VOR
Speaking Out for People
with Mental Retardation

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# Please Exercise Caution!
# Level Fund DD Act Programs for FY 2011

The three primary grant programs authorized by the federal Developmental Disabilities Assistance and Bill of Rights Act (DD Act) are state Developmental Disabilities Councils (DD Councils), state Protection and Advocacy (P&A) systems, and state University Centers for Excellence in Developmental Disabilities (UCEDD). These DD Act programs are included in the President's proposal to freeze discretionary spending for three years.

**We support the President's FY 2011 proposal to freeze funding levels for DD Act programs. There have been NO Congressional oversight hearings of these programs since 2000. Moreover, despite legitimate questions regarding program outcomes, appropriations for these programs have already been increased by 50% since 2000[1].**

It has been **a decade** since the DD Act of 2000 has been reauthorized. We strongly urge Congress to reform these programs, through the reauthorization process, in 2010.

Since the last reauthorization, the membership of the House and Senate authorizing committees has changed by more than 79% in the House and more than 72% in the Senate. ***ExpectMore.gov***, developed by the White House Office of Management and Budget in collaboration with federal agencies, ranks the DD Act grant programs as only "adequate," noting that "**While the program has performance measures, it lacks an efficiency measure to assess its cost-effectiveness and independent evaluations to assess its impact."** (http://www.whitehouse.gov/omb/expectmore/summary/10001056.2003.html).

Likewise, VOR seriously questions whether the DD programs are achieving their goals and submits that some federally-financed activities by these programs to eliminate Medicaid-licensed and funded Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR) are ***harming*** ICFs/MR residents and others who desperately need this specialized service option: our most needy citizens with severe and profound mental retardation and related developmental disabilities. In its report, "Abuse of DD Act Programs' Powers & Resources," the VOR DD Act Task Force documents more than 90 examples from 20 states of DD Act programs' anti-facility bias, the downsizing and closures that have resulted, and the sometimes tragic outcomes. See, http://www.vor.net/images/stories/pdf/DDActAbuseReport.doc for a summary of this report.

**The choice of an ICF/MR is one of a range of service options specifically supported by Medicaid law, the DD Act and the Supreme Court.** Congressional scrutiny is desperately needed. Until Congress is able to carefully examine the DD Act federal grant programs and make badly needed changes, VOR calls on Congress to exercise fiscal caution: **reject proposals for increased appropriations** and **level fund the DD Act programs** in FY 2011.

**About VOR:**

VOR is a national organization advocating for the right of individuals with developmental disabilities and their families to choose from a full array of high quality residential and other support options.

VOR members feel strongly, based on their individual experiences, that services received, regardless of setting, should be based on individual need and choice, whether in a family home, own home, community setting, or a facility.

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[1] In FY 2000, DD Act programs received $112,031,000. In FY 2010, these programs received $169,100,000.

ATTACHMENT

# Federal law does NOT mandate the closure of ICFs/MR and requires the involvement of families in making decisions

## Federal law created the ICF/MR program

ICFs/MR are Medicaid-certified and funded. For a program to be licensed as an ICF/MR, the Centers for Medicare and Medicaid Services (CMS) within HHS must certify, ***annually***, that it meets 8 conditions of participation including, but not limited to, client protection, adequate staffing, and appropriate health care. Within the eight conditions there are 378 specific federal standards and elements which every licensed ICF/MR must meet to remain federally-certified and funded. Through Medicaid, CMS also administers the Home and Community-Based waiver program as an alternative to ICFs/MR.

## The DD Act does not mandate deinstitutionalization

"Furthermore, the Committee would caution 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." [House Energy and Commerce Committee Report No. 103-378, November 18, 1993, pages 7-8 (to accompany H.R. 3505, the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1993, Section-by-Section Analysis, Section 3, adding Purposes and Policies to Findings)].

## The DD Act recognizes individuals and their families as the "primary decisionmakers"

"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." (42 U.S.C. §15001(c)(3)(2000)).

## The DD Act states it is the right of individuals with developmental disabilities to receive publicly supported treatment, services and habilitation that are appropriate to the needs of the individuals

"The Federal Government and the States both have an obligation to ensure that public funds are provided only to institutional programs, residential programs, and other community programs, including educational programs in which individuals with developmental disabilities participate, that . . . provide treatment, services, and habilitation that are appropriate to the needs of such individuals . . ." (42 U.S.C. §15009(a)(3)(A)(2000)).

## The Supreme Court (Olmstead) supports a full array of residential options and requires choice

In Olmstead v. L.C., the U.S. Supreme Court very clearly supports choice in residential options, finding that the decision of where someone is served must be grounded on need, choice and available resources (119 S. Ct. 2185, 2181 (1999), *see also* at 2187, "We emphasize that nothing in the ADA [Americans with Disabilities Act] or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings . . .Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it").