



“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.*).

**MICHIGAN:**  
**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. . . .”

**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.” 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.”

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. Nearly 80% (79.3%) of all ICF/MR residents experience severe or profound intellectual disabilities, functioning at an infant’s level although fully grown; they also endure multiple disabilities, chronic medical conditions and/or behavioral challenges. Many also have seizure disorders, behavior problems, 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.

## **MICHIGAN: 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**

1. In 2007, Elmer Cerano, the **Executive Director of Michigan Protection and Advocacy Services**, participated in a 16-member External Review Team that was assembled by the Michigan Department of Community Health (MDCH) to give an appraisal of problems at Mt. Pleasant Center, the only remaining ICF/MR in Michigan.

*The Report from the Mt. Pleasant Center External Review Team* concludes that most of the residents eligible for ICF/MR status could be better served in the community despite "...lack of guardian/family support" and acknowledges that "...there may not be local services currently available to safely serve these individuals in the community." (Michigan P&A, October 2007).

2. The Michigan Developmental Disabilities Council provided the Washtenaw Association for Community Advocacy a grant of \$200,000 for a 2 year "Preventing Guardianship" project designed to undermine and discourage the legitimate use of guardianships for

people with developmental disabilities to protect them from neglect, exploitation, and abuse. The Project Team consisted of Dohn Hoyle, then the President of ACA, Mary Bomgren from Michigan P&A, and Kathleen Harris, an attorney. (Michigan DD Council and Michigan P&A, October 2002 – September 2004).

## II. DEINSTITUTIONALIZATION – ICFs/MR CLOSURE ACTIVITIES

### A. Organizational priorities

1. The Michigan DD Council provides grants to the ARC of Michigan for the “Include All of Us” project and “Michigan Partners for Freedom.” The Arc of Michigan expressly supports the closure of “Michigan institutions that house individuals with developmental disabilities”. (Michigan DD Council, 2007).
2. The Request for Proposal documents from the Michigan DD Council states that “Council-funded projects may not operate in segregated, ‘disability-only’ settings”. By prohibiting projects that operate in “disability-only settings”, residents of Mt. Pleasant Center, Michigan’s only remaining ICF/MR, will not benefit from DD Council projects as long as they reside at Mt. Pleasant Center or another ICF/MR. (Michigan DD Council, October 2008).
3. The Michigan DD Council’s Strategic Plan for Fiscal Years 2007-2011 identified all the DD residents of Mount Pleasant Center, an ICF/MR, as being on a waiting list for services: “Approximately 183 persons with developmental disabilities reside in a single state institution and are waiting for community living opportunities with supports. This is a small number when considering Michigan’s 10,120,860 residents, but **the council’s position is all individuals, with supports, can live in communities.**” (Michigan DD Council, 2007-2011 Strategic Plan, p. 14).

### B. Litigation

In 1979, the Michigan P&A represented the Michigan Association for Retarded Citizens in its lawsuit against Plymouth Human Developmental Center. As a result of this litigation, Plymouth Center closed in 1979. (**Michigan P&A**).

### C. Legislative Advocacy

1. The DD Council, Michigan Protection and Advocacy Services, and other advocacy organizations that receive funds from the DD Council have been pushing the state to remove all the DD residents from Mount Pleasant Center over the objections of family/guardians of the residents. (Michigan DD Council and Michigan P&A, 2008 – 2009).
2. The Executive Director of Michigan P&A and all but one member of the External Review team agreed with the demand **to halt all administrative admissions of**

**people who are ICF/MR eligible to Mt. Pleasant Center and supported a deadline, September 30, 2008, by which all ICF/MR residents will be served in the community.** [Mt. Pleasant Center is still open in 2009 and has about 60 ICF/MR residents and others who are not ICF/MR eligible. The State has recently announced that it will close MPC by October, 2009.] In addition, the Executive Director of P&A along with all but one of the External Review Team demanded that Habilitation Supports Waivers be made available for each ICF/MR resident, but the report failed to mention that these waivers are only given to people who voluntarily give up their right to services in an ICF/MR. (Michigan P&A, October 2007).

### III. OUTCOMES:

#### **DISREGARD FOR INDIVIDUAL NEED AND NEGATIVE OUTCOMES FOLLOWING DEINSTITUTIONALIZATION / DISCRIMINATION AGAINST PEOPLE WITH SEVERE ID/DD**

- A. The Michigan DD Council's prohibition against funding programs in "segregated, 'disability-only' settings", [See II.A. 2. above] discriminates against people with severe MR/DD. They are the most likely to live in disability-only *community* settings and participate in disability-only activities. Residents of community group homes, supported living programs that house only people with disabilities, children who attend center-based educational programs and people who need a variety of community "disability-only" programs, including sports teams, social groups, recreational programs, day care, day programs, and respite programs, are likely to be excluded from any benefit from Michigan DD Council funded projects. (Michigan DD Council, October 2008).
- B. The Michigan DD Council characterizes all Mt. Pleasant Center residents as being "on the waiting list" for community services regardless of whether residents or their families desire or would benefit from community placements or services. At the same time the DD Council ignores people with developmental disabilities in the community who receive no services or less than adequate services, as well as those in nursing homes (over 300 in 2007, according to the ANCOR Michigan Fact Sheet). Michigan avoids the problem of waiting lists by using the term "priority list". The Michigan DD Council perpetuates the fiction that Michigan adequately provides all its developmentally disabled residents in the community with the services and living arrangements they need and want. (Michigan DD Council, 2007 –2011 Strategic Plan).
- C. The Executive Director of Michigan P&A agreed with all other members of the External Review Team for Mt. Pleasant Center that most of the ICF/MR eligible residents could be better served in the community. This conclusion was reached without regard for the legally mandated processes for making placement decisions: consideration of individual needs, inclusion of residents and their family/guardians in decision making, and giving residents and guardians the right to choose continued placement in an ICF/MR. In addition, the External Review Team report acknowledges that "...**there may not be local services currently available to safely serve these individuals in the community.**" (Michigan P&A, October 2007).

## **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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