
Reform and Reauthorization of the Developmental Disabilities Act Urgently Needed

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It has been 14 years since Congress reauthorized the Developmental Disabilities Assistance Act (DD Act). Authorizations for DD Act appropriations expired in 2007, although Congress has continued to fund these programs. 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 federal AIDD and DD Act programs is inadequate. Through lobbying, class action lawsuits and other tactics, some DD Act programs are using their public funds to achieve dangerous deinstitutionalization policies, evicting vulnerable people with intellectual disabilities from public and private Medicaid-certified homes, disregarding 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 law.

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

- A.** Suspend all DD Act program deinstitutionalization activities aimed at evicting fragile Americans from licensed, congregate facility settings ("deinstitutionalization") until such time as Congress has had opportunity to **(1)** investigate the causes of the unspeakable number of deaths in New York (*New York Times*, "Used and Abused" series), and around the country; and **(2)** make recommendations for changes in policy to prevent further such deaths (*Widespread Abuse, Neglect and Death in Small Settings Serving People with I/DD* (Jan. 2013), vor.net/images/AbuseandNeglect.pdf).
- 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 are violations of federal law.
- C.** Amend the DD Act to enforce DD Act program compliance with the residents' rights 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 profound intellectual and other developmental disabilities (e.g., ICFs/ID), in violation of the residents' civil rights.
- D.** Limit the reauthorization cycle to three years to assure ongoing Congressional oversight.

Congress in the DD Act 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 shut down federally-created and funded residential options. DD Act programs' deinstitutionalization activities force the eviction of thousands of vulnerable individuals from specialized homes that are uniquely suited to meet extreme and intensive needs, often resulting in predictable tragedies. **Congress has the authority and responsibility to immediately stop these unauthorized and reckless actions. Please act now!**