VOR

*Speaking out for people*
*with intellectual disabilities*

**Toll free**
877-399-4VOR

**Website**
www.vor.net

**Govt Relations/Advocacy**
P.O. Box 1208
Rapid City, SD 57709
605-399-1624 voice
605-399-1631 fax
thopp@vor.net

**Washington, D.C.**
529 Bay Dale Court
Arnold, MD 21012-2312
410-757-1VOR phone/fax
LarryInnis@aol.com

**Tax Deductible Dues/Contributions**
836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007
605-370-4652
605-271-0445 fax
jhuso@vor.net

Rev. January 2012

# VOR COMMENTS AND OBJECTIONS TO "REALIZING THE INTENT OF THE DD ACT: HOW THE DD NETWORK ADVANCES THE INDEPENDENCE, PRODUCTIVITY, AND INTEGRATION OF PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES"

# And

# VOR's CALL FOR A HALT TO DD ACT DEINSTITUTIONALIZATION ACTIVITIES CONSISTENT WITH CLEAR CONGRESSIONAL INTENT

The programs created under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) are: (1) state planning councils on developmental disabilities, (2) university centers of excellence on developmental disabilities and (3) protection and advocacy systems. The groups' national organizations are, respectively, NACDD, AUCD, and NDRN[1].

In its June 2011 newsletter, NACDD reported that "NACDD, in participation with AUCD and NDRN and in consultation with NASDDDS[2], is producing a white paper concerning the role that DD Networks have played in advancing systems change in select states. NACDD has initiated this project and remains in the lead." The resulting white paper, entitled "Realizing the Intent of the DD Act: How the DD Network Advances the Independence, Productivity, and Integration of People with Intellectual and Developmental Disabilities" is posted on both the NACDD and Administration on Developmental Disabilities (ADD) websites.

**VOR objects to the activities described and conclusions drawn in the paper**.

The white paper lauds the concerted activities of DD Act grantees to achieve destruction of congregate care settings for individuals with severe and profound disabilities. Such actions are not in the public interest and are directly contrary to the DD Act and its legislative history which endorsed individual choice and expressly opposed closure of residential institutions for persons with developmental disabilities.

In 1993, Congress amended the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes the P&A program, to provide that "individuals and their families are the primary decisionmakers" regarding services, supports and policies. [42 U.S.C. §15001(c)(3)]. The "primary decisionmaking" clause was added to the DD Act directly in response to concerns by families of individuals with profound developmental disabilities:

> The Committee has heard from many parents of individuals with developmental disabilities who reside in large institutional facilities. Among the concerns expressed by these parents is that the goal of independent, community-based living for some individuals not be seen as a mandate for all individuals with disabilities. The Committee recognizes and supports the belief that each individual and each respective family have different goals and needs. The Act should in no way be read to support one kind of residential placement over another. [House Committee Report, No. 103-378 (November 18, 1993)]

The Conference report retained the "primary decisionmaking" language and added the following additional explanation:

> "the 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)].

---

[1] **National Association of Councils on Developmental Disabilities (NACDD); Association of University Centers on Disabilities (AUCD); and National Disability Rights Network (NDRN)**

[2] **National Association of State Directors of Developmental Disabilities Services (NASDDDS)**

As documented in the NACDD report, many DD Act programs – through lobbying, class action lawsuits and other destructive tactics –are using their federal funds in violation of Congressional intent to eliminate the federally-created and funded residential option: Medicaid-certified Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR). DD Act deinstitutionalization practices force the transfer of thousands of vulnerable individuals from specialized ICFs/MR programs that are uniquely suited to meet their extreme and intensive needs, often resulting in predictable tragedies.

These destructive initiatives by DD Act Network partners have had a detrimental effect on the service systems for individuals with developmental disabilities and are an inappropriate use of public funds.

**Examples from Oregon and Wisconsin**

**Oregon**, which the white paper heralds as a "stellar example of how the collaborative efforts of the state DD Network partners have transformed the service system" saw its "system transformation" begin when Disability Rights Oregon filed litigation which ultimately resulted in the closure of Fairview, a state-operated ICF/MR. The NACDD report fails to mention the harmful outcomes to citizens with disabilities following the closure of Fairview. Articles from *The Oregonian* report abuse, neglect and exploitation of people with disabilities in Oregon following the closure of the state's ICF/MR programs. (*See also* http://www.vor.net/images/AbuseandNeglect.pdf)

The report also heralds **Wisconsin** as another great example of the "critical role" (as determined by the report's authors) played by DD Networks in the deinstitutionalization of individuals with developmental disabilities. Deinstitutionalization activities spearheaded by Wisconsin's Protection & Advocacy Program in coordination with Wisconsin's Developmental Disabilities (DD) Council, culminated in a plan to close a Medicaid-certified state-operated institution in the first state budget presented by a newly- elected governor. In the ensuing lawsuit filed by the affected families against the governor, Protection and Advocacy joined as a co-defendant in the lawsuit which ultimately resulted in the facility closure and forced resident relocation. The Protection and Advocacy program and the DD Council have acknowledged that the status of relocated individuals remains unknown.

**VOR calls on Congress to reform the DD Act to enforce DD Act Network program adherence to Congressional intent, through the following amendment:**

> "No funds expended for any Developmental Disabilities Assistance and Bill of Rights Act program may be used to effect closure of any Medicaid-certified Intermediate Care Facility for Persons with Mental Retardation or to support entities engaged in activities to close any such facility."

**The unabashed and blatant disregard for Congressional intent which expressly indicates that DD Act's goals with regard to integration and independence for *some* individuals not be read as Federal policy to support the closure of ICFs/MR for those who require this level of specialized care cannot be tolerated.**

**About VOR**: VOR is a national organization advocating for the right of individuals with intellectual and developmental disabilities and their families to choose from among a full array of high quality residential and other support options. For more information, please contact Tamie Hopp, Director of Government Relations and Advocacy at 605-399-1624 (direct); or thopp@vor.net