



Speaking out for people
with intellectual disabilities

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Office of Management and Budget
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Submitted by E-Mail: [OIRA SUBMISSION@OMB.EOP.GOV](mailto:OIRA_SUBMISSION@OMB.EOP.GOV)

Re: VOR Comments in Response to OMB No.: 0980-0172

Please accept these comments in response to the Office of Management and Budget's (OMB's) proposed collection of each State Developmental Disabilities Council's annual performance report for the preceding fiscal year of activities and accomplishments (OMB No.: 0980-0172). The opportunity for comment was published in the *Federal Register*, Vol. 77, Number 84 (Tuesday, May 1, 2012).

VOR is a national, nonprofit, advocacy organization representing individuals with intellectual and developmental disabilities (ID/DD) and their families. VOR advocates for a full array of residential services and supports, from own home to licensed facility-based care.

Summary of Comment

In principle, VOR agrees that each State Developmental Disabilities Council (DD Council) should be subject to accountability, including but not limited to annual performance reports *if independently audited*. We remain very concerned that nearly all measures of accountability for DD Councils are self-reported, including annual program performance reports.

It is alarming that these self-developed annual program performance reports will be used "(1) in the preparation of the biennial Report to the President, the Congress, and the National Council on Disabilities [NCD] and (2) to provide national perspective on program accomplishments and continuing challenges." At minimum, VOR suggests that program performance reports be subject to an *independent* audit to ensure accuracy. Additionally, organizations representing residents of licensed intermediate care facilities for persons with mental retardation (ICFs/MR) and their families, and others, should be allowed to review these reports prior to publication and be provided an opportunity to respond, with dissenting perspectives included in the reports submitted to the President, Congress and NCD.

As we have commented in past submissions, **performance reports prepared by the very staff who are directly accountable for grant outcomes have no practical utility**. Such reports will provide little insight into the actual effectiveness of these programs for their intended beneficiaries.

Detailed Comment:

Existing self-reports, self-audits, and lack of independent oversight have failed to identify and halt activities by DD Councils that are harming people with profound ID/DD

VOR has grave concerns regarding DD Act grantees' overall effectiveness with regard to individuals with profound intellectual disabilities, including State DD Councils. The vast majority of the people VOR represents are adults with mental ages ranging from newborn to one year old. They cannot care for themselves and have never spoken: they are the most medically fragile of our citizens. Many of these individuals receive life-sustaining, high quality residential supports at Medicaid-certified and funded Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR).

The real problem begins with the bias inherent in the DD Act programs' oversight agency, the Administration on Developmental Disabilities (ADD). A recent example dramatically demonstrates the shortcomings of ADD self-reporting. The *New York Times* investigative series, "[Abused and Used](#)" (March 2011 – current) has exposed [1,200 "unnatural or \[cause\] unknown"](#) deaths of individuals with ID/DD in New York group homes, as well as abuse, neglect and financial exploitation. In response to the *New York Times* series, ADD conducted an audit of the Commission on Quality Care & Oversight, New York's P&A. The role of the New York DD Council was not concerned. Specifically -

ADD conducted a Monitoring, Technical Assistance, Review System (MTARS) site visit of the New York Protection and Advocacy agency on July 13-15, 2011. ADD's visit was prompted by events described in recent *New York Times* articles, which heightened ADD's concerns about the P&A. (ADD's "[Findings Letter](#)" as submitted to the NY Commission on Quality Care & Oversight, December 13, 2011)

ADD's findings, in light of the enormity of human tragedy, are woefully inadequate and incomplete – but not surprising. ADD has supported the elimination of congregate settings -- removing vulnerable people from specialized care – in past policy statements and presentations, with disregard for well-documented tragedies and contrary to federal law.

NACDD shows similar disregard in its white paper, "Realizing the Intent of the DD Act" (July 2011), which considers the role that DD Act programs have played in systems change in select states. The white paper lauds the concerted activities of DD Act grantees, including State DD Councils, 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 DD Act to provide that DD Act programs, including DD Councils, adhere to the policy 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)].

See also, *Olmstead v. L.C.*, 119 S. Ct. 2185, 2187 (1999) (“We emphasize that nothing in the ADA 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.”); and *U.S. v. Virginia* (May 9, 2012) (“Petitioners [ICF/MR residents] have a federally protected right, under *Olmstead* and the ADA, to receive the appropriate care of their choice.”)

As documented in the NACDD white paper, 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 ICF/MR residential option. Consider these additional DD Council examples:

- In an April 2009 letter to Rep. Barney Frank, the **NACDD** and the National Disability Rights Network (NDRN, the national P&A association), with other organizations, wrote in opposition to H.R. 1255, a federal bill which would give individuals and their legal guardians an opportunity to be primary decision-makers in certain federally-funded deinstitutionalization lawsuits. To explain their opposition to this family rights bill, NACDD and NDRN, in part, characterize families as “unaware” about the care received by their disabled loved ones, alleging without any foundation that the families “rely on the very abusers themselves to assure them that all is well while, unbeknownst to them, their loved-ones suffer.” In a 2007 letter opposing similar legislation in an earlier Congress, families were described as “clueless.”
- The **NACDD** joined in the publication of a “Community for All” toolkit (2005) that included, “Background information for advocates involved in campaigns to close institutions . . . Information about policy and governmental action, and strategies that states can use in closing institutions.”

- The **Illinois** DD Council's *"The Blueprint for Systems Redesign in Illinois"* (January 2008) calls for moving people from ICF/MR settings over the objection and regardless of the concerns of legal guardians, stating, "[t]heir objections should not circumvent the process." The *Blueprint* calls for the closing of five state-operated ICFs/MR even while acknowledging that "there are major shortcomings in the delivery of community services."
- The **Wisconsin** DD Council granted \$6,000 (1999), \$25,000 (2001), and \$20,000 (2003) to People First of Wisconsin, an organization that states among its goals 1) "work toward closing all institutions," noting "they will not rest until all the state centers in Wisconsin are closed." In 2007, the Wisconsin DD Council issued a position which "supported the closure of Southern Wisconsin Center by June 30, 2007," without any regard for individual need or family/guardian choice.
- The **Washington** DD Council's 2006 Legislative Agenda Brochure included a priority to "Continue the process of consolidating the RHCs [ICFs/MR] and redirect the resources to community supports and services that enable people with developmental disabilities to live and work in their communities," despite resident and family support for RHCs.
- The **Missouri** DD Council took out a full page, full color advertisement in *St. Louis Post Dispatch* (2007) implying that ICFs/MR are like prisons, saying that ICFs/MR residents "who have committed no crime [are] locked away from society." In 2012, the Missouri DD Council's State Plan includes a position in support of "halt[ing] residential placements" in state ICFs/MR ("Habilitation Centers") and calls for the closure of 3 Habilitation Centers, despite family opposition to closure.
- The **Florida** DD Council opposed a bill that ultimately passed due to family support which provides zoning allowance for planned communities for persons with disabilities, their families, caregivers, employers and friends. Despite strong family support, FDDC lobbied the Florida legislature suggesting that the communities were too "segregated." Families who supported this legislation, which is now law, filed a formal complaint against the FDDC with the Florida Chief Inspector General in July 2010, charging "gross misconduct by a federally funded and state appointed agency," alleging a violation of the prohibition on lobbying activities by federally funded grantees; misuse of \$40,000 in grant funds for the purpose of a workgroup to study residential alternatives; and using "unsupported opinions, misrepresentation of the facts, use of inflammatory language, [and] disregard of family wishes in favor of FDDC policies." (Florida DD Council, 2009 and 2010).
- The **Arizona** DD Council supported a legislative proposal to close the Arizona Training Center, despite widespread opposition from family members. One Council member was removed from the DD Council for publicly opposing the Council's support for closing the Center. (Arizona DD Council).

- The **Maryland** DD Council’s Vision Statement (2008) states, “The Council believes that all people, regardless of how complex or severe their disability, belong in the community with the support they need to maximize independence, be productive, and lead the lives they choose. Practices that segregate and isolate people with disabilities must end.”

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 (see, [Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities](#) (VOR, rev. May 2012); [1,200 Deaths and Few Answers](#), *New York Times* (November 5, 2011); [At State-Run Homes, Abuse and Impunity](#), *New York Times* (March 12, 2011)).

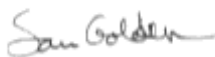
Yet, without doubt, DD Council Annual Reports will measure “success” based on the number of individuals transferred from ICF/MR settings and the number of ICFs/MR closed, without mention of outcome. OMB must insist upon an independent audit and solicit dissenting opinions.

A truly independent, unbiased review of DD Act grantee effectiveness, including State DD Councils, is long overdue. Reports which are limited to input from people who either work for a DD Act grantee or who have been well-served by a DD Act grantee will be incomplete and biased.

Additional resources are available on VOR’s websites; links are provided below.

Thank you for this opportunity to comment and for your thoughtful consideration of these concerns. If VOR can be a resource in any way, please let us know.

Sincerely,



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Additional Web-Based Resources

- **General:** <http://www.vor.net/legislative-voice/vor-helps-you-understand/75-developmental-disabilities-assistance-and-bill-of-rights-act-reauthorization>
- **“Why Congress Should Care About the ICF/MR Program and the People It Serves: The Human Consequences of the DD Act Programs’ Ideologically-Based Attacks on ICFs/MR,”** www.vor.net/images/DDActAbusesUS.pdf
- **“The Reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act: The Need for Immediate Reforms,”** www.vor.net/images/VORDDActPresentation.pdf
- **VOR Comments and Objections to “Realizing the Intent of the DD Act” and VOR’s Call for a Halt to DD Act Deinstitutionalization Activities Consistent with Clear Congressional Intent (rev. January 2012),** www.vor.net/images/VORResponseDDActIntent.pdf
- **VOR Federal Comments Urging Objective Performance – Not More Self-Reporting – of DD Act Programs (January 25, 2012),** www.vor.net/images/VORCommentDDActEvaluationJan2012.pdf
- **VOR Comments and Objections to “Rising Expectations: The Developmental Disabilities Act Revisited” (rev. November 2011),** www.vor.net/images/VORNCDResponse.pdf