Deinstitutionalization: Unfinished Business

Companion Paper to Unfinished Business Toolkit

National Council on Disability
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Deinstitutionalization: Unfinished Business, *Companion Paper to Unfinished Business Toolkit*

This report is also available in alternative formats and on the National Council on Disability (NCD) Web site (www.ncd.gov).

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Dedication

The National Council on Disability dedicates this paper to the memory of Susan M. Daniels, who was an extraordinary leader and advocate for equal opportunity, full participation, and the economic empowerment of people with disabilities around the world. Her vision and spirit live on in this paper.

Acknowledgments

The National Council on Disability (NCD) wishes to express its appreciation to Barbara Butz of Daniels & Associates, LLC, and consultants Nanette Goodman, Steve Allen, and Ellen Piekalkiewicz for their research and drafting of this paper. NCD also extends its thanks to the many self-advocates, family members, and others who shared their experiences with us.

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Introduction: Unfinished Business

The unfinished business of closing state-run institutions and other public and private institutional settings that have traditionally served people with intellectual disabilities and developmental disabilities (ID/DD) is an important first step and should be a top public policy priority in every state where such institutions exist. Equally important is ensuring that these people have access to services and supports in their communities that will enable them to lead rich and meaningful lives.

In reviewing the history of the movement to close institutions and examining efforts to focus the nation's resources on ensuring that people with ID/DD have access to community living, two key truths emerge:

- People with ID/DD have a legal right to live in the community and to receive necessary services and supports.
- Life in the community provides opportunities for dignity, freedom, choice, and a sense of belonging that are not possible in an institutional environment.

These truths are at the core of both the Americans with Disabilities Act (ADA) and the *Olmstead* decision. The courts have consistently upheld a person's right to receive services in the least restrictive environment possible. Closing institutions is not about "dumping" people into the community, nor is it about closing large institutions and moving people to smaller institutions or institution-like settings. Closing institutions is about developing strong and inclusive community supports and allowing people to have control over how they live their lives.

In 2011, the National Council on Disability (NCD) took a position on the evolving definition of an institution. NCD focused on the importance of the number of people who live in the same home and defined institutional settings as housing situations in which more than four people with ID/DD disabilities live in the same housing unit. This position reflects the belief that a smaller housing situation offers an opportunity for a higher quality of life.

This paper discusses the lessons learned regarding how to close large institutions, but it focuses on the movement to smaller community living settings that meet NCD's new definition. Regardless of the size of the institution, bringing people back into the community is only the beginning of the quest to help them achieve the highest possible quality of life. The paper examines some of the factors that advocates and self-advocates believe are important in defining "community living" and looks at how quality of life in the community can be and is being measured.

There is a growing consensus that true community living is defined by the extent to which people with ID/DD can choose how they spend their time, interact with others outside the home, and make decisions that affect their daily lives and schedules.

The paper identifies the most effective approaches and supports to help people with ID/DD transition from institutional settings of all sizes. With a focus on quality of life and community inclusion, the transition is certainly possible for both individuals and states.

This section, "Deinstitutionalization: The Right Thing to Do," reviews the history of life in institutions; it includes personal reflections of people with ID/DD who remember what institutional life was like and reflections on their lives in the community. This section also looks at the civil rights history of the deinstitutionalization movement and provides an overview of the evolving definition of "institution."

"Evolution: From Institution to Community" tracks the history of the movement from institution to community and identifies the role Medicaid has played in the development of home and community-based service systems and national deinstitutionalization efforts.

"Institutions: Definitions, Population, and Trends" paints a picture of the current state of the ID/DD housing system and explains that, although significant progress has been made, progress has been uneven and the job is incomplete.

"Deinstitutionalization: Goal and Strategies" describes what the deinstitutionalization movement seeks to accomplish and outlines specific actions that interested parties can take to bring us closer to protecting all the rights of each and every American citizen.

"Forging Ahead: Developing a Plan and Building Community Capacity" describes the basic elements of a closure and transition plan, as well as strategies for building a community's capacity to provide vital services and supports to community members.

"Overcoming Misconceptions: Myths and Realities" looks at key misconceptions that still exist in states and communities; these misconceptions can influence stakeholders if they do not have access to accurate information.

"Case Studies: Closing Institutions and Building Community Support Systems" looks at the closure experience in two states: Oregon, which has closed all state institutions, and

Georgia, which has just begun the process as part of its settlement agreement with the Department of Justice (DOJ 2011).

"Reflections: Individual Voices" highlights the experiences of people with disabilities in Georgia and Oregon who previously lived in institutions and now live in the community. Their stories are told in their own voices.

This paper is based on an extensive literature review and input from professionals, stakeholders, self-advocates, and government representatives obtained through interviews, focus groups, and the project's panel of experts. A companion toolkit provides more in-depth discussion of these important issues. The toolkit can be accessed at www.ncd.gov.

Deinstitutionalization: The Right Thing to Do

Deinstitutionalization is Possible

Ten states and the District of Columbia have no large state institutions and have found ways to provide care in the community to all people with intellectual disabilities or developmental disabilities (ID/DD), regardless of the severity of their disability. However, the remaining states continue to maintain facilities and deliver services in institutions, despite most families' preference for community-based services. As of 2009, 122,000 people with ID/DD were on waiting lists for residential services.[1] Even though they met the eligibility criteria for institutional care, which would be provided at no cost to them, they and their parents or caretakers opted against that setting, clearly rejecting institutional placement.

> "It is pretty sad that you are put in prison because you have a disability."
>
> —*Oregon self-advocate*

Most of these facilities, often called "developmental centers," were built between 50 and 100 years ago and were designed for many times the number of people they now house. By all estimates, the cost to provide services to people in this outdated mode of service far exceeds the cost to provide services in the community, and research consistently demonstrates that people with ID/DD achieve better outcomes in community settings.[2] Deinstitutionalization is a human and civil rights issue. People should not be required to give up their rights to receive the services they need.

Under the Americans with Disabilities Act (ADA, 1990), the Supreme Court's decision in *Olmstead v. L.C.* (1999), the New Freedom Initiative (NFI, 2001), the Developmental Disabilities Assistance and Bill of Rights Act (2000), and the Rehabilitation Act of 1973, community living should be the rule, rather than the exception.

The institution model costs $6 billion a year at a time when less costly and more effective service delivery models are available. Spending scarce resources on expensive and inhumane service models deprives people with disabilities of access to appropriate services.

Deinstitutionalization is the Right Thing to Do

Oregon helps us put a human face on this issue. The state closed all its institutions in 2007—an example of committed and creative deinstitutionalization. Oregon advocates have spent considerable time and energy documenting the reasons why this effort is so important, including the human costs and civil rights issues related to institutionalization. In *Erasing Fairview's Horror*, Sara Gelser says, "As the visible reminders of Fairview disappear, we must ensure that its history is not forgotten or sanitized."[3]

That history includes labeling individuals with developmental disabilities "inmates," performing more than 2,600 forced sterilizations, and, according to Governor John Kitzhaber, using "inhumane devices to restrain or control patients, including leather cuffs and helmets and straightjackets, and inappropriately high dosages of sedatives and psychotropic medications."

A study published in the *American Journal of Forensic Medicine and Pathology* found that between 1963 and 1987, Fairview residents were more than twice as likely to die from unnatural causes as noninstitutionalized people in Marion County.[4]

The voices of people with developmental disabilities who lived in Oregon's institutions serve as stark reminders of the importance of this movement:

> "I was handicapped, but it made me sicker to be there. It was like a prison. Handcuff. Shut door."
>
> "They were strict at Fairview. You got beat up, yelled at. They put us in closets."
>
> "If you don't behave yourself, they'd get you with the scalding hot water."[5]
>
> —*Oregon self-advocates*

Oregon remembers but is moving on. Perhaps this progress is best illustrated by the experience of one person who returned to Fairview with Michael Bailey, statewide community organizer for the Community Partnerships Project, when the institution closed its doors in 2000. After their visit Bailey said,

> “We drove off with one of the former ‘inmates.’ She had to return to her full-time job and at the end of the day would go home to her own apartment. There she would be alone with the memories of a life that had once labeled her a ‘victim of…’ and an ‘inmate’ and now, finally,… a respected, financially independent and successful professional woman.”
>
> *—Michael Bailey, Oregon advocate*

These experiences were well documented in Oregon, and instances of abuse continue to occur in institutions across the country. For example, the 2009 Texas “fight club” incident—in which institution workers forced residents to fight one another while employees taped the fights on their cell phones—made national news. In 2007 the *Atlanta Journal-Constitution* published an exposé of state mental health hospitals that revealed more than 100 suspicious patient deaths during the previous five years.[6] The 2002 death of Brian Kent at Kiley Center in Waukegan, Illinois, revealed a pattern of neglect caused by unprofessional attitudes, administrative indifference, lack of competence, and caregiver fatigue.[7]

Deinstitutionalization is a Civil Right

Clearly, deinstitutionalization and the development of a strong community-based system that helps people with ID/DD live in the community is both morally and ethically the right thing to do, but it is also a civil rights issue: The law supports the individual right to live in the community.

In crafting the ADA of 1990, Congress found that “the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals.”

In 1995, two residents of institutions in Georgia sued the state, claiming they had the right to receive care in the most integrated setting appropriate and their unnecessary institutionalization was discriminatory, in violation of the Americans with Disabilities Act (ADA). Eventually the case was heard by the United States Supreme Court. In 1999, the Court ruled in the case of *Olmstead v. L.C.*, 527 U.S. 581 (1999), that unnecessary institutionalization of people with disabilities constitutes discrimination under the ADA (*Olmstead v. L.C.*, 527 U.S. 581).

The decision included some definitive language about institutionalization. It said,

- Unjustified isolation, we hold, is properly regarded as discrimination based on disability.
- Institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.
- Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement and cultural enrichment.

The *Olmstead* decision requires community placement when the following three conditions are met:

- The person can handle or benefit from community placement,
- The transfer is not opposed by the affected person, and
- Community placement can be reasonably accommodated (i.e., would not impose a fundamental alteration, which the state must prove).

The *Olmstead* case focused on people who were currently in an institution and seeking community-based care. Subsequent cases have applied *Olmstead* to people at risk of institutionalization, including those on waiting lists, arguing that cuts in community services that would force a person into an institution violate the ADA.

In 2009, the Civil Rights Division of the Department of Justice (DOJ) launched an aggressive effort to enforce the *Olmstead* decision.

> President Obama issued a proclamation launching the "Year of Community Living," and has directed the Administration to redouble enforcement efforts. The Division has responded by working with state and local government officials, disability rights groups and attorneys around the country, and with representatives of the Department of Health and Human Services, to fashion an effective, nationwide program to enforce the integration mandate of the Department's regulations implementing Title II of the ADA.[8]

A technical assistance guide has been created to help people understand their rights and to help public entities understand their obligations under the ADA and *Olmstead.*[9]

Evolution: From Institutions to Community

Over the past 40 years, more than 230,000 people with intellectual and developmental disabilities were discharged from state institutions. As of June 30, 2009, 33,900 remained institutionalized. This movement from institutions to community is heavily influenced by the role of Medicaid funding in each state's plan.

Institutions and the ICF/DD Program

Large State Institutional Settings

The national peak of institutionalization for people with ID/DD was in 1967, when 194,650 people were housed in large state institutions and an additional 33,850 were housed in state psychiatric facilities.[10] However, even at the height of institutionalization, most people with developmental disabilities lived with families, as they do today. Families had few other options. Most residential care outside the family home was provided in large state-run facilities and financed entirely by state, local, and private funding.

In 1971, in response to evidence of the horrific conditions in which people with ID/DD were being warehoused, Congress established the Intermediate Care Facilities for the Developmentally Disabled (ICF/DD) program (formerly Intermediate Care Facilities for the Mentally Retarded (ICF/MR))[11] as a Medicaid benefit. The ICF/DD program was offered as an optional Medicaid program. A state could opt to include the program in its Medicaid plan, or it could continue to fund its institutions without federal financial participation. However, once a state included ICF/DD program dollars in its plan, it had to provide the service to anyone who was eligible for Medicaid services.

By the 1980s, all 50 states had adopted the ICF/DD program. In exchange for federal Medicaid funds, institutions had to comply with minimum federal requirements for safety, staffing levels, appropriate active treatment, qualified professional staff, and many other conditions.

Small State Institutional Settings

The ICF/DD program focused on large state institutions. However, federal regulations and guidelines made it clear that the same level of care could be delivered in state and private facilities that served 16 or fewer people. These smaller facilities offered another option for people with ID/DD. They were typically located in the community and were managed and financed through the state's optional ICF/DD program. However, they provided a regulated program of services in a formally certified setting, which meant that residents were still living an institutional life.

Community and the HCBS Waiver

Unlike the institutional setting, the community setting starts with recognition that people with ID/DD should have control over the delivery of services and supports, as well as the location and setting in which they receive them. These settings vary in size and type, but they are substantially smaller than the institutional setting. They include both in-home with family settings and out-of-home group settings, and offer a variety of services and supports.

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.

By 2009, 48 states and the District of Columbia operated 125 different HCBS waivers for people with DD, including waivers serving the broad population of people with DD and waivers targeting people with particular conditions, such as autism spectrum disorders and intellectual disabilities. The two other states, Arizona and Vermont, provided similar services as part of research and demonstration waivers authorized by Section 1115 of the Social Security Act.[12]

Community-based settings are available in a variety of types and sizes, and with various characteristics. The relationship between provider and consumer, the number of residents, and the style of service and support delivery are among the attributes that differentiate the choices available through the HCBS waiver.

Community-based setting types include specialized institutional facility, group home, apartment program, independent home/apartment, parent/relative's home, foster care/host home, and nursing facility.

Additional Community Program Funding

The Federal Government, through changes in the Medicaid program, has promoted community living through several initiatives in the past seven years, including the following:

Deficit Reduction Act (DRA) of 2005: This legislation created a new Medicaid option that covers certain HCBS waiver services without requiring states to go through the lengthy waiver application and approval process.[13]

Money Follows the Person (MFP), 2005: The MFP demonstration, first authorized by Congress as part of the 2005 DRA and then extended by the 2010 Patient Protection and Affordable Care Act (PPACA), provides grants to states to (1) transition people from nursing homes and other long-term care institutions (such as ICF/DDs) to homes, apartments, or group homes of four or fewer residents, and (2) change state policies so that Medicaid funds for long-term care services and supports can follow the person to the setting of his or her choice. As of 2010, the Center for Medicare and Medicaid Services (CMS) had awarded MFP grants to 30 states and the District of Columbia, and the demonstration is authorized through 2016.[14] To ease the transition to the community, the state provides MFP participants with a richer mix of services than is available to regular waiver participants, and states receive an enhanced federal match for providing these additional services.

American Recovery and Reinvestment Act of 2009 (ARRA): ARRA provides enhanced federal matching funds that enable states to continue funding HCBS waivers and other Medicaid services. The maintenance-of-eligibility requirement in ARRA restricts state options for reducing eligibility for services.[15]

Community First Choice Option (2011): This proposed rule implements Section 2401 of the Affordable Care Act (ACA), which establishes a new state option to provide home and community-based attendant services and supports. The Community First Choice Option adds a new section 1915(k) to the Social Security Act that allows states to provide home and community-based attendant services and supports under their state plans. First Choice, available beginning October 1, 2011, allows states to receive a 6 percentage point increase in federal matching payments for expenditures related to this option.

Community Choice Act (not enacted): The Community Choice Act (CCA), introduced in Congress in 2007 and again in 2009, would require state Medicaid plans to cover community-based attendant services and supports for people with disabilities, regardless of age or disability. The CCA would allow the dollars to follow the person and would allow eligible people or their representatives to choose where they would receive services and supports. Any person who is entitled to nursing home or other institutional services could choose where and how these services were provided. Despite advocacy efforts, the bill never got out of committee and the concept was not included in the 2010 health care reform.[16]

Institutions: Definitions, Populations, and Trends

Definitions

The definition of "institution" continues to evolve. This paper focuses on a traditional definition of an institution as a large, usually state-run, hospital-style setting, often located in a rural area. However, according to federal regulations, ICF/DDs, which include smaller community-based facilities with populations of 6–16, are also defined as institutions.

NCD believes that institutional care can exist not just in large state-run facilities but in small community-run small group homes as well; therefore, NCD has defined "institution" as a facility of four or more people who did not choose to live together. This new definition raises the standard and continues the trend toward smaller, more intimate housing situations for people with ID/DD. In this paper we use the more traditional definition of six or more, as data are not currently available for the lower number.

These definitions focus on the number of people who live in the same house, but advocates have developed a definition that focuses on quality of life and control issues. In 2011, a coalition of self-advocates defined institutions based on their own priorities in *Keeping the Promise – Self-Advocates Defining the Meaning of Community.*[17] They defined institutions as places that—

- Include only people with disabilities
- Include more than three people who have not chosen to live together
- Do not permit residents to lock the door to their bedroom or bathroom
- Enforce regimented meal and sleep times
- Limit visitors, including who may visit and when they may do so
- Restrict when a resident may enter or exit the home
- Restrict an individual's religious practices or beliefs
- Limit the ability of a resident to select or remove support staff
- Restrict residents' sexual preferences or activity
- Require residents to change housing if they wish to make changes in the personnel who provide their support or the nature of the support
- Restrict access to the telephone or Internet
- Restrict access to broader community life and activities

Population by Setting Type

In 2009, 469,123 people received services and supports while living in state or nonstate institutions, nursing facilities, small congregate residential settings, and even in their own homes. Another 599,152 received some services and supports while living with their families.[18]

> "Many of us don't live in institutions but lead institutional lives."
>
> —*Georgia focus group participant*

Historically, many stakeholders thought of community-based care as small group homes with three to six people staffed full time by providers, or small ICFs, which are similar to small group homes but more highly structured. However, states have been expanding options with six or fewer residents to respond to individual needs and allow people to live in the most homelike setting possible. As shown in Table 1, in 2009, 138,302 people lived in HCBS waiver group homes, 40,967 lived in host and foster homes, and 122,088 lived in their own homes.

The deinstitutionalization movement tends to focus on the 32,380 people in large state institutions. However, more than 100,000 people are in other restrictive settings, including smaller ICF/DDs with 7–15 residents and other large institutions and nursing homes.

Population Trends

The institutionalization of people with ID/DD peaked nationally in 1967, when 194,650 people with ID/DD were housed in large designated state institutions. By 2009, this number had been reduced to 32,909.[19]

Table 1. Residents with DD by Size and Type of Setting, 2009

Number of Residents and Type of Setting	Number	Percentage of Total in Residential Services
6 or fewer residents		
Non-ICF/DD group living home	138,302	
Host/foster home	40,967	
Own home	122,088	
ICF/DD group living	20,106	
Total 6 or fewer residents	**321,463**	**69%**
7–15 residents		
ICF/DD group living	19,392	
Non-ICF/DD group living	39,056	
Total 7–15	**58,448**	**12%**
16+ residents (institutions)		
State ICF/DD institutions	32,380	
Nonstate ICF/DD institutions	18,485	
State non-ICF/DD Institutions	529	
Nonstate, non-ICF/DD institutions	8,210	
Nursing facilities	29,608	
Total 16+	**89,212**	**19%**
Total receiving residential or nursing facility services	469,123	100%
Living with family members and receiving family support or other DD services	599,152	
Total receiving services	1,068,275	
Waitlisted for residential services	**122,870**	

Source: Data from Lakin et al. 2010.[20]

Most of the deinstitutionalization debate is focused on large state institutions. However, this represents only a portion of the people with ID/DD housed in institutions: 29,608 people with ID/DD are in nursing facilities and 18,485 are in private ICF/DDs with more than 16 residents.

Figure 1. Average Daily Census of People with ID/DD in Large State ID/DD Facilities, 1950–2009

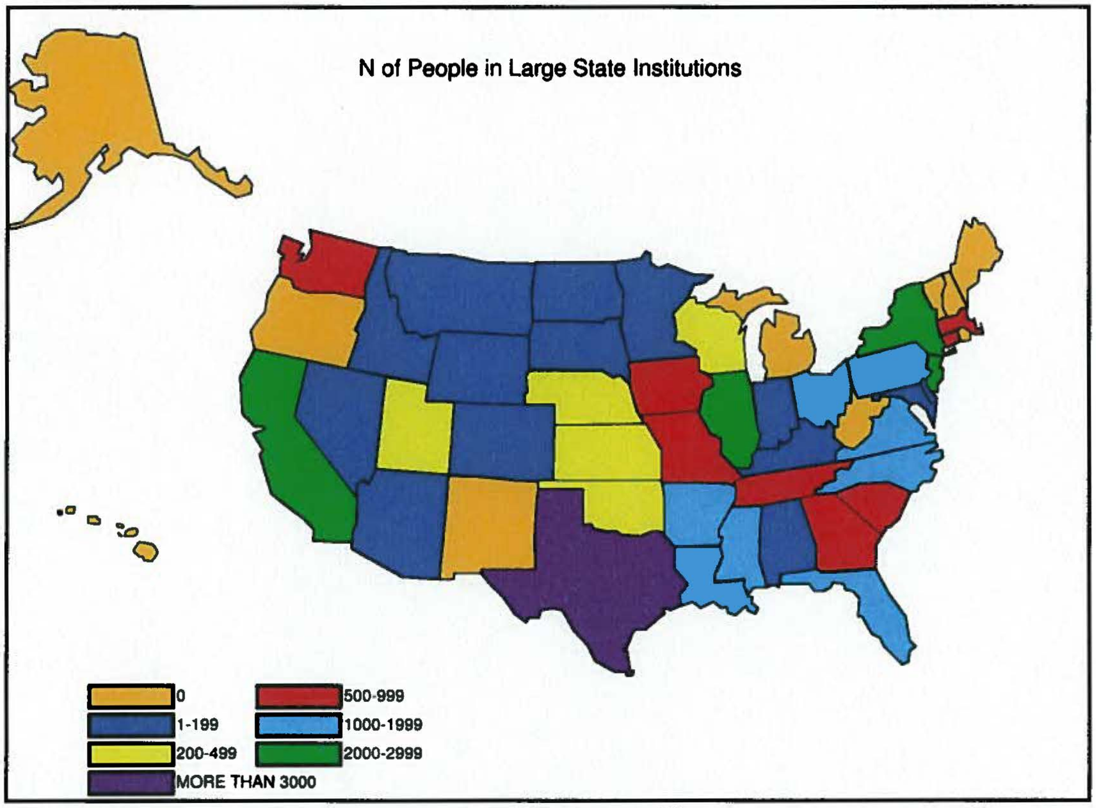
Source: Data from Lakin et al. 2010.[21]

Population Variation Among States

States vary widely in the number of residents in their state institutions. As of 2008, 85 percent of the nation's institutionalized population resided in 18 states, with Texas housing almost one in seven (14%) of all institution residents.

As shown in Figure 2, the number of people living in large state institutions varies by region and by state. A number of states in the East and Southeast still have more than 1,000 institution residents. States in the Midwest tend to have relatively few people in institutions, with the notable exception of Illinois, which currently has 2,254 people living in large institutional settings.[22]

Figure 2. Map of the Number of People with ID/DD Living in Large State Institutions



Source: Based on data from Lakin et al. 2010.[23]

Deinstitutionalization: Goal and Strategies

The Goal

The goal of deinstitutionalization is to move people with ID/DD out of segregated institutions to integrated lives in the community with services and supports. Research and experience clearly show the benefits of community living compared with living in an institution. These benefits include an increased quality of life for people with ID/DD, cost savings for the government, and the opportunity to use these savings to provide services to people who are currently not served.

> "The battle isn't between institutional care and community care. The battle is that people aren't getting the services they need. They are being unnecessarily subjected to harm, [even though]we know how to give them the services they need."
>
> —*Community living advocate in Georgia*

When the system works well, transitioning people from an institution to the community begins with a plan for each resident and results in each person living in a home; not just another residential setting, but a home, a sanctuary, a place where the residents have the most autonomy possible and are treated with dignity and respect.

Some people claim that every challenge must be overcome before deinstitutionalization; however, keeping institutions open slows the process of enhancing the community system. Institutions can absorb state resources and divert attention from the need to develop a quality home and community-based service (HCBS) delivery system.

The current fiscal constraints faced by states compound the challenge of developing and maintaining a strong community-based service system. Some states are cutting back on the amount of services they provide to each recipient or are limiting the number of service recipients.

Strategies that Work

Making a system work for people is not an easy task, but it can be done. Closing an institution is not one act; it is many pieces of work coming together to create the opportunity for a community to rethink how it serves and supports its citizens with intellectual and developmental disabilities. It is important to develop a plan that includes identifying allies and partners and their roles, and developing strategies to move the work forward. A successful transition also includes the creation of a robust community-based system of care and a commitment to quality assurance as an ongoing process involving a diverse group of stakeholders.

Strategies for the Deinstitutionalization Movement

Set a vision and comprehensive agenda. A clear vision and agenda are key to success.

Successful initiatives include several critical elements. They—

- Focus on the ideas that people with intellectual and developmental disabilities have the right to live in the least restrictive environment and that the state's resources should be allocated as efficiently as possible.
- Create broad and inclusive plans that begin with the most comprehensive vision of a system of community care for people who are currently in state institutions, in the community, and on waiting lists.
- Start with a vision based on ending segregation and discrimination, and stay focused on that vision rather than on cost, which is compelling but should not be the primary reason for closing institutions.

Stay focused on the goal. Once the vision has been identified and the agenda set, do not compromise on the vision or the values you have established. The political process tends to modify and cut down. You might have to compromise at some points in the process on details or timing, but the vision must remain clear.

Create a deinstitutionalization platform and an outline of principles. People with developmental disabilities have the right to live in the least restrictive setting. Strong communications are critical; position papers and a deinstitutionalization platform can help keep the coalition unified and anchored. The platform can also serve as a major educational tool with lawmakers and the media. An excellent example was developed by the Arc of Connecticut in its Platform for Reform which included concepts such as person-centered services, self-determination, full empowerment of families, and self-advocacy, as well as a commonsense plan for reform and implementation strategies that will effect real inclusion.

Several key strategies have worked well in states that have closed institutions and those that are in the process of closing them:

- **Frame the debate.** Frame the debate with vision and values. This puts the focus on the individual and his or her rights rather than the interests of other groups.
- **Focus on closure as a civil right.** This strategy shifts the discussion to a legal one and focuses the debate on the rights of people with disabilities rather than on the numbers, the economic benefits to the state, or the impact on the economy of the community that houses the institution. Individual rights are at the core of the litigation surrounding institutional closure. (See "Pursue a legal strategy" below.)
- **Define the choice—not "if" but "when" and "how."** The state can choose to frame the discussion in a way that focuses the community's attention on the important issues that surround the closing of an institution, such as capacity building and development of a quality assurance process. This approach includes all stakeholders and can create an environment of inclusion and ownership in the success of the closure and the transition of people into high-quality, person-centered living situations in the community.
- **Shut off new admissions.** States that use the deinstitutionalization strategy of shutting off new admissions have generally faced less opposition than states that close the doors at the beginning of the deinstitutionalization process. To successfully pursue this strategy, state officials and stakeholders must identify the pathways leading to institutionalization and offer alternatives. Some states (e.g., Georgia, Michigan, and New Hampshire) have chosen to focus on children first and then move on to adults. However, this strategy may take too long: Missouri, with no admissions in more than two years, still has six state-run institutions. Representative Scott Rupp has introduced legislation to close the facilities within five years.
- **Pursue a legal strategy.** Coalitions around the country have benefited from a legal strategy with the involvement of the state's protection and advocacy (P&A) agency, legal aid organizations, or the U.S. Department of Justice (DOJ). Federal policy and programs are evolving to support more people living in the community. In June 2011, the Department of Justice released a legal rights resource guide to help states identify tools and recent court decisions that can guide their strategy development. The guide can be accessed at: http://www.ada.gov/cguide.pdf.

In almost all states in which deinstitutionalization has occurred, litigation has played a strong role; in fact, it is often the initial impetus for closure or downsizing. Litigation continues to be among the strategies used to require states to cease alleged violations of federal Medicaid law, the ADA, Section 504 of the Rehabilitation Act, and the U.S. Constitution. Litigation has been successful in improving access to Medicaid home and community-based services, downsizing institutions, and challenging restrictions on the scope of services so people with developmental disabilities can live in the most integrated settings.

The legal consensus, developed over years of litigation and currently being enforced by DOJ, is that people have a fundamental right to live in the least restrictive environment that meets their needs.

Legal remedies have accelerated the pace of deinstitutionalization. In recent years, federal intervention—through DOJ lawsuits and formal and informal settlement agreements—is pushing states to move more quickly in their efforts to deinstitutionalize people with ID/DD. Under general rules governing lawsuits brought by the Federal Government, DOJ may not file a lawsuit unless it has first attempted to settle the dispute through negotiation. The *Olmstead* decision has often been called the *Brown v. Board of Education* of the disability rights movement. In June 2009, President Barack Obama, commemorating the anniversary of the *Olmstead* ruling, said,

> "The *Olmstead* ruling was a critical step forward for our nation, articulating one of the most fundamental rights of Americans with disabilities: having the choice to live independently. I am proud to launch this initiative to reaffirm my Administration's commitment to vigorous enforcement of civil rights for Americans with disabilities and to ensuring the fullest inclusion of all people in the life of our nation."
>
> *—President Barack Obama*[24]

Develop a working knowledge of Medicaid and the Affordable Health Care Act. Medicaid policies have evolved in recent years to provide additional options for facilitating community-based care, and many successful closures have capitalized on these opportunities. It is important to develop policy experts within the state Medicaid program and in the community, as well as expert contacts for the Patient Protection and Affordable

Care Act of 2010 (PPACA), which will affect the availability of some services as the plan rolls out over the next few years. It is especially important to know the following:

- Basic rules on eligibility and costs
- Basics of your state plan
- Provider rate structure and its impact on service availability; specifically, the availability of medical and dental providers

Build the case. The case for community-based rather than institutional care is very compelling. Provide cost data for the number of people who could be served in the community compared with the costs if they live in institutions, as well as data on quality of life and health outcome benefits associated with living in the community. Inform legislators and others about the ramifications of the law and interpretations such as the *Olmstead* decision. Advocates have found it necessary and important to debunk the many myths that exist regarding the civil rights issues at the core of this discussion.

Advocate for quality assurance standards that will protect the health and safety of people living in community settings. The deinstitutionalization plan should specify how the state agency will ensure that the standards of care identified in the plan will be monitored and what corrective action the state will take if it determines that care is not meeting these standards or is not being provided at all. Some states have developed local, regional, or state quality assurance councils to help with this important work. Success is a process, not a single event; it takes time to build the community capacity and the oversight systems that are necessary to ensure that people's needs are met.

Basic Advocacy Strategies to Support the Initiative

The following are some basic strategies that are key to all successful system change efforts.

- **Line up leadership.** To move the process forward, the coalition needs support from the state agency, the governor, and the legislature. Successful closures have been based on bipartisan support. To engage leaders, families must visit them and share their individual stories.
- **Be aware of the political environment.** Many factors are at play in the potential closure of an institution, including the economic impact on communities, concerns of people with ID/DD, and concerns of family members. It is important to understand the political environment, including the interests and positions of opponents of closure.

- **Seek out the challengers.** Challenges to institutional closure are often mounted by parents of institution residents or state workers at the institutions and the unions that represent them. The best approach is to hold informal meetings with businesses, families, union representatives, and local legislators to share information, focus the discussion on civil rights, negotiate, solve problems, and even engage these groups in the design of the deinstitutionalization plan.

  Rather than developing a "bunker mentality," successful closure coalitions tend to take an open-door problem-solving approach with challengers, without compromising on principles. Identify and discuss the needs and fears of people with ID/DD and their families. Communicate with families about their specific concerns, which might include access to regular health care and dental care, safety, and continuity and quality of care. Point out real-life situations (not just data and examples from other states) in which people just like their family members are living successfully in the community. Enabling people with disabilities to interact with others like themselves who are living in the community is a powerful tool. This has been done successfully.

- **Create timely, targeted communication, public education, and media relations.** To defuse challenges to the concept of institutional closure, proponents must mount a campaign to confront the stigma, misinformation, and negative attitudes associated with deinstitutionalization. Use real stories to change attitudes and foster a broader understanding of the nature of community-based living through public testimony and through personal conversations with legislators. Myths and misconceptions about how people can be served in the community and the effectiveness of community-based services can be difficult to overcome. Self-advocate and family testimony is powerful, especially when the discussion includes personal stories combined with national studies of effective interventions, treatment models, and outcomes.

Getting a deinstitutionalization plan approved and funded is only half the battle; implementation has its own unique challenges. The coalition must demonstrate that it is committed to individualized care plans with strong quality assurance measures. A one-size-fits-all plan will not work; it will not serve the individual well and will not address family concerns. The coalition should participate in the development of the implementation plan, monitoring progress and identifying concerns, which can then be addressed with the state agency or other implementing individuals or groups.

Forging Ahead: Developing a Plan and Building Community Capacity

To develop a transition plan and build on it, the planning process must include all stakeholders in both the institution and the community. Most effective planning processes include teams that have broad stakeholder participation, as well as specific person-centered teams that plan the transition of each individual into the community. In court-ordered closures, these plans are supervised by a court-appointed monitor.

The type and intensity of the services and supports a person needs vary dramatically depending on functional and medical status, family situation, and goals and dreams. All these factors should be considered in the development of both the community's plan and the individual plan.

Community planning focuses on meeting a variety of needs, such as these:

- Housing and necessary housing supports, such as live-in staff
- Habilitation and rehabilitation needs
- Medical and nursing supports
- Behavioral and mental health services and supports
- Personal assistance care, both in the home and on the job
- Independent living skills training and supports
- Employment
- Recreation

It is critical to the deinstitutionalization movement that these services and supports can be delivered in any type of residential setting, regardless of the intensity of the client's needs.

Many issues need to be addressed in the community plan to ensure that the system can meet the needs of the person who is transitioning from an institution to the community. These issues include the following:

- **Address the shortage of direct-support workers available to the community-based support system.**
  The success of community-based care relies on the availability of quality direct-support workers. However, the turnover rate averages of 50 percent a year and

the vacancy rate, 10 percent to 11 percent. States struggle to recruit and retain a reliable direct-care workforce.[25]

Direct-care workers in the community-based system earn, on average, $10.14 an hour, compared with $15.53 for direct-care workers employed in residential institutions.[26] This disparity contributes to the lower costs in the community.[27]

- **Be aware of best practices in the deinstitutionalization movement and the development of community capacity.**
  University Centers of Excellence in Developmental Disabilities (UCEDDs), funded by the Administration on Developmental Disabilities in conjunction with state DD agencies and other groups, have developed a number of best practices. For example, they have developed a person-centered planning process (PCP) in which the person with the disability and people important to that person develop a vision of his or her future life and identify the types of services and supports that will be needed to achieve that vision. This approach—combined with a personal budget allocation that the person may apply within the bounds of an approved service plan—has the potential to provide a cost-effective, individualized approach that maximizes quality of life. However, most people with ID/DD obtain community-based residential and day services from a provider agency that manages the facilities, personnel, and logistics of support and fits the clients into predetermined service plans.

- **Know how resources are allocated and the variables that affect quality of care.**
  The resources dedicated to people with ID/DD vary significantly across states, as does the quality of both institutional and community-based services. In some states the system works relatively well, while in others it takes a lot of ingenuity and commitment on the part of the family to obtain high-quality community services.

> “We will always need to work on convincing people that we are of value to the community and that we deserve every opportunity that we can get.”
>
> —*Oregon self-advocate*

- **Understand how the waiting lists for services work, what allowances are available, and how these affect the community's plan.**
  Under the Medicaid HCBS waiver program, states have considerable flexibility in determining the type of services they will provide and the number of people to whom they will provide the services. Many states have long waiting lists for services. Although current institution residents are guaranteed a space in the community and are not placed on a waiting list, the existence of waiting lists for people who are not in institutions casts doubt on a state's commitment to community living.
- **Understand the impact of individual and community attitudes, and develop strategies to address these when necessary.**
  Affording people with ID/DD the same rights and opportunities as other citizens is often hindered by low expectations for people with DD/ID and the belief that "separate but equal" is justified in this situation.
- **Focus on housing, and develop creative strategies to identify, maintain, and retain housing designed to accommodate the needs of people with ID/DD. Housing can be expensive, and it can be a challenge to find housing with the desired features in areas that allow group living situations.**
  A community-based service system depends on the availability of affordable, usable housing, which is typically scarce. Most systems rely on the use of publicly subsidized housing, in combination with individual Supplemental Security Income and Social Security Disability Insurance (SSI and SSDI) payments, because Medicaid does not cover housing costs in the community. Thus, people are often put on waiting lists or remain in their childhood homes far longer than they desire. One's housing options should not determine what services one gets. All these factors need to be addressed in the plan.
- **Identify a health care provider system that is accessible and accepting. Accessing health care can be challenging.**
  When people with disabilities are disbursed widely in a community, as is desirable, specialized health care and dental services may not be available locally. In 49 states, Medicaid does not pay for routine dental care. Furthermore, many service providers are unwilling to accept Medicaid reimbursement, which they believe is inadequate, further limiting the availability of some practitioners.

Overcoming Misconceptions: Myths and Realities

For many people with an intellectual or developmental disability and their parents, the transition from living in an institution to living in the community is a challenging time, and they have many concerns. Some of these concerns are based in fact and some are based on fear of the unknown and on myths and misinformation about community-based living. When the long-term health and welfare of a loved one is at stake, it is important to be able to separate the wheat from the chaff.

Arguments for and against deinstitutionalization remain, although the option of people with ID/DD to reside in the community is legally settled. An understanding of the community-based setting and the services and supports available can help address the concerns of family members. It can also help in the development of a more robust and comprehensive community service model.

Myth 1. Serving "Difficult to Serve" Populations

Statement of Myth

Some institutions must remain open to provide residential and therapeutic services for populations that are the most difficult to serve in the community, including people who are medically fragile, those who are dually diagnosed with ID/DD and mental illness, and those who are involved with the criminal justice system.

Statement of Reality

Eleven states have succeeded in closing all their state institutions and have developed a variety of approaches to provide necessary services and supports in community settings for all populations. These approaches include PCP that integrates ID/DD supports with medical or psychiatric care, crisis teams, short-term stabilization services, and specialized housing.

Supportive Information

Three groups of residents present additional challenges in closing an institution, but with appropriate planning, these challenges can be overcome.

- **Medically fragile:** Some institution residents have complex medical problems that require intensive medical support; for example, seizure disorder, aspiration risk, or dysphagia (difficulty swallowing). Successful states have developed strong PCP processes that include nursing and medical planning. Medical and nursing services for people with ID/DD exist in most communities, because they are similar to the services required by the medically fragile elderly.

- **Dual diagnoses:** Half of institution residents have a mental health condition that requires psychiatric attention.[28] Addressing these needs in the community requires integrated interventions from ID/DD and mental health providers. Some states have found that they need to provide additional training for mental health providers to address the special needs of ID/DD clients in order to accommodate the full range of therapeutic needs.[29] A number of states have developed short-term crisis homes staffed with behavioral specialists and other medically related staff who can stabilize people in crisis.
- **Involved with the criminal justice system:** This population presents a special challenge, because the developmental disabilities agencies must balance the public's demand for safety against the individual's right to the least restrictive environment. States that have closed all their institutions tend to provide a continuum of residential options. For example, in Oregon, a person might be assigned to a secured residential facility (6–16 residents), an unsecured facility with 24-hour awake supervision, a residential treatment home (five or fewer residents) with 24-hour awake supervision, or less intensive supervision in an adult foster home or independent living with frequent visits from a case manager.[30] In Vermont and Maryland, placement in small residences may include one-to-one supervision, awake overnight supervision, frequent reporting to a probation officer, or alarms on windows and doors.[31]

Each state has developed a system to determine what level of restriction is sufficient to protect public safety without infringing on the rights of the individual. The systems have several levels of screening and evaluation, and include input from the DD or mental health agency and the criminal justice system.

Avoiding unnecessary institutionalization: Mobile crisis teams and short-term stabilization services

People who have dual diagnoses of ID/DD and mental illness and those who are medically fragile are more likely than others to experience a crisis that threatens their ability to live successfully in the community. In states that still have institutions, these people might be relegated to an institution when they are in crisis, not because it is the most appropriate option but because it is the only option that is immediately available. In several recent settlements between DOJ and states, the state has been required to develop community-based crisis intervention strategies.

Georgia has recently established a system of mobile crisis units (MCUs) that can be dispatched to people with ID/DD quickly at any time of day or night. The team can provide a range of services, including assessment, crisis intervention, supportive counseling, information and referrals, links to appropriate community-based services for ongoing treatment, and follow-up. Before the development of the MCUs, people in crisis were often sent to ICF/DDs or mental health facilities. The services provided by the MCUs are designed to help a person remain in his or her current placement. In their first six months of operation, the crisis teams were dispatched more than 400 times. In three out of four cases (307 cases), the crisis was resolved at the person's home, either immediately or through intensive in-home supports. Among the remaining cases, 59 were transported to a crisis support home and 40 were admitted to inpatient mental hospitals, crisis support units, or other facilities. Most cases are resolved immediately or within a week. The system has been effective in reducing reliance on institutions and reducing the involvement of law enforcement. Since the implementation of the Georgia Crisis System, there has been a 40 percent drop in incidents involving law enforcement.[32]

Myth 2. Severity of Disability

Statement of Myth

People who are currently housed in institutions are more severely disabled than those who live in the community, and no evidence shows that they can be served effectively in the community.

Statement of Reality

More people with extensive support needs are served in the community rather than in institutions, demonstrating that *all* people with ID/DD can be served effectively in the community. While many people in institutions have very significant impairments and will require extensive supports to live in the community, many people with the same level of impairments are already successfully receiving those supports in the community. Many are living with families, with few paid supports.

Supportive information

People with ID/DD vary significantly in age, level of intellectual disability, additional conditions, and functional limitations. In the reduction of institutional populations over the past 40 years, those with higher functional skills and fewer complicating factors were generally discharged first. As a result, a large proportion of people currently living in institutions will need a high level of support when they move into the community.

Research has revealed two important facts about this population:

- More people with extensive support needs are served in the community than in institutions, indicating that all people with ID/DD can be served effectively in the community.
- On average, people who live in institutions have a higher level of support needs than those who live in the community.

Both of these facts are important. The first indicates that people with extensive support needs can be served effectively in the community. The second affects the cost estimates for serving them.

Lakin et al. (2006) found that "HCBS finances services for people with a full range of disabilities and support needs, but ICF/DD beneficiaries, on average, on a number of measures, exhibited substantially greater levels of impairment than HCBS recipients. Because of the greater total number of HCBS waiver recipients, there are more HCBS than ICF/DD recipients with substantial impairments."[33]

For example, data from California indicate that 18 percent of people in institutions and only 5 percent of people in the community are dependent on medical technology.[34] However, 80,862 people with ID/DD live in the community in California and 2,252 live in state institutions.[35] Thus, more than 4,000 technology-dependent people are living successfully in the community and 405 are in institutions.

Myth 3. Cost Comparison by Setting

Statement of Myth

Closing an institution and moving its residents into the community does not save money.

Statement of Reality

The average cost of residential services varies dramatically by type of setting. In 2009, the average annual per capita expenditures were as follows:[36]

- Large state institutions—$196,735
- ICF/DDs (including private institutions and smaller ICF/DD settings)—$138,980
- Home and community-based services—$43,969

On the basis of these figures, it might seem that moving residents from large state institutions to home and community-based services would save more than $150,000 per capita. However, because these figures are average costs calculated across all people residing in each setting, and the average level of need of people in institutions is higher than that of people currently living in the community, the actual savings are somewhat lower and vary significantly by state.

A number of studies show that although community-based services may be more expensive for a small number of people, closing an institution yields cost savings.[37] However, there is a risk in framing the deinstitutionalization debate as a cost issue rather than an issue of civil rights and quality of life. Although cost savings can motivate state legislators in the short run, the media may represent the decision as unwillingness to spend funds necessary to care for our most vulnerable citizens.

Supportive Information

Three factors explain why the cost is not reduced from an average of $196,735 to $43,969 when an institution resident is moved into the community.

- **Heterogeneous populations.** The average cost of care in the community is not necessarily comparable to the average cost for people in institutions owing to differences in severity of disability and the required services and supports. HCBS covers a wide range of services and supports, and each recipient receives only the ones that are necessary. Thus the average cost of HCBS includes people all along the spectrum—from those who are living with their families and receiving only minimal supports to those who are receiving intensive medical supports 24 hours a day and relying exclusively on paid supports. A greater percentage of the institution residents may require intensive levels of medical supports and services in community homes.
- **Complex funding.** The Medicaid ICF/DD program covers most of the costs associated with institutional care. However, a variety of funds are combined to cover the costs of community-based care. While Medicaid covers certain services under the HCBS waiver, other services and supports are funded solely by state funds or by combinations of funds from the U.S. Department of Housing and Urban Development, the Social Security Administration, mental health block grants, and other funding streams. The average HCBS cost figure includes only the Medicaid portion of community-based care.

- **Variability within and among states.** The costs of institutional and community-based services vary widely across states depending on the characteristics of users, staff levels, the types of services and supports offered in the waiver, the types of residential options available, and other factors.

A number of studies and state cost estimates address these issues; they consistently find that although community-based services might be more expensive for a small number of people, closing an institution yields cost savings overall.[38]

Studies conducted in the 1980s and 1990s found that moving people from institutions to community settings saved between 5 percent and 27 percent.[39] These savings are significant, especially as community care consistently yields better results than institutional care.

The range of expected savings may be even higher in the current environment than it was 20–30 years ago, because the cost of institutional care has skyrocketed. Unfortunately, no retrospective studies have been conducted recently. Three well-designed cost estimates suggest the range of savings that can be expected.

1. In 2011, Massachusetts estimated that providing community care for the remainder of the residents of its large state institutions would reduce the per capita expenditures for the current institutional population by 40 percent and save $42 million over five years.[40] The state based its findings on the financial experience of previous closures in the state.
2. Kansas assumed that most of the people in its institutions would qualify for the highest tier of community services, and yet the state would still save almost 50 percent per person. The 2011 estimate suggested that the state would save $25 million.[41]
3. Vermont reports that the average per person cost of supports in the most intensive community services category is $208,464 a year, which is 26 percent less than the estimated annual per person cost would have been at Brandon Training School in today's dollars ($283,470).[42]

Why Community-Based Care Is Cost-Effective

Community-based services include a diverse array of service types, ranging from minimal intermittent supports to residential and day program services, whereas institutions traditionally offer an established service package (e.g., ICF/DD services).

Thus, only a part of the range of community services is comparable with the services provided in a large ICF/DD.

Cost-effectiveness is possible for three basic reasons:

1. One of the major costs of providing services—and a major component of the cost differential between institutional and community-based care—is the cost of staff. As noted in many studies, from the Pennhurst study in 1985[43] to more recent studies,[44] the employees of large state institutions are generally unionized state employees who have much richer compensation packages than the people staffing private community-based services.
2. Institutions have a high fixed cost of maintaining the facility and ancillary services. Most institutions were built to hold many more residents than are currently using the facilities. Thus, the cost per person for the building, electricity, food service, and other services are spread over a small number of people, so it is quite high.
3. Once PCP is fully developed, states are finding that a significant number of people with developmental disabilities and their families or guardians begin to request less intense levels of specialized care over time than is typically provided in institutions.[45]

The "Woodwork Effect"

State legislators have expressed concern that closing institutions and expanding community-based services would result in a "woodwork effect." They contend that if states make it easy for people to get Medicaid to help pay for services in their homes, many people will want those services. Currently, people rely on unpaid help from family and friends to stay out of institutions. But once states offer decent in-home services, people will "come out of the woodwork" and start asking for them.

To argue that a state should maintain institutions rather than expand community services because too many people might want the latter is to argue that it is appropriate for the state to ration care by offering services no one wants.

In reality, most people with ID/DD who would access services if they were available are already out of the woodwork. They are on waiting lists. Thus, states already have some estimate of the number of people who would use the services if they were available.

Myth 4. Funding of Services and Supports

Statement of Myth

The major funding source for services to people with ID/DD are state taxes and local levies. Each state chooses the programs, services, and supports it will make available to people who live in institutions and those who live in the community.

Statement of Reality

Funding for services for people with ID/DD comes from a variety of sources, but Medicaid pays the lion's share. In 2009, Medicaid, with a combination of state and federal dollars, accounted for 76 percent of the $53.2 billion of public expenditures on services for people with ID/DD. The bulk of these expenditures are paid through the ICF/MR program and the HCBS waiver program.[46] The states' decisions about how to spend funds on Medicaid-eligible people are strongly influenced by Medicaid rules.

Supportive Information

Medicaid program dollars, through the ICF/DD program, are the major source of funding for people with ID/DD who live in institutions. They are also the major source for those who receive services in the community through the HCBS waiver program. Other funding for community-based services comes from the Social Security Administration through SSI and the SSDI) Adult Disabled Children program (ADC), both of which provide direct payments or cash benefits to people with disabilities. These cash benefits are not available to people with disabilities who live in institutions. A small percentage of the funding comes from Medicare, veterans' benefits, or private insurance.

Medicaid Funding

Because the majority of public financing for supports and programs for people with ID/DD is funded through Medicaid and the Social Security Administration, it is important to understand the role each plays in providing services and supports for people with ID/DD in both institutional and community settings.

The federal Medicaid program gives states two main options to include in their state plans for providing long-term care supports for people with ID/DD who are eligible for Medicaid services.

The ICF/DD program. Congress began offering states the option of including the ICF/DD program as a Medicaid benefit in 1971. A state could opt to include the program in its Medicaid plan or it could continue to fund its institutions without federal financial participation. In exchange for the Medicaid funds, institutions had to comply with federal requirements for safety, staffing levels, appropriate active treatment, and qualified professional staff, and meet many other conditions.

By the 1980s, all states had adopted the ICF/DD program. Medicaid contributes matching payments to states, ranging from 50 percent to 83 percent, on the basis of per capita income, giving states with lower per capita income a higher matching rate in an effort to equalize their ability to fund health care services.

HCBS waiver program. In 1981, Congress established the Medicaid HCBS waiver program. The waiver allows states to receive federal matching funds for a variety of residential and other services and supports in the community to Medicaid beneficiaries who would otherwise require institutional care. The program allows states to waive specific Medicaid regulations, including the requirement to provide the same services to all eligible Medicaid beneficiaries. This waiver allows states to cover a limited number of people or to offer the services only in certain geographic locations. The waiver also allows states to offer different groups of people different sets of services.

The HCBS waiver gives states the option of covering services needed to help a program participant avoid institutional placement. Each state can choose exactly what to offer, tailoring a package of services and defining the services to fit the target population of the particular waiver program. Once a person is enrolled in a waver program, however, the state may not limit access to covered services necessary to ensure his or her health and safety.

In 2009, 48 states and the District of Columbia operated 125 different HCBS waivers for people with ID/DD, including waivers serving the broad population of people with ID/DD and waivers targeting people with specific conditions such as autism spectrum disorders and intellectual disabilities. The two remaining states, Arizona and Vermont, provided similar services as part of research and demonstration waivers authorized by Section 1115 of the Social Security Act.[47]

Social Security Administration (SSA) Funding

A second source of support to people with ID/DD in community-based settings is the Social Security Administration. SSA provides income support for people with ID/DD through its SSDI program and—most important for the ID/DD population—its SSI program. State supplements to SSI/SSDI and other state funding resources make up the rest of the public sources of revenue for service and supports for people with ID/DD who live in the community. Because housing is not an allowable expense under Medicaid, these cash benefits, along with additional supplementary benefits provided by some states, are often used for housing in the community model.

Myth 5. Community Capacity and "Waiting Lists"

Statement of Myth

There is no room in the community-based service systems for people who are currently in institutions. Waiting lists are a testament to that reality.

Statement of Reality

People with ID/DD who are leaving institutions are entitled to HCBS waiver program services and supports, which must be made available in the community. The necessary services and supports are identified during discharge planning. Even though almost all states have waiting lists for services, the people who are leaving an institution do not compete with those on the waiting list. Waiver services, including residential supports, can be developed more quickly than institutional care; therefore, once funding is available, services can be quickly put into place.

Statement of Supportive Information

All people who meet the financial and other eligibility criteria for Medicaid and the level-of-care criteria for ICF/DD services are entitled to receive them in an institutional setting. As an extension of that entitlement, people who are being discharged from ICF/DDs are entitled to HCBS waiver services and thus, are exempt from waiting lists. As part of the discharge process, services and supports are identified and provided in the community using HCBS waiver program funds through Medicaid.

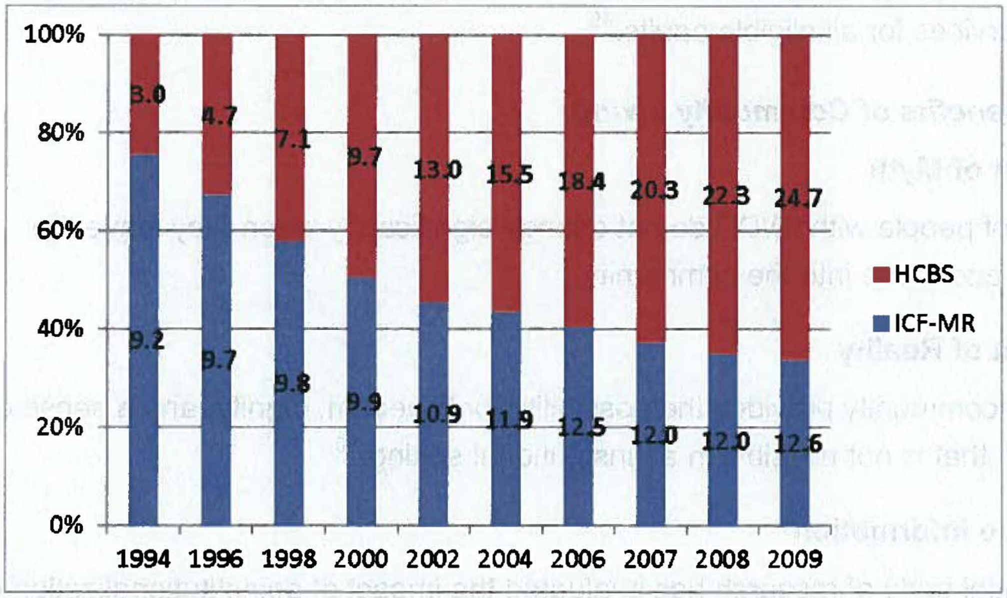
For those who do not currently live in an institutional setting, a state may limit the number of eligible Medicaid recipients to whom it provides HCBS waiver services. In other words, a community resident might qualify for Medicaid and meet the level-of-care criteria for the HCBS waiver but still not receive services because the state has reached its preset limit. In most states, these applicants are put on a waiting list. This situation leads to an institutional bias in the way Medicaid dollars are allocated.

Waiting Lists

In 2009, an estimated 122,000 people in the United States were on waiting lists for residential services. A state may modify the limit with permission from the Centers for Medicare and Medicaid Services (CMS).

Historically, spending for institutional care has exceeded expenditures for community care. However, the disproportionate spending on institutional care has diminished considerably in recent years. Nationally, ICF/DD expenditures as a percentage of Medicaid long-term care expenditures for ID/DD have been declining as HCBS waiver spending has increased (see Figure 3). However, states continue to apply a disproportionate amount of resources to institutions.

Figure 3. Annual Expenditures in Billions of Dollars for HCBS and ICF/MR as a Percentage of Total Expenditures, 1994–2009



Source: Data from Lakin et al. 2010, Table 3.17b.

In 2008, Medicaid spent $34.3 billion on long-term care for people with developmental disabilities. ICF/DD accounted for 35 percent of the spending ($12 billion), while HCBS waivers accounted for 65 percent ($22.3 billion). The institutional bias has declined since 1994, when Medicaid spent 78 percent of its DD long-term care dollars on ICF/DD.[48]

Elimination of waiting lists is a priority for advocates in the community, and this has been the target of both legal and legislative action in some states. After some institutions closed in Oregon, the issue of waiting lists arose; it was addressed through legal and legislative action.

In January 2000, five people with developmental disabilities and their families filed a lawsuit against the state. They claimed that they were unfairly being denied access to services they were entitled to receive. *Staley v. Kitzhaber* became a class action, representing more than 3,000 Oregonians with developmental disabilities. A settlement was reached in September 2000 and the Oregon Legislature made $37 million in general funds available for the first biennium of funding. Implementation of the *Staley v. Kitzhaber* settlement agreement began on July 1, 2001.

The settlement agreement is intended to eliminate or significantly reduce the number of people with developmental disabilities who are waiting for services by increasing the availability of comprehensive services on a noncrisis basis and providing self-directed support services for all eligible adults.[49]

Myth 6. Benefits of Community Living

Statement of Myth

The lives of people with ID/DD do not change significantly when they leave the institution and move into the community.

Statement of Reality

Life in the community provides the possibility for "freedom, dignity, and a sense of belonging" that is not possible in an institutional setting.[50]

Supportive Information

A substantial body of research has evaluated the impact of deinstitutionalization on quality of life, behavioral outcomes, life satisfaction, competence in activities of daily living, challenging behaviors, and health. The studies—regardless of analytical technique or country of origin—find that living in the community yields positive results in a number of quality of life domains.

Choice and self-determination. Compared with institution residents, community residents have more opportunities to make choices, as well as larger social networks and more friends. They access more mainstream facilities, participate more in community life, have more chances to acquire new skills and develop existing skills, and are more satisfied with their living arrangements.[51]

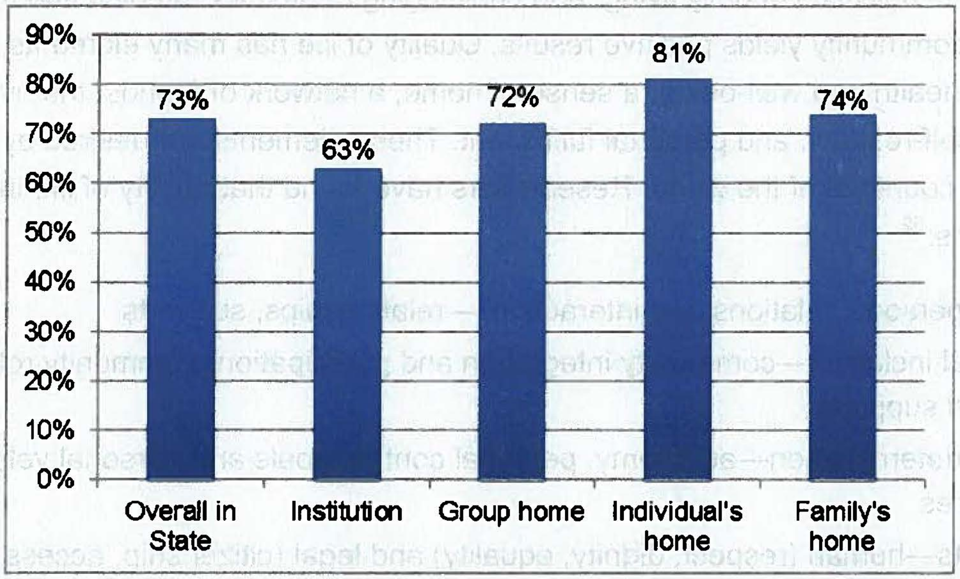
Quality of life indicators. Extensive research has evaluated the impact of deinstitutionalization on quality of life, behavioral outcomes, life satisfaction, competence in activities of daily living, and challenging behaviors. Studies find that living in the community yields positive results. Quality of life has many elements, such as personal health and well-being, a sense of home, a network of friends, the availability of choices, self-respect, and personal fulfillment. These elements are desired by all people in all countries of the world. Researchers have found that quality of life involves eight domains:[52]

1. Interpersonal relations and interactions—relationships, supports
2. Social inclusion—community integration and participation, community roles, social supports
3. Self-determination—autonomy, personal control, goals and personal values, choices
4. Rights—human (respect, dignity, equality) and legal (citizenship, access, due process)
5. Material well-being—financial status, employment, housing
6. Personal development—education, personal competence, performance
7. Emotional well-being—contentment, self-concept, lack of stress
8. Physical well-being—health and health care, activities of daily living, leisure

Measuring quality of life characteristics to determine the success of deinstitutionalization and improve the delivery of services and supports in community-based models is an important activity. The National Core Indicators (NCI) 2009–2010 survey shows some of these quality of life characteristics. This survey focuses on the level of community participation experienced by community-based service consumers in 16 states; Orange County, CA; and the District of Columbia. It compares these scores with the scores of those who reside in various settings, including institutions. In addition to background, population, and other statistical information, the survey measures consumer outcomes for certain core indicators.[53]

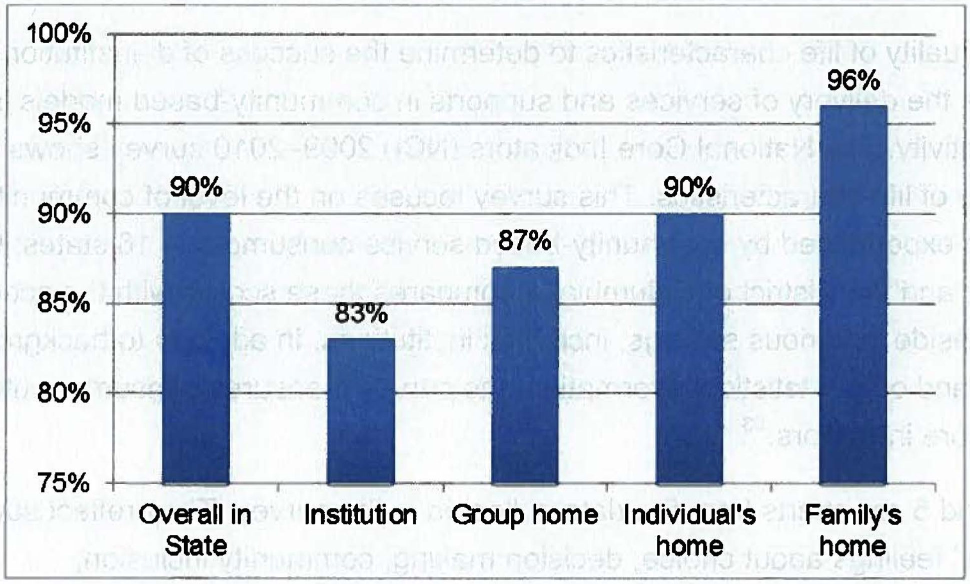
Figures 4 and 5 are charts from the data collected in the survey. They reflect survey respondents' feelings about choice, decision making, community inclusion, relationships, and satisfaction.

Figure 4. Proportion of People Who Report Having Friends and Caring Relationships with People Other Than Support Staff and Family Members



Source: Analysis by Valerie J. Bradley, Health Services Research Institute. Data from National Core Indicators project. Based on 6,711 adults with developmental disabilities who received services in participating NCI states during 2009–10. “Group home” includes all community-based settings except an individual’s home or a family’s home.

Figure 5. Proportion of People Who Like Their Home or Where They Live



Source: Analysis by Valerie J. Bradley, Health Services Research Institute. Data from National Core Indicators project. Based on 6,711 adults with developmental disabilities who received services in participating NCI states during 2009–10. “Group home” includes all community-based settings except an individual’s home or a family’s home.

Since 2005, at least four well-regarded meta-analyses of institutional versus community care have been published: Lakin et al.,[54] Kozma et al.,[55] Walsh et al.,[56] and Stancliffe et al.[57] Together, the analyses reviewed more than 150 articles that meet accepted criteria for quality research. The literature reviews indicate that community-based settings, services, and supports are superior to institutional settings in many areas, but certain key elements must be in place for the community living experience to be optimum.

Myth 7. Institutional Closure and the Impact on the Economy

Statement of Myth

We should keep institutions open to retain good jobs in the small towns and rural areas where many of them are located.

Statement of Reality

People with intellectual and developmental disabilities have a right to live in a setting of their choice; the impact of their choice on the economy of an area that houses an institution is not their responsibility. Moreover, with proper planning, states can mitigate the economic impact of closing institutions.

Supportive Information

Progress in deinstitutionalization in many states—such as Illinois, Kansas, Massachusetts, New Jersey, and Washington—has been stymied by the politics of institution closure. Communities that believe closure would devastate their local economy have reacted with outrage, and unions representing staff have rallied to prevent the loss of jobs.

Many institutions are in small towns and rural areas, and are major employers. Gary Blumenthal, president of the Association of Developmental Disability Providers in Massachusetts, says, "Opposition to institutional closure can be strictly parochial, including opposition from local legislators who represent communities with limited employment opportunities; thus the closure of the state institution may feel like a major economic drag. Regardless, holding people with disabilities hostage to local economic concerns is viewed by advocates as inappropriate treatment of people with disabilities."[58]

To address the difficult questions about economic impact on local communities and the loss of jobs, some states have created closure commissions to study the impact of specific closures on residents, their families, workers, and the economy of the community.

Concern over the economic impact of the closure of a large public employer is not unique to institutions that house people with ID/DD. Similar debates occur when governments close military bases or prisons and other correctional facilities.

Mitigating the Impact on Employees

Nancy Thaler, executive director of the National Association of State Directors of Developmental Disabilities Services (NASDDS), says, “No state has gone through the closure process without facing opposition of varying degrees from union or nonunion institution employees.” Others point out that employee opposition to closure isn’t just about jobs and salaries and benefits. Long-term employees of these institutions are genuinely concerned about residents’ care.[59]

Experts seem to agree that a key set of initial strategies can be helpful in this situation:[60]

- Include workers in closure commissions and work groups as early as possible in the closure process.
- Show employees that you respect them and value their input and participation.
- State officials should communicate directly with employees.

Studies have been conducted on the impact of the closure of state institutions and hospitals—including institutions serving people with ID/DD, as well as prisons and juvenile correction facilities. Although these studies have mentioned the economic impact in terms of cost savings, they have not focused specifically on the effects on workers and communities as a whole. Strategies to ameliorate these effects include the following:

- States have shifted positions from the institution to the community, so that workers remain employed and involved, but they work in the community rather than in an institution. California, Georgia, Kansas, Pennsylvania, Oregon, and Wisconsin have used this strategy.
- States, usually with the leadership of the governor, have adopted a hire-first policy that gives displaced institution workers priority for other state jobs.

- States have provided outplacement services to displaced workers that include retraining and placement assistance in the community. Indiana did an exemplary job of training workers for both state and private sector jobs.
- States have incentivized retirement, offering attractive "early out" packages. Alabama, California, Massachusetts, Michigan, and several other states have used this strategy.
- Some states have established state-operated community-based alternatives and reassign some of the institution staff to these new residences.

Some state employees faced with losing their jobs have responded entrepreneurially by forming their own companies. Snug Harbor Home Health in Indiana is one example of this approach.

Mitigating the Impact on the Economy of the Community

Closure of an institution can provide an opportunity and resources to reinvest the money earned by closure and the sale of the property. Oregon took advantage of this opportunity. In 1999, the legislature reinvested $10 million in savings from the Fairview closure to increase direct-care wages by $1/hour, create capacity in counties to respond to people in crisis (add staffing and funds for short-term diversion needs), and increase funds for family support from $3 million to $8 million.

In the same year, the legislature passed the Fairview Trust Fund bill, which directed the sale of the Fairview property and established a trust. Interest and a small amount of the principal from the trust are used to help people with developmental disabilities stay in their own homes in their own communities. The trust provides grants of less than $5,000 for housing modifications to people with ID/DD who are living in their own home or their family's home. In 2010, the state distributed $400,000.[61]

Appropriate Planning

In successful state closures, state officials, from legislators to the governor, must ensure that the savings from closure will be reinvested in community-based services and must engage their constituents at all levels in focusing on the potential for economic development of the property and the entrepreneurial opportunities for workers and community members in the postclosure environment. The following questions should be discussed openly and fairly:

- How many jobs will be eliminated?

- How will these job losses be staged over the course of the transition?
- What percentage of new jobs in the community will go to state workers?
- What efforts will be made to help employees find new state jobs? Other jobs?
- What is the anticipated impact of employees with seniority bumping employees who have special training or experience serving special populations?
- What retraining opportunities are available in the community?
- What is the anticipated economic impact on the local economy?
- What provisions will be made to help the community develop economic alternatives?

Careful planning, employee participation, and community inclusion can ease the impact of the closure and help keep the focus on the most important issue: the health and well-being of the people with ID/DD who live in the institution that is being closed.

Myth 8. Mortality

Statement of Myth

People with ID/DD who live in the community will experience higher mortality than those who receive care in an institutional setting.

Statement of Reality

The mortality rate of people with ID/DD is a function of quality of care and the availability and quality of services and supports, not the setting in which they receive care.

This myth is based on a 1998 study by O'Brian and Zaharia that statistically analyzed the mortality rate of people who were transferred out of institutions in California between 1993 and 1999. Their methodology and findings have been discredited by numerous other researchers, who have found no increase in mortality rates as a result of moving out of institutions.[62]

Supportive Information

Recent methodologically sound studies have found no increase in mortality.

- Conroy and Adler found improved survival for persons leaving the Pennhurst institution for life in the community and no evidence of transfer trauma.[63]

- Lerman, Apgar, and Jordan (2003) found that the death ratio of 150 movers who left a New Jersey institution was comparable to that of a matched group of 150 stayers, after controlling for critical high-risk variables.[64]
- Heller et al. (1998) found that although transitions from institutions or nursing homes to community settings may result in short-term stress and risks that *may* affect mortality (transfer trauma), overall, the long-term survival rates improve.[65]
- Hsieh et al. (2009) found that regardless of residential location, those who had a greater variation in the physical environment and greater involvement in social activities had a lower risk of mortality.[66]

In the 1990s, Strauss and his colleagues suggested that people with developmental disabilities, particularly those with severe disabilities, have higher mortality rates in the community than in institutions. Researchers have critiqued Strauss's methodology and the quality of his data[67] and have been unable to reproduce his results.[68]

All states must take measures to ensure that vulnerable people—whether living in institutions or in the community—are healthy, safe, and protected from harm. Newspaper reports, protection and advocacy (P&A) investigations, and state investigations show that instances of abuse and neglect occur in community settings, and some of these result in unnecessary deaths. However, the same can be said about institutions. If a state's safeguards are not rigorous, enforced, and closely monitored, people with developmental disabilities are not safe regardless of where they live.

As systems of care become more sophisticated and mature, states can increase their efforts in quality assurance to protect health and safety. Missouri, for example, has instituted a Health Identification Planning System (HIPS)—a quality monitoring process for the discovery and remediation of health and safety concerns for people in Division of Developmental Disability community residential services. A health inventory tool is completed when a person enters community placement, annually, and whenever a significant health change occurs. Regional office registered nurses complete nursing reviews on people with a certain score on their health inventory. Nursing reviews evaluate the provider's health supports and services and the person's response to treatment, and identify unmet health care needs.

An increasing number of states are also conducting mortality studies, reviewing each death, and have established proactive programs and initiatives to improve the health status of people with developmental disabilities.

Myth 9. Olmstead *and Choice*

Statement of Myth

The Supreme Court ruling in *Olmstead* guarantees people the option to choose, including the right to choose an institution.

Statement of Reality

The *Olmstead* decision was intended to ensure that people with disabilities have the right to treatment in the "most integrated setting appropriate to [their] needs." In most of the recent lower court decisions addressing the issue, the courts generally agreed that the ADA's antidiscrimination position does not provide an actionable right to institutional care.

Supportive Information

Some of those who oppose institutional closure claim that some people with ID/DD are so severely disabled that they cannot handle or benefit from community living and that institutions are the most integrated setting appropriate to their needs. They claim that *Olmstead* gives people with ID/DD and their guardians the right to choose the setting they believe is most appropriate, even if that setting is an institution.

However, the *Olmstead* decision says that state facilities *may* remain open without violating the ADA, but it does not say that states *must* keep institutions open (if they have them) to comply with the ADA. Courts generally agree that neither the ADA nor *Olmstead* gives people the right to institutional care.

The Olmstead *Decision*

In June 22, 1999, the United States Supreme Court held in *Olmstead v. L.C.* that the unnecessary segregation of people with disabilities in institutions may constitute discrimination based on disability. The court ruled that the ADA requires states to provide community-based services rather than institutional placements for people with disabilities if (a) community placement is appropriate; (b) the transfer is not opposed by the affected individual; and (c) the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others who are receiving state-supported services.[69]

The Court went on to say that a state can meet its *Olmstead* obligations if it has a "comprehensive, effectively working plan for evaluating and placing people with disabilities in less restrictive settings" and "a waiting list that moves at a reasonable pace and that is not controlled by the state's endeavors to keep its institutions fully populated."

Keeping the Promise: Self Advocates Defining the Meaning of Community Living

Background

In June 2009, the Centers for Medicare and Medicaid Services (CMS) announced they would be publishing regulations defining the character of home and community-based settings. CMS acknowledged that, "some individuals who receive Home and Community Based Services in a residential setting managed or operated by a service provider have experienced a provider-centered and institution-like living arrangement, instead of a person-centered and home-like environment with the freedoms that should be characteristic of any home and community-based setting[1]." CMS stated that using such settings to provide "home and community based" services are contrary to the purpose of the 1915(c) waiver program.

The purpose of this paper is to provide CMS with a definition of "community" that captures the most vital elements of community life. In addition, we believe that these comments are important contributions to policy issues in the areas of housing, education, employment and transportation.

Introduction

Over the course of the last half century, the United States has made many important promises to its citizens with intellectual and developmental disabilities. These promises are found in the Developmental Disabilities Assistance and Bill of Rights Act, the Americans with Disabilities Act (ADA), the decisions of the Supreme Court and other federal courts, the Individuals with Disabilities Education Act (IDEA), the Rehabilitation Act of 1973, and other laws, rules, decisions, and findings. Those of us on the "receiving end" of the promises have taken our Nation's commitments seriously. We expect that when our country guarantees "access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life" [as in the

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[1] "Medicaid Program; Home and Community-Based Services (HCBS) Waivers; Center for Medicare and Medicaid Services. Advance notice of proposed rulemaking." *Federal Register* 74 (June 22, 2009) Page 29453-29456

Developmental Disabilities Assistance and Bill of Rights Act] the promise will be kept. We believe that when our country recognizes “the right of individuals to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers and enjoy full inclusion and integration in the economic, political, social, cultural and educational mainstream of American society (as in the Rehabilitation Act of 1973 as amended, 29U.S.C.794), that we will indeed be in control of own lives.

When taken together these promises made to citizens with developmental disabilities establish a clear national purpose:

- Increasing self-determination and personal control in decisions affecting people with developmental disabilities and their families
- Providing opportunities for people with developmental disabilities to live and participate in their own communities
- Improving quality of life for individuals and families as they define it for themselves
- Supporting families as the most important and permanent unit of development, protection, and lifelong assistance to persons with developmental disabilities
- Investing in each individual’s developmental potential and capacity to contribute in age-related roles as productive and respected community members
- Ensuring access to sufficient, high-quality health and social supports to protect each person’s health, safety, rights, and well-being
- Moving people with developmental disabilities out of poverty by significantly increasing opportunities for real work with real pay

Together these points outline a national commitment to integrated and respected community living for people with developmental disabilities. We know this national commitment can only be achieved with assistance from service and support provider agencies that are committed to and capable of delivering on these collective promises. Because these agencies are funded through the Medicaid program, the Centers for Medicare and Medicaid Services (CMS) and associated state program agencies are responsible for the quality of service and support delivery. CMS's direction is central to setting standards and expectations for service providers.

Yet, despite this promise, many individuals who receive home and community based services do not experience genuine community settings or lifestyles. Many individuals are subjected to segregation, loss of control, lack of support, restrictions, no meaningful access to community and other challenges. Over time supporters of segregated, secluded, discriminatory or even exploitive models of care and support have adopted rhetorically the language of person-centered planning, insisting that its principles are at work in their program plans. Increasingly this has become a defense for practices that actually contradict the goals of individualized supports. Too much emphasis is being placed on the Person-Centered Planning rather than the measure of its outcomes. Did planning result in the individual having more control and choice in their life? Part of the problem is that often the choices being offered are from a profoundly limited menu.

Outcomes from self-directed lives must be the measures of success. Is the person enjoying a healthier and more satisfying life on their terms? Who is in charge? Does the individual have more control and choice? Is their participation in community genuine and meaningful? Are their relationships authentic?

To address these problems, the Autistic Self Advocacy Network (ASAN), Self-Advocates Becoming Empowered (SABE) and the National Youth Leadership Network convened a National Community Living Summit of self-advocates with developmental and intellectual disabilities. Twenty-five people attended the Summit. Immediately after the Summit, our team conducted 72 one-on-one interviews with our peers with developmental disabilities attending SABE's national self-advocacy conference. The Summit proceedings and interviews addressed three specific questions:

- What are three things that determine that a place or residential program is not part of the community?
- What are three things that determine that a place or program where a person gets residential services is truly in the community?

- What does Community Living really mean?

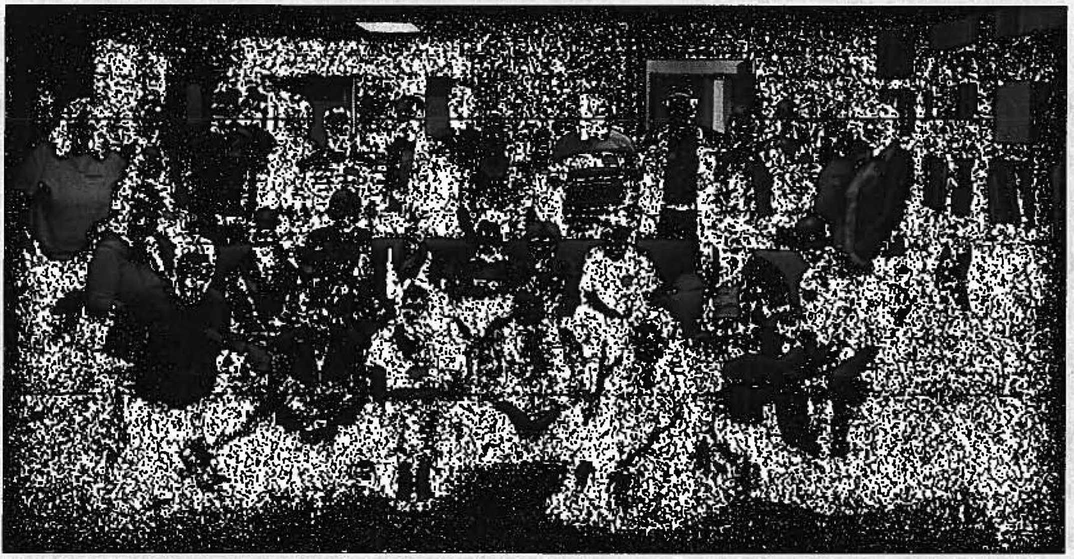
In attempting to answer these questions, we engaged both through our summit and through our interview team and interviewees a wide array of different backgrounds, experiences and identities reflective of the broad diversity of our great nation. Our participants came from across the country and from every age group. They differed not only in the types of disabilities and accommodations, but also in their languages, their incomes, their religious beliefs, their sexual orientations, their mode of communication, their races and ethnicities and every other manner of diversity. Some came from big cities, others small towns and rural areas. Some talked about having spent time in institutions - others had grown up in the community. Some have spent many years of their adult life in a sheltered workshop or day program – others are competitively employed. While we know that no effort can capture every aspect and facet of our wide and diverse community, we believe that this report and the process that led to it was broadly inclusive and captured many voices typically left out of these discussions. We assert the need to leave no voice behind and are proud of the diverse community this report represents.

From the answers to these questions, we found that over and over again people said that "community" was more than just a place, size or numbers. We found the definition of community living to be multi-dimensional with many different levels, layers and domains. Five particular "dimensions" stood out to us:

- physical size and structure;
- rights and self-determination;
- qualities and attitudes of providers;
- access to community life; and
- the meeting of support and access needs.

Our recommendations from the Summit and interviews are categorized into these five aspects of community living stated above. **To ensure that community integration is available to all people with disabilities regardless of where they live, we recommend applying these standards broadly to all community based services**

and settings, regardless of whether or not the building in which a person lives is owned by an agency, service provider, the person themselves or other third party entity. By these standards, we commit to hold those in power accountable to the promise made to us in the Americans with Disabilities Act, the Developmental Disabilities Assistance and Bill of Rights Act, the Rehabilitation Act, the Individuals with Disabilities Education Act and countless other pieces of legislation as well as regulations, proclamations and other public statements. Thus, we do declare that the following principles capture the meaning of living in the community:



Physical Structure and Size:

We are not in the community when we experience:

Segregation and Isolation: No matter the size, if services support segregation and isolation of people with intellectual and developmental disabilities from the community, it is not community. Segregation includes "locking" us away and is both wrong and dangerous, as it opens up the possibility of undetected abuse.

Policy Guideline: Gated communities, farmsteads, and clusters of group homes—even those that include both people with and without disabilities—are not in the community. When we live in those settings we become segregated from the general scope of community life. One summit participant noted that community must "integrate with people who don't have disabilities, and this does not mean staff."

Lack of Control: It is not community when a provider, licensing authority or the physical structure of a building takes away control from the people who live there. We must be free to come and go as we please. It is also a problem when we lack the ability to control the privacy of our own lives, by limiting our ability to lock the door of our rooms or our bathrooms or by forcing us to share a room with someone we don't know or don't desire to live with.

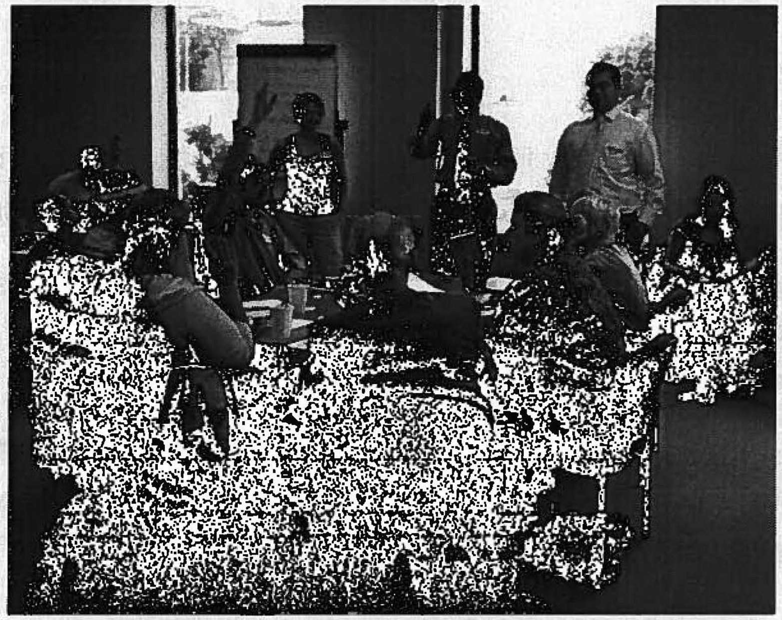
Policy Guideline: Homes in our community must reflect the personal style and preferences of the people who live there. We should have a key to our homes and be able to lock our bedrooms and bathrooms for privacy. We should not be forced to share a room with an unknown or undesired roommate. We should have the right to freely access and use kitchens, laundry rooms, and other social and domestic areas of the home.

Policy Guideline: People should have the freedom to choose whether to live in a rural, urban or suburban community. People should have reasonable access to places of commerce, recreation, and other aspects of community life.

Large Size: A large congregate care facility is not a home in the community. If a half dozen or more people live in a provider-owned group home, it is almost never controlled by the people who live there.

Policy Guideline: A home should not be considered "in the community" if more than four unrelated people live there.

Policy Guideline: We should live in apartments, houses, condominiums, trailers, etc. located in rural, urban, or suburban communities with typical public resources such as shops, houses of worship, places to work, and accessible transportation systems. We have the right to live in a safe community among people with and without disabilities.



Rights and Self Determination

We are restricted from experiencing community life by:

Rules: When we have to do what we are told and staff watch our every move. When we don't get to make rules where we live.

Lack of voice: When opportunities for typical life activities are strictly limited to what the provider will allow, not our own preferences.

No ability to see friends or family: When we experience limits on our freedom of association. When we are restricted and at times punished for expressing our sexuality. There is a lack of freedom to come and go. When we feel like we are being locked in.

No say: When we feel disempowered (due to restrictions on freedom and strong self-advocacy).

No choices: When we have no or limited choices. People make decision for us - limiting choices about where to live, food, clothing, health care, and spending money.

Policy Guideline: We must have a right to privacy. We must be able to have time to ourselves and have a private space with a door that can be locked against intrusion by staff or housemates.

Policy Guideline: We must have rights of freedom of mobility, choice, and association. Staff cannot set rules about: a) where we go and when, b) when and what we eat or drink, and c) who may be invited into our home and at what time.

People are empowered to live in the community by:

Choice: We have choices about where and with whom we live, how to spend our time, what to buy, what to eat and drink, where to go, how to have fun, what to wear, where to work, who to chill with, who we date and marry. We are supported to make our own medical and sexual decisions. We choose who will give us advice.

Policy Guidelines: Meals are not brought in from a central location designed only to prepare food for people with disabilities. We have the right to choose what to eat, when to eat and where to eat. When eating at home, meals are prepared in a kitchen unless food is ordered from a restaurant or another location available to both individuals with and without disabilities. We can choose to make our own meals and use the kitchen when and how we want to.

Risk: We are supported to take risks, even if others don't approve. It is not a big deal when one of us makes a mistake. We get support to carry out a plan even when a provider does not agree with the decision being made. Service providers support us to get non-biased information when making decisions.

Policy Guidelines: We should receive value-neutral support (if requested) to make decisions about employment, spending money, diet, entertainment, travel, clothing, recreation, friendship, sexuality, relationships, medical decisions, and other relevant parts of community life. We may reject this support and choose to make a different decision; we may choose not to receive this support if we do not desire it.

Policy Guideline: We, as persons with disabilities, are required to follow one set of laws (the same as for other U.S. citizens and residents). We live free of rules established to control people with disabilities.

Qualities and Attitudes of Providers

Attitudes and qualities of providers which limit our opportunity to be a part of the community include:

Group Treatment: Agencies that operate programs of congregate care and group treatment that diminish our opportunities for a life and daily routines of our own choosing.

Power Difference: Agencies that create power differences between those providing services and those receiving service so that we are controlled, disrespected and denied a chance for self-determination.

Denial of Choice: Agencies that do not take the time or have the skill to listen for and identify our personal goals and preferred lifestyles. Agencies that are not committed or able to give us the chance to do the things and to be with the people that are most important to us.

Lack of Respect: Agencies that fail to teach their employees of the value of each person and the ability of each person to communicate his or her desires. Agencies that fail to teach their support staff to respond to us in a respectful, age-appropriate and helpful manner.

Branding: Agencies that draw attention to themselves at the cost of the persons they support by branding their homes, their vehicles, and their activities.

Dual Loyalty: Agencies that communicate to support providers that they are working for the agency first and for us, the people they support, second.

Attitudes and qualities of providers which enhance people's opportunity to be a part of the community include:

Respect: Agencies that teach respect for each individual they support as an important person by listening, learning and responding in ways that honor us as individuals and increase our control over our own lives

Uniqueness: Agencies that teach and help support providers to know and respond in age-appropriate ways to each of us as a unique person with unique interests, preferences, needs and goals- not as a person defined by our disabilities.

Independence: Agencies that teach and expect support providers to truly support us to be more independent rather than to do things for us.

Choice: Agencies that measure how they are doing in responding to our preferences and desires for life as a community member and make changes as needed.

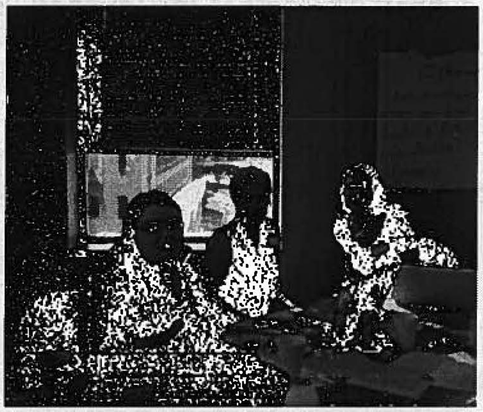
Equality: Agencies that respect us as having and deserving real homes that are respected in the same ways as the homes of everyone else in the community.

Person-Centered Culture: Agencies that fosters personalized services through a person-centered culture of respect for both support receivers and support providers, including value-based training, low staff turnover and choice of support providers.

Freedom from Fear: Agencies that provide us with an environment in which we can live safely and without fear of harm, neglect, or exploitation from others, including from support providers, other program participants, or others in the community.

<u>Policy Guideline</u>: Those of us receiving services must have control over hiring, firing, and supervising staff. This supports our right to self-determination, balances the staff/consumer relationship, and makes clear that our needs determine the type of support provided.

<u>Policy Guideline</u>: Staff working to support us as persons with disabilities in the community must be trained about our rights, including the right to self-determination, and how to support our exercising choice and control in our own lives. There must be trained staff to support us in our home, to work, and to participate in the life of our local community.



Access to Community:

Community living is not:

Segregation: If we are forced to literally live outside a community, it cannot be a community living setting. If we live on the outskirts of town, and lack access to the mainstream of community life, we are effectively segregated.

Lack of Transportation: When we lack accessible, affordable transportation, we are kept out of our communities. It is important for us to have access to navigational aids so we can find bus stops, as well as access to training on how to use public transit. Segregated transportation (for example, a bus that is run by a disability provider agency just for people with disabilities) is not what we want. We must have access to transportation on a basis that is consistent with individuals without disabilities. In rural areas or other places with poor access to public transit, it is important that additional measures be taken to ensure we as people with disabilities are not isolated and thus left more vulnerable to abuse and being left out of community.

Policy Guideline: Those of us receiving home and community-based services must have access to accessible, affordable transportation.

Denial of Choice in Relationships: We should be able to spend time with who we want. All of our relationships should be respected. Services and supports should accommodate our relationships, not the other way around. Absolute rules like unreasonable sleep time restrictions or not being allowed in each other's rooms do not respect our right to be with other persons. We also believe some regulations must be changed. We should not be prevented from marrying because of guardianship, Medicaid, or Social Security rules.

Policy Guideline: We should not be forced to surrender our right to associate with who we want and when we want to communicate as a pre-condition for receiving services. In addition, changes to Medicaid, Social Security, and state guardianship laws should ensure that people with disabilities have the right to marry and live with whom we choose.

Employment:

Whether we work in sheltered workshops, enclaves, or day habilitation centers, vocational segregation of us from people without disabilities does not count as community living. It is not gainful employment if we do not have the opportunity to make money at the same levels as other people who work in our community. We lose an important aspect of community life if we spend our time only around people with disabilities, in day habilitation centers, and are not able to be included in our broader communities.

Policy Guideline: We must have opportunities to work in jobs as part of the general work force, among people who do not have disabilities. Opportunities for earning wages and benefits should be the same as everyone else. CMS funding should be used for supported employment and not be used for sheltered workshops or settings paying sub-minimum wage for people with disabilities. CMS community funding should not be used for any segregated settings, including day habilitation centers. Anything that segregates us from our communities is not community.

Community living is:

Choice and Agency: We can do what we want when we want to do it, instead of having to decide as a big group of people and move together. This does not mean being alone in our independence, but exercising our self-determination.

Full Citizenship. We should be able to contribute fully to the community. This should include voting and participating in civic organizations.

Making a contribution. We believe in reciprocity (two-way relationships), to be able to pay forward society's support. For example, if friends drive us somewhere, we might watch their kids in return. We should have the opportunity to volunteer and participate in civic life like everyone else.

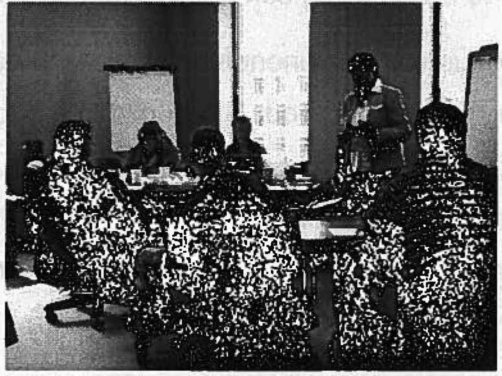
Knowing What is Going On in the Community We want to know what events and activities are happening. We want support to understand information about important community issues to make good decisions and have opinions.

Access to Community Resources. If we have a problem, we want to know where to go in the community to help us with solutions. Libraries, service systems, governments, and churches should be accessible sources of information and support for us.

Being a Part of a Neighborhood. We should live in a neighborhood where we can connect with community members who live next door. We would like to be treated like neighbors, and have the opportunity to work to make the neighborhood a better place.

Policy Guideline: State laws that prevent voting by people under guardianship must be amended to honor a person's right to vote.

Policy Guideline; Rules must not exist that restrict relationships between us as people with disabilities and our neighbors in the community. Visiting with neighbors should be routine and unobstructed by rules about privacy or liability.



Support and Access Needs:

Community living is not:

Aversives, Restraint, and Seclusion: When we are subjected to aversives, restraints, or seclusion, we are excluded from the community by abusive, inhumane violations of our rights that are sanctioned and tolerated by those in power.

Lack of Control: If we don't have control over our own personal belongings, money, or personal space, we are not in the community.

Policy Guideline: We must have the ability to hire, fire, train, and evaluate our staff without restriction or limitation—including no limitations set through options approved by an agency.

Policy Guideline: Typically systems do not separate housing from the services received by a person who needs support 24 hours a day. This creates a situation where we are not truly in charge of the place where we live. CMS must address the issue of separating housing and supports. Changing providers should not require us to leave the homes where we desire to live.

Community living is:

Control: We are in charge of our lives, which includes directing our services.

Communication: A fundamental aspect of community participation is the ability to communicate. Individuals must have access to needed augmentative and alternative communication (AAC) support, including the assessment, education, technology, and support systems needed to make aided communication meaningful.

Policy Guideline: Those of us who experience challenges in spoken communication should be supported to try various methods of alternatives and augmentative communication (AAC). As new technology becomes available, we should have the opportunity to use it to communicate. Staff should keep trying to see what might work and support our opportunities to improve our ability to communicate with modes of AAC that progressively vary in capability. Medicaid should pay for AAC devices, including AAC provided on "dual-use" devices and systems like iPhones or iPads.

Digital Inclusion: Telecommunications is a part of the modern community. While living in the community, we should have access to a phone, a computer, the Internet, necessary assistive technology devices and, if needed, digital literacy training to make long-distance and short-distance interpersonal communication meaningful. No limits should be set by staff on when and how we access these systems or what types of content we can access.

Policy Guideline: CMS funding should support us as persons receiving services to access the Internet and learn how to use online technologies.

Accessibility: Homes, transportation, and other aspects of community life and methods of support must be accessible—not just within the guidelines of physical access set by the ADA, but truly accessible to us as individuals living there. This means that our broader access needs are met—even if they are non-traditional.

Policy Guideline: Wherever possible, support should be provided in ways that maximizes our use of natural and peer supports in the community, not just paid staff and providers.

Policy Guideline: The goal of support and services should be to maximize our independence and empowerment. Respect the dignity of risk—avoid making suggestions that could take control of us in the context of providing support.

Conclusion

Self-Advocates Becoming Empowered (SABE), Autistic Self Advocacy Network (ASAN) and the National Youth Leadership Network (NYLN) want to acknowledge and thank Commissioner Sharon Lewis for asking us to present this information from the stand point of self-advocates which will show how decisions impact people's lives. This is in keeping with President Obama's charge to his administration. We have jointly presented indicators of what community is and what it is not. However, people don't need special skills or education to differentiate between "genuine community" and "community-like" settings or lifestyles. Genuine community means having real choice in assistance, friends, partners, supports and living circumstances. Genuine community happens in inclusive, diverse and mixed neighborhoods. Living in genuine community means making your own decisions and being an independent and self-sufficient citizen. Living in genuine community is enjoying all the same rights, privileges and responsibilities of every other citizen. In genuine community people have names not labels, live in neighborhoods not on campuses, make their own choices, and enjoy privacy and genuine relationships of equality.

To some people, these ideas may seem radical. Some people may say that they go too far. We disagree – it is only because of the low standards that have controlled the world of disability service-provision for too long are these ideas viewed as new or unusual. We believe that we should have the same rights and opportunities as anyone else. People with disabilities should be, and are by right, equal to people without disabilities. This simple but revolutionary idea is what has guided all of our recommendations and discussions. We refuse to settle for less any longer. We demand for ourselves and for our peers a community that places us in a position of equality to our neighbors. We reject the old models of "care" and "charity" for a world that is instead ruled by rights, interdependence and true community. By these principles, we make common cause and declare to a candid world a new chapter in the disability rights struggle.

Summit participants were of leaders from the Autistic Self Advocacy Network, the National Youth Leadership Network, Self-Advocates Becoming Empowered, and allies.

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