

# Introduction

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## Deinstitutionalization: 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 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 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 dignity, freedom, choice, and a sense of belonging that is not possible in an institutional environment.

These truths are at the core of both the Americans with Disabilities Act (ADA) and the Olmstead Supreme Court decision, and lower federal court decisions have consistently upheld an individual’s right to receive services in the least restrictive environment possible.

One focus of this toolkit is the lessons learned about how to close large institutions, but the findings in the companion paper will focus on the movement to smaller community living settings that meet the new definition set by NCD, referenced below. Regardless of the size of the institution, bringing people back into the community is only the beginning of the quest for the highest possible quality of life for people with ID/DD. The paper also 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 and is being measured.

There is a growing consensus that true community living is also defined by the extent to which people with ID/DD have a choice over how they spend their time, interact with others outside the home, and make decisions that affect their daily lives and schedules. The companion paper focuses on identifying

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 for both individuals and states is certainly possible.

The content in NCD's Deinstitutionalization Toolkit and "Deinstitutionalization: Unfinished Business" companion 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 paper has been developed to facilitate in-depth discussion of these important issues. This paper can be accessed at: <https://admin.ncd.gov/NCD/publications/2012/Sept192012/>

## **Evolving Definition of Institution**

### **Definitions**

The definition of institution continues to evolve. Although this toolkit focuses on a traditional definition of institution as a large, usually state-run hospital-style setting, often located in a rural area, the definition has also come to encompass Intermediate Care Facilities for people with Developmental Disabilities ICF (ICF/DD), which include smaller community-based facilities with populations of six to 16.

NCD believes that institutions can be not just large state-run institutions, but community-run small group homes, and therefore has defined "institution" as a facility of four or more individuals. As a new definition, this raises the standard in a way that has not been previously tracked and continues the trend toward smaller, more intimate housing situations for people with intellectual disabilities and developmental disabilities (ID/DD) who choose with whom they wish to live. For the purpose of this toolkit, we will be looking at the more traditional definition of six or more residents, as data are not currently available for the lower number.

Although these definitions focus on the number of individuals who live in the same home, advocates have developed a definition that focuses on choice, 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 Living* (Autistic Self Advocacy Network, the National Youth Leadership Network, and Self-Advocates Becoming Empowered, 2011). 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 individuals 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 individuals can enter or exit their home,
- Restrict an individual's religious practices or beliefs,
- Limit the ability of the individual to select or remove support staff at the individual's request,
- Restrict an individual's sexual preferences or activity,
- Require individuals to change housing if they wish to alter the personnel providing their support or the nature of their support,

- Restrict access to the telephone or Internet, and
- Restrict access to broader community life and activities.

## 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 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 a waiting list for residential services (Lakin et al., 2010). 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 (Kim, Larson, and Lakin, 1999; Kozma, Mansell, and Beadle-Brown, 2009; Stancliffe et al., 2009). Deinstitutionalization is a human and civil rights issue. People should not be required to give up their rights in order to receive the services they need.

Under the Americans with Disabilities Act (ADA) the Supreme Court's decision in *Olmstead v. L.C.* (1999), the New Freedom Initiative (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 prevents people with disabilities from accessing appropriate services.

## Deinstitutionalization Is the Right Thing to Do

Oregon helps us to put a human face to this issue. Having closed all of its institutions in 2007, it is an example of both committed and creative deinstitutionalization. However, Oregon advocates have also spent considerable time and energy documenting "why" this effort is so important, as well as the human cost and civil rights issues related to institutionalization. In *Erasing Fairview's Horrors*, Sara Gelser states, "As the visible reminders of Fairview disappear, we must ensure that its history is not forgotten or sanitized" (2010). That history includes labeling people with developmental disabilities "inmates," performing more than 2,600 forced sterilizations, and according to former Governor John Kitzhaber, using "inhumane devices to restrain or control patients, including leather cuffs and helmets and straitjackets and inappropriately high dosages of sedations 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. The “voices” of people with developmental disabilities who lived in Oregon’s institutions also 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 they don’t behave yourself, they’d get you with the scalding hot water.” (Gelser, 2010)*

—Oregon Self-Advocates

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

*“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, to that of a respected, financially independent, and successful professional woman.”*

—Oregon Advocate

These experiences occurred, well documented by Oregon, and instances of abuse continue to occur in institutions across the country. For example, the 2009 “fight club” incident where 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 on state mental health hospitals that revealed more than 100 suspicious deaths of patients during the previous five years (Judd, 2010). The 2002 death of Brian Kent in Kiley Center in Waukegan, Illinois, revealed a pattern of neglect caused by unprofessional attitudes, administrative indifference, lack of competence, and caregiver fatigue (Equip for Equality, 2008).

### **Deinstitutionalization Is a Civil Right**

Clearly, deinstitutionalization and the development of strong community-based systems, which allow people with ID/DD to live in the community, is both morally and ethically the “right thing” to do, but it is also a civil rights issue, and law supports this individual right to live in community. In 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 that they had the right to receive care in the most integrated setting appropriate and that their unnecessary institutionalization was discriminatory, in violation of the ADA. Eventually, the case made it to the U.S. Supreme Court, which 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. The decision included some definitive language about institutionalization:

- “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 decision requires community placement when the following three conditions are met:

- The individual can handle or benefit from community placement,
- The transfer is not opposed by the affected individual, 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 sought 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 an individual into an institution violate the ADA. In 2009, the Civil Rights Division of the Department of Justice launched an aggressive effort to enforce the Supreme Court’s decision in *Olmstead v. L.C.*

*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.*

A technical assistance guide has been created to assist people in understanding their rights and public entities in understanding their obligations under the ADA and *Olmstead*. It is located at:

[http://www.ada.gov/olmstead/q&a\\_olmstead.htm](http://www.ada.gov/olmstead/q&a_olmstead.htm).

## References

Autistic Self Advocacy Network, the National Youth Leadership Network, and Self-Advocates Becoming Empowered (2011). *Keeping the Promise: Self Advocates Defining the Meaning of Community Living*. Accessed March 25, 2012.

<http://www.acf.hhs.gov/programs/add/adddocs/KeepingthePromiseofCommunitySABEFinalApproved.pdf>

Batten, P. J. (1992). The Descriptive Epidemiology of Unnatural Deaths in Oregon’s State Institutions: A 25-Year (1963–1987) Study: III. A 25-Year Overview of Unnatural Deaths in the Mental and Correctional Facilities. *The American Journal of Forensic Medicine and Pathology*. 13(2): 159–172.

Department of Justice (2012). *Olmstead: Community Integration for Everyone*. Accessed March 25, 2012.

<http://www.ada.gov/olmstead/index.htm>

Equip for Equality (2008). *Life and Death in State-Operated Developmental Disability Institutions*. Accessed January 23, 2011. <http://www.equipforequality.org/publications/01-10-08.pdf>

Gelser, S. (2010). *Erasing Fairview's Horrors*. OregonLive.com. Accessed March 25, 2012. [http://www.oregonlive.com/opinion/index.ssf/2010/01/erasing\\_fairviews\\_horrors.html](http://www.oregonlive.com/opinion/index.ssf/2010/01/erasing_fairviews_horrors.html)

Judd, A. (2010). Georgia Mental Health Talks Fail. *Atlanta Journal Constitution*. July 1, 2010.

Kim, S., S. A. Larson, and K. C. Lakin. (1999). *Behavioral Outcomes of Deinstitutionalization for People with Intellectual Disabilities: A Review of Studies Conducted Between 1980 and 1999*. Policy Research Brief. Minneapolis: University of Minnesota, Institute on Community Integration.

Kozma, A., J. Mansell, and J. Beadle-Brown. (2009). Outcomes in Different Residential Settings for People with Intellectual Disability: A Systematic Review. *American Journal of Intellectual and Developmental Disabilities*. 114(3): 193–222.

Lakin, K. C., S. Larson, P. Salmi, and A. Webster. (2010). *Residential Services for Persons with Developmental Disabilities: Status and Trends through 2009*. Research and Training Center on Community Living Institute on Community Integration/UCEDD, College of Education and Human Development, University of Minnesota. Accessed July 21, 2011. <http://rtc.umn.edu/docs/risp2009.pdf>

Stancliffe, R. J., K. C. Lakin, S. Taub, G. Chiri, and S. Y. Byun. (2009). Satisfaction and Sense of Well Being among Medicaid ICF/MR and HCBS Recipients in Six States. *Intellectual and Developmental Disabilities*. 47(2): 63–83.