

**Testimony of  
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**SENATE COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS  
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**The American Disabilities Act and *Olmstead* Enforcement:  
Ensuring Community Opportunities for Individuals with Disabilities**

Chairman Harkin, Ranking Member Enzi, Members of the Committee, thank you for the opportunity to appear today to discuss the successes and challenges states have experienced in providing community opportunities for individuals with developmental disabilities.

I am the Executive Director of the National Association of State Directors of Developmental Disabilities Services (NASDDDS). I began my career in 1971 working in nonprofit agencies developing community services for children and adults with developmental disabilities. Six years after joining Pennsylvania state government, I was appointed the state's Deputy Secretary for Mental Retardation where, from 1993 to 2003, I managed a system of institutional and community services for over 80,000 individuals. During my tenure as the state director there was significant expansion of community services for Pennsylvanians with disabilities who were on the waiting list for community services, including those living in institutions. During that time, over 2,000 people in institutions were provided with the opportunity for community living, reducing the institutional population by more than 55 percent. From 2003-2005, I served as the Director of Quality Improvement for the U.S. Department of Health and Human Services' Centers for Medicare and Medicaid Services (CMS), Disabled and Elderly Health Programs Group, and was responsible for developing federal oversight of state-operated Medicaid Home and Community-Based Services Waiver programs. My husband and I are adoptive parents of an adult son with developmental disabilities who spent much of his childhood in an institution and now lives and works in the community.

The National Association of State Directors of Developmental Disabilities Services provides an array of services to developmental disability (DD) agencies in the 50 states and the District of Columbia. The NASDDDS mission is to assist member state agencies in building effective, efficient person-centered systems of services and supports for people with developmental disabilities and their families. NASDDDS strives to provide member state agencies with timely analyses of federal statutory and regulatory policies that affect people with disabilities; to disseminate information on state-of-the-art programs and service delivery practices; to supply technical assistance

and support to member states; and to offer a forum for the development of state and national policy initiatives.

## **Progress in Ensuring Community Opportunities for Individuals with Disabilities**

In 1967, the number of people with what was then called mental retardation living in large state institutions reached its high point, with 228,500 in large state intellectual/developmental disability (I/DD) institutions and 33,850 in psychiatric institutions. Much has changed since 1967. The most recent national data from 2008 indicates that there were 36,508 in state I/DD institutions – a drop of 194,650 people (84%) since 1967; and 767 in psychiatric institutions, a drop of 33,083 people (98%).<sup>1</sup>

Between 1967 and the mid-1980s, 5,000 to 10,000 people moved back into the community each year.<sup>2</sup> The civil rights movement that swept the country reached all elements of society, including people living in institutions. Many individuals who learned that they had a right to leave the institution, and had the capacity to do so without special assistance, simply left. The individuals who remained in institutions in the mid 1980s by and large could not leave to live in the community without special assistance.

In 1982 the adoption of the Medicaid Home and Community-Based Services (HCBS) Waiver made that assistance available. Allowing funds that were previously reserved for institutional services to be used for community services enabled state DD departments to build systems of community services that initially supported people leaving institutions and soon expanded to those at risk of institutionalization. For the next two decades, the institutional census continued to drop annually by 4,000 to 5,000 people.

Today, 10 states and the District of Columbia have no institutions for people with developmental disabilities; and 12 states have less than 200 people still living in institutions – Michigan with less than 5 and Minnesota with less than 25. A recent survey conducted by our association found that 67 percent of the states with institutions have plans to downsize or close facilities in the next few years.

By 2006, all but one state was spending more for community services than for institutional services. And, of the approximately 1 million people receiving services, less than 3.6 percent reside in institutions. By 2008, 66 percent of the \$43.83 billion of state and federal funds that support people with I/DD were committed to community services.<sup>3</sup>

Why has there been such an overwhelming trend toward community services in the developmental disabilities services systems? There are many reasons and there have been many drivers.

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<sup>1</sup> *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007* Lakin, K.C., Larson, S.A., Salmi, P. & Scott, N.

<sup>2</sup> *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007* Lakin, K.C., Larson, S.A., Salmi, P. & Scott, N.

<sup>3</sup> *The State of the States in Developmental Disabilities 2008* Braddock, Hemp, Rizzolo Coleman Institute for Cognitive Disabilities, The University of Colorado

## **Key Factors Driving the Development of Community Services**

**First and Foremost is the Parent/Advocacy Movement.** Outrage at horrific conditions in public institutions in the 1960s and the lack of services for children and adults living with their families in the community fueled simultaneous efforts at: reforming public institutions; establishing a right to education; and creating services for adults living with their families. The thinking quickly evolved – reforming institutions, while important in the short run, was not the final goal. Offering everyone a life in the community became a focus of the advocacy agenda.

By the early 1970s, parents and advocates were experiencing success. Several institutional law suits had been filed resulting in improvements in the institutions as well as expanded opportunities for people to move to the community. Advocacy efforts to achieve the right to education resulted in landmark legislation first in the states, and then at the national level with the adoption of the *Education for All Handicapped Children Act* (Public Law 94-142) in 1975.

**The right to education** profoundly changed the experiences of children with developmental disabilities and the expectations of parents. Prior to the right to education, parents had two choices: to institutionalize their children – something routinely recommended by medical professionals – or to keep their child at home 24 hours-a-day without support or training. Many parents chose to keep their children at home rather than follow the advice of their doctor. But as their children grew, so too did the stress of being an unsupported care giver. When parents came looking for help, all that states had to offer was the institution. So with grief and often guilt, parents sought admission for their children.

The right to education changed things. When schools opened their doors, admission of children to institutions dropped significantly – and the expectations of families rose just as quickly. If children could live with their families and go to school, then why wouldn't they live their entire life in the community?

**Private nonprofit agencies** found in the baby boomers they hired in the 1970s and 80s people who were ready and eager to develop community services. Founded by families, faith-based organizations, and community groups, these nonprofits turned a vision into a reality for thousands of people with disabilities. Opening group homes, vocational training programs, and recreational programs they championed the cause of people with intellectual and developmental disabilities and helped them become part of the community.

And as they did so, they built more and more evidence that community living was, in fact, better for people who were once believed to need institutions. It was better for the person – and also better for their families who could now see them more frequently because the group homes were in the family's community rather than far away in a remote part of the state.

**The Department of Justice and Protection and Advocacy** also played a significant role in the shift from institutions to the community. Using the Civil Rights of Institutionalized Persons Act, the Department of Justice conducted investigations and litigation to press for improvements in facilities with the most egregious rights violations. Protection and Advocacy organizations, often contacted by families of those living in institutions, conducted investigations, and initiated litigation when conditions did not improve.

The result of these interventions was increased investment in the institutions to improve conditions, along with agreements to decrease the number of people in the institutions – and in many cases agreements to simply close facilities.

Adoption of the Americans with Disabilities Act (ADA), reinforced by the ***Olmstead*** decision, provided additional tools for organizations to advocate for community services, and it solidified the right of people to live in the community. The ADA and ***Olmstead*** are landmark statutes that have validated the values of the DD systems in this country.

**Medicaid Funding and Federal Statutes.** Statutes, regulations, funding, and technical assistance all play an important role in assisting states to make community opportunities available for people in institutions and on waiting lists.

The Developmental Disabilities Act, the Americans with Disability Act, the Individuals with Disability Education Act, amendments to the Title XIX of the Social Security Act, and so many other statutes have opened doors and served as vehicles for states to provide services in the community. Most recently new Medicaid state plan options and Money Follows the Person grants have provided states with even more tools.

New Medicaid options have enabled states to expand services. While many states already had programs providing community services to individuals with developmental disabilities, usually called “family supports,” the advent in 1982 of the 1915(c) Home and Community-Based Services (HCBS) Medicaid waiver program meant the availability of federal funds to support individuals in the community – and this drove rapid expansion of such programs. Allowing states to waive comparability (i.e., target specific populations) and to include a diverse set of non-medical supports and services in their 1915(c) programs gave them the opportunity to innovate and to build systems of support around the specific needs of individuals. Paradoxically, allowing states to cap the number of waiver participants has played a key role in the robust growth of the program, as states have been able to expand their community infrastructure, develop a broad array of services and the capacity to provide them, and build expertise in serving individuals with developmental disabilities in the community, while retaining the tools they need to manage financial risk and ensure the survival of HCBS programs. Because of this freedom to innovate, states have become experts at serving individuals in the community who not long ago would have been considered impossible to serve outside of an institution.

Money Follows the Person (MFP) grants are assisting 27 of the 30 grant states to move people with developmental disabilities out of institutions and into the community. The grants are directly focused on a key barrier states have faced to rebalancing their systems of long-term supports and services: While we know that serving individuals in the community rather than in institutions is ultimately more cost effective, the up-front transition costs involved in moving individuals into the community can often act as a deterrent to state efforts. The CMS implementation of MFP focused on effective transition procedures and used, as one measure of success, rate of return to facilities. The increased appropriation in the Patient Protection and Affordable Care Act (PPACA) will allow more states, and more individuals currently residing in institutions, to benefit from this valuable program.

The recent addition of the 1915(i) state plan option for HCBS, the Community First Choice Option, and enhanced Federal Financial Participation (FFP) for those states whose investment in community services is less than 50 percent are all examples of recent federal initiatives aimed at giving states more opportunities to provide services to individuals in community settings.

The Centers for Medicare and Medicaid Services (CMS) has partnered with state agencies to explore ways in which CMS can assist states in advancing community services. The willingness of CMS leadership to meet regularly with the national associations representing various state agencies and to fund technical assistance to states is particularly noteworthy.

**A new generation of families with young children** who have benefited from early intervention services, public education, medical and clinical advances, and more importantly, have raised their children in a world that is more accepting of people with disabilities, a world that sees the value in diversity, a world that can recognize the gifts that each person brings. They are demanding even more change.

Families of young children not only reject institutions, they also reject community models that segregate or isolate their sons and daughters from typical life. They expect their sons and daughters to graduate from school, to get a job, to have meaningful relationships and to participate in the life of their community.

**The cost of institutional services** has also been a factor in the transition from the institution to community services. While the cost of providing services to each individual differs as systems respond to individual needs, in the aggregate, it is far more cost-effective to customize support that builds on each individual's strengths and the natural supports they have in their family and community, than to create a residential model that provides comprehensive services whether an individual needs them or not. In addition, investment in models of service that do not provide an environment where people grow and achieve positive outcomes is questionable public policy.

Cost is a factor because people with developmental disabilities do not enjoy an entitlement to services. Resources used inefficiently add numbers to the waiting list.

The meager data on waiting lists indicates that over 100,000 people are waiting to be served.

**State Authority.** The effectiveness with which states have transferred funds from the institutional system to the community is directly related to the fact that states own and operate the institutional facilities and have full authority to determine the number of certified beds and the disposition of resources. However, privately operated ICFs/MR and nursing homes, however, present a challenge to rebalancing the system because states do not have the authority to close beds other than in situations where the facilities or the providers do not meet certification standards.

**And most importantly, people with intellectual and developmental disabilities** themselves have driven the change. An outgrowth of the movement of people from institutions to the community has been the growth of self-advocacy; i.e., people finding their voice and advocating for themselves. Self-advocates have survived indignities and often abuse in institutions and have demonstrated a level of courage, fortitude, and forgiveness that inspires everyone who hears their stories.

### **Challenges Remain**

The barriers to creating community opportunities for people who remain in the institutions are the same barriers that have been with states since the 1980s.

**The Availability of State Funding has been and Continues to be a Barrier.** While the Medicaid Home and Community-Based Services Waiver program provides significant federal funding for services, it does so only on a matching basis – which requires states to fund up to 50 percent of the cost of services, depending on each state's matching rate. The scope of programs competing for resources within each state's budget include education, transportation, and law enforcement, coupled with a constitutional requirement to balance annual budgets that affects the growth rate of Home and Community-Based Services. The current fiscal crisis, which has meant precipitous drops in state revenue, has recently compounded the problem. States have embraced the Medicaid Waiver program because it provides them with tools to manage growth within the confines of the state's economic conditions. During times of economic gains, states will typically expand their waiver programs. Conversely, during times of economic distress, they will curtail growth.

**Opposition from employees** has been a factor in downsizing and closing of institutions. An institution may be the primary employer in a geographical area. In fact, some were established in rural areas many years ago precisely for the purpose of providing employment. Employees often enjoy robust wages and benefits that are difficult to replicate in other fields or in the private sector. It should come as no surprise that employees often oppose the downsizing and closure of facilities and that their opposition includes solicitations of support from legislators in their districts. Strategies used by states to overcome this barrier, such as guaranteeing employment in other state operations or in-state operated community services, are not always feasible. Each

facility closure has been accomplished by employing multiple strategies crafted uniquely for that particular facility.

**Opposition from families** is another challenge – and the most complex one. What we know from 40 years of experience is that people do better in the community than in institutions. No matter their age, they learn new skills, develop new competencies and appear to be much happier. We know this from research which has established that all individuals make gains but those with the most significant disabilities make the most gains after moving to small community residences.<sup>4</sup> But just as importantly, the thousands of provider staff, clinicians, and leaders in our field know this – because they have witnessed it.

We know that, regardless of the intensity of the opposition from families, once the person moves to the community the opposition melts and the family sees the benefits of community living. In fact, rarely has any family member requested the return of their son, daughter, sister or brother to the institution.

Opposition can be based on any number of assumptions. One is that the services in the community will be discontinued over time, leaving the family entirely responsible for providing both support and living arrangements. The fact that the Medicaid Waiver is funded with precisely the same funding sources as the institution – and that most community service systems are now over 50 years old – can assuage some of those fears.

Opposition based on the assumption that their family member can't live in the community can be addressed by taking families to visit community services that support people with the same level of needs as their family member. Arranging meetings for family members with people living in the community can also help to address those fears. In the past it has been said that for every person living in an institution, there is one in the community. Today it would not be an exaggeration to say that for every person living in an institution, there are thousands living in the community.

Opposition based on fear of abuse and neglect requires a frank discussion that acknowledges that abuse and neglect have been serious problems in institutions and can be an equally serious problem in the community. States must explain the processes they have built into community systems to prevent abuse and neglect, to detect it as soon as it occurs, to inform family members and to respond promptly.

The institution is often perceived as better able to provide intense and specialized services. It is important to educate families about the impact of environment and experience on learning and that, while the institution may have specialists, the environment and the routines of the institution lack the real life experiences of daily living. Activities as simple as buying weekly groceries and making meals, going to the bank or post office, taking in a movie, or greeting neighbors are the experiences through

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<sup>4</sup> Bradley, V.J., & Conroy, J.W. *The Pennhurst Longitudinal Study Executive Summary* Philadelphia: Temple University Developmental Disabilities Center, 1985.

which people develop competencies and social skills. The availability of medical services may also be a concern, and can be addressed by involving families in establishing a relationship with medical professionals in the community prior to their family member leaving the facility.

The absence of oversight to assure quality is often incorrectly identified as a weakness in the community system. What is often not recognized is the considerable attention the Centers for Medicare and Medicaid Services and the states have placed on quality assurance. The application states must complete to obtain approval to operate a Home and Community-Based Services Waiver requires states to provide detailed descriptions of provider qualifications, oversight functions, and quality management practices. States are then required to report the findings from their oversight activities on an annual basis and approval to continue to operate a Medicaid Waiver is contingent upon assuring CMS of the health and safety of waiver participants.

Lastly, there are those who say that families should have absolute authority to make any decisions that affect their family member, and that any government participation constitutes interference with the family relationship. The central question that should be the primary focus of both family members and state professionals and the basis for any decision making is “what would benefit the person most?” And, it is this question that drives state agency professionals to continue to create community service opportunities for people living in institutions. Having assisted hundreds of people to move from institutions to the community, having witnessed their growth and development and the satisfaction that families inevitably experience, professionals are bound by professional ethics and compelled by their personal commitment to pursue community options for people living in institutions.

It would be a far easier path to simply let the issue go for the 36,000 people still living in institutions, to avoid asking families to reopen the decision they made to institutionalize their family member 30 or even 50 years ago. But knowing what is possible and what is right, professionals working in state agencies cannot do that.

There is another compelling reason for public officials to stay the course of reducing the number of people in institutions: the need to manage public resources, to manage long-term care systems, in as cost effective a manner as possible. Large facilities are generally the most costly service model in state systems. States that have significantly reduced the number of people in facilities have made more progress in expanding services for people in the community. Savings from reducing or eliminating the use of the most expensive model of care are an important resource for those on the waiting list.

While opposition can be intense, there are also many stories of family groups working hand in hand with states to close institutions and participating actively in the development of community services. The state of Wyoming is a model of what may be one of the best closure processes in the country, and won the NASDDDS Censoni award for outstanding achievement in public services. As is so often true, the story

begins with litigation. But the path Wyoming took to respond to that litigation was not to oppose the plaintiffs and argue the case out in court for 10 years, but instead to seize the opportunity to build a robust community service system where there had been none, to serve not only the people from the Wyoming State Training School but also people who were already living in the community with their families and were at risk of institutionalization. Wyoming was among the first states to demonstrate that the thoughtful development of a community system with a wide-range of services eliminates the need for an institution.

**Preventing Institutionalization: The Waiting List Challenge.** There is no entitlement to Home and Community-Based Services and states are restricted in their capacity to expand services. Therefore waiting lists are a reality in most state developmental disability systems. Advocacy efforts, law suits, a booming economy, and funds available from the closure of institutions have allowed many states to expand services for people on the waiting list over the past two decades. But few states have achieved enough growth that important services can be made available promptly to every eligible applicant upon request. Emergencies and crises become the entry point into Home and Community-Based Services systems for many. There is no reliable national data on the number of people waiting for services but we know that in many states the number is in the thousands and the wait can be as long as 10 years. Many states do not maintain a count of people on the waiting list for fear of creating expectations they cannot meet.

The barrier to meeting the needs of people on the waiting list are purely financial. The inability to provide state funds to earn federal matching dollars controls the pace of growth.

**The Choice Paradox.** The statutory basis for community services is the right to receive services in an institution – an Interim Care Facility for the Mentally Retarded (ICF/MR). When individuals apply for community services, they must first formally “opt out” of receiving services in an institution and affirmatively choose Home and Community-Based Services. This is called choice. However, we know from the work of Richard H. Thaler and Professor Cass R. Sunstein, authors of *Nudge*, that in presenting individuals with choice, the decision process can be structured in a way that will “influence people’s behavior in order to make their lives longer, healthier and better.” For instance, an “opt out” decision process is often recommended for the administration of employee retirement programs because it results in more people enrolling in a retirement program which will presumably make their life better when they reach retirement age

What is the message in requiring individuals to opt out of institutional services in order to receive Home and Community-Based Services? The message is a mixed one because it promotes the institution even for those who desire and are requesting services in the community. More than one state Developmental Disability Director has identified this “quirk” in the Medicaid program as problematic when promoting Home and Community-Based Services.

## **The Goal of Full Inclusion in Community Life through the Delivery of High Quality Services**

Creating community opportunities is only a beginning. The goal of our DD services systems is the full participation of people in the life of their community. A real job at competitive wages, membership in civic organizations, knowing the neighbors, and having friends are the real measures of our success.

Services must be designed to do more than maintain people in the community. They must be of high-quality and designed to achieve real life outcomes. People working in developmental disability systems across this country have pioneered strategies to assist people with disabilities to achieve a life of full inclusion and participation in their communities. Individualized planning, supported employment, self-determination, positive behavioral practices, and more recently person-centered planning, individualized budgeting, and consumer directed services have been adopted by support infrastructures for other populations, including mental health and aging systems.

Measuring quality has been a long standing priority for states. In 1997, NASDDDS launched the National Core Indicators Program (NCI) in partnership with the Human Services Research Institute (HSRI). NCI is a set of system performance indicators organized into domains such as Health, Welfare, and Rights which measure the performance of each state and makes benchmarking between and among states possible.

### **Apologies**

Recently the state of Minnesota became the sixth state in the nation to issue an apology to people with developmental disabilities for the years of incarceration, abuse, and neglect in state operated institutions. Such an apology is an indication of a sea change in attitudes. States are apologizing to a group of people who in very recent history were stripped of all rights as citizens, who were denied an education and often medical treatment, who were sterilized without consent and were presumed to have nothing to offer society. These apologies, coupled with the almost complete abandonment of the term “mental retardation” from the names of state agencies are indications that our public systems are about more than providing services; they are about respecting the rights and dignity of people with developmental disabilities and creating opportunities for full participation in community life.

Change has reached all 50 states and the District of Columbia. They are all progressing – each at a different pace – but they are all making progress toward comprehensive systems of community supports and services.