VOR
Speaking out for people
with intellectual disabilities

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January 25, 2012

Robert Sargis, ACF Reports Clearance Officer
Administration for Children and Families
Office of Administration
Office of Information Services
370 L'Enfant Promenade S.W.
Washington, DC 20447,

Submitted by E-Mail: *infocollection@acf.hhs.gov*

Re: VOR Comments in Response to ACF–OGM–SF–PPR–Form B—Program Indicators (OMB No. New Collection)

Dear Mr. Sargis:

Please accept these comments in response to the proposed program performance data for the Administration for Children and Families' (ACF) discretionary grantees (ACF-OGM-SF-PPR-Form B – Program Indicators), as released in the *Federal Register*, Vol. 76, No. 228 (November 28, 2011).

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.

The proposed collection activity will secure performance data from all ACF discretionary grantees using a form from the basic Office of Management and Budget (OMB) approved template. It is proposed that the Office of Grants Management (OGM), in ACF, will use the data collected to determine if grantees are proceeding in a satisfactory manner in meeting approved goals and objectives, and if funding should be continued for another budget period.

VOR will limit its comments to the discretionary grant programs funded through the Administration on Developmental Disabilities (ADD), within ACF, as authorized by the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. 15001 *et seq.* (2000) (DD Act). The three primary discretionary grant programs authorized for federal HHS/ACF funding by the DD Act are state-based Developmental Disabilities Councils, Protection and Advocacy Systems, and University Centers for Excellence in Developmental Disabilities.

Summary of Comment

In principal, VOR agrees that all ACF grantees, including DD Act grantees, should be subject to enhanced accountability that focuses on whether "grantees are proceeding in a satisfactory manner in meeting the approved goals and objectives" for the purpose of determining whether federal funding should be continued for another period.

It is not clear from the proposed rule, however, if the proposed form – the ACF Performance Progress Report, ACF-OGM SF-PPR form – is self-administered or will be used by an *independent* entity to "audit" DD Act grantees.

If administered by an independent entity, VOR strongly supports this enhanced, independent, audit of DD Act grantee performance. It has been nearly 12 years since Congress last exercised its critical oversight role, scrutinized the effectiveness of DD Act programs and their impact on people with ID/DD, made necessary amendments, and reauthorized the DD Act. With the exception of this long overdue Congressional oversight, nearly all other ADD and DD Act grantee performance evaluation are based on self-reporting mechanisms.

If, however, the proposed form will be self-administered, whether by ADD or individual DD Act grantees, VOR feels strongly that it will have no practical utility. Relying on staff who are directly accountable for grant outcomes amounts to nothing more than self-reporting and will provide little value or insight into the actual effectiveness of these programs for their intended beneficiaries. In short, additional DD Act grantee "self-audits" will lack any "quality, utility, and clarity," as sought by the OGM.

Detailed Comment:
Existing self-reports, self-audits, and lack of independent oversight have failed to halt activities by DD Act grantees 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. 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).

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 its own New York P&A, the New York Commission on Quality Care & Oversight. Specifically -

> ADD conducted a Monitoring, Technical Assistance, Review System (MTARS) site visit of the New York Protection and Advocacy agency on July l3-15, 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. The report focuses predominately on process and budgeting and **fails to even consider that ADD's support and funding of deinstitutionalization efforts – removing**

vulnerable people from specialized care – may be one of the major causes of problems in New York and other states.

In another ADD-funded report, the National Disability Rights Network (NDRN) (P&A), actually acknowledged problems with community-based care in two states, Alabama and North Carolina (*see*, *Keeping the Promise: True Community Integration and the Need for Monitoring and Advocacy*, November 2011). In this report, the Alabama Disabilities Advocacy Program (P&A) revealed this alarming finding:

> The most significant safety issue that arose during our monitoring project was assuring quality of care for persons with medically complex needs at the time of their transition. Due to four deaths that occurred in a short period when persons with medically complex needs were transitioned from Partlow to community nursing homes or hospitals, ADAP was profoundly concerned about all planned moves of persons with medically complex needs. (Keeping the Promise, p. 25).

Alabama's P&A called for Partlow's closing in 2008 and subsequently received federal funding to investigate how former residents were doing. Despite uncovering instances of abuse and neglect, the Alabama P&A continued to push for closure. It received additional federal funding ($42,500) for continued monitoring of displaced Partlow residents:

> On the heels of the announced closing of the W.D. Partlow Developmental Center, the Alabama Disabilities Advocacy Program (ADAP) has been awarded a $42,500 contract to monitor and advocate on behalf of individuals with intellectual disabilities transitioning to community settings. The funds were provided by the Administration on Developmental Disabilities to the National Disability Rights Network (NDRN) who made the award to ADAP. (ADAP Press Release, March 9, 2011). (Note: Alabama P&A celebrated Partlow's closing in December 2011).

Indeed, more federal funding for monitoring displaced ICF/MR residents (often at the hands of P&A in the first place) is the primary recommendation in the *Keeping the Promise* report (see, Conclusions and Recommendations, p. 22). The conflict of interest is clear. P&A receives federal funding to push for closures of ICFs/MR, despite repeated accounts of death, abuse and neglect, and then receives federal funding to help address the problem it helped create in the first place.

These "self-audits" do not address the difficult question of whether small settings are prepared to safely care for all individuals with profound ID/DD. Indeed, DD Act grantees proceed to push for ICF/MR closures regardless of outcome and irrespective of individual choice and need, and without regard to family input or concerns. In one case, Disability Rights California, the designated P&A, wrote to a parent/conservator:

> "You wanted your son, [MK], to be kept in a state hospital instead of returning him to the community . . . I explained to you, Disability Rights California and the Office of Clients' Rights Advocacy, has a policy of advocating for least restrictive placement settings. Our office does not advocate for individuals with developmental disabilities to be institutionalized." (October 26, 2008).

In other examples –

> The elderly mother of a 47 year old daughter with severe mental retardation sought help from the Ohio P&A to secure services for her daughter at an Ohio Developmental Center. She was told, "We don't help place people in institutions, our mission is to get them out of institutions." (Ohio P&A).
>
> Family advocates for ICFs/MR residents wrote to Utah's Lieutenant Governor with complaints about the Utah P&A noting in part, "The DLC [Disability Law Center] refuses any help or to provide any services to individuals and their families, who may choose USDC [Utah State Developmental Center] or a private ICF/MR as a place of residence for a family member. However, they are most willing to help if an individual wants to move to the Home and Community Based Program from USDC or a private ICF/MR." (Utah P&A).

Deinstitutionalization activities contrary to federal law

Initiatives by DD Act grantees to close federally authorized and funded ICFs/MR without regard to need, choice or the preparedness of the "community" to care for the displaced individuals are contrary to the DD Act and its legislative history which endorses individual choice and expressly opposes 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)].

We also believe that the DD Act grantees bias against the ICF/MR is contrary to the Supreme Court's *Olmstead* decision. The *Olmstead* holding includes individual choice as one prerequisite before community placement is required, and the Court expressly cautioned against forcibly removing people from the care settings they choose and require:

> "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*." Olmstead v. L.C.*, 119 S. Ct. 2185, 2187 (1999).
>
> "As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk... 'Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution'[quoting VOR's *Amici Curiae* brief]." Id at 2189.

Additional Resources

VOR feels strongly that the DD Act programs have, since their inception, so fervently sought "community integration" for ALL people with developmental disabilities that their actions have resulted in a segment of their constituency being denied access to the life-sustaining services that they or their families or guardians desire.

We have shared with federal officials compelling examples of these abuses, which in some cases have led to significant tragedy and in nearly every case denied the right of the individuals and their families to be the "primary decisionmakers" regarding services, supports and policies, as required by the DD Act. The following documents, attached, provide a comprehensive discussion on what VOR believes to be DD Act abuses:

> "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 ICF/MRs"
>
> "The Reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act: The Need for Immediate Reforms"

Conclusion

Given the enormity of human tragedies taking place in New York and other states – tragedies that are sometimes caused directly by DD Act grantees and nearly always ignored by DD Act grantees – the Office of Grants Management within ACF must require that DD Act grantees be subject to an "independent (non-biased)" performance review that considers the basic question of the impact of DD Act grantee deinstitutionalization activities on their *entire* constituency, including people with the most severe intellectual disabilities whose care needs are far greater than others with lesser degrees of disability.

A truly independent, unbiased study of DD Act grantee effectiveness is long overdue. A study which is limited to 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.

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,

Sam Golden

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