

March 2004

Federal, State and Case Law Regarding Institutionalization of People with Disabilities

What Does the National Conference of State Legislators (NCSL) State About Olmstead and its impact on Deinstitutionalization and Waiting Lists?

NCSL NEWS (March 29, 2001):

"In June 1999, The Supreme Court ruled in *L.C. & E.W. vs. Olmstead* that it is a violation of the Americans with Disabilities Act for states to discriminate against people with disabilities by providing services in institutions when the individual could be served more appropriately in a community-based setting."

NCLS State Legislative Report (March 2002), Volume 27, Number 7:

The Court suggests ways by which a state can show compliance with Olmstead.

1. A state may develop a comprehensive, effective working plan, including timetables and progress reports, for placing qualified people in community-based settings.
2. A state may maintain a waiting list for community-based services, but the list must move at a reasonable pace and may not be motivated by a desire to fill institutions.

What Does *Olmstead v. L.C.*,¹ Find?

- "Unjustified isolation...is properly regarded as discrimination based on disability."²
- Affirms the Department of Justice's stance that "undue institutionalization qualifies as discrimination 'by reason of ... disability.'"³

¹ 527 U.S. 581 (1999). *Olmstead* is a landmark Supreme Court Case that serves to advance the rights of people with disabilities. In *Olmstead*, the Supreme Court held that the Americans with Disabilities Act required that individuals with disabilities be placed in the community rather than in institutions. *Id.* Lower courts (federal and state) have interpreted *Olmstead* as a prohibition, mandated by federal law, against "avoidable" and "unnecessary" institutionalization of individuals with developmental disabilities, and as a requirement that states make "reasonable efforts to place institutionalized individuals with developmental disabilities in the community." *Id.*

² See *Olmstead*, 527 U.S. at 597 (discussing unjustified isolation in terms of institutionalization).

³ See *id.*, at 597-598.

- "...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."⁴
- "...Under Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."⁵

What Does The Developmentally Disabled Assistance and Bill of Rights Act⁶ Say About Institutionalization of People with Developmental Disabilities?

- "Treatment, services, and habilitation for a person with developmental disabilities ... should be provided in the setting that is **least restrictive** of the person's personal liberty."⁷

What Do Federal Regulations Say About Institutionalization of People with Disabilities?

- "A public entity shall administer services, programs, and activities in the **most integrated setting** appropriate to the needs of qualified individuals with disabilities."⁸

What Does The Americans with Disabilities Act⁹ Says About Institutionalization of People with Disabilities?

- "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;
- Discrimination against individuals with disabilities persists in such critical areas as . . . institutionalization. . .;

⁴ See *id.*, at 601.

⁵ See *Olmstead*, 527 U.S. at 607.

⁶ 42 U.S.C §6001 (2000).

⁷ 42 U.S.C. § 6010(2) (1976 ed.) [Emphasis added].

⁸ See 28 C.F.R. 35.130(d) (1998) [Emphasis added].

⁹ 42 U.S.C. §12101 (1990).

- Individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, . . .failure to make modifications to existing facilities and practices, . . .[and] segregation" ¹⁰

What Does Evolving Case Law State About Institutionalization?

- If an individual opposes community placement, does the individual have a right to remain in an institution?

NO. This issue came before the Pennsylvania District Court which ruled that Olmstead does not give a person the right to remain in an institutional. Advocates for institutionalization sought to intervene in *Richard C. v. Houstoun*, (W.D.Pa. September 29, 1999). The proposed interveners argued that the facility's residents have a right to remain in the facility if they oppose community placement. The District Court rejected the proposed interveners' argument and made it clear that nothing in the Olmstead decision precludes a state from closing or downsizing institutions or placing individual residents into the community and that the ADA does not confer on individuals the right to veto such actions. ¹¹

What Does Maryland Law Say About Institutionalization of People with Developmental Disabilities?

Maryland Health-General Article 7-102. Legislative Policy states: "To advance the public interest, it is the policy of this State:

- "(4) To foster the integration of individuals with developmental disability into the ordinary life of the communities where these individuals live.
- (5) To support and provide resources to operate community services to sustain individuals with developmental disability in the community, rather than in institutions.
- (6) To require the Administration to designate sufficient resources to foster and strengthen a permanent comprehensive system of community programming for individuals with developmental disability as an alternative to institutional care."¹²

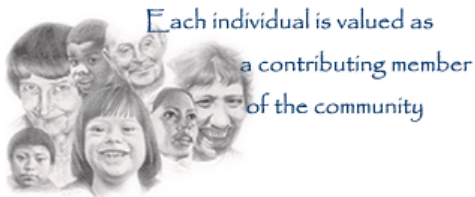
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¹⁰ See 42 U.S.C. §§12101(a)(2), (3), (5).

¹¹ NAPAS, Washington, D.C.

¹² See §7-102(4-6) (2000).



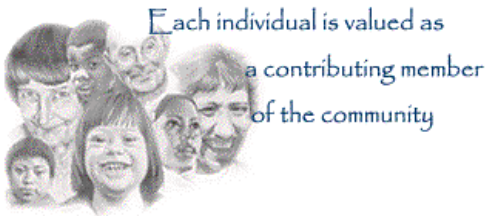
March 2004

Outcomes for People Leaving Institutions: What Research Tells Us

A review of all reports published between 1980 to 1999 about behavioral changes when people with intellectual disabilities move from institutions to community settings found the following¹:

- Studies of over 2,600 subjects demonstrate strongly and consistently that people who move from institutions to community settings have experiences that help them to improve their adaptive behavior skills. This is a robust array of research whose findings are remarkable for their consistency
- Individuals who left institutions used significantly more community places, engaged in significantly more social activities, experienced significantly more personal integration, had significantly more family contacts, and made significantly more choices at an adjusted expenditure that was 66% of that of their counterparts who remained in institutions.
- All of the studies published in 1990 or later reporting significant findings regarding changes in challenging behavior reported significant improvements.
- Many studies have examined changes in adaptive or challenging behavior associated with movement from institutions to community settings. Summaries of this research noted that, overall, adaptive behavior was almost always found to improve with movement to community settings from institutions, and that parents who were often as a group initially opposed to deinstitutionalization were almost always satisfied with the results of the move to the community after it occurred.

¹Source: Lakin and Larson, 1999, Research & Training Center on Community Living, University of Minnesota. "Behavioral Outcomes of Deinstitutionalization for People with Intellectual Disabilities: A Review of Studies Conducted Between 1980 and 1999."



**ROSEWOOD CENTER SHOULD NOT REMAIN OPEN AND BECOME A
“COMMUNITY RESOURCE CENTER”**

WHY?

Do we need a “Community Resource Center” at Rosewood Center to provide optimum health care for persons with developmental disabilities?

No.

- The Baltimore Area is nationally recognized as having the most advanced health care in the nation. The Johns Hopkins Medical Center and the University of Maryland Medical Center are teaching hospitals that attract specialists who are widely respected in their field.
- These Teaching Facilities eagerly accept persons with complex medical needs and pride themselves on finding answers that improve the lives of all persons who need their services.

Are community Physicians, Dentists and other Health Care Providers ill equipped to provide care to persons with intensive needs?

No.

- Community health care providers are very capable. Sometimes additional training and coordination is needed; however training at an institution is not the answer. One proven approach is occurring in the Philadelphia area. The Commonwealth of Pennsylvania has established Philadelphia Coordinated Health Care that provides technical assistance and training for medical personnel, including physicians, dentists and medical students; individuals with developmental disabilities and their families; and community support staff. Collaborative efforts result in accessible quality medical, dental, and behavioral health care. PCHC works with each county to develop a plan to address disability priorities in the health care arena.

Is a “Resource Center” located at an institution necessary to train staff of community service providers?

No.

- The Developmental Disabilities Administration requires intensive training of community staff. Adult training is best done in an experiential manner and not in an artificial setting such as the buildings of an institution. Training can always be improved, but it is best done in the community where people are living. It should be done by those who receive services, their families, and professionals in the field.
- In the last few years, some agencies have pooled their resources and enlisted the assistance of local community colleges to enhance the professional standards for staff. We must build upon existing community and college resources, rather than establishing a new bureaucracy and program housed at an institution.

Do we need Rosewood Center to provide respite care and other services to people who live in the community?

No.

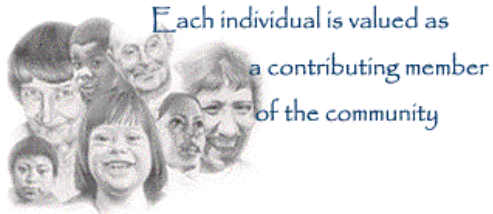
- Families overwhelmingly report that they want access to respite care and other supportive services in their home or home community, rather than traveling to an institution. The market demands quality respite care and other services in the community.
- Individuals living in the community are not attracted to large segregated sites for respite or other services. Community respite services have been provided in more inclusive settings for more than 15 years. Younger families are more comfortable with community settings.
- Maintaining and improving increasingly deteriorating buildings at state institutions is expensive and unnecessary.

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January 2004

Shattering Myths *about* **Choice**

Q: Should a continuum of services include institutions?

A: No.

- Society has no responsibility to subsidize segregation.
- Society's values change as civil rights, contemporary technology, and new medical and health approaches are incorporated into mainstream society. Outdated technologies and treatment approaches are then replaced by more advanced practice. Institutions are no longer the contemporary approach for the way individuals with disabilities seek to live and receive treatment and supports.

Q: Should parents have the choice to place or keep their child in an institution?

A: No.

- None of us, whether we have a disability or not, has unlimited choices in life.
- Governmental and societal strictures do not allow any of us to choose anything we wish. Some options are excluded or forbidden, either in the interest of the community's overall welfare or as a result of government responsibility to set priorities and allocate its resources.

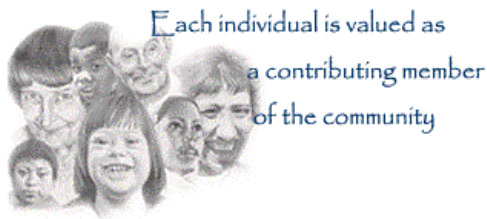
It is NOT reasonable to segregate people in institutions when experience and research prove that even people with significant disabilities and intensive needs can be supported in the community.

It is NOT reasonable to continue to invest scarce public dollars operating large, inefficient congregate settings.

It is NOT reasonable to deny even one person the right to live among us in the community, where services and supports can be provided.

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March 2004

Shattering Myths *about* **Closure Impact on the Local Economy and Workforce**

Q. Is the local economy & workforce negatively impacted when a State Residential Center closes?

A: No.

The Great Oaks State Residential Center was closed seven years ago. All residents were transitioned to individually designed community residential and day supports. The Center's buildings were demolished. The property was sold to Erickson Retirement Community who constructed Riderwood Village on the property that formerly housed the Great Oaks Center.



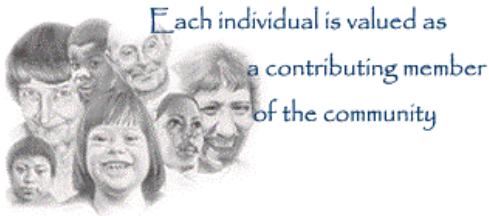
Construction Investment: \$560 Million in Private Investment

- **Annual Operating Budget: Approximately \$60 Million**
- **Local Taxes: \$1.4 Million per year**
- **Number of Employees: 712**
- **Annual Payroll: 2003 - \$12.3 Million; As of Completion in 2006: \$23.8 Million**
- **Median Income of Residents Served: \$48,168**

Riderwood Village, upon completion in 2006, will include approximately 2,000 independent living units, 250 assisted living units and 400 skilled nursing units. The Project also includes four community buildings and related support facilities and common areas, e.g. dining rooms, convenience stores, bank branches, beauty salons, game rooms, aquatic center, classrooms, woodworking shop, in-house cable television station, non-denominational chapel, walking paths, nature trail and health club. Services provided in the common facilities include an on-site medical center and services for resident organizations.

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October 2003

Shattering Myths *about* **Community Placement**

Q: Can institutions serve people on DDA's Waiting List?

A: No.

- “*Over my dead body.*” ~ quote from Waiting List families.
Families on the Waiting List have struggled for years to meet their loved one's needs with little or no outside help. They did this so their son or daughter with a disability could remain a part of the family and community. That's what they want to continue, with adequate community supports.

Q: Will people lose their jobs if an institution closes? Will hundreds of people become unemployed if an institution closes?

A: This should not even be a consideration.

- We shouldn't keep people institutionalized just so others can keep their current jobs.

A: Many staff could find work in community programs.

- In fact, many institution staff are already working in community programs.

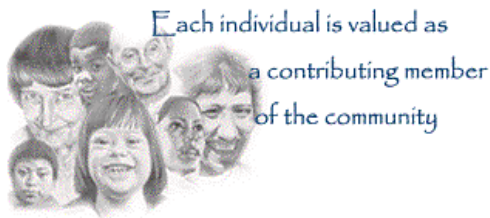
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January 2004

Shattering Myths *about* **The Cost of Services**

Q: Should people move to the community only if the State can save money?

A: No.

- Moving people to the community is not an issue of cost; it is an issue of human and civil rights.
- In fulfillment of human rights and in securing optimum opportunities for development, all people, regardless of the severity of their disability, are entitled to community living.ⁱ

Q: Is there a cost savings when an institution closes?

A: Yes.

- The proceeds from the sale of institutions go into Maryland's Community Services Trust Fund. Investment earnings generated by the Fund are used to support more people with developmental disabilities and their families in critical need of community services. In addition, closure of an institution means that the state can stop spending scarce public funds on costly maintenance and upkeep of antiquated buildings.

Q: Are institutions cost-effective?

A: No.

- Recent cost comparisons of community and institutional services refute claims that institutions offer "economies of scale" or that the centralization of services at institutions is more cost-effective.ⁱⁱ
- The cost of community services depends on each individual's needs and may or may not cost less.

Q: Why not operate an institutional system and a community system?

A: This is not fiscally or socially responsible.

- More than 11,000 people are on DDA's waiting list for community services. Policymakers must take their needs into account. Limited public resources must be spent in a fiscally and socially responsible manner.

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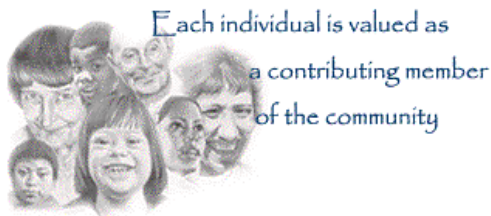
ⁱ *The Community Imperative: A refutation of all arguments in support of institutionalizing anybody because of mental retardation* (1979). Center on Human Policy at Syracuse University.

Established that all human beings, regardless of nature and severity of disability, are inherently valuable, have fundamental rights, and are capable of learning, growth, and development.

ⁱⁱ Taylor, S.J. (2003, June) *The Editor's Perspective on Institutional and Community Costs*. *Mental Retardation*, 41,125-126

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February 2004

Shattering Myths *about* **People with Intensive Needs Living in the Community**

Q: Can everyone with a developmental disability be served in the community? Are there individuals who are not able to live outside of an institution?

A: All people currently in institutions can live in the community.ⁱ

- Former Great Oaks Center residents who rely upon ventilators and portable oxygen, require positioning every two hours, and need suctioning are now living safely with home and community supports in Maryland.
- Nine states, plus the District of Columbia, have closed all state institutions: Alaska, Hawaii, Maine, Minnesota, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia. People are living successfully in the community.
- People are receiving 24-hour care and support, 365 days a year, when needed, to be safe in the community. They also have a better quality of life.

Q: Are people in institutions more challenging and disabled than people living in the community?

A: No.

- While many people remaining in institutions do have multiple disabilities and extensive support needs, there are people with similar disabilities and more intensive needs who are living with their families or are supported in community programs throughout Maryland.

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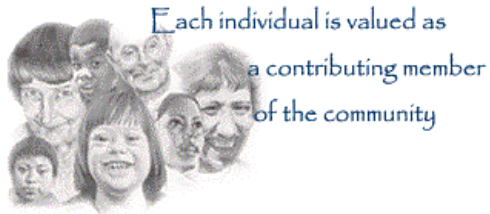
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ⁱ Some people in DDA institutions are there under a court order because of involvement with the criminal justice system. They are referred to as the forensics population. Whether or not they can be served in the community is under the jurisdiction of the court, and therefore, not a part of this discussion.

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January 2004

Shattering Myths *about* **Quality of Life & Quality of Services**

Q: Has moving from institutions to small community homes been successful? Are outcomes for people better in the community?

A: Yes.

- Research demonstrates that moving people from institutions to the community has been extremely successful and that outcomes for people in the community are better than for individuals segregated in institutions.ⁱ Recent research has also found this to be true of people with very serious challenges.ⁱⁱ In fact, from the large body of research evidence now available, researchers make this statement: “*Deinstitutionalization of people with developmental disabilities in America has been one of the most successful and cost-effective social experiments in the past two decades.*”ⁱⁱⁱ

Q: Do parents who fear their loved ones will not be safe and will suffer in the community continue to feel this way after their family member leaves the institution?

A: No.

- Research shows that family member attitudes change dramatically after community placement. Before community placement, less than 20% of families agreed with community placement and 58% strongly opposed community placement; However, after placement, 66% of families strongly agreed with community placement and less than 5% opposed.^{iv}

Q: Is community living a “one size fits all” approach?

A: No.

- Smaller community settings are more likely to address unique needs and preferences than larger institutions. Community programs, including staff training, are designed around the needs of the person.
- Everyone who leaves a DDA institution does so ONLY after thorough individualized team planning and when all needed community-based services and supports have been identified. In addition, everyone leaving an institution is assigned a resource coordinator to monitor and assist in carrying out his or her plan.
- It is actually institutions – with large numbers of people and set routines – that epitomize “one size fits all.”

Q: Is there widespread abuse in community programs? Are institutions safer?

A: No.

- Institutions and community programs in Maryland are licensed and certified by the same state and federal agencies. When people live in the community, neighbors, friends, and the public

can see and report any abuse--something less likely to happen for an individual living in an isolated setting.

- A recent study found allegations of abuse actually decreased after community placement.^v
- Direct comparisons of the number of abuse allegations in institutions and community programs are misleading, as they must be considered in the context of the total number of people served -- 22,000 people with developmental disabilities are supported in community programs while about 400 people live in institutions.
- Abuse, unfortunately, also occurs in institutions.

Q: Aren't institutions home-like?

A: No.

- “As much as we try to create a home-like environment in an institution, institutions are not homes. You cannot take 200 people and create a home. It’s not individual. And you just cannot measure the importance of environment.” ~ Bill Brooks, retired superintendent of Winfield State Hospital^{vi}

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ⁱ Lakin, K.C. (1999). *A review of literature of home and community services for persons with mental retardation and related conditions*. Minneapolis: University of Minnesota, Research and Training center on Community Living, Institute on Community Integration.

ⁱⁱ Conroy, J., Spreat, S., Yuskas & Elks, M. (2003). The Hissom Closure Outcomes Study: A Report on Six Years of Movement to Supported Living. *Mental Retardation*. 41, 263-273.

ⁱⁱⁱ Conroy, J., Garrow G., Fullerton, A., Brown, M. & Vascile, F. (2003). *Initial Outcomes of Community Placement for the People Who Moved From Stockley Center*. Completed for the Delaware Division of Developmental Disabilities Services.

^{iv} Conroy J. & Bradley, V. (1985). The Pennhurst Longitudinal Study: A Report of Years of Research and Analysis.

^v Conroy J., et. al (2003). *Initial Outcomes of Community Placement for the People Who Moved From Stockley Center*.

^{vi} *The Right Thing To Do*. 1998. The Kansas Council on Developmental Disabilities.

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