

**TESTIMONY OF CAROL NOVAK, MEMBER  
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**before the U.S. Senate Committee on Finance  
“Strategies to Improve Access to Medicaid Home  
and Community Based Services”**

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Good day distinguished members of the Senate Finance Committee. My name is Carol Novak. I am a Board Member on the National Council on Disability (NCD). I am also the parent of a remarkable young man who is currently trying to create his own vision for independence and community living.

Thank you for inviting NCD to be here today. NCD is an independent federal agency making recommendations to the President and Congress on issues affecting 54 million Americans with disabilities. It is composed of 15 members appointed by the President and confirmed by the U.S. Senate. NCD is charged by Congress with monitoring federal statutes and programs pertaining to people with disabilities, and assessing the effectiveness of those programs in meeting the needs of people with disabilities. As part of its mission, NCD provides a voice in the Federal Government and to Congress for all people with disabilities in the development of policies and delivery of programs that affect their lives.

As our nation’s population ages, the costs and alternatives for community living, long-term care, and support services have become a subject of growing attention and concern. For many people with disabilities, including people living in institutions because of the lack of community-based or in-home alternatives and those at risk of entering institutional care settings against their will, the issues take on pressing personal significance.

Fortunately, there are some initiatives that have garnered attention and momentum in our nation that can correct this nationwide problem. The first is MiCASSA; the second is *Olmstead*; the third is Money Follows the Person. Together, these three initiatives represent a community imperative and a vision for promoting the independence of people with disabilities in all walks and circumstances of American life. These initiatives and this vision are part and parcel of the New Freedom Initiative, and are rightfully at the heart of today’s Senate hearing.

## **The New Freedom Initiative and Community Living**

On June 18, 2001, President George W. Bush, pursuant to his New Freedom Initiative, issued Executive Order No. 13217, committing the Administration to implement the integration mandate of the ADA as interpreted in *Olmstead*. The Executive Order required federal agencies to promote community living for persons with disabilities by providing coordinated technical assistance to states, identifying specific barriers in federal law, regulation, policy and practice that impede community participation, and enforcing the rights of persons with disabilities. As a result of that Executive Order, federal agencies evaluated their own programs to identify barriers, and issued their final reports on March 25, 2002.

All together, these federal agencies' reports acknowledged the many barriers to community integration of persons with disabilities, including the institutional bias of the Medicaid program, unaffordable and inaccessible housing, a critical shortage of personal assistants and direct support professionals, and the unavailability of supported employment, and the need for early treatment and adequate mental health services for youth with disabilities. A majority of the proposed agency actions consisted of technical assistance, training, research, demonstration, policy review, public awareness campaigns, outreach, enforcement of existing regulations, information dissemination, convening of advisory committees and interagency coordination and collaboration.

Notwithstanding the early intentions and efforts of the NFI, and Executive Order 13217, the nature and scope of the problems facing millions of Americans with disabilities is daunting. Correcting these problems requires our best efforts and concerted attention.

### **A Community Imperative**

The extent of unnecessary institutionalization of people with disabilities in the United States is shameful. There are too many hundreds of thousands of people with disabilities who, because of the bias of the current Medicaid system, are destined to spend their lives in nursing homes or institutions against their wishes.

If people who have economic needs require assistance, the default given to them through Medicaid is a nursing home or an institutional placement. It should be the other way around. The person first should be given the opportunity to live in the community. States should be obliged to provide assistance and supports in the community, and only if there is no other alternative to community based living, would states then consider nursing home or institutional placement. This is essentially one way to effectively reverse the Medicaid institutional bias that dominates too many lives in America today. People are most productive and have the highest quality of life in an integrated community with friends and family members nearby.

MiCASSA, introduced but not yet enacted in the last several sessions of Congress, and supported overwhelmingly by the disability rights movement, is important because it would end the institutional bias of Title XIX of the Social Security Act by allowing people eligible for services from nursing facilities or intermediate care facilities for people with intellectual disabilities the

election to receive community-based attendant services and support. Services covered by MiCASSA would include assistance with activities of daily living, including personal care, household chores, shopping, managing finances, using the telephone, participating in community activities, supervision, and teaching community living skills. MiCASSA would require services that are provided in the most integrated setting appropriate to the needs of the individual;

- based on functional need, rather than diagnosis or age;
- in home or community settings, including school, work, recreation, or religious settings;
- selected, managed, and controlled by the consumer of the services;
- supplemented with backup and emergency attendant services;
- furnished according to a service plan agreed to by the consumer; and
- accompanied by voluntary training on selecting, managing, and dismissing attendants.

MiCASSA would allow consumers to choose among various consumer-controlled service delivery models, including vouchers, direct cash payments, fiscal agents, and agency providers.

### ***Olmstead***

The Supreme Court's 1999 *Olmstead* decision has become a powerful impetus for a national effort to increase community-based alternatives and eliminate unjustified and restrictive institutional placements.

In September 2003 NCD published *Olmstead: Reclaiming Institutionalized Lives*, located on our web site (at <http://www.ncd.gov/newsroom/publications/reclaimabridged.html>). NCD's 2003 report on the status of *Olmstead* implementation indicates that, overall, progress to varying degrees has occurred in the implementation of the *Olmstead* decision. In this study, NCD heard from representatives of all disability groups who agreed that lack of affordable and accessible housing is the single biggest barrier to community integration in the United States. People with disabilities whose incomes depend on government benefits need housing subsidies or shared housing to live in the community.

Unfortunately, because of systemic barriers, people with disabilities tend not to receive their fair share of the approximately \$7 billion in federal housing subsidy programs, and the various Section 8 housing subsidy programs targeted to persons with disabilities are funded at a relatively modest amount (\$271 million in 2001) in comparison. An additional barrier is the lack of meaningful collaboration between human services agencies and housing agencies. High unemployment rates for persons with significant disabilities (typically, 60 to 90 percent) maintain dependence on public benefits.

The institutional bias of the Title XIX (Medicaid) program, in which home and community based waiver-funded services and personal care are optional while nursing facility services are required, and financial eligibility rules for institutional residents are more generous than those for people living in their own homes, greatly compounds the problem. Title XIX waivers have significantly expanded available funding for home and community based services, but have not

leveled the playing field; because state governments do not recognize home and community based waiver services as entitlements, waiting lists for waiver services are long in most states.

The unavailability of Title XIX reimbursement for services to adults below the age of 65 in institutions for mental diseases poses a significant barrier to the use of home and community based waivers to fund community mental health services.

And, from other research (National Academy of Sciences, Institute of Medicine's 1998 report on the "Quality of Long-term Care"), we know that one of the most important and frequently reported barriers to the expansion of Medicaid waiver services is the shortage of direct care workers, particularly those working in the home. States with large rural populations faced particularly imposing challenges. State officials identified these shortages as being related to the growing competition in the labor market and the low state Medicaid reimbursement rates for Home and Community Based Service providers. Low wages and benefits severely limit the availability of personal assistants and other direct support professionals. In turn, low wages are the result of low reimbursement rates for community services. Lack of quality health care and dependable transportation are also significant barriers.

Although the experiences of states and stakeholders in implementing *Olmstead* vary widely, NCD's study documents some key overarching findings, including:

- Plans do not consistently provide for opportunities for living in the most integrated setting as people with disabilities define "the most integrated setting."
- The majority of states have not planned to identify or provide community placement to all institutionalized persons who do not oppose community placement.
- Few plans identify systemic barriers to community placement or state action steps to remove them and few plans contain timelines and targets for community placement.
- State budgets often do not reflect *Olmstead* planning goals.

However, given the many areas where progress has not yet been achieved and in recognition of the relatively brief time since the decision was rendered and governmental initiatives were undertaken, it is clear that further efforts are necessary to increase public awareness of *Olmstead*. It is also necessary to provide education and clarification regarding the applications and implications of the decision to relevant entities, and provide resources necessary to both encourage and to ensure effective adherence to the spirit and intent of *Olmstead*.

### **Children and Mental Health**

Consistent with both the New Freedom Initiative's commitment to *Olmstead* implementation, and the findings contained in the President's New Freedom Commission on Mental Health report of 2003, NCD found that far too many children with emotional disturbance cannot get the mental health care they need. (See, <http://www.ncd.gov/newsroom/publications/mentalhealth.html>). As

a result they often end up in foster care or juvenile justice, and are too often consigned to institutional settings where they are further cut off from support systems.

The lack of home- and community-based services has negative consequences. The lack accounts for unnecessary hospitalization of children and youth with emotional disturbance. It also contributes to readmission. For lack of services that might ease the transition from hospital to home, including respite services for their families, these children cycle back and forth between hospital and the community without ever achieving stability. In turn, unnecessary hospitalization usurps the limited resources of state mental health budgets, thus obstructing the provision of services that might have prevented institutionalization and perpetuating an unproductive cycle.

The failure to identify (and treat) emotional disturbances is also associated with the growing problem of teen suicides and/or suicide attempts. If properly implemented, Medicaid's Early Periodic Screening Diagnosis and Treatment program should assist parents of youth with emotional disturbance and school personnel in identifying their disabilities, providing the appropriate treatment, and preventing suicide and unnecessary institutionalization.

If all aspects of the system—from assessment to treatment—took into account the long-term needs of children, rather than episodic or crisis occurrence, children's needs would be described in terms of their underlying issues and in the context of their family and living situation instead of mere documentation of short-term behavior or services available. For some children, the system must be prepared to make a commitment to serve the child for their entire childhood, with easy entry and re-entry into the system.

### **Money Follows the Individual Rebalancing Demonstration**

The Administration wants to build on the federal-state partnership to assure Medicaid-eligible individuals with disabilities are served in the most appropriate setting according to their own needs and preferences. There is a tremendous opportunity to serve people who meet nursing facility levels of care in their own homes or other community residential settings without increasing costs.

Many states have engaged in activities and developed programs that serve persons in the most appropriate community setting rather than in an institution. These programs and activities, developed under existing authority, have included diversion programs to maintain people in the community, transition programs to actively move individuals from institutional settings to alternative community placements, and program models in which the 'money follows the person' to assure stability of community living.

### **Real Lives for Real People: Seeing the Big Picture**

In our efforts to empower Americans with disabilities of all ages to live lives with choice, opportunity, and dignity, we face real challenges. Some challenges are of our own making.

The first challenge involves the coordination of funding and services. Disability programs and policies are so fragmented between Administrative Agencies and Legislative Committees that it is difficult to achieve the combination of Personal Assistance Services + Affordable, Accessible Housing + Affordable, Accessible Transportation + Livable Communities: any combination of which are often essential to a quality life in the community for people with disabilities.

The second challenge involves the shortage of quality direct service and/or support providers. Establishing eligibility for personal assistance services is only one part of the picture. Hiring and keeping capable, trustworthy personal assistants will continue to be difficult until competitive wages and health insurance benefits are offered. Establishing personal assistance as a respected career through competitive pay, benefits and training will attract the caliber of employees needed.

In our attempt to empower Americans with disabilities we also face major opposition to change. Some of the opposition is of our own making; some of it is not.

The first type of opposition to change comes from special interests. Those who profit from the existing Medicaid long term care structure, such as nursing home owners, state and federal bureaucracies, and employees' unions, want to maintain the institutional status quo. They are powerful and cannot be ignored. In order to achieve real change, these special interests' concerns must be acknowledged and their opportunities in a new system that empowers and supports people in living the life of their choice must be made clear to them. As long as America's public policies continue to fund programs instead of individuals, services and supports will be provided in a manner that benefits those who control the money rather than the individuals we intend to serve and support.

The second type of opposition to change comes from redundant, inefficient bureaucracies. The separate administrative structures for each of the States' Medicaid Home and Community Based waivers and for institutional Long-Term Services and Supports absorb an excessive amount of funding that would be better spent on direct services. The parallel bureaucracies also make it challenging and confusing for beneficiaries and their families to transition from one model of Medicaid long term service to another. For example, transitioning my father-in-law from a nursing home to an Assisted Living Facility meant that his first Medicaid number was cancelled and he was issued a new Medicaid number. However, his essential medication could not be billed to the new number for several days, yet the nursing home had to turn in all of the medication he had not yet taken because it was billed to the nursing home Medicaid number.

In our efforts to empower Americans with disabilities, we need to recognize and act on those opportunities for change that could enhance peoples' lives.

Currently, people who rely on Medicaid Home and Community Based waiver services do not have the freedom to move from one state to another because there is no portability from one state's Medicaid program to another. If people do take the risk of moving to another state, they lose all Personal Assistance Services and have no idea how long they will have to wait for services in another state. They also have to contend with the disparity of Home and Community

Based waiver services among states because each state designs its own waivers with different target populations and service menus.

The notion of transforming Medicaid Long Term Care into a coordinated program administered by a single agency that is responsible for all models of long term services and supports, including Personal Assistance Services, could give people the freedom to move from one state to another, eliminate the disparity in services between states and the difficulty in transitioning from one model of Medicaid Long Term Care to another, reduce the number of bureaucracies, and make it easier to establish Personal Assistance Services as a viable career. It could also make coordination with housing and transportation entities easier to achieve. You may want to consider this strategy.

Often Home and Community Based waivers do not provide enough hours of personal assistance services for individuals to realistically and safely live on their own in the community. Innovative utilization of resources and service options must be employed in order for people to have adequate hours of service to make community life feasible.

Finally, personal assistance services need to be available to adults with disabilities in the workplace if meaningful employment for disabled adults is to become a reality.

In our efforts to empower Americans with disabilities, we need to take advantage of options for cost-effectiveness. These options include: private long-term care insurance; support for family caregivers; and, utilizing natural supports in the community.

Most of the people in Medicaid nursing home beds today acquired their disability as a consequence of aging. Despite being productive throughout most of their lives, their assets were quickly exhausted and they became eligible for Medicaid. Encouraging younger Americans who are not disabled to buy private long term care insurance by implementing a tax credit for the premium will ultimately save Medicaid billions of long term care dollars that can be allocated to provide personal assistance services for people with disabilities who cannot buy private long-term care insurance. Having private long-term care insurance also gives beneficiaries choice of and control over services.

Family caregivers provide millions of hours of unpaid care each year. Without their participation, the long-term services and supports system would crumble. Many states provide inadequate or no respite services to relieve family caregivers. This eventually leads to caregiver 'burnout' and institutionalization of the person with a disability. By supplementing the efforts of family caregivers, costly institutionalization can be avoided and impairment of caregivers' health can be prevented.

When vulnerable people live in the community, they have the opportunity to avail themselves of 'natural supports' in the form of family, friends, neighbors, faith-based organizations, etc. These natural supports complement paid supports and enrich the lives of both the disabled individual and the people involved with them.

## **Ongoing and Relevant NCD Policy Work**

NCD is currently evaluating a range of promising community-based and consumer-oriented service and support reforms and initiatives. We believe that the results of our current policy research will also be of value to this Committee in the months ahead. NCD's current work includes: (a) an evaluation of federal and state initiatives in the area of consumer-directed reform through Medicaid and Medicare; (b) Livable Communities for people with disabilities and people who are elderly; and c) Long-Term Services and Supports refinancing and systems reform.

Through this policy work, NCD will continue to provide objective advice to policymakers, public and private agencies, consumers, researchers and others to refine the knowledge we have, identify new information about what works, and help policymakers build capacity within our communities and our nation to meet these challenges.

## **Conclusion**

America needs to develop delivery systems, service capacity and financing streams that provide an increasing number of people with disabilities with choices about how to live their lives and receive the services and supports they need in community based settings. We need to pay particular attention to supportive services and housing issues, which determine whether individuals can maintain the autonomy and independence they desire. Our nation will be much more prosperous when it makes real the right of people with disabilities to live in the most integrated setting.

Thank you for inviting the National Council on Disability to this critically important hearing today.