
Reform and Reauthorization of the Developmental Disabilities Act Urgently Needed

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It has been 17 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 Affiliated Programs, operate in every state. The administering agency for DD Act programs is HHS' Administration on Intellectual and Developmental Disabilities (AIDD).

Since 2000, the House has held no oversight hearings and the Senate only three. Absent oversight, these federally-funded entities have continued to pursue an ideological agenda of denigrating a proven system of centralized care through lobbying, class action lawsuits and other tactics. As a result, the most vulnerable people with intellectual and developmental disabilities (I/DD) have been evicted from large public and private Medicaid-certified homes (e.g., Intermediate Care Facilities for Individuals with Intellectual Disabilities [ICFs/IID]) 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 (May, 2017).¹ 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, the Supreme Court's *Olmstead* decision and Medicaid law.

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, abuse and neglect around the country and (2) make recommendations for changes in policy to prevent further tragedies.
- 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 the actions of DD Act programs result in the closure of Medicaid-certified facility homes, in violation of federal law.
- C. Amend the Act to enforce program compliance with the right of individuals to receive appropriate services according to choice and need, as required by law, and prohibit federally-funded DD Act programs from pursuing the closure of any Medicaid-certified facility home for individuals with I/DD, in violation of their civil rights.
- D. Limit the reauthorization cycle to 3 years to assure ongoing Congressional oversight.

These actions will enforce Congressional disability policy that supports 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 of federal funds to denigrate and dismantle federally-created and funded residential options. The time is long overdue to stop these unauthorized and reckless actions that run counter to the law and civil rights.

¹ <http://www.vor.net/get-help/more-resources/item/abuse-and-neglect-document>