

September 2011

Reform and Reauthorization of the Developmental Disabilities Act Urgently Needed

It has been 11 years since the Congress last reauthorized the Developmental Disabilities Assistance and Bill of Rights Act (DD Act). Some of the DD Act programs have been violating the intent of the Act in ways that have been harmful to the vulnerable people the Act was intended to help. We urge you to **reform** and reauthorize the DD Act this year.

The Congress, in the DD Act and its legislative history, endorsed individual choice and opposed closure of residential institutions:

“Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families.” DD Act, 42 U.S.C. 15001(c)(3)(2000).

[T]he goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities may not be read as a Federal policy supporting the closure of residential institutions. [(H. Rep. 103-442 (March 21, 1994)].

Yet, many DD Act programs – through lobbying, class action lawsuits and other destructive tactics – use their federal funds to eliminate one federally-created and funded residential option: Medicaid-certified Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR). DD Act deinstitutionalization practices force the transfer of thousands of vulnerable individuals from specialized ICFs/MR that are uniquely suited to meet their extreme and intensive needs, often resulting in predictable tragedies. **VOR urges Congress to take the following actions:**

- 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.

About VOR: VOR is a national organization advocating for the right of individuals with intellectual and developmental disabilities and their families to choose from among a full array of high quality residential and other support options. For more information, please contact Tamie Hopp, Director of Government Relations and Advocacy at 605-399-1624 (direct); or thopp@vor.net.