VOR

Toll free
877-399-4867

www.vor.net

Executive Director
Julie M. Huso
836 S. Arlington Heights Rd, #351
Elk Grove Village, IL 60007
605-370-4652 Voice
605-271-0445 Fax
jhuso@vor.net

Dir. of Govt. Relations & Advocacy
Tamie Hopp
PO Box 1208
Rapid City, SD 57709
605-399-1624 Voice
605-399-1631 Fax
thopp@vor.net

Washington, D.C.
Larry Innis
529 Bay Dale Court
Arnold, MD 21012-2312
410-751-1VOR Voice/Fax
LarryInnis@aol.com

June 2011

SUPPORTING COMMON SENSE and LAW:

INDIVIDUALS and FAMILIES AS "PRIMARY DECISIONMAKERS":

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) creates and authorizes appropriations for federal funding of three primary programs: state Developmental Disabilities Councils (**DD Councils**), state Protection and Advocacy (**P&A**) systems, and state University Centers for Excellence in Developmental Disabilities (**UCEDD**).

Among other federal legislative directives, funding for DD Act programs is conditioned upon adherence to the following policy requirement:

> (3) 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 decision making roles in policies and programs that affect the lives of such individuals and their families; (42 U.S.C. 15001(c)(3)).

The "primary decisionmaking" policy language was added by then-Health Subcommittee Chairman Henry Waxman in 1993 after hearing from families of individuals with profound developmental disabilities. These families expressed concern about DD Act programs ignoring their need for specialized care for their loved ones with severe cognitive disabilities and, worse, actively working to eliminate these specialized residential programs. The accompanying **House Energy and Commerce Committee Report** expanded on the meaning of the primary decisionmaking language as follows:

> **"[T]he 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."** [H.Rpt 103-378 (to accompany H.R. 3505, the Developmental Disabilities Act Amendments of 1993)].

Despite this clear language in favor of residential choice, some DD Act-funded programs have engaged in activities that have resulted in the loss of facility-based care for persons with MR/DD, over the wishes of the residents and their parents and guardians and to the detriment of many former residents. In its report, VOR's DD Act Task Force documents over 90 examples from 20 states of DD Act programs' anti-facility bias. (*see*, http://www.vor.net/images/stories/pdf/DDActAbuseReport.doc)

Congressional support for families as primary decisionmakers makes good common sense. Involved families, many of whom are also court-appointed legal guardians, are in the best position to make care decisions on behalf of their family members with profound developmental disabilities. Specialized residential settings – federally licensed, Medicaid-funded ICFs/MR – often provide the best environment for individuals with significant cognitive, physical, medical and behavior challenges.

Congress will soon consider the reauthorization of the DD Act. When it does, **please STRONGLY SUPPORT individuals and their families as PRIMARY DECISIONMAKERS**, as well as consider other reforms that will put a stop to DD Act activities which ignore this important policy directive.