



“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.*).

## **KENTUCKY:**

### **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 ICFs/MR**

#### **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**

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 decision makers” 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 (Intermediate Care Facility for Persons with Mental Retardation) 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.

## 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.

### KENTUCKY: 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. Litigation

The **Kentucky P&A** program on February 7, 2002 filed a class action lawsuit in the United States District Court in Lexington, KY on behalf of persons with intellectual disabilities living with a caregiver who have not received community based services. Kentucky public ICFs/MR were not named in the complaint. On March 28, 2006 a final hearing was held on the settlement agreement agreed to by the Commonwealth and P&A. In late February or early March 2006, less than 30 days from the hearing, the parent groups from several Kentucky public ICFs/MR inadvertently learned of a scheduled settlement agreement that contained a provision which would close admissions to *all* state-operated developmental centers, or ICFs/MR. Family groups associated with the affected ICFs/MR were not included in settlement discussions and had to retain counsel to object to the settlement but were not successful in having the draconian "no admissions" requirement removed.

As family caregivers age and seek safe and appropriate developmental center placement for their loved ones, critical services will no longer be available. As Kentucky developmental center residents die or transition, the closed admissions policy will result in a reality that the centers will no longer be cost-effective; "consolidation" will then occur and center residents will be forced from their long-time homes; the trained workforce and specialty services will downsize and ultimately cease; the state's safety-net for persons with intellectual disabilities will disappear.

For additional information see this [family testimonial](#).

***Issue: Community expansion is a need in Kentucky which merits support. However, it should not be at the expense of another segment of the ID/DD population.***

## II. DEINSTITUTIONALIZATION – ICFs/MR CLOSURE ACTIVITIES

### A. Organizational priorities

The **Kentucky P&A** program Executive Director undermined a proposal to place additional, smaller ICF/MR units on the campus of Hazelwood Center. The Executive Director stated: “By clustering the smaller boxes with the bigger box, in a sort of disability ghetto, if you will.... We oppose this proposal.” (Louisville Courier-Journal May, 2007)

A **Kentucky P&A program** publication included this statement: “The settlement calls for..... Adoption of ‘money follows the person’ for people leaving publicly funded ICFs/MR, with a pledge to leave those beds empty. This policy is expected to encourage the downsizing of institutions for people with MR/DD.” (“Rights Advocate” Volume 6 Number 1, Page 2, March 2006; See, <http://www.kypa.net/drupal/?q=node/431>).

In 2008 the **Kentucky UCEDD** program collaborated with the ARC of Kentucky in distributing two PowerPoint presentations to policy makers using inflammatory, misleading language regarding facility-based systems of care (ICFs/MR) for persons with developmental disabilities. These presentations promoted one needed system of care (“community care” only), calling for the elimination of another needed system of care (federally licensed ICFs/MR). See here for the [UCEDD's proposal](#) and related [PowerPoint presentation](#) in support of facility closure."

The **Kentucky UCEDD** and ARC of Kentucky PowerPoint presentations from 2008 also include the following unfair, incorrect, short sighted and potentially harmful cost savings measures: 1) the State might use its powers as public legal guardian for 52 residents currently receiving services at a public Intermediate Care Facility to transition these vulnerable individuals from facility-based care to “community care”, and 2) the State would receive one full year of “free” care for these individuals from its “Money Follows the Person” grant funds (which is incorrect). See here for the [UCEDD's proposal](#) and related [PowerPoint presentation](#) in support of facility closure."

***Issue: Some P&A and UCEDD programs misuse the public trust & misuse public funds.***

### **Additional Resources**

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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