



“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.*).

## **GEORGIA:**

### **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 examples of DD Act program abuse are not limited to **Georgia**. These abuses are widespread and represent a national problem. To fully appreciate the scope of these abuses, and the resulting harm to people with profound developmental disabilities see <http://www.vor.net/images/stories/pdf/TaskForceReport.doc> for a report that includes at least 90 citations from 20 states.

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

## **GEORGIA: 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**

Ann Knighton, whose daughter Erica is resides at East Central Regional Hospital's Gracewood Campus (a state ICFs/MR), filed a Discrimination Complaint on February 5, 2009 with the Office of Civil Rights in response to a settlement agreement between the OCR and the State of Georgia. The settlement agreement calls for the complete closure of Georgia's ICFs/MR, including Gracewood, in response to "integration" complaints filed by the Georgia Advocacy Office (P&A) and others.

Ms. Knighton alleges that that she and other parents were "not consulted during negotiations leading up to the finalized Settlement Agreement." She notes that "most families of Georgia's ICF/MR residents learned about the agreement, which calls for the closure of our loved one's homes, in the newspaper. The Georgia Advocacy Office . . . does not and should not speak for us."

Ms. Knighton's Complaint also raises questions about the composition of the Olmstead Planning Committee, which was created as a requirement of the settlement agreement but which does not appear to include any ICFs/MR family/legal guardian representative. (Georgia P&A, 2009).

## II. DEINSTITUTIONALIZATION – ICFs/MR CLOSURE ACTIVITIES

### A. Organizational priorities

The Georgia DD Council Public Policy statement leaves little to no room for supporting ICFs/MR supports: "Striving to support conceptually coherent policy for integrated life in the community for people with developmental disabilities and the people who support them." [Georgia DD Council, 2009 (website)].

### B. Litigation

The Georgia P&A joined an *Amici Curiae* brief submitted to the U.S. Supreme Court in the Olmstead case that unfairly and grossly inaccurately characterized ICFs/MR supports as segregated, noting that residents are "confined" and that "institutionalization is a formula for stagnation or decay." *Amici*, including the Georgia P&A, suggested that ICFs/MR residents, like in days long past, are needlessly "segregated" and "shutter[ed] behind the walls of stultifying and abusive state institutions." [Georgia P&A (1998)].

The Georgia Advocacy Office (P&A) with other organizations filed class action complaints with the U.S. Department of Health and Human Services' Office of Civil Rights (OCR) alleging that the state failed to serve persons with developmental disabilities in the most integrated setting appropriate. These complaints led to a State/OCR settlement agreement which mandates the elimination of state ICFs/MR ("institutions") for persons with developmental disabilities. (Georgia P&A, July 2008).

### C. Legislative Advocacy

In 2007, the Georgia Advocacy Office (P&A) sent a letter to state legislators to express its concern with regard to "congregate" care alleging that "The highest threat that any group of people can face is to be congregated and separated away from the rest of society," suggesting that ICFs/MR settings are isolating and abusive. (Georgia P&A, 2007).

### III. OUTCOMES: DISREGARD FOR INDIVIDUAL NEED AND NEGATIVE OUTCOMES FOLLOWING DEINSTITUTIONALIZATION / DISCRIMINATION AGAINST PEOPLE WITH SEVERE MR/DD

#### Quality of Care in Community Settings

In June 1997, an independent panel assembled by the Georgia Advocacy Office concluded the state's efforts to close Brook Run ICF/MR should be delayed by at least a year. In 2000, the Georgia Advocacy Center published a document that stated that "accurate, clear and understandable information [regarding community services in Georgia] is hard to come by." (David Truran, Georgia Advocacy Office, "What are we waiting for? Promoting Personalized Residential and Community Supports in Georgia," January 2000). In 2001, an investigative media series confirmed worries that Georgia was not prepared to safely serve former Brook Run residents, finding that "group home deaths [of former Brook Run residents] reveal ugly picture of state care," (see, *Atlanta Constitution-Journal*, "Dying in Darkness," December 2001). The Georgia Advocacy Office's own investigation of a former resident's death confirmed, according to the Director of the Georgia Advocacy Office that "the accountability within the system now is not working." Then, in 2003, the *Atlanta Journal-Constitution* published another article that confirmed continuing systemic quality of care problems (see, "Agency failed clients; Poor service may be linked to 6 deaths," February 2003).

Given the Georgia Advocacy Office's apparent concern in 1997, 1999, 2000 and 2001, that Georgia's community system of care was unprepared to safely serve Brook Run residents, why would this organization support a federal settlement that calls for the exodus of ALL public ICF/MR residents to community settings? Has the system improved that dramatically?

#### The Waiting List

The Georgia Advocacy Office believes that every public ICF/MR resident is on the waiting list for community services, without regard to need and choice:

"If current institution residents were queried in a responsible way (not threatened one way or the other and resource transfers guaranteed), all might choose to move to the community and therefore should be on the waiting list for community services. So, all 1,889 individuals with developmental disabilities currently in public institutions should be considered 'on the waiting list.'" ((David Truran, Georgia Advocacy Office, "What are we waiting for? Promoting Personalized Residential and Community Supports in Georgia," January 2000 (citing, Prouty & Lakin, 1998).

## **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**

**Tamie Hopp**  
**Director, VOR Govt Relations & Advocacy**  
P. O. Box 1208  
Rapid City, SD 57709  
605-399-1624 office/direct  
605-484-8300 cell  
605-399-1631 fax  
[thopp@vor.net](mailto:thopp@vor.net)