
Reform and Reauthorization of the Developmental Disabilities Act Urgently Needed

June 2016

It has been 16 years since Congress reauthorized the Developmental Disabilities Assistance and Bill of Rights Act (DD Act). Authorizations for DD Act appropriations expired in 2007, leaving the Congress to continue to fund these programs through annual appropriations. DD Act programs, including Protection & Advocacy (P&A), DD Councils, and University Programs, operate in every state. The DD Act programs' administering agency is the Administration on Intellectual and Developmental Disabilities (AIDD).

Oversight of AIDD and the DD Act programs is grossly inadequate. By denigrating a proven system of centralized care through lobbying, class action lawsuits and other tactics, these federally-funded entities have evicted the most vulnerable people with intellectual and developmental disabilities (I/DD) from public and private Medicaid-certified homes that are uniquely suited to meet their intensive needs. These programs' deinstitutionalization activities, under the guise of "integration," have too often resulted in predictable tragedies (*Widespread Abuse, Neglect and Death in Small Settings Serving People with I/DD* (March 2015), (vor.net/images/stories/pdf/AbuseandNeglect.pdf)). In pursuing such dangerous deinstitutionalization policies, the DD Act programs disregard individual choice and the legal right to appropriate services, as required by the DD Act, the Americans with Disabilities Act (as interpreted by the Supreme Court's *Olmstead* decision) and Medicaid.

We urge Congress to reform the DD Act by taking the following actions:

- A.** Suspend all DD Act program "deinstitutionalization" activities conducted under the guise of "integration" aimed at evicting fragile Americans from licensed, congregate facility settings until such time as Congress has had opportunity to **(1)** investigate the causes of the unspeakable number of deaths around the country and **(2)** make recommendations for changes in policy to prevent further such deaths
- B.** Schedule public hearings on the DD Act as soon as possible, to **(1)** provide opportunity for affected individuals and their families to testify and **(2)** determine the extent to which DD Act programs' actions to close and remove residents of Medicaid-certified facility homes violate federal law.
- C.** Amend the Act to enforce program compliance with individuals' right to receive appropriate services according to choice and need, as required by law, and to prohibit federally-funded DD Act programs from pursuing the closure of any Medicaid-certified home serving people with severe and profound intellectual and/or other developmental disabilities (e.g., ICFs/IID), in violation of the individuals' civil rights.
- D.** Limit the reauthorization cycle to three years to assure ongoing Congressional oversight.

These actions will enforce Congressional disability policy supporting individual choice among residential options:

"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)].

VOR urges you to act immediately to end the use federal funds to denigrate and dismantle federally-created and funded residential options. The time is long overdue to stop these unauthorized and reckless actions!