Deinstitutionalization: Unfinished Business

Companion Paper to Unfinished Business Toolkit

National Council on Disability
October 23, 2012

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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).

October 23, 2012

The views contained in this report do not necessarily represent those of the Administration, as this and all NCD documents are not subject to the A-19 Executive Branch review process.

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.

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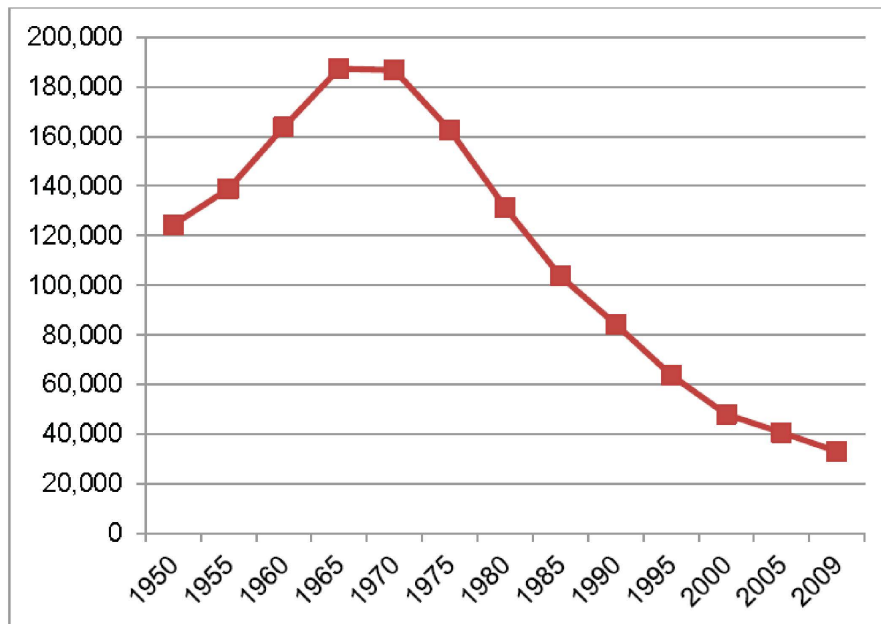
Source: Data from Lakin et al. 2010.[21]

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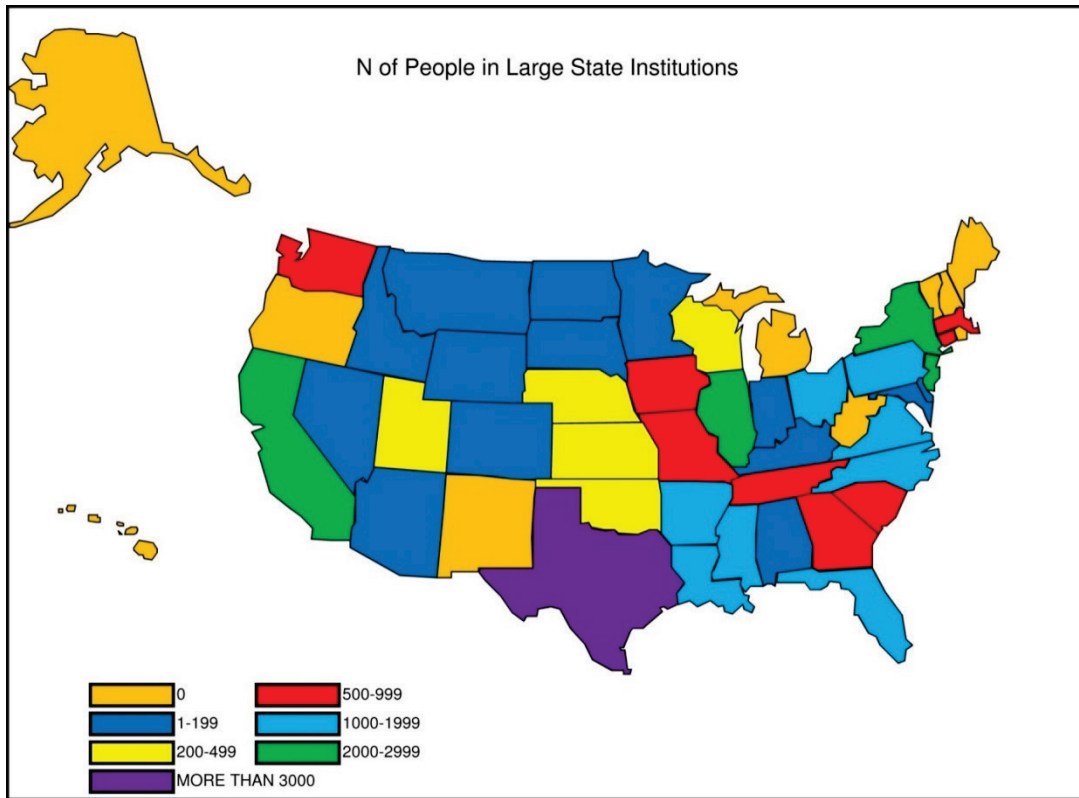
Source: Based on data from Lakin et al. 2010.[23]

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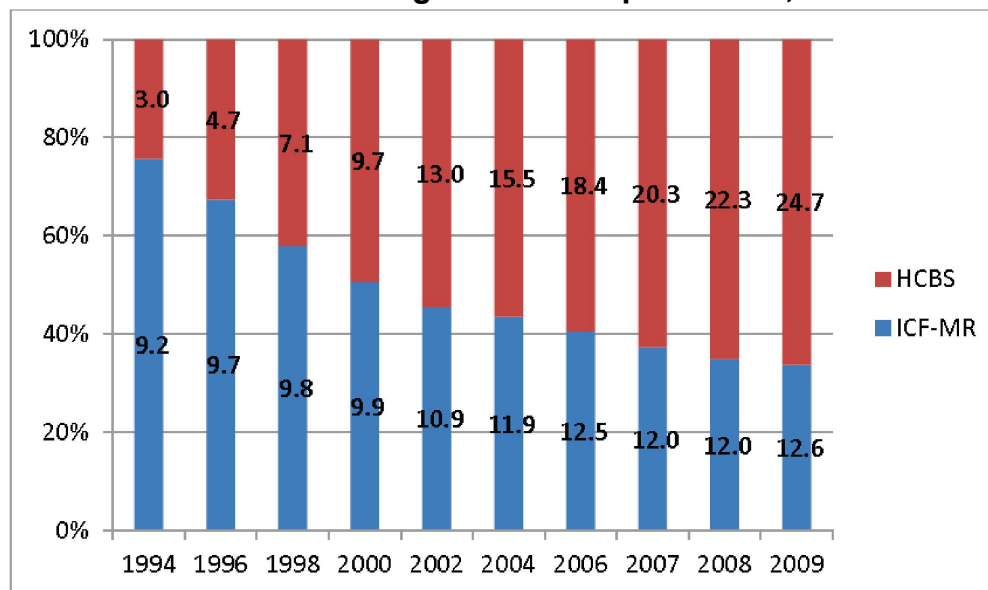
Source: Data from Lakin et al. 2010, Table 3.17b.

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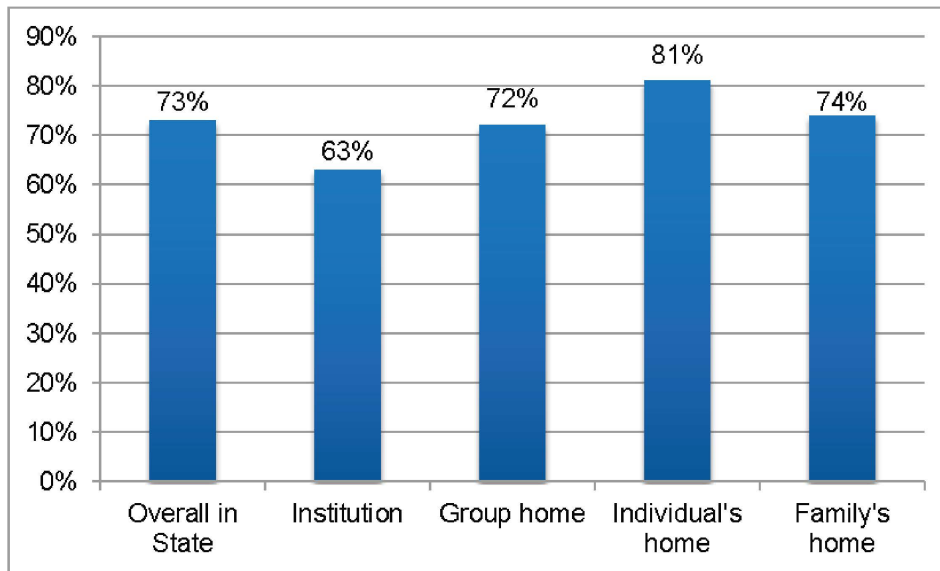
Source: Analysis by Valerie J. Bradley, Health Services Research Institute. Data from National Core Indicators project. Based on 6,711 adults with developmental disabilities who received services in participating NCI states during 2009–10. "Group home" includes all community-based settings except an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

Figure 5. Proportion of People Who Like Their Home or Where They Live
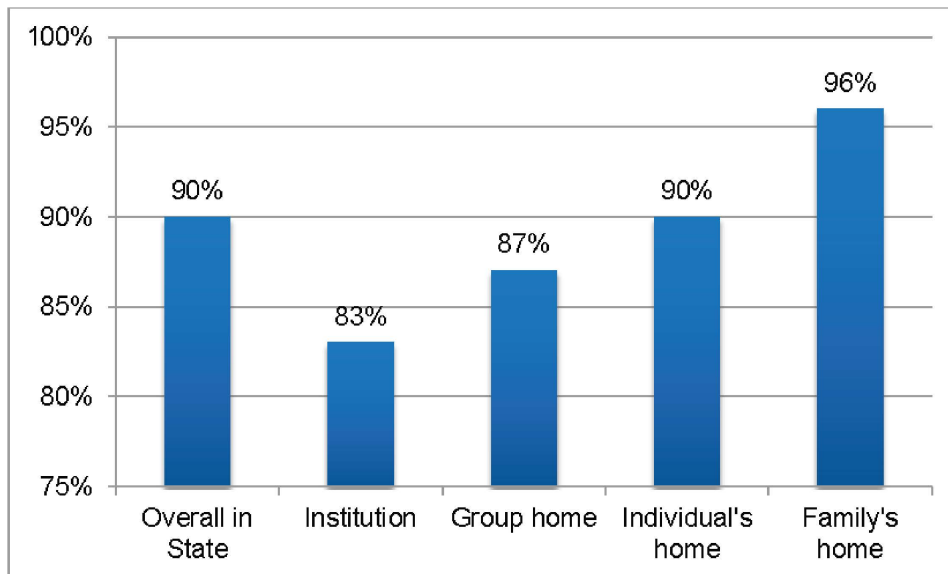
Source: Analysis by Valerie J. Bradley, Health Services Research Institute. Data from National Core Indicators project. Based on 6,711 adults with developmental disabilities who received services in participating NCI states during 2009–10. "Group home" includes all community-based settings except an individual's home or a family's home.

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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."

Oregon and Georgia: Closing Institutions and Building Community Support Systems

The Oregon and Georgia Experiences

Deinstitutionalization: Unfinished Business provides a national perspective on the history of deinstitutionalization and the current status of the movement, as well as a review of issues related to strategy, cost, and building community capacity. The case studies in this section look at the experience of two states, Oregon and Georgia. Oregon has been working on these issues since 1987 and closed its last state institution in 2007. Georgia, on the other hand, began work on closing institutions in 2005 by committing to closing admissions to children. The state's process was expedited by a Department of Justice intervention in 2010, with a settlement that outlined a five-year plan beginning in 2011.

The experiences in these two states illustrate some of the factors that affect success, the necessity of working with all stakeholders, and the importance of building community capacity and shifting the focus of service from large groups to individuals, thus ensuring a richer and more diverse life in the community than is possible even in a small institutional setting.

As part of this project, the research team conducted two focus groups—one in Georgia and one in Oregon—and 20 interviews that included 26 individuals: self-advocates and representatives of the state Developmental Disabilities Councils, protection and advocacy agencies, University Centers for Excellence in Developmental Disabilities, and legal aid groups. The interviews examined the implementation of deinstitutionalization around the country, specifically in Georgia and Oregon.

The interviews and the in-depth state studies focused on the political genesis of deinstitutionalization in Georgia and Oregon and the specific elements of implementation in those states.

Methodology

Key Questions

The focus groups and interviews used a set of key questions, including the following:

- Tell us about your specific experience with institutional closure.
- Based on this experience, what do you think are the most important keys to successfully closing an institution?

- What were the key barriers to successful closure, in your opinion?

- If you were to advise advocates who are working on this issue, what would be your key recommendations?

- How can quality be assured in the community? What are the best plans you have seen?

- How do you talk about the cost savings of closure?

Selection of Interviewees and Focus Group Participants

Individual participants were chosen because of their knowledge and experience with the closure of institutions. In some cases this knowledge was personal, and in some cases it was professional. The participants included leaders of all the key national organizations related to this issue, a former judge, state officials who have participated in past closures or are currently participating in closure activities, service providers, parents, and self-advocates who have lived in institutions.

Key Discussion Topics

The following key topics were discussed:

- Dealing with the concerns of parents

- Creating new person-centered housing options in communities

- Strategies for separating the provider of housing and the provider of services

- The cost savings of community living versus institutional living and the best way to talk about them

- Identifying and overcoming barriers presented by groups who are opposed to closing institutions

- Identifying the key elements of good transition planning

- Identifying the key elements of an effective quality assurance plan

- The role of the community—parents and advocates—in plan monitoring

- Ongoing development of community resources

- Funding of community resources in these financially challenging times

Key Discussion Threads

The following thematic trends emerged from the interviews:

- Closing institutions does save money, but most successful states did it because "it was the right thing to do."

- The allocation of resources is a major issue—serving a relatively few people in institutions consumes resources that could serve many more people in the community.

- The most powerful act a state can take is to make the decision to "close the door" and not allow anyone else to become institutionalized. This changes the entire debate from "if" to "when" and "how."

- Parents' needs and fears must be identified and addressed. Helping parents see people with disabilities like those of their child living in the community is a powerful tool. This has been done successfully.

- Success is a process, not a single event. It takes time to build community capacity and the oversight systems that are necessary to ensure that people's needs are met.

Oregon

> "Our system of community-based supports is not perfect. It remains underfunded, provider wages and training are inadequate, and we must improve client safety in the system. However, Oregonians with disabilities have some things today they didn't have 30 years ago at Fairview: freedom, dignity and a sense of belonging."
>
> *—Sara Gelser, Oregon state representative*

Timeline

Oregon is a national leader in this field; it has no more large state institutions. The closure effort began in 1987, the last institution was closed in 2007, and the final activity required by the Staley settlement was completed in 2011. The following is a timeline for Oregon's institutional closures and the development of a robust community-based services system:

1987: The state Office of Developmental Disabilities Services (ODDS) creates a diversion team. The goal is to prevent people from entering Fairview. At this time,

the state was averaging 11 new admissions a month. At the end of the first year, this number had dropped to one to three admissions a month. Within two years, the institution had zero admissions.

1990: Fairview is decertified. Funds are turned back on when the institution agrees to a Plan of Correction and Reduction. The institution commits to staffing ratios and agrees to move 300 people over two years (1991–1993). In 1990 there were about 1,200 residents.

1991–1997: Another 600 people are moved, and community capacity is increased to support those with significant needs.

1996: Long-Term Planning Team convenes. Work teams are formed to look at issues related to labor, family with relatives at Fairview, unmet needs in the community, and the capacity required to support all people with ID/DD in the community. A plan is completed and delivered to the Oregon Legislature in 1997.

1997: Legislature agrees to close Fairview, which requires moving the last 300 people to communities.

1999: Legislature reinvests $10 million from the Fairview closure to increase direct-care wages by $1/hour, create capacity in counties to respond to people in crisis (adding staffing and funds for short-term diversion), and increase funds for family support from $3 million to $8 million.

1999: Legislature passes Fairview Trust Fund bill and directs the sale of the Fairview property at market value and establishes a trust. Interest from the trust is to be used to make housing modifications for people with ID/DD who are living in their own or their family's home.

February 2000: Last person leaves Fairview.

2000: Five individuals with developmental disabilities and The Arc of Oregon file a class action suit (Staley settlement) claiming people in the community have been waiting too long for access to Medicaid services.

2001: Staley settlement establishes the entitlement of adults with ID/DD to a support services benefit, which is capped at $20,000 a year. People will self-direct and hire/contract. Support brokerages are established to provide personal agent support and serve as the fiscal intermediary.

2005: Oregon Legislature directs the department to determine the impact of closing the last ICFMR. Planning groups look at labor issues, costs of services, client needs, and community capacity.

2007: Oregon Legislature approves closure of Eastern Oregon Training Center.

October 2009: Last person moved from Eastern Oregon Training Center.

June 2011: Terms of the Staley settlement are successfully implemented. In 10 years, the number of people enrolled in community-based services went from zero to 7,000.

Focus Group

In May 2010, a focus group was conducted in conjunction with the National Council on Disability's forum in Portland, Oregon. This group brought together the key players in the decades-long effort to close all institutions and develop and maintain a robust community system of services and supports. The focus group was made up of professionals and one self-advocate.

Mary Lee Fay, administrator, Office of Developmental Disabilities Services

Jack Morgan, former deputy administrator, Office of Developmental Disabilities Services

George Braddock, president, Creative Housing Solutions

Bob Clabby, former superintendent, Eastern Oregon Training Center

Judy Cunie, self-advocate, former resident of an institution

Kathryn Weit, executive director, Oregon Council on Developmental Disabilities

Gary Blumenthal, NCD board member

Joan Durocher, NCD General Counsel and Director of Policy

Barbara Butz, facilitator, Daniels & Associates

Steven Allen, technical coordinator, Daniels & Associates

Topic 1. The People Factor: Relationships and What Made Them Work

Stable leadership

"We have longevity in all of our roles. Even when we retire we don't really go away. We have leadership that has survived multiple governors. Partially because the program is low enough in the governor's work that it can fly under the governor's radar."

"As architects, we had a lot of opportunities to correct things as we go. We didn't have to wait until everything was in the perfect shape at the beginning. We are OK with good enough to get started and then make changes."

"We had a guy that could lay out that vision—James Toews. We kept increasing the staffing because we were under the consent decree. James Toews was superb at laying out a vision."

"The attorneys said you have to do it (deinstitutionalize). They could articulate it in a way that we could not. And they had the credibility that the state service agency didn't have. That got it moving. If we have to do something...how best to do it. We had people in the community service system that were ready to expand. Had relationships, a lot of pent-up demand and frustrations. Readiness and eagerness to show that things could be done in the community. There was a lot of excitement and easy collaboration."

Managing displaced workers

"We worked with groups from the employment division, people could go to training, looking for other jobs on their work time, and the Governor did a hire first policy."

Training is key to making the transition

"Before people left the institution the staff who would be working with them had to spend at least two weeks in training…often living at the institution. We did it because it was cheap for the provider but it turned out to be really insightful."

"As a support person, with all the different organizations that support people with disabilities… hiring, training and retaining workforce is a challenge."

Topic 2. Vision and Values

Listening to families

"So the debate wasn't 'should we.' We didn't look for compromise but we had to really listen. When families said 'We don't want to,' we would end up translating it to mean, 'I'm afraid of quality assurance, How will I know? Can I show up anytime I want?' When you got past the conversation of 'No, you can't close the institution,' you got to reasonable demands. We had a family-directed volunteer that would do reports. I don't think it changed the quality of services but it helped buy-in."

"It's easier to serve people in the community and they deserve to have community life. It is pretty sad that you are put in prison because you have a disability. It has been proven over and over—what people can do if they are given the opportunity. There are so many things that we can contribute and we deserve to be a part of our community. 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."

"We didn't have a high-powered, well-funded parent group…against closure. …once we went through a very individualized process with the parents, parents saw the staff and providers as their friends."

Leveraging stakeholder interests

"When we talked to political groups we talked about the finances. But why we were doing it…it was values. Someone else said economics played in a big way. We have our attorneys to thank for that…. They said we had to do it. That got it moving. If we have to do something...how best to do it."

"We had people in the community service system that were ready to expand. Had relationships, a lot of pent-up demand and frustrations, a readiness and eagerness to show that things could be done in the community. There was a lot of excitement and easy collaboration."

"…disjointed incrementalism. As long as you keep the vision…you can keep going in the right direction. Persistence—they had a vision of closing the last institution 20 years ago."

"Important that one or more people that really count need to believe that it needs to happen. It doesn't necessarily have to be the governor."

"If it wasn't a civil right, it was based on an understanding that people needed to be in the community."

Topic 3. Strategies and Program Structure

Understanding capacity

"We are not a private market. In the aging world only 30 percent of the money is Medicaid. In our world it is much more. We have to be very precise because a provider can't build and then wait for people to fill the slots. We are building and doing at the same time."

Oregon started a state-operated community-based program. This program is designed to serve only people for whom there is no other option.

"We had started this in 1990 when we were closing institutions for kids because we had two populations that the community system wasn't ready to take care of—people with significant medical needs (ventilator dependent) and people with significant behavioral issues. Throughout every downsizing period we added one to two group homes. They were three to five people ranged within a 100-mile radius. Same as other group homes but run by state staff. We now have 136 people. We have a lot of families that say, 'I want State Ops,' but it is based on need. Now it is mostly a safety net. Only a few people stay there for a long time (but it is because the needs continue). We have very few medical homes; it is now mostly behavior support needs. Most are now coming in from criminal, corrections, forensic psychiatric review boards and with co-occurring mental health issues. State Ops can't say no. There are people with the same challenges in the community…but one of the criteria is that we have exhausted looking for a provider who would agree to support them. 138 out of 10,000 are in State Ops."

"Fairview had 3,000 in 1987. First thing that we needed to figure out [was] crisis response. Who went into the institution because there was

no other option? Before we had good crisis response, 10 people a month were entering institutions...six years later it was zero."

Process of closure

Three key teams did a tremendous amount of work in the actual closure. The Transition Team took the lead in ensuring that people were up to date with physicals and initiated a series of transition meetings with the person, parents—everyone involved. The Housing Team was in charge of staff, timing, and logistics. The Development Team developed person-centered plans for everyone, and that's how Oregon did community designs: one person at a time. The team focused on understanding individual needs, compatibility, what community the person has family in. The team tried to ensure that doctors and supports were in place.

Topic 4. Housing

Separating housing from support services

"[We]separated housing ownership from the selection of provider. This has turned out great because we can stop licensing a provider and people don't have to move because the house was not owned by the provider."

Getting the right expertise

"We brought people in who really know housing. Our state housing agency provided the funding. Several advantages: They knew the issues [and] they had the resources. They could talk effectively with the legislature. They could deal with housing much better than a service provider. We hired people in the housing industry. Housing was owned by organizations that specialized in owning and managing property rather than the service providers. They knew what needed to be done to maintain housing/property values. Those people were the intermediaries…."

"[The] contractor was [the] point of entry for neighbors who were scared. They thought property values were going to tank. They were most concerned about cars and staff. They were OK with diversity, even weird diversity. They were worried about staffing coming and going, playing their boom boxes, flicking cigarette butts, taking all the

parking spots on the street. We taught our contractors to really talk to the neighborhood. In one case the church adopted the house and it really helped create community."

"In a couple of cases we used local housing authorities. Housing staff in the agency [were] really important. They knew the business. They knew the DD housing needs and the type of things that housing authorities usually build."

Thinking through the financing

"Paying attention to not just staffing, also housing, affordability, how to make it work. [We] took advantage of other financing options."

Topic 5. Strategies that Paid Off

"Design focused on conforming to the look and feel of the neighborhood. Structure and paint had to blend in with what existed. Landscaping was considered important; they did not attempt to cut costs by omitting landscaping, which was a big issue for the neighborhood.

Confronting county fears was also seen as a priority. The state government defines programs and provides funding; counties administer the programs. Counties had concerns about taking care of 'these folks' (people with ID/DD who were leaving an institution) and having them in the community. They were concerned about whether funding would be adequate. People tended to compare the projects with downsizing in corrections and mental health, which did not have enough funding in the community and were not done well. Fears about personal safety and property values were also a factor."

Litigation

All the participants in the litigation process communicated with each other regularly and informally. State attorneys general came and went—most of them were portrayed as people who wanted to do the right thing. The DD agency did not get to pick its attorneys but could convince them that they should represent the agency as the customer.

"If we fight this and win we will have a very expensive institution and will have spent millions of dollars to get this."

Part of the role of litigation was sustaining the focus. The focus group members believed that it was very important to concentrate on individuals and their rights. Litigation made it clear that serving a small number of people in institutions took a large percentage of resources in terms of both financing and staff time. For 10 years, a large percentage of the energy of the staff had been used for people in institutions.

Every institution is different. Strategies for closing Eastern were very different from those used at Fairview. Oregon had begun person-centered planning with its DD clients. Staff saw closure as a completion of their job. The vision never changed. The vision combined two elements: closing the facility and doing so in a way that would strengthen the community system. With calculated planning, they aligned resources to strengthen the general DD system as well as the services former institution residents were going to use.

After the closure of Fairview, the next lawsuit focused on access to home and community-based services. The timing was perfect. Some states see a lawsuit as a personal insult; others can see it as an asset in getting the resources they need.

> "We didn't start out with a closure plan. We started out with a downsizing plan. We could move down the path, gave us some experience. People didn't have to make an enormous decision. At the same time the economics are working on your side. As you downsize, the cost per person increases with no end in sight. By the time the legislature actually went to close the institution, half the people were already gone."

The focus group saw this as overcoming opposition by articulating a simple vision.

Topic 6. What's Next?

What is left to be done?

> The self-advocate said, "Attitudes."

Now that Oregon has a community-based system, it becomes a question of what people are doing in the community.

Shift to Employment First policy

> "Oregon needs a better employment policy. For a while, when the state was closing Fairview, it capped the number of people in sheltered workshops, but then the focus shifted to final closure. Some believed that the culture had changed enough so that employment would just happen and that the move to person-directed services would create a demand for jobs, but that didn't happen. The team has collected data and is now focusing on expectations about employment and training to an 'employment first' policy. The Medicaid Infrastructure Grant (MIG) is providing funds. They have nine training teams and are still adjusting the rates so they support the outcome they want and don't leave people vulnerable."

Quality assurance and system shifts after closure

The nature of the conversation changes after closure. Moving people out of institutions is a different conversation than the one that occurs when people are no longer in institutions. You move on really quickly. There are still battles, but they are different ones—primarily about quality assurance.

The focus group agreed that systemic change is necessary to avoid going backwards. The team is seeing people slide back to segregated classrooms and agreed that more attention should be paid to early education.

The focus group suggested that Oregon does not support families in a planned way. The state offers some waivers but should invest more in families. There is a growing awareness that the state needs to be thinking more holistically. Most of the things you do for the support provider systems (such as backup systems), you should also do to support family providers.

Access to health care and the quality of health care are ongoing issues.

Education issues

> "Moving backward into self-contained classrooms feeds into problems in the adult system, such as the need to cut transition programs and get employment on the radar screen. The DD system should pick up where the education system drops off and be more aggressive as a system to take on the education system."

"They don't have nearly the structure or sense of what they are trying to accomplish with children that they have with adults. They have 5,000 kids enrolled in case management, but they don't do a very good job. School districts are aggressive in pushing back. Lawyers find it lucrative to get contracts with school districts."

"The DD system did a good job making changes in pediatric nursing homes. In the past, an adult average stay was four months; for children it was seven years. Now they're backsliding."

New housing issues

"Gated communities represent a new type of segregated housing. People with resources are setting up these communities because they are not getting the services they need in the community. In Oregon, the state is pushing back against a group that is trying to set up a gated community for people with ID/DD. But, it is not clear whether the State is on firm legal ground in its pushback. The state has established rates that would make it difficult to sustain something like this—they don't want to provide a financial incentive to group people together. Self-advocates said they are working on getting younger people involved so they can say they don't want this. They want something different in their lives."

Quality assurance

Advocates and professionals are concerned about how to make sure people get the services they need when they are spread out in the community.

Quality assurance (QA) is a challenge. It is hard to invest in infrastructure when individual needs are not being met. The counties are statutorily involved in running the system. On the aging side, half the programs are run by the state, half by counties. It is not clear which is better.

"I don't have a lot of faith in the county system. A lot of attention on excluding people from work who have certain conditions, etc. It all depends on the staff. Need staff that buys into the system."

"Depends on leadership. not sure what the best system is. It is a challenge when you have 32 different entities."

The system depends on case managers for quality assurance—to promote individual goals and look for incidents that indicate poor quality. The team is less into quality improvement than in the past. They use abuse information, serious event reports, licensing data, and customer surveys, but that doesn't provide a complete picture. Their approach is more protective now. As they train on person-centered strategies and positive interventions (rather than physical intervention), they lay the groundwork for higher expectations. The team has laid the groundwork, but they don't have the full QA system in place as they envision it.

Topic 7. Advice to Other States

Advice

"Close the front door."

"Get some rest."

Georgia

Georgia was selected for a case study because it had recently signed a statewide settlement agreement with the United States Department of Justice (DOJ) to provide community alternatives to institutionalization for people with developmental disabilities and mental illnesses. DOJ has indicated that this settlement agreement will serve as its template as it works with other states. The agreement also provides services for people at risk of institutionalization, to prevent future admissions to state hospitals. The negotiation process with DOJ and the state of Georgia was heavily influenced by stakeholder groups, including the Georgia Developmental Disabilities Council and the Georgia Advocacy Office (the state protection and advocacy agency).

Settlement Agreement

Under the agreement, the state stopped admitting people whose primary diagnosis is a developmental disability into state hospitals in July 2011 and instead placed them directly into community services. The settlement agreement builds on the work of the Georgia Children's Freedom Initiative, which was launched in 2005 to focus advocacy and action on moving all children in state institutions into community-based settings. The coalition formed to advance the Freedom Initiative had immediate success by getting House Resolution 633 passed by the Georgia House of Representatives, urging the State to develop a plan to serve all children in community-based settings that focused on family reunification. The coalition did not stress cost savings because of

members' belief that it might not be cheaper to serve people in the community. Rather, the coalition argued for the human and civil right to live in the community and worked on building a consensus around these concepts. For example, the coalition held a summit in 2005, with more than 100 participants, to raise awareness, discuss the alternatives, and build political will. The coalition worked closely with parents who were reluctant to move their children to community-based settings, organizing tours of community placements that proved to be very successful in convincing these parents of the possibility of successful community placement. All the parents wanted assurance that the people who were going to serve their children would make a significant commitment, rather than having shifts of strangers rotating through.

When the initiative was established, about 45 children were in state hospitals; only 5 or 6 are still there, as a result of parental concerns. The coalition documented all the stories in a video of the children who came out of the institutions. The remaining challenges include capacity in rural areas and parental rights issues for children still in institutions.

The state has halted admissions to state hospitals for all children under 18. Crisis respite homes are being set up in the community in response to the DOJ settlement. The crisis teams will be able to respond anywhere in the state within 90 minutes. Because of the settlement, people leaving the hospital will get priority. Everyone in state facilities is guaranteed a waiver slot. Thirty slots were set aside for youth aging out of foster care.

The coalition has continued its legislative advocacy, making informal presentations to groups of legislators around the state. Members have been educating legislators about the DOJ settlement, and a tour for legislators is being planned. The biggest challenge the coalition sees for the future is ensuring community capacity.

Everyone interviewed during the site visit in Georgia said that the impact of DOJ is very important. It has had an impact on the governor's staff and agency staff. DOJ is driving the conversation. The DOJ settlement has focused on where people sleep, not how they live. Without the settlement, the pace of closure would have been much slower. Community capacity would not have increased and there would not have been a moratorium on admissions.

The parents and guardians who attended the focus group expressed their strong support for their family member living in the community, although they deal with the system in different ways. They faced enormous challenges and had to do a lot of finagling to get it

right. Georgia has some exemplary providers, who are under pressure to expand. They recognize the need to find ways to help others create similar programs. However, they see provider rates and program infrastructure as huge hurdles in expanding quality services.

Georgia has increased the monitoring, quality improvement, and control of community-based placements. A state official said one of the things that helps states be successful is to develop a "healthy obsession with quality." The state needs to be clear about what it is and is not willing to fund. When Georgia has an unsuccessful transition, the state conducts a root cause analysis to figure out what went wrong. The state is also expanding the quality improvement process to provide technical assistance to providers through Quality Improvement Regional Councils staffed by the Delmarva Foundation, under contract with the state. Providers who have already participated in a Quality Enhancement Provider Review (QEPR) can ask Delmarva to provide additional technical assistance in a specific subject area such as documentation, policy and procedures, or developing person-centered supports and services. Georgia providers are requesting additional training and technical assistance. Providers, family members, and staff officials know that infrastructure and capacity are not adequate. The state is exploring the idea of bringing in national providers to increase capacity. Access to services is a problem throughout the state, but especially in rural areas. The state has been conducting a needs assessment—mapping out where people with ID/DD are and how many are more than 10, 20, or 50 miles from the nearest provider.

In summary, the DOJ settlement has moved the Georgia deinstitutionalization effort into high gear with a rapid rollout. Challenges include ensuring a uniform quality standard for services throughout the state and developing adequate capacity to serve people where they want to live.

Focus Group

In May 24, 2011, a focus group was organized with the help of the Georgia Developmental Disabilities Council. The group, convened at the Shepherd Center for Rehabilitation in Atlanta, brought together the key players in the effort to close institutions for people with ID/DD. The following is a summary of this session. This participants were—

> Sam Trogdon, parent of Susannah Trogdon
>
> Allison Peters Whittle, guardian of Nicki Raisler

Nicki Raisler, self-advocate

Susan Jamieson, Mental Health and Disability Rights, Atlanta Legal Aid

Eric E. Jacobson, Georgia Council on Developmental Disabilities

Anna Watson, Georgia Diagnostic Classification Center

Victoria Richbourg, Serenity BHS and a parent

Daniel Crimmins, Center for Leadership in Disability, Georgia State University

Nancy Vara, parent

Nola Sayne, self-advocate

Eddie Towson, Lead On Quality Assurance, Georgia Developmental Services

Renita Bundrage, parent

Ruby Moore, Georgia Advocacy Office

Barbara Butz, facilitator, Daniels & Associates

Ellen Piekalkiewicz, facilitator, Daniels & Associates

Topic 1. Personal Experiences of Self-Advocates and Parents of Children with Developmental Disabilities

Self-advocates, parents, and guardians who attended the focus group expressed their strong support for people with ID/DD living in the community and not in institutions, although they have dealt with the system in different ways. They faced enormous challenges and had to be very persistent. There are some exemplary providers, and they are under pressure to expand. The participants recognized the need to help other providers create similar programs. Two significant hurdles are program infrastructure and the rates paid to providers.

"Many of us don't live in institutions but lead institutional lives."

The Georgia P&A agency was working with families and the State to determine where people were located in nursing facilities. Their data are not complete and not every person was accounted for. Some Georgia children are in institutions in Alabama. One parent's son is still living in a nursing home in Alabama, where he was placed as a child. She is working with the state to get her son into a community-based setting.

One self-advocate's sister is in a group home, but she wants her to come home. Difficulties with program infrastructure are blocking the move. The goal is to have the sisters live together with the self-advocate's guardian as a family unit.

One self-advocate attends a day program and is trying to get a job.

One client is home after a bad experience. She had never lived in an institution but did briefly live in a group home. She did not do well in the group home and was not thriving. Her father says that she is doing well enough with him but worries what will happen to her when he is too old to care for her. She is on a waiting list for a waiver.

Another participant was a mother who is also a behavioral service provider. When her son came out of high school, she was fortunate enough to have him go into her program.

> "I was hoping he would be able to move into an apartment but they reduced the daily rate for apartment living to a level that was not financially viable to staff. So now they are taking people out of their own homes and putting them back into group homes."

A parent reported that her son has a micro board that is supported by the state of Georgia. Micro boards apply to become licensed service providers for one person.

Getting the right services is often a long, bumpy road. Advocates and parents banded together and went straight to the people who held the purse strings. They invited local legislators and senators into their homes.

> "So [my son] moved to Athens and lives independently with supports in his own home. He has not been hospitalized again in nine years and he has a job. When he was in the institution, they said, 'he won't make it.'"

Topic 2. The People Factor

Direct-care workforce—availability and training

> "There is a critical need for a direct-care workforce."

> "How can we make sure the person with the most extreme needs [is] addressed in a thoughtful, competent way?"

> "Those are the individuals that people make the argument about that the institution has to exist. Presumptively we think those people's needs are being met in this congregate setting…they are not."

A number of years ago a state program spent millions of dollars training state workers. When people were transferred to community-based services, advocates wanted the training dollars to be spent on community workers. But the state would not pay for the training because the workers were not state workers.

The Developmental Disability Council created a values-based curriculum that is used in 13 colleges around the state. The course is co-taught by a person with a disability. When the funding is exhausted, the council will not be able to keep it going.

Providers say they need additional help. The Division of Developmental Disabilities is expanding its in-house training program and quality improvement process to provide technical assistance. The division has been collecting data and is trying to use it for continuous quality improvement and to develop new processes. It used to be "You're doing badly—you figure out how to fix it." Now the division is putting processes into place to bring providers up to at least a minimum standard. But the infrastructure is not there. The division is considering bringing in some national providers to increase capacity. Access to services is a problem throughout the state, but particularly in rural areas.

Georgia conducted a large rate study which concluded that providers are paid too much. If this analysis is acted upon, many providers might close their doors. Currently, everyone gets the same rate regardless of their needs, but that is changing.

> "We wanted to show how much it costs us and it backfired. The people that work for me get paid about minimum wage even after 25 years. They have to work two jobs to survive."

> "Some folks simply have no family to count on."

> "Most of the people I serve don't have family or the family rights have been terminated."

Topic 3. Vision and Values

Some people in Georgia believe that closure will happen and are trying to figure out how to serve former institution residents in the community. Most focus group participants agreed that there is momentum, but they are struggling to make sure people will be landing safely.

Georgia has one example of what the transition to the community looks like when it is done really well: Georgia Options. Other providers offer residences but not necessarily homes. Georgia Options has strong leadership and serves one person at a time. It employs micro boards and practices transparency regarding abuse and neglect.

> "They know what home is. It is a sanctuary, it's your own space, and you get to say who comes through the front door. The individual is afforded a lot of autonomy and dignity and respect that is elevated to a cultural norm. Unfortunately that is not the norm."

Topic 4. Strategies and Programs

There was consensus in the group that you practically have to get the entire legislature into your house to convince them of the need for changes in the system.

> "The system is dysfunctional."

Parents and guardians have valid concerns. Many of them need to see how well community living can work before they agree to move their family member out of an institution.

> "The problem is that people can't see how it will work.…The Children's Freedom Coalition and the Georgia Developmental Disability Council sponsor tours that help families see how this could work for their loved ones."

The state has begun offering tours to highlight living options and services available in the community. They have been very successful. One of the mothers participating in the focus group had taken a tour and subsequently agreed to bring her son home from an institution in Alabama.

> "The parents' concerns were: I want to know that my child is safe, having a good life and that there is some possibility that people who serve him can make a significant commitment to him so it is not just shifts of strangers rotating through."

In an institution, up to 40 percent of residents have dual diagnoses. People seem focused on the behavioral issues. The community programs are not prepared to

serve people with dual diagnoses, because the behavioral issues often overshadow the mental health issues.

> "You can't just throw meds at them."

Professional and dental services are provided at the institution, but Georgia is down at the bottom in dental care. They are trying to push advocates to take this issue to the legislature. Every year there is a battle in the legislature over dental services funded by Medicaid—it is the first thing they cut. Right now, they are just trying to keep it as a covered service.

> "I have a waiver and I live on my own. I have had trouble getting dental care. Nobody takes Medicaid. They will not do a root canal."

Topic 5. Quality Assurance

One of the things that helps states succeed is to develop a "healthy obsession with quality." The state needs to be clear about what it is and is not willing to fund.

Georgia has started doing needs assessment, mapping out where people are living and how many are more than 10, 20, or 50 miles from the nearest provider. The state is beginning to understand where it needs to develop services.

Topic 6. Successful Transitions and Safeguards

The people who are coming out now have the most needs.

When transitions into the community are not going well—especially as a result of behavioral issues—the transition team meets with the provider, hospital staff psychiatrist, case expediters, regional staff, and state staff. This root cause analysis is conducted for any unsuccessful transition.

> "When we have an unsuccessful transition, we are doing a root cause analysis to figure out what went wrong. Unfortunately, we have found that when we bring everyone to the table, people are not being forthcoming as to what needs to be said."

The role of the parent in the root cause analysis is still evolving. Unless people who truly care about the person are involved, long-term resolution is not possible.

> "When I am sitting with providers, I hear that the families 'don't get it.' That really gets my blood pressure up. Don't tell me I don't get it. I've

raised my kid…I understand and I've been at IEPs, I've been to PTs. I've been there for the long haul."

Topic 7. Litigation

It took years and Federal Government intervention to turn things around in Georgia. At the same time expectations were rising, the DOJ settlement forced the state to move. But the settlement will not be successful and progress will be slow unless the system can address individual problems and concerns, which are not hard to identify.

> "We are all looking for systemic change but there is no way to solve individual problems. It takes three weeks to get to the right person to talk to."

Reflections: Individual Voices

Methodology

As a part of the case study work in Oregon and Georgia, researchers interviewed former residents of institutions who are now living in the community. In Oregon, the interviewees were former residents of Fairview who had been living in the community for a significant period. In Georgia, they were former residents of Southwestern State Hospital, Rose Haven Unit, who had only recently been released to begin their lives in the community.

The interviews in Oregon were conducted by Becky Thrash and Carol Loop, staff members of the Oregon Council on Developmental Disabilities. The interviews in Georgia were conducted by Ellen Piekalkiewicz of the Daniels and Associates research team.

The interviews are included in their entirety to allow these former residents to tell their stories in the context of their experiences as a residents of an institution and as members of a community. The names of all interviewees have been changed to protect their privacy.

Highlights

In Oregon, five people were interviewed. All of them were living in the community: four in group living situations with other people with disabilities and 24/7 staff, and one independently in an apartment.

All were enjoying their living situations and took pleasure in simple activities in the community—going out to eat, shopping, going to a pet store—and in having the freedom to pursue their own interests.

Four of the five people were working or involved in sheltered employment through day programs run by three different providers. One person had retired after years of working two separate jobs; she completed her work life as a line supervisor at St. Vincent de Paul.

In Georgia, three people were interviewed. Two had recently been discharged from Southwestern State Hospital, Rose Haven Unit, and the third was living in a group home whose ownership was recently transferred from Southwestern State Hospital to the community provider in Thomasville. Southwestern State Hospital was one of Thomas

County's largest employers, with more than 800 employees. Over the past several years, state hospitals in Georgia that serve people with developmental disabilities and mental illnesses have been the focus of allegations of abuse, neglect, and substandard medical care that have contributed to more than 100 deaths under suspicious circumstance since 2002.

All three interviewees are in group living situations with four other people with disabilities and 24/7 staff. They have their own rooms and participate in activities in the community: working, going out to eat, going bowling, playing ball. Staff report that these three people led very structured lives at the state hospital and even in the group home when it was run by the state. Staff are trying to change the regimented nature of their lives, but residents still tend to wake up very early, around 5:30 a.m., and go to sleep by 8 p.m. All the residents were on a strict 1,500 calories a day diet at the state hospital. With their new freedom to eat what they want, some weight gain issues have arisen. The three interviewees are involved in sheltered employment in day programs, and two of them are working in the community as well.

Deinstitutionalization: Unfinished Business

National Council on Disability and
Daniels and Associates, LLC

Interviewer Script

The National Council on Disability has asked Daniels and Associates to talk with people with disabilities about their experiences—living in institutions and then living in the community. Your answers to these questions will help people all over the country to understand these issues better and we hope that this information will encourage states to close all institutions and provide quality living situations for people with disabilities in the community.

Thank you for agreeing to talk with us.

Personal Information
Charlie* remembers living in Fairview from the time he was very little. He is approximately 60 years old now. He appears to have mild cognitive disabilities and uses a wheelchair. He communicates well. He lives in a three-bedroom home with two other men, one of whom has been a good friend for many years. The home is in a nice neighborhood. It is clear that they have decorated it themselves with many personal items and pictures. Live-in staff rotate throughout the week. Additional staff are available during the day. Charlie spends time in a sheltered workshop/day program. He likes making money to go shopping. He appeared to have no complaints about his life. He was not uncomfortable answering questions. He liked to talk about going out into the community. He likes watching people at malls, restaurants, and parks. He likes to go camping.

*Name changed to protect privacy.

> **Did you live in an institution at some point in your life?**
> "Yes."

> **What was the name of the institution?**
> "Fairview."

> **How long did you live there?**
> "My housemate and I lived there when we were young."

(Staff: 40+ years; Charlie was placed there as a young boy.)

General Experience

What was it like for you as a person with a disability to live in an institution and not in the community?

Do you have specific memories of a time in the institution which you think will help people understand what it was like for you?

"They would take my picture and then I would get ice cream and pop."

(Staff: Residents' pictures were taken each year and put into their records. Charlie still likes to have his picture taken, and he always requests ice cream and two cans of pop.)

Housing Arrangements

What type of housing arrangement do you have?

Are you living independently?

"No."

Do you live with family members?

"No."

Do you share a home with other individuals?

(Lives with two other housemates, who also lived at Fairview.)

Do they have disabilities also?

"Yes."

Is there staff to help you there?

(Staff are there 24/7.)

If none of these describe the place where you live—please tell us about it.

What do you like about where you live?

"I help with dishes (in the kitchen). Watching TV in here." (He points to the television in front of him, in the living room.)

What would you like to change about where you live?

"I like my house."

Community Life

What is the thing you enjoy most about your life in the community?

"John takes me with him. We go places."

(Staff: His friend John comes quarterly. They go see the lady at the pet shop and go out to eat and other activities.)

Do you get to go out and "do things" in the community?

"They take me downtown and I get me something."

(Staff: He likes buying arts and crafts, coloring books, and other supplies. He likes the color red. When he picked out a recliner at the store, it had to be red.)

What are your favorite things to do?

"Go on picnics. Watch children play on the jungle gym at the playground."

(Staff: He likes watching cars go by and especially watching people.)

Employment

Are you working? If you are working, tell us a little about your job.

"I put nails on racks. I have four different jobs." (He showed that he does things with his hand. Gesturing, moving his hand back and forth.)

Are you working at a job where most of the other individuals are also people with disabilities?

"Yes, it's either a sheltered workshop or a day program called Day Break."

Do you have assistance on the job—like a job coach or other aids?

"There is staff at Day Break."

What do you like about your job?

"I get money when I work."

What would you like to change about your job?

Personal Information
Alice* is approximately 50 years old. Alice is very verbal and likes to engage with people. She lives with two other people in a home that has rotating 24-hour awake staff and a live-in. Alice has no teeth. The interviewers noted that teeth may be removed if a person bites others, but they did not know whether this was true for Alice. She made it clear that her experiences at Fairview were very bad—she didn't want to discuss them because the memories upset her.

*Name changed to protect privacy.

Did you live in an institution at some point in your life?

"Yes, from the age of 12."

What was the name of the institution?

"Fairview."

(Gaines and McGruder cottages, among others. Gaines was reserved for very aggressive or self-abusive residents who required one-on-one staffing. McGruder was for aggressive women. When Alice mentioned these names, she became very agitated.)

How long did you live there?

"Age 12 until I got out."

(She was relocated from Fairview in the late 1990s.)

General Experience

What was it like for you as a person with a disability to live in an institution and not in the community?

"I didn't like it there at all. Don't want to talk about it. Don't want to discuss it. It was bad. Bad. Nobody should be there."

(She started rubbing her face.)

Do you have specific memories of a time in the institution which you think will help people understand what it was like for you?

(She didn't want to talk about living there.)

"I was placed there after I threw my brother out a window and pushed my sister down the stairs."

(She didn't attend school while she was there.)

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Housing Arrangements

What type of housing arrangement do you have?

"I have my own bathroom and the big bedroom."

Are you living independently?

"No."

Do you live with family members?

"No."

Do you share a home with other individuals?

"Yes, I have two roommates."

Do they have disabilities also?

"Yes."

Is there staff to help you there?

"Yes."

(24/7 staff, very structured and stable. One staff member mentioned that as Alice's life has become more stable, she has exhibited less bad behavior.)

If none of these describe the place where you live—please tell us about it.

What do you like about where you live?

(She seemed very happy about where she lives.)

"I like that I have the big bedroom."

What would you like to change about where you live?

"I would like to live closer to Mom."

(Her mother lives in Portland. It sounded as though relationships with Mom and siblings were strained.)

Community Life

What is the thing you enjoy most about your life in the community?

"I like working. I like to clean. I clean toilets and sinks. I answer phones and take messages. I like doing my job and I like when people say I have done a good job."

(Staff commented that she is very polite and professional on the phone.)

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Do you get to go out and "do things" in the community?

"I like shopping for groceries. I like getting my hair colored."

(She participates in a weight loss program called TOPS. She was proud that she had lost weight.)

What are your favorite things to do?

"I like Blazers (basketball) and Volcanoes (baseball) games. I have a boyfriend. I have baseball cards. I like watching shows."

(She likes watching game shows. She sees her boyfriend occasionally.)

Employment

Are you working?

"Yes."

If you are working, tell us a little about your job.

"I work at SRC."

Are you working at a job where most of the other individuals are also people with disabilities?

"Yes."

Do you have assistance on the job—like a job coach or other aids?

"Staff is there to help."

What do you like about your job?

"I clean floors, vacuum, clean toilets, answer the phone, and take messages."

What would you like to change about your job?

"Nothing."

Personal Information
Jimmy* gets very agitated when people don't understand him. He uses only a few words at a time. He gets frustrated when people ask him questions. He often looked at his sister and said, "Sissy, Sissy, Sissy." He lives in a very fancy house on a golf course with one other person who has autism. He has the big bedroom with his own bathroom. There are glow-in-the-dark stars on the walls. The house does not look as though the residents provide much input into the decorations. He loves his big-screen TV and old westerns. He has all the westerns memorized. He also watches the golf channel.

*Name changed to protect privacy

Did you live in an institution at some point in your life?

"Yes."

What was the name of the institution?

"Fairview."

How long did you live there?

"Was placed there at age 20 and left at age 48. He has been with the current provider for 12 years."

General Experience

What was it like for you as a person with a disability to live in an institution and not in the community?

"His parents placed him there because they felt it would be secure for him. He was a 'runner.'"

Do you have specific memories of a time in the institution which you think will help people understand what it was like for you?

"Very difficult for him. He was teased a lot; it's not clear whether by residents or staff. The structure of staffing and residents was always changing and it was very noisy. He didn't sleep well at Fairview. He became very closed-in. He would go home on weekends and sleep. He would cry when he knew it was time to go back. He had stomach issues that led to surgery. Staff tried having him live with a roommate in an apartment on the Fairview campus, but that was a disaster because he would run away."

Housing Arrangements

What type of housing arrangement do you have?

"In a house."

Are you living independently?

"No."

Do you live with family members?

"He visits his sister's house every other weekend. He is very excited about going to visit his sister. He was planning on going with his sister after the interview and was anxious to get moving. He put on his coat and hat."

Do you share a home with other individuals?

"Only one other person."

Do they have disabilities also?

"Yes."

Is there staff to help you there?

"Staff 24/7, live-in staff rotate, very structured schedule."

If none of these describe the place where you live—please tell us about it.

What do you like about where you live?

"He seems to like where he lives very much. He showed the interviewers his room. He likes to help make cookies and other goodies. He gave the interviewers cookies he had made for them the day before."

What would you like to change about where you live?

"Nothing."

Community Life

What is the thing you enjoy most about your life in the community?

"He can visit other homes the provider runs. He likes one-on-one time with staff."

Do you get to go out and "do things" in the community?

"He likes to watch people line dancing at a local bar called the Silver Spur. He loves to go shopping and to go to the casino and eat at the buffet, which he mentioned several times. He liked going for a drive. He really

enjoys it when he stays with his sister. He helps to get ingredients when she is cooking and gets a kick out of it when she forgets something."

What are your favorite things to do?

"He likes going with one of the staff to get hard candy at Dee Dee's, a local deli."

Employment

Are you working?

If you are working, tell us a little about your job.

"He is the 'official' mailman at PCL. He sorts color-coded mail and delivers mail to different homes. He delivers mail from the provider to the courthouse."

Are you working at a job where most of the other individuals are also people with disabilities?

"Yes, at PCL. Also does limited delivery to the Marion County Courthouse."

Do you have assistance on the job—like a job coach or other aids?

"Staff."

What do you like about your job?

"He really enjoys delivering the mail. Has his route memorized. They are trying to incorporate a color-coded system but he's not too happy about some changes in the color coding."

What would you like to change about your job?

"He would like to do this job every day. He doesn't like days off."

Personal Information
Tom* was quite anxious when talking about the institution. He has moved around a lot and was concerned that the interviewers were going to move him again. Tom doesn't initiate conversation very often. For example, he doesn't voluntarily share when he hurts or feels ill but will talk with a doctor when he gets to the office. He is about 60 and uses a walker. Tom is very detail-oriented and likes things to be arranged in a certain way. His room was very neat, and his *National Geographic*s were stacked in order. At least one of the staff members was someone he knew in Fairview and seemed to like a lot.

*Name changed to protect privacy

Did you live in an institution at some point in your life?

"Yes."

(Most of his life was spent in an institution. He made it very clear that where he is living today is where he wants to stay. He was concerned that talking about institutions meant having to go back to the institution.)

What was the name of the institution?

"Fairview."

How long did you live there?

"Not sure."

(Staff: More than 40 years.)

General Experience

What was it like for you as a person with a disability to live in an institution and not in the community?

"I stay here." (He seemed a little fearful or concerned. He did not like living at Fairview. He was moved to Keizer, South Salem, and Monmouth, and now here. He doesn't want to move from where he lives now.)

Do you have specific memories of a time in the institution which you think will help people understand what it was like for you?

"No. I like where I live now. I stay here." (He repeated this several times.)

Housing Arrangements

What type of housing arrangement do you have?

(Shares the home with two other men.)

Are you living independently?

"No."

Do you live with family members?

"No."

Do you share a home with other individuals?

"Yes."

Do they have disabilities also?

"Yes."

Is there staff to help you there?

"Yes, staff does everything. I want to start helping in the kitchen."

If none of these describe the place where you live—please tell us about it.

What do you like about where you live?

"Like where I live. I stay here. Pictures on the wall in my room."

He showed us his room. On one wall was a collage of pictures from magazines; it was about four feet wide and seven feet high. He continues to add to the collage until it gets so heavy that it falls down, then he starts over again. Each picture in the collage is connected to other pictures. For example, he had pictures of the singer Amy Winehouse, who had recently died. Next to them were pictures of alcohol bottles and other items related to her.)

Asked him if he listened to her music.

"Yes, I do."

(He reads the newspaper every day. He requested a copy of this document when it was printed.)

(Staff: He keeps track of everyone's schedule, both staff and housemates. He knows when they are supposed to be there and will say so.)

What would you like to change about where you live?

"Like where I live."

(Staff: He doesn't tell them when he is sick or where it hurts.)

"I talk to my doctor."

(Staff: This is a great improvement that he can talk with his doctor about what is wrong.)

"The doctor talks to me, not to staff."

Community Life

What is the thing you enjoy most about your life in the community?

"Josh and Kelly's house, fried chicken."

(Staff: Josh was a staff member who previously worked with him. Josh and his family stay involved with him and take him out and to their home.)

Do you get to go out and "do things" in the community?

"Yes. Shop for stuff. Go out to dinner."

What are your favorite things to do?

"Go to McDonalds. Like cartoons, but not ones on TV now."

Employment

Are you working?

"Yes."

If you are working, tell us a little about your job.

"Day Break."

Are you working at a job where most of the other individuals are also people with disabilities?

"Yes."

Do you have assistance on the job—like a job coach or other aids?

"Yes."

What do you like about your job?

"Taking pictures out of magazines and coloring."

What would you like to change about your job?

"No, like Day Break."

Personal Information
Sharon* is 58 years old. She is living in a housing complex in a unit by herself. She lives with no support except a person who helps with finances and email. Sharon is very independent. Her house is immaculate and she is very proud of it. She monitors who comes and goes in the complex and knows everyone. She appears to be very well liked. Sharon was married and had two children that she raised. She now has grandchildren.

*Name changed to protect privacy

Did you live in an institution at some point in your life?

"Yes."

What was the name of the institution?

"Fairview."

How long did you live there?

"I was there from about the age of 2 until I was 18 and graduated there. I had encephalitis when I was very young. I think I was maybe 1. Doctors told my parents that I wasn't expected to live. I didn't speak for about 200 days. Doctors didn't think I would ever talk. The doctors didn't know if I could even learn anything. They told my parents not to expect much."

General Experience

What was it like for you as a person with a disability to live in an institution and not in the community?

"I didn't know any different when I was placed there. When I first left Fairview I was very sad, but I don't miss it at all anymore. I remember as a child going home by bus every other weekend to be with my parents. I moved in with my parents after I left Fairview. I helped take care of them as they grew older."

Do you have specific memories of a time in the institution which you think will help people understand what it was like for you?

"As I got older I worked with the kids who were serviced through the Hearing and Speech area. I walked them to and from appointments and activities. I also walked the blind children. I didn't get paid. I helped in the kitchen and helped to feed other patients."

"I remember being in Special Olympics. In the cottages we could play inside or play outside with other kids. I remember going to the State Fair every year. I had lots of friends and had some special teachers. There was one teacher that was very encouraging to me. She made me feel very good about myself. We had to carry a colored card with us at all times. A green card meant you could go anywhere on campus. I left Fairview in 1973."

"I would sometimes go to parties at an-off campus house where there were young children." (This was called Baby Louise's Haven. It was established by a nurse at Fairview for infants and toddlers who would ultimately move to Fairview when they were older).

(Sharon showed us certificates and photos that she has saved. She still has her diploma and the awards ceremony program.)

Housing Arrangements

(Sharon's house is very homey and clearly decorated by her. Lots of family photos, her lighthouse collection, and a cat. She also has photos of friends and the friends' family members because they are all close.)

What type of housing arrangement do you have?

"Apartment through HAP—Housing Assistance Program."

Are you living independently?

"Yes."

Do you live with family members?

"No."

Do you share a home with other individuals?

"No."

Do they have disabilities also?

"No."

Is there staff to help you there?

"I have staff from my brokerage that helps me. Joan helps me check my email on Tuesdays."

If none of these describe the place where you live—please tell us about it.

What do you like about where you live?

"I very much like where I live."

What would you like to change about where you live?

"It is difficult to sit down in my bathtub, so I use a shower bench. I would like to have the type of tub you step into."

Community Life

What is the thing you enjoy most about your life in the community?

"I can do anything I want. My friends are like family. I like helping the manager with the yard work and I help to keep the laundry room clean. I go to visit my grandkids in Northern California and relatives in Spokane, Washington."

Do you get to go out and "do things" in the community?

"I go to Weight Watchers and to visit some close friends often."

What are your favorite things to do?

"Cross stitch."

Employment

Are you working? If you are working, tell us a little about your job?

"I don't work anymore. I did work in a factory in Beaverton for 17 years making soaker hoses. I was on my feet for 8 to 10 hours at a time. I also worked at St Vincent de Paul and worked up to a line supervisor."

(She cleans the homes of two friends and house-sits when they are gone. Another friend is very ill and Sharon checks on her daily. She rides the city bus.)

Are you working at a job where most of the other individuals are also people with disabilities?

Do you have assistance on the job—like a job coach or other aids?

What do you like about your job?

What would you like to change about your job?

Georgia Interviews

Personal Information
Carrie* lives in a group home whose ownership was recently transferred from Southwestern State Hospital to Thomas Grady Service Center, the community provider in Thomasville, Georgia, that serves people with developmental disabilities. Carrie has four roommates with whom she has lived for many years. She was able to stay with the same roommates when ownership was transferred. She is approximately 40 years old. In addition to cognitive issues, she appears to have a neurological disorder that causes her hands to shake. She has her own bedroom, which she has decorated. Live-in staff rotate throughout the week, and Carrie spends time in a sheltered workshop/day program. She did not seem too interested in answering questions but was very verbal about the subjects she wanted to talk about.

*Name changed to protect privacy.

Did you live in an institution at some point in your life?

"No."

(Carrie lives in a group home that was previously owned and operated by the state of Georgia through Southwestern State Hospital.)

What was the name of the institution?

How long did you live there?

General Experience

What was it like for you as a person with a disability to live in an institution and not in the community?

Do you have specific memories of a time in the institution which you think will help people understand what it was like for you?

Housing Arrangements

What type of housing arrangement do you have?

Are you living independently?

"Yes, I have my own bedroom."

Do you live with family members?

"No, my mom died and my dad died of cancer."

(Staff reports that she has developed a sister-like relationship with one of her roommates.)

Do you share a home with other individuals?

"I have four roommates."

Do they have disabilities also?

(Yes, it is a group home for people with disabilities.)

Is there staff to help you there?

"Yes, we have someone who is at the house and makes us breakfast and dinner and stays overnight."

If none of these describe the place where you live—please tell us about it.

What do you like about where you live?

"My room is pretty. I like my room and watching TV. No strangers can come in the house. We eat dinner at the house, but I do not help with dinner. Sometimes I make cookies and cupcakes. I love my roommates a lot."

What would you like to change about where you live?

"Nothing."

Community Life

What is the thing you enjoy most about your life in the community?

"Every day I have a Dr. Pepper at 10 a.m., but sometimes they sell out because everyone loves it."

Do you get to go out and "do things" in the community?

"I come every day to the Training Center. I paint pictures. I play bingo and Candy Land. Kim, who lives with us, painted my nails red."

What are your favorite things to do?

"I don't swim but I love to go to the swimming pool because it is hot."

Employment

Are you working? If you are working, tell us a little about your job.

"I want to work at Wal-Mart because my sister works there."

(Staff indicated that she volunteers at the local elementary school, reading to children.)

Are you working at a job where most of the other individuals are also people with disabilities?

"No."

Do you have assistance on the job—like a job coach or other aids?

What do you like about your job?

What would you like to change about your job?

Personal Information
Corey* is 53 years old. He likes to engage with people. He has severe balance problems and is prone to falling, so he wears a helmet. He also has a severe skin condition. He lives in a historic home in Thomasville with four other people and has 24/7 staff. Corey did not mention the fact that he spent a significant part of his life in Southwestern State Hospital, Rose Haven Unit.

*Name changed to protect privacy.

Did you live in an institution at some point in your life?

"No, I lived in Tifton, Georgia."

(Staff explained that he was originally from Tifton but had lived at Southwestern State Hospital for many years beginning in childhood.)

What was the name of the institution?

How long did you live there?

General Experience

What was it like for you as a person with a disability to live in an institution and not in the community?

Do you have specific memories of a time in the institution which you think will help people understand what it was like for you?

(He did not want to talk about living there. Staff said Corey has some challenging behavioral issues and they were warned by state hospital staff and his family that he would not be able to live in the community. However, there have been no incidents since he moved out of the state hospital.)

Housing Arrangements

What type of housing arrangement do you have?

"I have my own bedroom."

Are you living independently?

"No."

Do you live with family members?

"No."

Do you share a home with other individuals?

"Yes, I have four roommates."

Do they have disabilities also?

"Yes."

Is there staff to help you there?

"Yes, Diane takes care of us."

If none of these describe the place where you live—please tell us about it.

What do you like about where you live?

"I have a TV in my room."

What would you like to change about where you live?

"I would like to mow grass."

Community Life

What is the thing you enjoy most about your life in the community?

"I like to mow grass. My brothers and sisters are taking me out to dinner for my birthday on Friday. I want to go to Red Lobster."

Do you get to go out and "do things" in the community?

"No. I come to the Training Center every day and I like to play bingo. I like to go outside and take walks with my friends. I like the Police Department."

What are your favorite things to do?

"Mow grass. I like watching shows."

Employment

Are you working?

"No."

Are you working at a job where most of the other individuals are also people with disabilities?

Do you have assistance on the job—like a job coach or other aids?

What do you like about your job?

What would you like to change about your job?

Personal Information
George* is approximately 40 years old. He talks a lot but is very hard to understand. He does not seem to have additional medical problems, but he pretends to cry when he does not want to do something…like answer questions. George likes donuts and got a package of donuts for our interview. He wanted to finish them before we could talk.

*Name changed to protect privacy.

Did you live in an institution at some point in your life?
> "Yes."

What was the name of the institution?
> "Rose Haven."

How long did you live there?

General Experience

What was it like for you as a person with a disability to live in an institution and not in the community?

Do you have specific memories of a time in the institution which you think will help people understand what it was like for you?
> "My dad was very mean and he died. My mom is in a home in Thomasville."

> (He seems to understand that his mother was not able to take care of him at home.)

Housing Arrangements

What type of housing arrangement do you have?
> "I live in a house. I have my own room, but I did not get to choose the color my room was painted. It is white."

Are you living independently?
> "No I live with four roommates."

Do you live with family members?
> "I have brothers and sisters and they visit me."

Do you share a home with other individuals?

Do they have disabilities also?

"Yes, they are like me."

Is there staff to help you there?

"Yes, there is staff to help us and they take me to see my mom in the home."

If none of these describe the place where you live—please tell us about it.

What do you like about where you live?

"I like donuts. I like to play ball."

What would you like to change about where you live?

"I want to live in Florida with my brother."

Community Life

What is the thing you enjoy most about your life in the community?

"I like to play ball and go bowling."

Do you get to go out and "do things" in the community?

"Bowling."

What are your favorite things to do?

"I like to go see Mom."

Employment

Are you working?

"I work bagging groceries three times a week."

(Staff reports that he works once a month and that he is very popular at work. He works every day in the sheltered workshop.)

Are you working at a job where most of the other individuals are also people with disabilities?

"No."

Do you have assistance on the job—like a job coach or other aids?

"No."

What do you like about your job?

"I like seeing all the people at the grocery store. I like to have money."

What would you like to change about your job?

(He would like to work more at the grocery store. He doesn't like days off.)

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