



“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.*).

## **MASSACHUSETTS’ Developmental Disabilities Assistance and Bill of Rights Act (DD Act) Programs: An Overview of Their Effectiveness and Activities**

### **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. . . .”

### **Congressional Intent**

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.”

In both statute and report language, Congress made it clear that individuals and their families, not the DD Act programs, were the “**primary decisionmakers**” regarding needed and desired services, “**including regarding choosing where the individuals live.**” Congress expressly cautioned, in the House Energy and Commerce Committee report accompanying 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.**” life. . . .”

### **The Role of ICFs/MR in the Continuum of Care**

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.

## **MASSACHUSETTS DD ACT PROGRAMS**

There are three primary DD Act programs: the DD council, the P&A service, and the University Centers of Excellence.

### **1. The DD Council in Massachusetts is not very active. Membership does not include a facility family/guardian representative.**

Typically, the DD Council makes a list of legislative bills to support. In general, these bills are positive. The only one facility family advocates opposed last year was a well-intended bill to fund an experimental guardianship council in one county. Facility families opposed it because it did not require family member representation on the body created, and because the ARC in that county had just been found to have removed 8-10 of its wards from their longtime homes in an ICF, in one case moving a 91-year-old woman against her will. She died within months of being moved.

The DD Council's other primary function is giving grants. Although the grants focus on integration of relatively high-functioning people, they are positive activities. The DD Council has not been active in the battles over Developmental Centers, and is not likely to become so, since the Governor is required by the 1993 court order (see below) to appoint a Commission on Mental Retardation. The present governor, having failed to reappoint this commission for an entire year, recently did so, declared it an important advisor on the facility closing plan, and picked a body with not one facility family represented.

### **2. There are two University Centers for Excellence in Massachusetts; neither are politically involved.**

The Institute for Community Inclusion, attached to the University of Massachusetts in Boston publishes useful materials about the SSI system and employment for various disability groups.

The Eunice K. Shriver Center, formally attached to the University of Massachusetts Medical Center in Worcester, is more focused on developmental disability, and encourages scientific research. It has a building on the campus of the Fernald Center, but has not been part of the debate over closure, except that the heating costs and some landscaping are unfairly attributed to the cost of maintaining residents there.

### **3. The officially funded P&A service is the Disability Law Center (DLC). The P&A situation in Massachusetts is complicated.**

The DLC has "intervenor" status in the 35-year old *Ricci v. Okin* federal case that both reformed the developmental centers for people with intellectual disabilities, and mandated the development of a funded community residential system for people who "wanted" to leave them. As an intervenor, the DLC has supported the Massachusetts Department of

Mental Retardation **against** the family groups, including in the State's appeal of the August, 2007 court order that upheld the rights of Fernald residents to have Individual Service Plan meetings without coercion and at which Fernald placement was an express option.

In becoming an intervenor, the DLC argued in favor of former Mass. Governor Romney's plan to close all six developmental centers in Massachusetts: "Stan Eichner, director of litigation for the Disability Law Center (DLC), a private nonprofit funded mostly with federal funds, which represents the needs of the developmentally disabled, agrees with the state's plans. In a motion to intervene in the reopening of the Ricci lawsuit, the DLC cites a 'core priority' of 'advocating for the treatment of individuals with disabilities in the least restrictive environment and supporting efforts by DMR to follow the nationwide trend of moving [them] out of institutional settings and into appropriate, supported community settings.'"

A newspaper report of the oral arguments earlier in 2007 has the DLC position thus: "Richard Glassman, an attorney with the Disability Law Center, responded to [U.S. Attorney, special court monitor Michael] Sullivan's report in court and asked Tauro to lift the bar on transfers from Fernald. 'We have been concerned over the past year that there are people who want to move to the community,' Glassman said. He said it comes down to a freedom of choice for those who want to leave and that halting further transfers violates federal laws against involuntary commitment to an institution."

### **The Center for Public Representation (CPR) activities, including P&A training and technical assistance**

The more active firm is a **former** P&A designate for Massachusetts, the Center for Public Representation (CPR).

The funding for CPR is somewhat obscure in their I-990 filings, but a substantial fraction is a grant from the **Massachusetts Legal Assistance Corporation**, itself half funded by Massachusetts, and half by the interest of certain bank accounts held by probate courts.

A large CPR project is training and technical assistance to the P&A services of all the states through their national umbrella, The National Disability Rights Network:

"The Center is also a national support center, providing training, and technical assistance to protection and advocacy programs (P&As) in each of the fifty states and territories under a contract with [National Disability Rights Network \(NDRN\)](http://www.nationaldisabilityrights.org). It serves as the national technical assistance and support center on all institutional and community issues involving persons confined in psychiatric hospitals, mental retardation centers, nursing homes, jails, prisons, forensic institutions, juvenile justice facilities, and all types of community programs." (source: <http://www.centerforpublicrep.org>).

CPR has a small but longstanding contract with the Maryland Disability Law Center (MDLC, Maryland's P&A), probably in connection with their major campaign to close the

Rosewood Center. In February 2007, MDLC issued a public report titled, "Rosewood Center: A Demand for Closure."

CPR's website mentions briefs submitted in favor of closing ICFs in Florida, Alabama, Washington, Georgia, Kentucky, and Pennsylvania, and amicus briefs in eleven other states (possibly including some of those mentioned previously). CPR claims to have coordinated seven *amicus briefs* on *Olmstead v. LC*, developing the argument that the ADA now requires facility closures despite contrary language in the *Olmstead* opinions.

### **Quality in the Committee: Where are Massachusetts' DD Act programs?**

Although the Disability Law Center supports the closure of Fernald Developmental Center and other licensed Intermediate Care Facilities for Persons with Mental Retardation in Massachusetts, there does not appear to be any concern about the quality of care in the community programs that would serve residents transferred from Massachusetts-run ICFs/MR.

In the *Ricci* litigation, the District Court Monitor, US Attorney Michael Sullivan examined the group home system in Massachusetts. He found that "equal or better" access to medical care in the community is only assured when group-home staff made great efforts, and even then, it was often delayed until transportation was available:

"Ultimately, this process takes much longer than the process at Fernald and is more difficult to coordinate (i.e. our office noted that community residences have one wheelchair-adaptive vehicle assigned per house. If this vehicle has to be used for pick-up and drop-off of other residents from day programs, coordination must be made with other vehicles operated by the provider). Based on the information provided one could not conclude that quicker access to medical care in and of itself equated to better care (the bedside manner of the community doctor located 20 minutes away could be better than the facility doctor that is on call, or just the opposite could be the case). But, given the physical limitations, and fragile emotional state of members of this population, coupled with a reduced mental capacity to communicate and explain an increase or decrease in the intensity of an ailment, we certainly understand the potential risks and why some guardians would prefer to have their ward in an ICF/MR and have a facility doctor on call."

In studying 11 years of records at the Massachusetts Disabled Persons Protection Commission, Sullivan found a greater risk of abuse and neglect, especially sexual abuse, in vendor-operated group homes than in developmental centers and state-operated group homes:

"Unfortunately, after reviewing data from the Disabled Persons Protection Commission, our office did note some very concerning neglect and abuse trends in Contract Vendor operated community residences, as compared to the ICF/MRs and State operated community residences. These neglect and abuse trends, particularly sexual abuse, were of

great concern to our office and shows that residents in our community homes are at a greater risk of being abused and/or neglected."

His final recommendation:

"As a result of a yearlong investigation, our office has concluded that some of the residents at Fernald could suffer an adverse impact, either emotionally and/or physically, if they were forced to transfer from Fernald to another ICF/MR or to a community residence. Our office would recommend the implementation of a development plan that would enable Fernald to remain open and provide services to some of the Commonwealth's most vulnerable citizens."

Of 49 people who transferred out of Fernald in 2003-2005, six died within two years.

**In response to these deaths and the system failures identified by Mr. Sullivan, where is the DLC and the DD Council?**

### **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.

### **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.

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