



Statement of

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Before the

**SUBCOMMITTEE ON HEALTH
HOUSE COMMITTEE ON ENERGY AND COMMERCE**

Regarding

**LONG-TERM CARE AND MEDICAID: SPIRALING COSTS
AND THE NEED FOR REFORM**

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Mr. Chairman, members of the Committee, my name is Lee Page. I am an Associate Advocacy Director for the Paralyzed Veterans of America (PVA). PVA is a non-profit national Veterans Service Organization chartered by the Congress of the United States and dedicated to meeting the needs of its members - veterans of military service who are paralyzed as a result of spinal cord injury or disease. While almost all PVA members rely on the Department of Veterans Affairs for

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health care and support services, potential changes to the VA system may have ramifications for other federal programs such as Medicaid. I also serve as a Co-Chair of the Long-Term Services and Supports Task Force of the Consortium for Citizens with Disabilities (CCD), a Washington-based coalition of a more than 100 national disability consumer, provider, and advocacy organizations. I work very closely with a range of national consumer-led disability organizations. As the Congress considers a range of policy options with regard to restructuring of Medicaid long-term services, I am here to offer a perspective from people with disabilities. I will focus my comments on issues affecting non-elderly people with disabilities. For non-veteran people with disabilities, Medicaid is perhaps the most critical program essential to their well-being. Let me also add the observation that cuts of the magnitude contemplated in the budget resolution will preclude any positive reforms that will be meaningful to the many people with disabilities who rely on Medicaid.

The first point that I would like to make is that more must be done to improve and expand access to community-based long-term services and supports. Currently, Medicaid has a spending bias based on a 1965 medical model that refers 70% of funding towards institutional settings and allows only 30% for community and home based long term supports and services.¹ At the dawn of the 21st century and 15 years after the passage of the Americans with Disabilities Act (ADA), people with disabilities are being integrated into all aspects of society. And yet, for the many people with disabilities that rely on Medicaid services, policies are being implemented or contemplated that will drive them back into isolation.

I believe that real and lasting progress in this regard will be made only if Congress protects the fundamental structure of the program that has enabled Medicaid to be a source of progress for the past four decades. Critical features of Medicaid that must be protected include an enforceable

individual entitlement to coverage; the strong federal-state partnership, in which the federal government guarantees that it will match state spending, no matter how many people the program serves or how costly the critical Medicaid services that are provided; and critical consumer protections that ensure that, with limited exceptions, all Medicaid beneficiaries have a right to be treated equally and have a right to receive Medicaid covered services when they are medically necessary.

Recently, HHS Secretary Leavitt has made statements that he believes that states should be given greater “flexibility” with regard to Medicaid's so-called optional populations and optional services.² From the disability community’s perspective, this so-called flexibility is more appropriately characterized as discrimination. The flexibility that is proposed would permit states to make arbitrary distinctions between Medicaid beneficiaries on the basis of whether they fall into mandatory or optional categories. This has nothing whatsoever to do with the level of disability, the need for services, or any factor that could justify disparate treatment. Furthermore, this so-called flexibility would permit states to ignore current Medicaid rules that ensure that services are delivered fairly—such as the requirement that benefits must be comparable across beneficiary groups. Since Medicaid services are provided only when they have been prescribed by qualified health professionals, this so-called flexibility could only lead to some Medicaid services being denied to people who need them. It is important to note that a significant proportion of people with disabilities qualify for Medicaid through optional eligibility categories. Further, the majority of Medicaid spending on people with disabilities is on optional services.³ Optional services are mainly disability focused. What may be considered optional by states and Medicaid administrators in some cases may be essential to a person’s efforts to remain independent and fully participate in the mainstream of society.

For Medicaid beneficiaries with disabilities, optional services are not optional. A 35 year old man with schizophrenia may have to take three prescriptions daily to avoid recurrence of symptoms that would place him in an institution. A 25 year old woman with cerebral palsy needs her wheelchair to continue to work part time. A 30 year old man who sustained a spinal cord injury resulting in quadriplegia needs attendant care in bathing, getting dressed, eating and transferring in order to go back to school.

I would like to turn to the important role of Medicaid in providing long-term services and supports to people with disabilities. In addition to Medicaid's role in providing a range of acute care services to people with disabilities, many people with serious and long-lasting disabilities end up on Medicaid because they require long-term services and supports. Medicaid is the largest source of funding for long-term care. The private insurance market generally does not provide long-term services, and Medicare's coverage for long-term services is very limited. People with disabilities often end up on Medicaid because it is the only place that they can turn to receive the array of services and supports that they need to survive. For people who are less familiar with these issues, long-term services and supports are generally non-medical services that provide assistance with core activities of everyday life such as eating and preparing meals, dressing and toileting, and managing a home or personal finances. These services are a critical part of the Medicaid program and were defined in the program's statutory purpose: "and (2) rehabilitation and other services to help such families and individuals attain or retain capability for independence or self care..."

I know that some proponents have advocated for a greater reliance on private long-term care insurance as a policy response to growing Medicaid costs for long-term care. I am skeptical that, without fundamental restructuring and greater regulation of the long-term care market, private long-term care insurance can ever develop into a viable tool for retirement planning or for helping

individuals and families to plan for long-term care needs later in life. However, it is clear that private long-term care insurance is not a policy solution for financing the long-term care needs of non-elderly people with disabilities. These policies were not developed for children, young adults and younger working people—and in the current market, such coverage would be unavailable or unaffordable to people with disabilities.

While Medicaid plays an essential role in providing long-term services, this is also an area where the program must do better. People with disabilities are looking to the Congress to urgently address barriers that prevent Medicaid beneficiaries with disabilities from receiving community-based long-term services. Medicaid law requires states to provide nursing home care, without requiring states to provide the same level and types of services in the community. This is the “institutional bias.” Hundreds of thousands of people with disabilities would like to and could live in their own home and community, if they received long-term services and supports that enable them to do so. According to CMS' Minimum Data Set -- Nationally, there are 1,404,406 persons (by definition they are disabled) residing in nursing homes of whom 19.5% (273,859 disabled persons) have stated they want to live in the community. But these individuals are forced to be segregated in an institution as their only option for receiving this assistance.

Virtually all policy makers agree with the disability community that we need to rebalance the Medicaid long-term care system so that all Medicaid beneficiaries have the option of receiving long-term services in their homes and communities. This issue was given momentum five years ago when the United States Supreme Court held in its *Olmstead*⁴ decision that the unjustified institutional isolation of people with disabilities is discriminatory and unlawful under the Americans with Disabilities Act. While this decision has enormous implications for Medicaid, it did not change

the Medicaid law or require an end to the institutional bias. The disability community's preferred solution is for the Congress to swiftly enact the Medicaid Community Attendant Services and Supports Act (MiCASSA), H.R. 910 and S. 401. This legislation would mandate that states offer home and community based services for those individuals with disabilities who are in or are eligible for institutional settings. Some policy makers have misgivings with the MiCASSA model out of concern for the potential cost. While we believe that the only meaningful solution to the challenge of providing expanded access to community-based services will require new resources, the disability community is also supportive of several other initiatives that would make incremental progress toward achieving MiCASSA's goals.

This includes strongly supporting the Money Follows the Person Act, S. 528, an important first step that would provide competitive demonstration projects to enable Medicaid-eligible individuals to receive long-term services in the setting of their choice. States would receive expanded funding for one year for each person that a state moves out of a nursing home or other institution into the community with appropriate services. We have worked closely with Dr. McClellan and the Bush Administration on this initiative which is a central element of the President's New Freedom Initiative of 2001. However, after 5 years, the Bush administration has failed to put forth comprehensive legislation addressing the goals of the New Freedom Initiative, including any proposal to assist states' compliance with the Supreme Court's *Olmstead* decision.

Please note we also support companion legislation, the Family Opportunity Act, that would provide states with the option to provide critical support for families with children with serious disabilities. At the end of the 108th Congress, this Committee linked the two pieces of legislation (FOA and Money Follows the Person) in hopes of moving them together for passage. Unfortunately, that did not happen. We had hoped that the legislation would be introduced as a package in the 109th

Congress, sending a strong message that Congress and the Administration are ready to move this issue. Unfortunately, this has not yet happened.

Additionally, we believe there are other incremental steps that the Congress can take to expand access to community-based long-term services. Twenty-nine states provide community long-term services through use of the personal care option and 44 states rely on the rehabilitation services option. These are critical optional services that states have relied upon to develop innovative models for providing community-based long-term services.⁵ We believe that the federal government could assist states in rebalancing their long-term care programs through providing an enhanced match for personal care and rehabilitation services. These approaches could be phased in over time.

It is seductive to think that easy solutions are out there for improving Medicaid. Some claim that reverse mortgages are a policy innovation that will assist Medicaid beneficiaries in financing the cost of long-term services and supports—in a way that lowers federal costs. Similarly, several Members of Congress and the Bush Administration have proposed new restrictions on the transfer of assets before individuals qualify for Medicaid coverage. Easy solutions do not exist and the potential benefits of reverse mortgages or asset transfer restrictions are being oversold. More importantly, however, these policies are largely irrelevant to non-elderly people with disabilities. Non-elderly people with disabilities have lower incomes and fewer resources than many seniors. Many people with disabilities have not had the opportunity to accumulate assets. They have not built up significant equity in their homes with which to take a reverse mortgage and that assumes they can afford to own a home. Moreover, as with other non-elderly individuals, policy makers should be encouraging people with disabilities to accumulate assets for use in their later years, making reverse mortgages particularly inappropriate for these individuals.

In conclusion, as has happened several times in the past, Medicaid is at a critical juncture. The actions of this Congress will determine whether or not Medicaid continues to evolve and adapt to improve the lives of people with disabilities and other Medicaid beneficiaries. It is hard to imagine, however, how positive progress can be made if the Congress enacts large Medicaid cuts—such as the \$10 billion in savings that are being contemplated per the budget resolution. Our perspective is that Medicaid is an effective model of a flexible, adaptable, and working public program that should be expanded and not cut. By protecting the core features of Medicaid, it will continue to serve as a mechanism for achieving an important national goal—and necessity—to assist people with disabilities to live full and meaningful lives, integrated fully in their communities. I urge Congress to look beyond the short-term budget debate and enact forward-looking policies that people with disabilities and all Americans can applaud.