Commemorating 40 Years
Of Disability Advocacy
1973-2013

September 30, 2013

The Honorable Max Baucus
Chairman
Senate Finance Committee
219 Dirksen Senate Office Bldg.
Washington, D.C. 20510

The Honorable Orrin G. Hatch
Ranking Member
Senate Finance Committee
219 Dirksen Senate Office Bldg.
Washington, D.C. 20510

Dear Chairman Baucus and Senator Hatch:

The Consortium for Citizens with Disabilities (CCD) Health Task Force is writing in response to your letter of August 1, 2013 seeking better solutions to financing improved community-based services for people living with severe mental illnesses. CCD is a coalition of national disability organizations working together to advocate for policies that ensure the self-determination, independence, empowerment, integration and inclusion of people with disabilities in all aspects of society.

Background:

Consistent with the Supreme Court holding in *Olmstead v. L.C.*, 527 U.S. 581 (1999), CCD has long advocated for changes in Medicaid law that support community living for people with disabilities. Over the past five decades, persons with serious mental disorders have made significant strides in living with their fellow citizens in communities across the nation. Specifically, at the dawn of the "de-institutionalization" movement in late 1960s, fully 500,000 people with schizophrenia, bipolar disorder and other mental disabilities lived in state psychiatric hospitals fulltime – often in horrific conditions. Today, those same facilities serve fewer than 60,000 Americans.

At the same time, the failure of federal and state governments to provide appropriate community-based services and housing for individuals with mental disorders has resulted in what is now commonly called the "re-institutionalization" of children and adults with mental illnesses. This phenomenon has several manifestations. First and foremost, relative to Medicaid reimbursement practices, documents from the Center for Medicare and Medicaid Services (CMS) provided in response to Freedom of Information Act requests show that more than 125,000 disabled, non-elderly adults with serious mental illnesses lived in U.S. nursing homes in 2008. That represented a 41% increase from 2002, when nursing facilities housed nearly 89,000 people with mental illnesses aged 22 to 64. Most states saw increases, with Utah, Nevada, Missouri, Alabama and Texas showing the steepest climbs. Overall, in 2008 non-elderly adults with serious mental disorders made up more than 9% of the nation's nearly 1.4 million nursing home

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residents – with the number continuing to increase given significant state mental health funding reductions that began in earnest in FY 2009.

Another indicator of "re-institutionalization" is the percentage of persons with mental illnesses incarcerated in penal facilities at all levels. In a 2006 Special Report, the U.S. Justice Department's Bureau of Justice Statistics (BJS) estimated that "705,000 mentally ill adults were incarcerated in State prisons, 78,800 in Federal prisons and 479,900 in local jails." In addition, research suggests that "people with mental illnesses are overrepresented in probation and parole populations at estimated rates ranging from two to four times the general population (Prins and Draper, 2009). Indeed, the Los Angeles and Cook County jail systems often vie for the title of the largest inpatient psychiatric hospitals in the United States.

President George W. Bush's New Freedom Commission on Mental Health summed it up best, when it declared more than ten years ago that,…."the mental health delivery system is fragmented and in disarray….lead[ing] to unnecessary and costly disability, homelessness, school failure, and incarceration."

Senate Finance Committee Questions

I. "What administrative and legislative barriers prevent…….Medicaid recipients from obtaining the mental and behavioral health care they need?"

In brief, Medicaid still maintains a strong institutional bias. Currently 57% of Medicaid's long term services and supports funding goes to institutional care. This bias towards institutional care is due to the fact that nursing homes are mandatory for states, while various Home and Community Based Services (HCBS) are optional.

There are cost-effective community-based services and supports that enable people with even the most significant mental health needs to recover and succeed and which states can choose to cover through the Medicaid program. These services include ACT (assertive community treatment), supportive housing, supported employment, mobile crisis services, peer support services, and intensive case management. States have not sufficiently invested in these services, however, and as a result have continued to spend money on costly services in hospitals, emergency rooms, shelters, jails, and prisons.

II. "What are the key policies that have led to improved outcomes for beneficiaries in programs that have tried integrated care models."

The answer is twofold. With respect to improved outcomes, states currently have two main options to fund HCBS – the HCBS waiver (Section 1915(c)) or the HCBS state plan option (Section 1915(i)). The 1915(c) waiver rarely applies to Medicaid beneficiaries with mental illness because it is only available to individuals who qualify for an institutional level of care – and Medicaid is prohibited from paying for inpatient psychiatric services for adults with mental illnesses. Under this waiver, states can cap the number of eligible people, maintain waiting lists, and limit services to certain geographic areas. Additionally, states must apply for renewal of the waiver from Medicaid, which is a complex and lengthy process.

The 1915(i) state plan option, on the other hand, allows states to have eligibility that is below the institutional level of care – before people need nursing home care. Due to amendments made in the Affordable Care Act, the 1915(i) state plan option no longer allows states to cap the number of eligible people, keep waiting lists, or limit services to certain geographic areas. They may target services to certain populations such as persons with severe mental illnesses.

The 1915(i) option can also be used to provide all of the community-based services listed above, which have proven extremely effective in producing good outcomes. They dramatically reduce hospitalizations and health care costs, and enable individuals with serious mental illnesses to maintain housing, find and maintain employment, and stay engaged with families and friends. Only a handful of states, however, have used the 1915(i) option to cover services for individuals with mental illness and many thousands of individuals who need these services do not receive them.

When states choose to use these options, they are very effective. In one prominent example, the Oregon Health Authority has been particularly innovative in using 1915(i) state plan services both to integrate services and facilitate community integration for individuals with conditions like schizophrenia or bipolar disorder. Under the Oregon approach, habilitation services have been added as a new service option enabling community providers to assist an individual to acquire, retain or improve skills across a range of daily living activities including cooking, mobility, socialization and adaptive skills.

Of particular significance, the Oregon 1915(i) option actively integrates habilitation services with personal care and rehabilitative services – while specifically authorizing the provision of an integrated services package to Medicaid recipients living in the community including their own home, a family home, or in supported housing.

III. "How can……Medicaid be cost-effectively reformed to improve access to and quality of care for people with mental and behavioral disorders."

The answer to this critical question involves a mix of enacting new Medicaid financing mechanisms, removing Medicaid barriers that prohibit payment for key services, and encouraging states to employ Medicaid options available in current law.

Enact the Stabenow/Blunt Excellence in Mental Health Act.

S. 264 takes a substantial step toward improving access to care by providing a secure source of Medicaid financing for an array of intensive community-based mental health services for persons with serious and persistent mental illnesses. Specifically, Stabenow/Blunt requires that certified Community Behavioral Health Clinics provide targeted case management, crisis mental health services, psychiatric rehabilitation and other intensive community-based interventions to low income children and adults with severe mental disorders. The Senate Finance Committee faces a straightforward choice: either improve reimbursement for these critical community interventions or continue current policies that encourage the "re-institutionalization" of persons living with mental illnesses in nursing facilities and America's prison system.

Encourage States To Pursue Existing Medicaid Optional Community Programs.

The ACA expanded community-based programs, such as the 1915(i) option and the Money Follows the Person Program, and created new community-based options, such as the Community First Choice option (to cover attendant services and supports with an enhanced federal match) and the Balancing Incentives Program (providing an enhanced federal match for states to reduce expenditures for institution-based services and increase expenditures for community-based services). Despite the availability of additional options, few states have taken advantage of them. Congress should take steps to encourage more states to utilize these options to provide necessary community-based services and supports to individuals with mental illness.

Increasing our investment in these community options would allow states to provide the core services that enable people with serious mental illnesses to live successfully in their communities. It would dramatically improve the lives of individuals with significant psychiatric disabilities and also reduce costs to state and federal governments. Strategies such as enhancing the federal Medicaid match for these services and streamlining and simplifying Medicaid home and community-based waiver programs and other state options would make a significant difference in making these services more available and avoiding needless and costly institutionalization. Making these services more available would also promote states' compliance with the Americans with Disabilities Act and the Supreme Court's decision in Olmstead vs. L.C., requiring states to administer services to individuals with disabilities in the most integrated setting appropriate to their needs.

Continue Emphasis On Finding Long-Term Solutions.

CCD strongly believes individuals and families should not be forced to impoverish themselves to cover the costs of services they or their family members need in the event of disability or advancing age. However, for many individuals with disabilities and their families, Medicaid is the only option for paying for long-term services and supports. Providing long-term services and supports puts enormous strain on both families and the federal-state Medicaid program. We urge Congress to address the impending crisis in financing long-term services and supports confronting our nation.

In conclusion, NOW is the time to act on improving community-based care for people with psychiatric disabilities. The disability community will work side-by-side with you as the Senate Finance Committee seeks better solutions in this critical area.

Sincerely,

The CCD Health Task Force Co-chairs: Mary Andrus, Easter Seals, Lisa Ekman, Health and Disability Advocates, Theresa Morgan, American Academy of Physical Medicine and Rehabilitation, Peter Thomas, Brain Injury Association of America, Julie Ward, The Arc

The CCD Long Term Services and Supports Co-chairs: Maureen Fitzgerald, The Arc, Lee Page, Paralyzed Veterans of America, Laura Weidner, National Multiple Sclerosis Society