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Before the Senate Committee on Health, Education, Labor and Pensions

Roundtable Discussion: "Moving Toward Greater Community Inclusion—*Olmstead* at 15"

Tuesday, June 24, 2014

Thank you Mr. Chairman, Ranking Member Alexander, my own Senator, Senator Hatch, and members of the Committee, for inviting me to participate in this roundtable discussion about the progress made, current challenges, and the future for more than fifty-six million Americans with disabilities[1] as a result of the Americans with Disabilities Act[2] celebrating its twenty-fourth anniversary next month and the United States Supreme Court *Olmstead*[3]*vs. L.C.* decision that was issued fifteen years ago this past Sunday. The focus of my comments today surround efforts to realize *Olmstead's* promise of creating and providing more home and community-based supports and services (HCBS[4]) for individuals with disabilities and their families throughout this nation.

The *Olmstead* decision requires states to make reasonable modifications in their policies and long-term services and supports (LTSS) so that people with significant disabilities can leave state institutions and nursing homes or not enter such facilities in the first place. *Olmstead* recognized that people with disabilities should have the choice of where they want to live and the services they need should follow them. *Olmstead* reversed a long-time trend of funding institutions and limiting choice to that option only. Since the *Olmstead* decision, an increase of about one-million-one-hundred thousand people have benefited from HCBS without first becoming institutionalized, and about three-hundred thousand people have left institutions to live in homes and communities of their choice. These changes in policies are to a large degree, based on improvements in the federal/state partnership in the Medicaid[5] program administered by the Center for Medicaid and Medicare at the Department of Health and Human Services.

However, more changes in federal policy readily can be made to allow states to implement increased changes that will increase the quality of life even more for people with disabilities. And Medicare[6] can be modernized to reduce costs and provide for LTSS in home settings.

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[1] About 56.7 million people — 19 percent of the population — had a disability in 2010, according to a broad definition of disability, with more than half of them reporting the disability was severe, according to a comprehensive report on this population released by the U.S. Census Bureau July 2012.

[2] Public Law 101-336; Stat. 104 Stat. 327

[3] *OLMSTEAD V. L. C*. (98-536) 527 U.S. 581 (1999) 138 F.3d 893, affirmed in part, vacated in part, and remanded.

[4] In 1981, Congress established the Medicaid Home and Community-Based Services (HCBS) waiver program. The HCBS waiver allows states to receive federal matching funds for a variety of residential services and supports to Medicaid beneficiaries who would otherwise require institutional care.

[5] Medicaid was created by the Social Security Amendments of 1965 which added Title XIX to the Social Security Act. Medicaid is capped based on income and other personal resources.

[6] In 1965 Congress created Medicare under Title XVIII of the Social Security Act to provide health insurance to people age 65 and older, regardless of income or medical history.

Currently, services for institutional care are mandatory under Medicaid, but merely optional for states to cover when providing HCBS. Despite efforts to reduce institutional care or rebalance Medicaid, the program is still weighted in favor of institutional facilities, instead of providing these services to people with disabilities as they live in their homes and communities. Fifty-seven percent of Medicaid's long-term care funding goes to institutional care. Today, states must request from the Center for Medicaid and Medicare Services a waiver[7] of the law through a complicated lengthy process to use funds for HCBS. This rationale is counter to the Supreme Court's *Olmstead* holding. To illustrate the point in real terms, today people with disabilities are entitled to go to a nursing home at an average cost of $62,750 per year. The same services, by contrast, can be provided in homes and communities at an average cost of $31,341 per year[8].

However, there is a cost savings solution to part of the problem. Stated simply, Congress could rebalance Medicaid's LTSS funds by equally funding nursing home care and HCBS at a 50-50 percent balance. This would give a 7% increase in HCBS without increasing appropriations from either state or federal dollars. This step would modernize the nearly fifty year old Medicaid LTSS system. This shift away from a bias toward institutional facilities to creating greater options for community living would also significantly improve the lives of millions of people with disabilities and their families---a cost savings with important and long-term rippling positive results for every American.

Senators, I am an example of the ADA. I have a significant disability. I graduated from college, graduate school, and earned a doctorate from Vanderbilt University, and I paid my own way. I paid off my student loans and rose to the rank of career senior executive service and served as a political appointee. I learned that the complexities of living with a disability required me to become an expert in planning for the fact that I would one day need LTSS. I saved a monthly percentage of my income for the time I would need to pay for LTSS. I am now at that time. I spend more than $4,000 per month in supports to remain in my home. Although I spend $4,000 per month I have no support services after about 7 pm weeknights, and no weekend or holiday assistance at all. The compliance process for directly hiring support staff is too complex and regulated to the point that I cannot manage all the federal laws to avoid a tax audit or other employment regulatory barriers. The current tax structure does not allow deductions until I reach the Internal Revenue Services' medical deduction threshold. I, like many people with disabilities, was never eligible for long-term care insurance because my condition was

[7] States have several options for funding HCBS – the HCBS waiver (Section 1915(c)), the HCBS state plan option (Section 1915(i)), the Community First Choice (CFC) Option (Section 1915(k)), and the Section 1115 Demonstration waiver. The 1915(c) waiver is only available to individuals who qualify for an institutional level of care. Under this waiver, states can cap the number of eligible people, keep 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 allows states to provide any number of HCBS to individuals before they need institutional care.

[8] See page 55 of Medicaid Managed Care for People with Disabilities: Policy and Implementation Considerations for State and Federal Policymakers, National Council on Disability, (www.ncd.gov), March 18, 2013.

considered pre-existing. Further, I cannot use Medicare because I am not eligible without first going to a three day stay at a hospital each year—by the way, I have not had an overnight stay in a hospital in more than thirty years. I have turned down a college presidency, promotions, and liquidated assets in attempts to simply hire in-home support services. I cannot access my retirement funds without substantial penalties to use for LTSS. I have been encouraged to declare bankruptcy by several program administrators as the only option to become eligible for LTSS. I spend countless hours each month tracking every expense to manage the tax system to remain independent.

I speak with many families and young adults with disabilities capable of pursuing college degrees, wonderful careers, and opportunities to become significant contributors to society and lead independent lives. It is difficult to explain that working hard leads to a lifetime of ineligibility to actually remain independent and that the current system, although not intentional, supports choices that lead to poverty, purposeful unemployment, and forced institutional living.

Olmstead continues to move positive change for our nation. The time has come to re-evaluate our system of providing long-term supports and modernize the system to encourage more independence especially for the millions of young Americans with disabilities to successfully contribute to their communities rather than live in poverty simply to have services.

While many doors have been opened, the lack of access to services and supports that allow people with significant disabilities to live and work independently while achieving even a modest level of economic security has hindered the progress that might otherwise have been made. For example, allowing states flexibility in a wavier program to create a risk pool for the only two percent of people who are ever expected to use LTSS with flexible criterion allowing people with disabilities to remain gainfully employed and advance in their careers would be one option that decouples the need for LTSS from the healthcare paradigm—this is not healthcare, it is support services like a worker helping a disabled professional dress for work every morning. Participation in a risk pool if CMS gave the state flexibility to design the program to promote gainful employment would be an option worth further analysis that could result in millions more Americans returning to higher paying careers if they could have some minimal hours of support at key times of the day.

I am prepared to discuss more specific detailed policy issues to increase access to independence, employment, increased access in the community, and ways to allow states greater flexibility to progress further and modify outdated policies that will fundamentally alter the lives of millions of Americans with Disabilities.

Thank you for the opportunity to appear before you today.