the individual and pooled trusts contain assets.

Increase Access to Medicaid HCBS Waivers and the Medicaid HCBS State Plan Option (pages 51-52)

We are pleased to see the proposed options and appreciate the Committee's recognition that current statutory provisions of the 1915(i) state plan benefit and 1915(c) waivers permit states to limit (cap) the number of beneficiaries for these services and to maintain waiting lists. These limitations continue the present institutional bias in Medicaid and serve as barriers to more cost-effective and preferred home and community-based services. We welcome the Committee's emphasis on expanding beneficiary access to HCBS.

We support efforts to eliminate the institutional bias in Medicaid and believe that the proposed options to increase access to home and community-based services for individuals with disabilities of all ages are steps in the right direction. However, given the current economic crisis, we also recognize challenges in changing state behavior related to expanding access and note that state decisions related to budget shortfalls may well result in unintended consequences that would adversely affect participation under one or both authorities, such as states choosing to no longer maintain identifiable waiting lists or choosing to significantly reduce available supports services. We provide the following comments and recommendations to ensure that states would, in fact, *increase* access under both the 1915(i) state plan benefit and 1915(c) waivers.

States currently use the ability to cap HCBS waivers as a means to control and predict their Medicaid HCBS costs. Removing this tool creates an entitlement to Medicaid-funded HCBS services for any Medicaid-eligible individual who meets the program's level-of-care criteria and we are on record as supporting this change. We are in strong support of ensuring that every Medicaid-eligible beneficiary who needs HCBS has access to these services. However, we are concerned that, if this policy option is not accompanied by significant additional funding, it may have the unintended consequence of reducing participation in

HCBS through states addressing budget challenges by using other means to control the cost of their waiver programs. In the face of severely restricted budgets, States could decide to control spending by tightening level-of-care criteria to reduce the numbers of individuals served, significantly reducing benefit packages, or discontinuing their waiver programs or HCBS state plan options altogether.

States often use *state only* dollars, forgoing federal Medicaid match funding, to provide HCBS outside of Medicaid-funded HCBS services. Therefore, it is certainly in the interest of states to maximize the Medicaid federal funding to expand access to HCBS. However, in a budget environment that does not allow for borrowing or deficit spending, there is a competing drive to control cost through limiting beneficiaries from accessing HCBS.

We urge the Committee to consider the proposed options to increase access under both the 1915(i) and 1915(c) authorities in combination with other Committee changes to Medicaid—including an increase in the HCBS FMAP and targeting of higher levels of enhanced FMAP to help states that lag behind in expanding HCBS to individuals with disabilities of all ages. We support the following approaches to ensure real change in behavior of states:

- Provide a significant FMAP increase (3 percent to 5 percent) to provide states with the way to pay for significant increases in numbers of **new individuals enrolled** in both authorities. The increased FMAP should only apply to new enrollees, not to improving the level of services and supports to current enrollees, and as a means of **diverting** beneficiaries from being forced into institutions as the only means to obtain long-term services and supports, and removal of beneficiaries from waiting lists. Within this range of increased FMAP, the federal funding could be targeted and made available to states that provide assurances that they will increase HCBS services on the basis of reaching specific percentage increase in enrollees (10 percent, 20 percent) within specific periods of time. This financing option might enable states to increase the number of persons under the cap, but would not be sufficient funding to enable states to totally eliminate waiting lists.
- Provide 100% FMAP targeted to states that have, until now, invested in serving only 50 percent or fewer of eligible individuals in HCBS to increase access for new enrollees in HCBS. The increased federal funding could be made available to states that provide assurances that the state will reach specific realignment goals by specific years.

Increase Federal Match for Medicaid HCBS (page 52)

We strongly support increasing the FMAP for HCBS under Medicaid. While this is a step in the right direction, we believe that a one percent increase may not be sufficient to change state behavior. We also urge the Committee to consider a higher level that could be targeted (as demonstrated above) to have a greater impact on the policy objective of assisting states to rebalance their systems and reduce waiting lists for HCBS services. A targeted FMAP increase would also benefit the economy by producing new jobs. For every \$1 billion dollars allocated to states through an increased FMAP targeted towards increased access to services, an estimated 24,340 full-time direct support jobs could be created and administratively supported.

Medicaid Spousal Impoverishment Rules (pages 52-53) and Medicaid Resource/Asset Test (page 53-54)

We support the proposed options designed to address Medicaid spousal impoverishment rules and to address the Medicaid resources/assets test. By allowing the states to provide for protection of spouses for people receiving HCBS services and to allow for higher asset/resource levels for people using HCBS services, Congress would again be eliminating an aspect of the institutional bias in the Medicaid program. We believe that the states should be required to couple these two provisions to ensure equity at the state level as discussed below.

We urge the Committee to avoid creating an inconsistency in the treatment of single individuals and married individuals. If the Committee adopts only the option regarding spousal impoverishment rules, then an inequity may be created in the asset limits, and therefore the living conditions, of beneficiaries who are single versus those who are married and enjoy the increased resources of the “community spouse” with whom they are living. Like married couples and the “community spouse”, the single beneficiary living in the community would also face the costs of rent or mortgage, food, home repairs, utilities, and other expenses of living in the community not covered by the Medicaid benefit. Improving the financial status of the community spouse alone does not improve the situation for the single beneficiary. Therefore, we believe that the improvements to the spousal impoverishment rules should be coupled with the option to allow individual beneficiaries to retain higher levels of assets. Together, these two provisions would assist in eliminating another aspect of the institutional bias in Medicaid.

We also support the proposed option to reset the look-back period for asset transfers to 36 months.

Long Term Care Grants Program (pages 54-55)

We recommend that any grant programs must address not only the needs of older individuals, but also the needs of individuals with disabilities across the lifespan. Nearly half of all individuals who need long-term services and supports are under 65 years of age.

We strongly recommend the addition of a separate funding mechanism to address the current shortage and looming crisis in the recruitment and retention of direct support professionals (i.e. direct support workers, personal assistants) who daily assist individuals with disabilities to live and work in their communities. These “frontline” workers enable people of all ages with a wide range of disabilities to function within their homes and communities with hands-on assistance with their daily activities and most intimate needs, such as eating, bathing and toileting, dressing, meal preparation, mobility and transportation, and vocational training. This workforce also provides family caregivers with much needed respite care.

The demographic imbalance between consumer demand and worker supply will result in substantial shortages and frustrate the recruitment, retention, and training of DSP's. Failure to address the workforce crisis will have a major impact on the future cost and availability of home and community-based services and supports.

While the Committee is considering options to address the *health care* workforce (licensed professionals, such as physicians and nurses)—including a national commission—we urge the Committee to include focus on the frontline workforce that provides long-term services and supports for people with disabilities of all ages.

We recommend the following:

- Provide an enhanced FMAP to states for a limited period of time to increase wages and benefits for direct support professionals who provide assistance to individuals of all ages with disabilities.
- Provide designated federal funding to states to create statewide commissions that bring together stakeholders - including individuals with disabilities, families, providers of long-term services, and workers - representing the elderly and people with mental disabilities, physical disabilities, and intellectual/developmental disabilities, to recommend a system to set wages and benefits to address recruitment, retention, and quality within the long term services workforce; facilitate the training and recruitment of direct support workers; and identify alternative successful retention strategies.
- Create an HHS National Direct Support Commission that includes representatives of all stakeholders including individuals with disabilities of all ages, families, providers of long-term services, and workers.

Money Follows the Person Rebalancing Demonstration (page 56)

We strongly support extending the demonstration for five more years. These grants to states provide an important means of targeting Medicaid funding for states to move individuals from institutions into home and community settings.

Working People with Disabilities

Health care reform may also be an avenue for addressing the changes needed in Medicare, Medicaid, SSI, and SSDI to remove barriers to work for adults with disabilities. Many people with significant disabilities are discouraged from working because their health care coverage is tied to these federal programs. We encourage the Committee to address issues like reconciling the Medicaid buy-in program with the normal retirement age and addressing work disincentives for those transitioning from SSI to SSDI.

VIII. Health Disparities and Public Reporting

CCD is particularly pleased with the proposal to add disability as a health disparity category alongside race, ethnicity, gender, and rural status. We also strongly support requirements for CMS to determine where people with disabilities access primary care and the number of providers with accessible facilities and equipment to meet the needs of persons with disabilities. The addition of “disability” as a category for purposes of tracking health disparities is a significant advance for those with chronic illnesses and disabilities, as ongoing monitoring and reporting will raise the awareness level on the disability population’s unequal access to quality health care services.

Required Collection of Data

Upgrades to the Social Security Administration’s (SSA) computer system, as provided for under the American Recovery and Reinvestment Act of 2009 (P.L. 111-5), should also include the capability to collect disability data on Medicare enrollees along with data on race, ethnicity, and language. This data is essential so that researchers to have access to data at a

scale that will enable them to investigate the reasons for health disparities experienced by people with disabilities and produce meaningful results. This tool of potential data therefore represents an invaluable resource.

Data Collection Methods

Federal research agencies collect a broad range of data for measuring disparities in the quality of and access to health care for various racial and ethnic groups, yet even when sponsoring agency surveys contain questions that 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 also collect sufficient data on people with disabilities to generate statistically reliable estimates in studies comparing health disparities populations.

Language Access

We commend the Committee for proposing an option that would extend the 75% matching rate for translation services to all Medicaid beneficiaries for whom English is not the primary language and that would establish culturally and linguistically appropriate service (CLAS) delivery standards for private insurers in the Health Insurance Exchange. We recommend that these standards also include coverage of American Sign Language interpreters for people who are deaf.

Conclusion

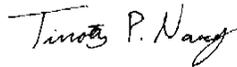
Thank you for your leadership on the critical issues addressed in these proposals. We appreciate the opportunity to provide comments and look forward to working with you and your staff to ensure passage of meaningful health reform legislation for all Americans, including people with disabilities and chronic conditions this year.

Sincerely,

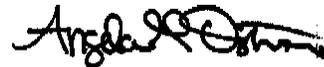
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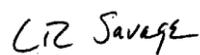
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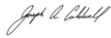


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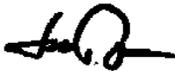
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