CONSORTIUM FOR CITIZENS WITH DISABILITIES

Comments of the

Consortium for Citizens with Disabilities

Before the

National Commission on Fiscal Responsibility and Reform

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At the dawn of the 21st Century, a number of laws stand to protect, provide for, and assist people with disabilities. Some are longstanding entitlements, such as Social Security cash benefits and Medicaid and Medicare health care and long term services and supports. Some provide for innovative approaches, such as the Assistive Technology Act of 1998. Some protect and provide services for children and families, such as Child Abuse Prevention and Treatment Act.

Other laws stand to protect the rights of people with disabilities. The Individuals with Disabilities Education Act (IDEA) protects the rights of children with disabilities to obtain a free and appropriate public education. The Fair Housing Amendments Act (FHA) protects against discrimination in Housing. The Air Carrier Access Act (ACAA) protects against discrimination in air transportation. The Rehabilitation Act protects against discrimination in employment, training and any program that receives federal funding; and the Help America Vote Act (HAVA) ensures full access to participation in the electoral processes of our country.

The Americans with Disabilities Act (ADA), is the most comprehensive federal civil-rights statute protecting the rights of people with disabilities to date. It affects access to employment; state and local government programs and services; places of public accommodation, and telecommunications. The legal and political roots of the ADA are deep in the civil rights movement, and its legal precedent lies in two great civil rights statutes, the Civil Rights Act of 1964 and Title V of the Rehabilitation Act of 1973.

Sadly, the promises of these and many more laws that address rights and services for children and adults with disabilities often remain unfulfilled.

Sound federal fiscal policy is critical to ensure adequate resources to support programs that promote the independence and productivity of children and adults with disabilities in the United States. Unfortunately, federal resources for these vital programs have been eroding over the past decade. The result of this lack of investment is that more, not fewer, children are deprived of all of the best in a free, appropriate public education. More, not fewer, people with disabilities find it hard to get and keep gainful employment. More, not fewer, families are financially devastated by the lack of assistance with excessive health care expenses for their family member with a disability. And more, not fewer communities are diminished by the lack of inclusion of and participation from some of their most valuable citizens, those with disabilities.

CCD supports working toward a strong economy. This can be accomplished if:

- Federal funding decisions and tax policy do not result in a federal budget that is crafted at the expense of people with disabilities;
- Services, supports, and benefits critical to the well-being of people with disabilities and their families are protected, improved, and expanded; and

- When needed, the federal government leads or assists states in being fair and efficient in carrying out their responsibilities to people with disabilities and their families.

Reductions in entitlement spending threaten the health care and quality of life for people with disabilities. Adverse Medicaid policy changes as well as changes at the state level could adversely affect our constituents. Since Medicaid finances lifesaving health care and long term supports for most of our vulnerable constituencies who receive supports, their futures are inextricably linked to any shift in Medicaid policy. Certain changes to our Social Security system also could have a devastating impact on beneficiaries and on human services funding.

The Consortium for Citizens with Disabilities urges the Commission to consider the following priorities:

- The failure of our nation, states, and communities to honor the civil rights of individuals of all ages with disabilities is a cost we cannot afford;
- CCD believes it is critical to let the potential savings realized from health reform begin to materialize before reducing critical health supports for people with disabilities;
- We urge the Commission to make no recommendations regarding [these] long term services and supports programs, instead allowing them to play out in the states and nationwide and allow their cost-effectiveness to take effect over time;
- Address the significant unmet needs of people with disabilities and their families by increasing existing federal funding and expanding the federal government's investment in people with disabilities to enable them to live and work as independently as possible in the community with appropriate flexible long term individual and family supports;
- Ensure that eligibility for services and benefits is not restricted and that the level of services and benefits for entitlement programs is not reduced or limited in order to achieve a balanced budget;
- Remove the Social Security Administration's administrative budget from any budget cap requirements for the Departments of Labor, Health and Human Services, and Education;
- Assure that the unmet needs of people with disabilities and their families are met before making further tax cuts or reforming tax policy in a manner that negatively affects low wage earners and other vulnerable people;
- Protect low income tax payers from paying higher taxes;
- Raise sufficient revenues to balance the annual budget and finance the federal government's role in providing essential supports, services, and benefits for people with disabilities and their families;
- Roll back or repeal tax cuts and adjust other tax policies that create a deficit or put existing disability programs at risk;
- Assure the continuing ability of non-governmental entities to support people with disabilities and their families. and
- Recognize that Social Security is fully funded for more than 25 years; thereafter it has sufficient funds to meet 75 percent of promised benefits. To reassure

Americans that Social Security will be there for them, Congress should act in the coming few years outside the context of deficit reduction to close this funding gap and to ensure the long-term solvency of the Social Security trust funds.

There are three particular areas where CCD believes that reducing federal spending could have a particularly harmful effect:

- Employment;
- Health; and,
- Long-Term services and supports.

Employment

Employment and training activities for people with disabilities are an essential part of helping to reduce the federal deficit. Investment in these programs moves individuals towards becoming tax payers and has a long-term impact of reducing the need for increased federal spending on supports and services.

Receipt of Social Security disability benefits has often been described as "merely the last stop on a long journey that many people with disabilities make from the point of disability onset to the moment at which disability is so severe that work is, at least temporarily, not possible."[i] For other individuals with disabilities, such as those with life-long developmental disabilities, it is often not an issue of returning to work or maintaining employment but having the services and supports to secure employment. Reliance on services and supports to gain and maintain employment may be short lived or last a lifetime but it is a certainty that for these individuals Social Security benefits provide much needed income support and access to the services and supports to live and work independently in the community.

During the spring of this year, the Department of Labor Office of Disability Employment Policy [ODEP] conducted a series of listening sessions throughout the country from which it gleaned a wealth of information about challenges facing -- as well as models of effectiveness within – this nation's disability employment services system. ODEP found an ongoing need for better coordination of programs and services that help people with disabilities get and keep a job. Witnesses repeatedly called for changes in policy that eliminate Social Security work disincentives. There are still too many individuals with disabilities barred from the workforce due to inadequacy of accessible technology. At the same time, these forums heard praise for programs that provide service coordination for employment of youth with disabilities, benefits counseling to help people navigate the complexities of working with a disability, independent living services that advance community integration and self-sufficiency for those with disabilities and supported and customized employment programs that enable those with the most significant disabilities to thrive in the workforce. Many stakeholders with disabilities reported that the Medicaid infrastructure grants and Medicaid buy-in programs have been a lifeline providing them health care and long term services that are critical to their ability to work.

Recent evaluations of Social Security's Ticket to Work Program discovered that 40 percent of all disability beneficiaries want to work and that those who participate in the Ticket program "are more likely to leave the rolls because of work than non-participants, and they remain off the rolls longer." Moreover, when a cohort of beneficiaries was followed over a long period of time, the research revealed that Social Security "does not so much have a problem with getting people to work – SSA has a problem with keeping people at work." [ii]

The Administration has proposed the elimination of several small employment programs for persons with disabilities including supported employment state grants, Projects with Industry, Migrant and Seasonal Farmworkers, and AgrAbility. Rather than eliminating this type of programs, they should be expanded since they help persons with disabilities become tax payers instead of having to rely on Social Security and other government programs. Increased funding for employment programs will have a positive benefit on the growing deficit.

As demonstrated through these and many other public forums and research studies, millions of people with disabilities want to work, want to be part of their communities want to be contributing members of society. In order for them to do so, this requires sufficient direction of public dollars to many of the discretionary programs now drawing scrutiny from this Commission. In order to ensure that citizens with disabilities are afforded the opportunity to be engaged in their communities and live active and productive lives, it is essential that funding for these various programs continue. When these programs are forced to endure severe reductions or even elimination, it will be the Social Security disability system that bears the consequences of those actions.

Health

The new health reform law will extend coverage to over 30 million uninsured Americans and provide important consumer protections to tens of millions of insured Americans whose coverage may have critical gaps. This is a significant issue for people with disabilities.

The unrelenting and unsustainable reality of America's health care system suggested to law makers that the cost of doing nothing was not a viable option. With the recent passage of health reform, an expected $143 billion, will be saved according to the Congressional Budget Office and bring down the federal budget deficit by about one-half percent of GDP in the next decade. Health reform also includes an extensive array of provisions that hold considerable potential for slowing the growth in health care costs over the long haul.

The following reflect major sources of savings through health reform:

- Reducing Medicare Advantage overpayments. The Medicare Advantage program provides coverage to about one-quarter of Medicare beneficiaries through private insurance companies. Currently, Medicare pays those insurers about 13 percent

more per beneficiary, on average, than it would cost to cover these beneficiaries in traditional Medicare. The health reform law scales back these overpayments;

- Reducing Medicare fee-for-service payment rates. The health reform law reduces Medicare's annual payment updates to hospitals, skilled nursing facilities, and certain other providers, in part to account for improvements in economy-wide productivity. It also reduces payments to home health agencies and inpatient rehabilitation facilities, as the Medicare Payment Advisory Commission (Congress's expert advisory body on Medicare payment policies) has recommended;
- Reducing Medicaid prescription drug costs. To participate in Medicaid, drug manufacturers must pay rebates to the federal and state governments for prescription drugs dispensed to beneficiaries. The health reform law will increase those rebates to continue to ensure that state Medicaid programs pay no more than private purchasers for the same drugs, and;
- Reducing spending for hospitals serving the uninsured. Because the health reform law expands coverage and shrink the ranks of the uninsured, it will reduce the amounts that Medicare and Medicaid provide hospitals for treating uninsured patients.

The following reflect major sources of revenue through health reform:

- Increasing the Medicare tax on those with high-incomes. The health reform law raises the Medicare tax rate for individuals with incomes over $200,000 and couples with incomes over $250,000. It also extends the tax to these households' dividend, capital gains, and other unearned income;
- New fees on drug companies, medical device manufacturers, and health insurers that will gain new customers as a result of the expansion of health coverage. Imposing employer and individual responsibility requirements. The health reform law requires larger employers to share the responsibility for assuring that their employees have health coverage. Large firms that employ full-time workers who get subsidized health insurance in the new insurance exchanges — rather than through their employer — will pay a penalty. In addition, individuals who do not have health coverage will face a modest penalty, unless coverage would not be affordable for them, and;
- Imposing an excise tax on high -cost health plans. To help reduce the growth in health care costs over time, the health reform law imposes an excise tax on very high-cost plans offered through employers.

Overall, health reform will reduce the nation's deficit. Constraining health care spending has been part of the health reform debate from the very beginning, and CCD believes it is critical to let the potential savings realized from health reform begin to materialize before reducing critical health supports for people with disabilities.

Long-Term Services and Supports

Nationally, 73% of Medicaid long-term services' resources devoted to older people and adults with physical disabilities are spent on institutional services, even though most beneficiaries prefer the less expensive and more cost-effective home and community-based services. Faced with a growing population of baby-boomers that will need long term supports and services over the coming decades, the current system places growing fiscal pressure on federal and state governments and leaves many consumers unable to get the services and supports they need to live at home.
Most individuals with a significant disability who need long term services and supports (LTSS)—whether the need occurs at birth, before adulthood, or at any time during their working life—have few options for financing the cost of these services. Many individuals rely on their own resources and help from family members. Private long-term care insurance, where available, is not the answer for most people because it is often too expensive, does not provide life-time guarantees, or covers limited and inflexible options.

The federal-state jointly financed Medicaid program -- primary payer for the cost of LTSS—is generally only available when individuals have depleted virtually all their assets to qualify. In addition, the only guaranteed provision for Medicaid LTSS is the nursing home institutional setting. All other Medicaid LTSS provisions are state options.

Health reform ushered in significant improvements that will promote greater independence, choice, dignity, and personal responsibility for people who need long term services and supports. These changes also offer cost-effective public and private approaches to the long-term fiscal challenges of Americans of all ages who need vital long-term supports and services. These changes will result in:

1) reducing Medicaid's institutional bias;
2) enhancing state options for the most cost-effective and consumer-preferred and self-directed Medicaid home and community based services;
3) establishing a new voluntary, actuarially-sound, premium-based, national long term services insurance option that enables most Americans to take personal responsibility for planning and saving for future long-term supports and services—without having to impoverish themselves to become eligible for Medicaid; and
4) helping to reduce future federal and state Medicaid expenditures on LTSS.

Specifically, the new health reform law includes a voluntary, self-financing national insurance program for LTSS. The Community Living Assistance Services and Supports (CLASS) program takes a major step forward in addressing the financial costs most American households will face when confronted with the high cost of long term care. It provides a flexible means for individuals to take personal and fiscal responsibility for planning and saving for their future need for these services —whether the individuals need and choose LTSS to live and work in their own home or community or if they choose institutional settings.

The CLASS program offers a fiscally sound solution to this financing challenge that:

- Is financed through private contributions, requires no lifetime caps, and requires no medical underwriting to participate;
- Makes the program primary payer for CLASS participants who still retain eligibility for Medicaid;
- Promotes work by making enrollment a payroll deduction based process;
- Requires premium financing that ensures 75-year solvency and requires participants to continue paying premiums to continue receiving benefits;
- Enables individuals of all ages with disabilities who meet the functional level of need for LTSS to receive services and supports so that they may continue working and paying local, state and federal taxes;
- Reduces the need for individuals with disabilities of all ages to impoverish themselves and be forced to enroll in the federal and state jointly-financed Medicaid program, and;
- Reduces future federal and state Medicaid expenditures on long-term services and supports.

The CBO estimated federal Medicaid savings of $2 billion in the initial CLASS benefit-paying years._This estimate, of course, does not reflect savings to local and state Medicaid programs.

In addition to our support for CLASS, CCD has advocated for years to end Medicaid's institutional bias that provides nursing homes as the only guarantee for long-term services. Health care reform also contained a number of important provisions that begin to move our nation away from this heavy reliance on institutional long term care.

Improvements to Medicaid's LTSS options in the new law include:

- The Community First Choice program, which creates a state plan option for certain HCBS to individuals with disabilities who require an institutional level of care. States would be eligible for an enhanced federal match rate of an additional six percentage points for reimbursable program expenses that enable individuals to live and work in their own homes and communities;
- Removal of Barriers to Providing Home and Community-Based Services provision, which offers incentives to states to enhance alternatives to institutional services. The provision temporarily increases the federal matching rate for HCBS for states that undertake structural reforms to increase diversion from institutions (including nursing homes and intermediate care facilities for people with intellectual and developmental disabilities) and expand the number of people receiving HCBS under Medicaid. States could offer HCBS through a waiver or state plan amendment (SPA), with those choosing a SPA allowed to include individuals with incomes up to 300% of SSI, and;
- Money Follows the Person, which extends the popular Money Follows the Person demonstration grants that help state Medicaid programs defray the cost of moving eligible Medicaid beneficiaries who have resided in an institutional setting (nursing home or intermediate care facility for persons with intellectual and developmental disabilities) into the home and community.

We urge the Commission to embrace the CLASS program as a valued and cost-effective option for addressing our nation's long-term fiscal challenges and to make no recommendations regarding these long term services and supports programs, instead allowing them to play out in the states and nationwide and allow their cost-effectiveness to take effect over time. CCD recommends that the Commission recognize the importance of the recent enactments of long term services and supports provisions and the positive effect they will have in meeting future long-term fiscal challenges and reducing the costs of the Medicaid program.

Finally, we ask the Commission to consider how all of these programs that serve individuals with disabilities will allow the nation to address the promises of the Americans with Disabilities Act and the U.S. Supreme Court's *Olmstead* decision. The failure of our nation, states, and communities to honor the civil rights of individuals of all ages with disabilities is a cost we cannot afford.

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[i] Joan Durocher, National Council on Disability, to the Social Security Advisory Board, January 31, 2006

[ii] Center for Studying Disability Policy, Mathematica Policy Research Inc. Forum, "A Dynamic Perspective on the Employment of Social Security Disability Beneficiaries, May 19, 2010