



“Each disabled person is entitled to treatment in the most integrated setting possible for that person - recognizing on a case-by-case basis, that setting may be an institution.” (U.S. Supreme Court, *Olmstead v. L.C.*).

MARYLAND

Why Congress Should Care About the ICF/MR Program and the People It Serves The Human Consequences of the DD Act Programs’ Ideologically-Based Attacks on ICF/MRs

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act)

The DD Act authorizes three primary grant programs designed to “assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life. . . .”

The three primary programs authorized by the DD Act are the state Developmental Disabilities Councils (**DD Councils**), state Protection and Advocacy (**P&A**) systems, and state University Centers for Excellence in Developmental Disabilities (**UCEDD**).

Congressional Intent and the Role of ICFs/MR in the Continuum of Care

As clarified by Congress, the DD Act’s support for these goals is “not [to be] read as a Federal policy supporting the closure of residential institutions.” [House Energy and Commerce Committee Report No. 103-378, November 18, 1993 (to accompany H.R. 3505, the Developmental Disabilities Act Amendments of 1993)]. In the 1993 Amendments, in both statute and report language, Congress made it clear that individuals and their families, not the DD Act programs, are the “primary decisionmakers” regarding needed and desired services, “including regarding choosing where the individuals live.” Congress expressly cautioned, in the House Committee report explaining this language, “that goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities not be read as a Federal policy supporting the closure of residential institutions. It would be contrary to Federal intent to use the language or resources of this Act to support such actions, whether in the judicial or legislative system.”

Why did the Congress support the continuation of residential institutions? The answer lies in the population who reside in such facilities and the care they receive. Residents of ICFs/MR are among the neediest, most fragile and most disabled members of our society. They need substantial support in every aspect of life including walking, communicating, bathing, eating and toileting. According to a 2007 University of Minnesota study, nearly 80% of the nation’s ICF/MR residents experience severe or profound intellectual

disabilities, functioning at an infant or toddler's level although fully grown; they also endure multiple disabilities, chronic medical conditions and/or behavioral challenges. Many also have seizure disorders, mental illness, visual or hearing impairments, or have a combination of these conditions.

ICFs/MR are often the best way to meet the needs of the most vulnerable of the population with intellectual and developmental disabilities, providing them with comprehensive around-the-clock supports to assure their safety and enable them to live their lives to the fullest.

Currently, the federal government helps fund and monitor 6,381 ICFs/MR that are home to 93,164 people.

Additional Resources And Legislative Recommendations

The full report on which this document is based is available online at:
<http://www.vor.net/images/stories/pdf/TaskForceReport.doc>.

Recommendations for DD Act reform can be found at the end of this document.

MARYLAND: All three primary DD Act programs pursue activities which violate Congressional intent

I. DISREGARD FOR FAMILY INPUT, IN VIOLATION OF THE DD ACT'S REQUIREMENT THAT INDIVIDUALS AND FAMILIES BE THE "PRIMARY DECISIONMAKERS"

A. Organizational Priorities

The Cross Disability Rights Coalition (CDRC) is funded by a 3 year grant from the Maryland DD Council. The CDRC is dedicated to ending institutionalization with a particular focus on Rosewood despite a very public "save Rosewood" campaign by the families of Rosewood residents. ([Maryland DD Council](#)).

"The Developmental Disabilities Council (DD Council, our funders) has approved CDRC to be funded for a 7th year. This means CDRC will be able to keep working on issues that are important to the disability community such as de-institutionalization, (getting folks out of nursing facilities and State Residential Centers), ending the institutional funding bias in Maryland, disability related policy, and everything else we do." (CDRC newsletter 09/08).

B. Litigation

Hunt v. Meszaros was filed in 1991. The lawsuit led to the closure of Great Oaks ICFs/MR in 1996, despite known family/guardian objection, including efforts by families to intervene, and meetings between plaintiffs' and concerned families. The facility closed in 1996. (Maryland P&A).

C. Legislative Advocacy

Testimony in support of closing Rosewood, saying, "no one should have to live in an institution . . . the model of warehousing people . . . is an outdated relic of history." (Maryland P&A). February 16, 2006

Support for the passage of HB 794 which led to an individual planning process that presumed ALL Marylanders with developmental disabilities could be served appropriately in community settings, and defined families as one potential "barrier" to community placement (Maryland DD Council; Maryland P&A) 2005

Opposition to a law that expands respite opportunities to desperate families because respite would be provided Maryland's ICFs/MR (Maryland DD Council; Maryland Disability Law Center). 2004

SB 338 required the Department of Health and Mental Hygiene to reserve a certain percentage of beds at state residential centers for respite care. The DD Coalition strongly opposed this bill as it could divert the establishment of respite services in the community, and is moving back to dependency on institutions. The Senate Finance Committee, in a very close vote, gave the bill an unfavorable vote.

HB 475 requires state residential centers operated by the Department of Health and Mental Hygiene to provide respite care in the facility. The DD Coalition strongly opposed the bill. The end result was a weaker bill that allows in a limited manner respite in a state residential center. This bill passed with its weakening amendments. (Maryland P & A)

(From http://www.mdcbalto.org/worddocs/2004legislative_summary.doc)

"I strongly disagree with the agenda of the MDLC [MD P&A] and the MD DD Coalition [-close State Residential Centers. I find it outrageous that these agencies receive Federal dollars to promote an agenda that is not supported by MANY taxpaying citizens. These agencies do not represent my daughter and her rights to continue to receive care in the most appropriate setting – Holly Center." (Mary Lou Chandler, ADD Public Forum Testimony, 2006). (Maryland DD Council).

II. DEINSTITUTIONALIZATION – ICFs/MR CLOSURE ACTIVITIES

A. Organizational priorities

“The Council believes that all people, regardless of how complex or severe their disability, belong in the community with the support they need to maximize independence, be productive, and lead the lives they choose. Practices that segregate and isolate people with disabilities must end.” (Maryland DD Council vision statement.- 2009)

“Advocates for institutions and segregated schools have become more vocal over the past five years and have at least one prominent ally in the House of Delegates. State residential centers (SRCs) have been made available for respite care rather than developing more community options and repeated efforts have been attempted to open SRCs to more admissions. This will continue over the next five years and could be a significant policy set-back for Maryland.” (Maryland DD Council - 5 year plan 2006-2011, page 7.)

“. . . our raison d'etre is getting people out of institutions. In fact, reducing the number of disabled people warehoused in psychiatric hospitals, nursing homes and other institutions are issues one, two and three for MDLC,” said Philip J. Fornaci, MDLC executive director (*Daily Record*, 2002). (Maryland P&A).

The Maryland DD Council and Maryland P&A endorsed “The Community Imperative,” which states that “*all* people, no matter what their abilities, have the right to live in the community.” (Maryland DD Council; Maryland P&A). , most recently in 2009

B. Litigation

Hunt v. Meszaros was filed in 1991. Over a period of time, 435 people were transferred from Great Oaks Developmental Center, resulting in its closure in 1996. (Maryland P&A).

C. Legislative Advocacy

“Undertaking a media initiative to communicate effectively with the public and policymakers about why Rosewood Center must close” (Maryland DD Council, *Highlights*, 2007).

“Co-sponsoring a 2-day symposium to develop alternatives to institutionalization for individuals with developmental disabilities involved in the criminal justice system. Over 100 participants attended the symposium including judges, state officials, service providers and advocates” (Maryland DD Council, *Highlights*, 2007).

“Supporting the publication of ‘Rosewood Center: A Demand for Closure’ by the Maryland Disability Law Center [Maryland’s P&A]. The publication detailed seriously failed practices and treatment at the center. Over 400 publications were distributed throughout the state and to all policymakers in Maryland” (Maryland DD Council, Highlights, 2007; Maryland P&A, “Rosewood Center: A Demand for Closure,” 2007).

“Unrelenting advocacy with the Governor, high-level policymakers and lawmakers about the problems at Rosewood and recommendations about appropriate community alternatives based on national best practice” (Maryland DD Council, Highlights, 2007).

“Other political challenges include . . . gaining a commitment from the Governor and legislature to significantly downsize and eventually close SRCs . . .” (Maryland DD Council, Five Year Plan, 2006-2011).

Testimony against ICF/MR option and for shifting ICF/MR funding to “people in need on the waiting list.” (Maryland P&A).

Funding for, and membership on, the “Close Rosewood Coalition.” (Maryland P&A; Maryland DD Council). 2007 Close Rosewood Coalition

“Just a reminder, CDRC, People On the Go, and Maryland Disability Law Center are hosting a “CLOSE ROSEWOOD PARTY”. We are CELEBRATING the closure of Rosewood. Mingle with former residents, advocates, and legislators while enjoying hors d’oeuvres and listening to great music”. (Maryland P & A ; MD DD Council) www.thecdrc.org September 2008 newsletter

In coalition with others, the Maryland P&A and Maryland DD Council testified in support of closing Rosewood, a public ICF/MR. (Maryland P&A; Maryland DD Council. <http://www.md-council.org/resources/PDF/Rosewood%20Report%20final%20MM.pdf> February 1, 2007 to coincide with House hearing: “Rosewood, A Demand for Closure.”

III. ACTIVITIES WHICH DISCRIMINATE AGAINST PEOPLE WITH SEVERE AND PROFOUND INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, AND THE IMPACT OF THESE ACTIVITIES ON THESE PEOPLE

Letter dated 10/06/2006 from Maryland DD Council and MDLC (MD P & A) as members of the DD Coalition to Governor Ehrlich and Sec. McCann (DHMH) demanding closure of Rosewood and move to a community – only services model for all and saying Maryland cannot fund dual systems. **Page 1 of the letter follows on next page:**

Developmental Disabilities Coalition

Supporting people with developmental disabilities in their communities throughout Maryland

The Arc of Maryland, Inc.
49 Old Solomon's Island Rd. # 205
Annapolis, MD 21401
410-974-6139 Fax: 410-974-6021



MD Association of Community Services
877 Baltimore Annapolis Blvd., #111
Severna Park, MD 21146
410-518-9874 Fax: 410-518-9875



Maryland Developmental Disabilities Council
217 E. Redwood Street, Suite 1300
Baltimore, MD 21202
410-767-3671 FAX: 410-333-3686



Maryland Disability Law Center
1800 N. Charles Street, Suite 400
Baltimore, MD 21201
410-727-6352 Fax: 410-727-6389



People on the Go of Maryland
49 Old Solomon's Island Rd. # 205
Annapolis, MD 21401
410-974-6895 Fax: 410-974-6021



October 6, 2006

Honorable Robert L. Ehrlich, Jr.
Governor of Maryland
Maryland State House
100 State Circle
Annapolis, Maryland 21401-1925

Honorable S. Anthony McCann
Secretary
Department of Health and Mental Hygiene
201 West Preston Street
Baltimore, Maryland 21201

Re: DD Coalition Request for Transfer of Residents and Closure of Rosewood

Dear Governor Ehrlich and Secretary McCann:

The Developmental Disabilities Coalition (DD Coalition) is a statewide network advocating for the rights of people with developmental disabilities. We write to demand the creation and implementation of a plan to transition all Rosewood State Residential Center (Rosewood) residents into quality, safe, community-based programs and close this dangerous, outmoded facility once and for all.

The *New Freedom Initiative* for Maryland promised four years ago to close state institutions and meet goals to provide appropriate services to individuals, regardless of their disability, in community settings. Notably, it states:

It is time to develop a concrete plan to start closing state institutions that warehouse people, rob them of their freedom, and waste state taxpayer dollars. Not only is moving to community-based care the right thing to do, but it is fiscally-responsible. Maryland cannot afford fully funding both institutional care and community-based services for people with disabilities. Despite the *Olmstead* decision, Maryland currently funds resource-draining institutions, limiting resources from the community-based services system that benefits the majority of people with disabilities. Bob Ehrlich recognizes that people deserve the respect and freedom to live in the community.

Opposition to HB 1234 that would have required training for staff who work with residents at Rosewood (Maryland P&A). “MDLC opposed HB 1234 that would have required training for staff who work with residents at Rosewood..” <http://www.mdclaw.org/chemicalcms/legislative.php> MDLC legislative report dated 04/24/08 (Maryland P & A)

A former social worker and incident data analyst with the Maryland Developmental Disabilities Administration, who oversaw some community placements during the closure of Great Oaks Center stated, "If Rosewood is closed in the fashion of the Great Oaks experience, medically fragile residents, and those individuals who are dangerous to themselves, will die in the community at a rate of 400 percent greater than if they stay at Rosewood; 13.5 percent will die within the first 18 month" (Ron Coleman, Sept. 2006). Great Oaks was closed due to an MDLC (P&A) class action lawsuit. (Maryland P&A).

No apparent systemic response to repeated well-publicized concerns relating to Maryland's community-based system:

- “A failure to protect – Maryland’s troubled group homes,” *The Baltimore Sun*, April 10-17, 2005
- “Safeguards meant to protect the disabled in Maryland group homes failed,” *The Baltimore Sun*, August 1, 2004
- “Violence raises concerns over group homes,” *The Baltimore Sun*, July 21, 2002
- “Md. concedes failings of group home system,” *Washington Post*, May 8, 2002
- “State reports cited agency for poor living conditions,” *Herald Mail*, July 23, 2001

(Maryland DD Council; Maryland P&A)

Under the link from the MDLC (P & A) home page for tab "Abuse and Neglect" the one page result and only option is entitled: “Abuse, Neglect & Harm in Institutions” and reads: “As the designated Protection and Advocacy agency for the State of Maryland, part of MDLC's core mission is to make sure people with disabilities living in institutions are protected from harm.” http://www.mdclaw.org/chemicalcms/abuse_and_neglect.php

Recommended reforms, next page

Recommended Reforms

In light of these activities by DD Act programs – all of which violate Congressional intent and bring harm to the very constituents they are charged to advocate for and protect, VOR calls on Congress to take the following actions aimed at assuring that DD Act program recipients carry out the Act's mandate to respect choice in residential settings and family decision-making:

- A. Schedule public hearings on the DD Act as soon as possible, providing opportunity for affected individuals and their families to testify.
- B. Amend the DD Act to enforce DD Act program adherence to residential choice, as is clearly supported by Congressional intent and the U.S. Supreme Court's *Olmstead* decision:

“No funds expended for any Developmental Disabilities Assistance and Bill of Rights Act program may be used to effect closure of any Medicaid-certified Intermediate Care Facility for Persons with Mental Retardation or to support entities engaged in activities to close any such facility.”
- C. Enact the provisions of H.R. 2032 to require DD Act programs to notify the residents of an ICF/MR or, where appointed, their legal representatives (defined to include legal guardians and conservators) before filing a class action and provide them with a time-limited opportunity to opt out of the class action.
- D. Limit the reauthorization cycle to three years.

For More Information:

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