

THE POLICY RESOURCE CENTER

INSTITUTE FOR HEALTH, LAW, AND ETHICS AT FRANKLIN PIERCE LAW CENTER

W I N T E R 2 0 0 3 / I S S U E 1

PIERCE  LAW
FRANKLIN PIERCE LAW CENTER

THE NEW FREEDOM INITIATIVE

Community-Based Alternatives for People with Disabilities

“My Administration is committed to tearing down the barriers to equality that face many of the 54 million Americans with disabilities. My New Freedom Initiative will help Americans with disabilities by increasing access to assistive technologies, expanding educational opportunities, increasing the ability of Americans with disabilities to integrate into the workforce, and promoting increased access into daily community life.”

President George W. Bush, Forward to the New Freedom Initiative (2001)

In Executive Order 13217, President Bush affirmed his commitment to eliminate barriers to equality for people with disabilities and ordered federal assistance to states to swiftly implement the Olmstead holding.

Olmstead - Unjustified Institutionalization Is Discrimination.

In a 1999 landmark ruling, *Olmstead v. L.C.*, the United States Supreme Court held that states may not unnecessarily institutionalize people with disabilities. In *Olmstead*, two individuals sued the state of Georgia for discrimination under the Americans with Disabilities Act (ADA) because they were forced to live in an institution even though treatment professionals determined that their needs could be appropriately met in one of the community-based programs the state supported. The state of Georgia argued that this was not “discrimination” but rather the result of inadequate funding for community-based programs. The Court found for the plaintiffs and held that unjustified institutionalization is a form of discrimination.

Specifically, the Court found that in the Americans with Disabilities Act (ADA) “Congress explicitly identified unjustified ‘segregation’ of persons with disabilities as a ‘form of discrimination.’”¹

Historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem. (ADA, 42 U.S.C. § 1201(a)(2).)

Individuals with disabilities continually encounter various forms of discrimination, including . . . segregation. (ADA, 42 U.S.C. § 1201(a)(5).)

Title II of the ADA also requires that public entities, such as the state, administer their programs in “the most integrated setting appropriate to the needs of” the individual with a disability.

The Court further concluded that when we recognize unjustified institutionalization as a form of discrimination we do so based on two judgments:

T (1) Unjustified institutionalization “perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life;” and

(2) Unjustified institutionalization “severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”²

In the nursing home I had few real choices. Now I live in my own home and choose what I eat, when I eat, when I go to bed. I can invite my family and friends over whenever I want and go out whenever I want and I don't have to leave to fit the nursing home's schedule. I have a dog. I couldn't do any of these things when I lived in the nursing home.

Claire Shepardson, Nashua - Lived in a nursing home for over 20 years.



Moving back to my home has made all the difference in the world. In the nursing home I was told, I could never go home, that's strong medicine. I kept thinking, okay I'm going to die here and so lets get it over with. Not that a nursing home is a bad place. The people who work there are committed and good people who are not paid enough. But I made it home and it has made all the difference in the world. Now I look forward to every day and the pleasure it can bring. At home I can do what I want, when I want.

Ralph Kelly, aged 81, Hudson. - Lived in a nursing home for 1 year, nine months and two days.

OLMSTEAD REMEDY – REASONABLE MODIFICATIONS IN STATE SYSTEMS

The Supreme Court provided a “reasonable” remedy to unjustified institutionalization, a remedy based upon ADA regulations. ADA regulations require that a public entity “make reasonable modifications in policies, practices or procedures when the modifications are necessary to avoid discrimination . . . unless the public entity can demonstrate that making the modification would fundamentally alter the nature of the service, program or activity.”³ In essence, the Court found that a fundamental alteration is an alteration that would result in an inequitable allocation of available resources given the responsibility the state has to the overall population of people with disabilities.

Therefore, pursuant to the ADA, the Court held that:

A state must provide community-based services to people when:

1. The State's treatment professionals determine that community placement is appropriate;
2. The individual with the disability does not oppose community placement; and
3. The placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with similar disabilities.⁴

New Freedom Initiative Policy

President Bush reemphasized the holding and findings of Olmstead and further stated:

- ▶ Community-based services advance the best interests of Americans.
- ▶ Community-based programs must foster independence and community participation.
- ▶ Swift implementation of the Olmstead decision is necessary to ensure that all Americans have the opportunity to live close to their families and friends, to live more independently, to engage in productive employment, and to participate in community life.

Swift Interagency Implementation of the Olmstead Decision

The Bush administration recognized the breadth of federal programs affecting people with disabilities and the need for interagency cooperation to ensure an effective community-based infrastructure to support people with disabilities. Therefore, the President ordered six key federal agencies to work cooperatively as the Interagency Council on Community Living to ensure timely implementation of the Olmstead decision.

Each federal agency was to evaluate its policies, programs, statutes and regulations to determine whether revision or modification was necessary to improve the availability of community-based services to people with disabilities. The President further directed each agency to include public input as a central component of the review.

Delivering on the Promise

Each agency performed an extensive program review. More than 800 individuals and organizations provided public comment. In the end, the agencies identified over 400 steps to eliminate barriers and improve community integration for people with disabilities. A final compilation of the agencies' reports was presented to President Bush in March 2002.⁵ Highlighted barrier areas include:

Health Care Structuring and Financing	Employment
Housing	Education
Caregiver and Family Support	Access to Technology
Transportation	Accountability and Legal Compliance
Personal Assistance, Direct-Care Services and Community Workers	Public Awareness, Outreach and Partnerships

Fulfilling the Promise

The intent of the New Freedom Initiative is to enable a swift implementation of the Olmstead decision throughout the nation. States are encouraged to develop complementary initiatives that will help further the goals of the New Freedom Initiative at the community level. In partnership with the states, the New Freedom Initiative presents a realistic opportunity for people with disabilities to have greater independence and participation in community life, resulting in a higher quality of life and richer communities. New Hampshire has been awarded three Real Choice grants to support this work.

1 527 U.S. at 600.

2 527 U.S. at 600.

3 28 C.F.R.- 35.130 (b)(7).

4 527 U.S. at 607.

5 Delivering on the Promise agency reports can be found at <http://www.hhs.gov/newfreedom/final/>.

NATIONAL FACTS ON DISABILITY

▶ The prevalence of disability increases with age.*

Ages 6 to 14 - 1 in 9 children

Ages 15 to 64 - 1 in 5 people

Ages 65 and older - 1 in 2 people

▶ Of all working age people with disabilities (aged 18-64), only 3 out of 10 are employed full or part-time, compared to 8 in 10 working-age people without disabilities. Of the total number, 56% of people with disabilities who are able to work are working.**

▶ People with disabilities are almost three times as likely as people without disabilities to live in poverty.**

▶ People with disabilities are four times as likely, when compared to people without disabilities, to have special needs that are not covered by their health insurance.**

▶ People with disabilities are much more likely to consider inadequate transportation to be a problem (30% versus 10%, respectively).**

▶ People with disabilities are less likely than people without disabilities to:

- Visit a supermarket at least once per week (55% versus 83%);

- Visit a department store, mall or shopping center at least once per week (23% versus 41%);

- Go to the movies or theater four or more times per year (22% versus 48%);

- Go to live popular music performances four or more times per year (9% versus 16%);

- Go to a sports event four or more times per year (15% versus 35%); or

- Go to events related to their hobbies, such as dancing or art shows, four or more times per year (21% versus 36%).**

▶ Religious faith is equally important to people with disabilities as it is to people without. However, only 47% of people with disabilities attend religious services at least once per month compared to 65% of people without disabilities.**

* U.S. Census, 1997.

** National Organization on Disability/Harris Survey of People with Disabilities (2000).

The Policy Resource Center (PRC) at the Institute for Health, Law, and Ethics was established in 2002 under a Real Choice Systems Change Grant from the Centers for Medicare and Medicaid Services. The mission of the PRC is to identify barriers to real choice and consumer directed services for elders and persons with disabilities and to recommend reforms in policy, regulatory structure and practices. PRC partners include: Consumers, Institute on Disability at UNH, Granite State Independent Living, and the New Hampshire Department of Health and Human Services (Divisions of Elderly and Adult Services, Behavioral Health and Developmental Services and the Office of Health Planning and Medicaid).

THE POLICY RESOURCE CENTER

INSTITUTE FOR HEALTH, LAW, AND ETHICS AT FRANKLIN PIERCE LAW CENTER

