

NJ Council On Developmental Disabilities Position Statement On Deinstitutionalization

BACKGROUND

Legal Mandates

The Developmental Disabilities Assistance and Bill of Rights Act establishes "the policy of the United States that ... individuals with developmental disabilities, including those with the most severe developmental disabilities, are capable of self-determination, independence, productivity, and integration and inclusion in all facets of community life."

Consistent with this vision, the guiding principle of the United States Supreme Court decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999) is the inherent right of an individual to be free from unnecessary segregation from the general public. The Court made it clear that unnecessary institutionalization is a form of discrimination under the Americans with Disabilities Act (ADA), and explained that "segregation perpetuates unwarranted assumptions that institutionalized people are incapable or unworthy of participating in community life." [1]

The Justices also concluded that "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." [2] Accordingly, the Court reasoned that people with disabilities cannot be required to give up the benefits of full participation in their communities in order to obtain needed medical services and supports. [3] Therefore, states must make services available in inclusive, community based settings.

New Jersey Facts

Nearly 3,000 people with developmental disabilities live in our seven large State-run developmental centers, which are referred to under Medicaid law as Intermediate Care Facilities for the Mentally Retarded [4] (ICFs-MR). In many respects, this practice leaves New Jersey significantly out of step with the nation:

- Half of the states in the country (25) have a total statewide institutional population of less than 1,000.
- Nearly half of the states in the country (24) have two or fewer such institutions.
- Nine states have no state institutions at all. [5]

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1. *Id.* At 597, and 600-01.
2. *Id.* at 600-01.
3. *Id.* at 601.

4. The Council recognizes that this term, found in federal Medicaid statutes, is outdated and offensive. It is only included here to identify the specific provisions of the federal Medicaid statute that govern New Jersey's developmental centers.
5. As of 2008, the following states reported no large residential institutions for people with developmental disabilities: Alaska, Hawaii, Indiana, Maine, New Hampshire, New Mexico, Rhode Island, Vermont and West Virginia.

COUNCIL FINDINGS AND RECOMMENDATIONS

The Council finds as follows:

New Jersey continues to rely on large institutions as a default placement and has not committed sufficient resources to free people with developmental disabilities from unnecessary confinement in large restrictive institutions.

The National Conference of State Legislators correctly concluded that, "[a]s long as states continue to operate large public facilities, state funds will be used to support those facilities, per capita costs of operating facilities will continue to increase, and expansion of community services will decline. [6]

New Jersey's over-reliance on institutional settings for emergent and long-term care significantly hinders the State's ability to develop the resources needed to provide quality community-based services and supports.

The State has a legal and social imperative to act immediately to develop a community infrastructure of housing, health care, direct care, transportation, along with behavioral, recreational, educational and vocational supports to ensure that our State has the capacity to serve all DDD-eligible individuals who seek home- and community-based services and supports.

Based on all of the above, the Council calls upon the State to:

- Develop the capacity to provide persons with developmental disabilities with self-determined, safe and effective services in community settings.

Develop a plan and timetable to:

1. close developmental centers
2. reduce the population in developmental centers that remain open
3. prevent new admissions to developmental centers
4. redirect some of the funds currently used to maintain seven large developmental centers to the development of safe and effective self-directed home and community-based services and supports

Immediately allocate federal and State funds to meet the following goals:

1. stop new admissions to developmental centers of people who could be served in the community by, among other things, meeting emergency requests for services in less restrictive settings
2. increase the pace of transitioning to the community the more than 2,000 developmental center residents whom the State has identified as waiting for less restrictive settings
3. annually meet the needs of at least 10% (400) of the current number of people on the State's growing priority waiting list for community based services and reduce the presently unacceptable length of time people remain on the priority waiting list for community services.

REVISED POLICY ADOPTED: March 20, 2009

This revised policy replaces all previously adopted policies on deinstitutionalization.

[6] Davis, DeWayne Fox-Grage, Wendy and Gehshan, Shelly. Deinstitutionalization of Persons with Developmental Disabilities: A Technical Assistance Report for Legislators. National Conference of State Legislatures. May 19, 2000.