

June 28, 2012

Administration for Children and Families
Office of Planning, Research and Evaluation
370 L'Enfant Promenade, SW
Washington, D.C. 20447

Attn: Robert Sargis, ACF Reports Clearance Officer
Submitted by E-Mail: Infocollection@acf.hhs.gov

**Re: Developmental Disabilities Annual Protection and Advocacy
Systems Program Performance Report (OMB No.: 0980-0160);
VOR Comments in Response**

Dear Mr. Sargis,

Please accept these comments in response to the Office of Management and Budget's (OMB's) proposed collection of each "State Protection and Advocacy System's annual performance report for the preceding fiscal year of activities and accomplishments and of conditions in the State. It will also provide the Administration on Developmental Disabilities (ADD) with an overview of program trends and achievements and will enable ADD to respond to administration and congressional requests for specific information about program activities." (OMB No.: 0980-0160). 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.

I. Summary of Comment

In principle, VOR agrees that each State Protection and Advocacy System (P&A) 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 P&As are self-reported, including annual program performance reports. Although subject to reauthorization, Congress has not reviewed DD Act program outcomes and considered reauthorization since 2000.

It is alarming that these self-developed annual program performance reports will be used by ADD to "respond to administration and congressional requests for specific information about program activities" and "to submit a Centennial Report to Congress." These are self-reporting activities that are of little objective value in measuring "Performance and Results."

At minimum, VOR suggests that P&A 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 Administration and Congress.

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.

II. Detailed Comment:

A. Existing self-reports, self-audits, and lack of independent oversight have failed to identify and halt activities by P&As 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 P&A. 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 proposed requirement to provide the Administration on Developmental Disabilities (ADD) with an overview of program trends and achievements (what about failings?) is also of little value. ADD receives and distributes the federal funding for each State's P&A. ADD has little incentive to consider objectively P&A self-claimed "achievements." Any critical review could well mean less federal funding for ADD and the programs it oversees. It's akin to the "fox watching the hen house."

A recent example dramatically demonstrates the shortcomings of ADD oversight and 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. 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 (see below).

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.

The DD Network, comprised of P&As, DD Councils and University Centers of Excellence programs, shows similar disregard in its white paper, "Realizing the Intent of the DD Act" (July 2011). This paper 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 P&As, 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 (see below).

“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. Consider these examples:

In an April 2009 letter to Rep. Barney Frank, 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, 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*.”

"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." (California P&A, October 26, 2008).

The elderly mother of a 47 year old daughter with severe intellectual disabilities 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).

State P&A’s have also pursued litigation solely (since 1996) for the purpose of displacing fragile people from their ICF/MR homes:

Benjamin v. Department of Public Welfare was filed in 2009 as a class action alleging that State failed to offer and provide residents of all State ICFs/MR with community-based services. Families of the affected facility residents have sought intervention over strong objections by Pennsylvania P&A. Families are also challenging a settlement agreement that they feel will force the closure of their family members’ homes. P&A has

not only disregarded individual and family decision-making authority, but taken opposing positions with regard to individual and family choice and involvement. (**Pennsylvania P&A**).

The Arc of Virginia v. Kaine (2009) opposed planned renovations of a state-operated ICFs/MR despite support for such renovations by the family association representing residents. Choice prevailed with the federal judge citing *Olmstead*, expressing stating that plaintiffs (represented by P&A) and the Department of Justice forgot about choice, a key principle of the *Olmstead* decision. (**Virginia P&A**).

Coffelt v. Department of Developmental Services was filed 1994 irrespective of the fact that 98% of the developmental center family/guardian survey respondents opposed P&A representation of their family members. As a result, 2 centers closed and 2,500 residents were transferred from developmental centers to community settings, resulted in well-documented higher mortality rates. One peer-reviewed study found risk of mortality to be 82% higher in community-based settings. (**California P&A**).

“Coffelt II” was filed in 2002. P&A challenged intervention efforts by parent/guardian representatives, arguing, “As a matter of substantive law, parents and guardians of institutionalized persons have different and potentially conflicting interests on matters pertaining to their child’s or ward’s constitutional or statutory rights to liberty and due process.” The Court rejected P&A’s challenge. (**California P&A**).

Brown v. Bush was filed in 1996. Families unsuccessfully sought intervention in a P&A lawsuit that expressly calls for the closure of public ICFs/MR. The families’ attempt at intervention was denied as untimely because families learned of the lawsuit too late (they read about the settlement in the newspaper). In this same case, P&A wrote to a concerned mother saying large facilities are a “despicable way for government and society to treat people who happen to have a developmental disability.” (**Florida P&A**).

Michelle P. v. Holsinger was filed in 2002. Families and guardians filed a lawsuit to oppose a settlement agreement between P&A and the State of Kentucky that calls for transferring individuals from state ICFs/MR and then closing those beds to future admissions. The lawsuit was necessary because families learned of the settlement too late to challenge its terms. The families’ bid for intervention was rejected and settlement implementation of the agreement is underway. (**Kentucky P&A**).

Martin v. Taft was filed in 1989. More than 31,000 people, including families and guardians, successfully opposed a proposed settlement between the Ohio P&A (OLRS) and the State to eliminate entirely the ICF/MR program. “For the past sixteen years, families of individuals who chose to live in state-operated and private ICFs/MR, wrote to OLRS, asking that their loved ones be removed as part of the class . . . Shouldn’t families and guardians be allowed a more active voice in litigation involving their family members with mental retardation?” (Letter from the Ohio League for the Mentally Retarded (OLMR), a statewide family/guardian association, June 2006). (**Ohio P&A**).

Porter, et al v. Knickreim, was filed in 2003. The Arkansas P&A brought the case. The named plaintiff was a resident of an ICF/MR whose legal guardian was not consulted. The suit challenged Arkansas' admission and discharge policies to the state's six ICFs/MR. Later, after the named plaintiff died, three other individuals who had legal guardians that were not consulted were added to the case as named plaintiffs. Families and Friends of Care Facility Residents successfully intervened. The case was ultimately dismissed. Arkansas P&A then brought a related case, but did not seek class certification. Several District Court rulings on pretrial motions were appealed. The 8th Circuit Court affirmed the Arkansas District Court's ruling that state court hearings for admissions to developmental centers are not required to satisfy due process standards. (**Arkansas P&A**).

Richard v. Snider was filed in 1993 by the Pennsylvania P&A. As a result of the lawsuit, Western Center was closed, despite strong objections by the families and legal guardians of the residents. In response, the families of Western Center residents filed a lawsuit following the center's closure. In addition to other claims, the families challenged the manner in which the center was closed – families were separated from their relatives by 20-30 state police as the remaining 49 residents were loaded into vans and transported to places unknown to them or their families. About a month after this incident, and in response to 30 complaints filed by family members, the Executive Director of P&A insisted that "the behavior of Office of Mental Retardation and center staff during those three days was exemplary." (**Pennsylvania P&A**).

Parrent v. Angus was filed in 1989 by the Utah P&A. Known as the Lisa P. lawsuit, the certified class was all residents of the Utah State Developmental Center. The remedy sought was community placement. The lawsuit was strongly opposed by the families and legal guardians of the residents. The case was settled in 1993 and since then, more than 100 people have transferred from the Center. Between 1993 and 2001, the litigation cost the state \$1.7 million. (**Utah P&A**).

Ligas v. Maram was filed in 2005 by the Illinois P&A. The complaint claims that all residents at private ICFs/MR with more than 8 residents "experience unnecessary regression, deterioration, isolation and segregation," "prefer to live in a home that is integrated in the community rather than an institution," live in a "harmful institutional system," live in "segregated, isolating institutions that deprive them of basic liberties," live in a place that "lacks privacy, [is] cold and unwelcoming, [is] sparsely furnished and do[es] not contain furnishings or personal items one would normally associate with a home," and "have regressed and become less independent" as a result of living in their institution. The case was brought on behalf of 6,000 people who reside in private ICFs/MR with more than 8 residents. Nine residents of private ICFs/MR, sought intervention, objecting to the plaintiffs' claims and to P&A representation of their family members. In 2008, the parties proposed a settlement agreement which calls the reduction of ICFs/MR beds over a period of time, among other "system change" proposals. Ultimately, after 5 years of opposition and intervention efforts, families persuaded the federal court to allow intervention and accept a settlement agreement premised on choice. (**Illinois P&A**).

Steven B. was filed in 1999. In this case, an official for Dauphin County filed a petition in Pennsylvania's Court of Common Pleas for Steven's involuntary transfer from Selinsgrove Center, a state-operated ICF/MR, to a community-based placement. His parents and guardians, Mr. and Mrs. B., opposed the commitment and were allowed to intervene. The Pennsylvania P&A filed an Amicus Curiae brief in support of Steven's transfer to the community, completely disregarding his parents/legal guardians' objections. The family ultimately prevailed. The judge concluded that Selinsgrove Center was an appropriate placement for their son; Steven was not required to move. (**Pennsylvania P&A**).

Angela S. v. Wisconsin was filed in 1991 by the Wisconsin P&A. This class action lawsuit on behalf of minors (under age 14) at the Central Wisconsin Center (CWC) alleged that children were "languishing" at CWC without due process review. The parents were informed via letter after the lawsuit was filed. Families strongly objected. (**Wisconsin P&A**).

Disability Rights Wisconsin v. Walworth County Board of Supervisors was filed in 2006 by the Wisconsin P&A. The lawsuit was filed to halt the expansion and renovation of Lakeland School, a special education school, claiming it to be "segregated." In opposition, over 100 families filed a Civil Rights Complaint. (**Wisconsin P&A**).

New Jersey Protection & Advocacy v. Davy was filed in 2005. Complaint alleges that New Jersey unnecessarily confines at least 1550 individuals with developmental disabilities in its state Developmental Centers. Families strongly oppose this lawsuit. (**New Jersey P&A**).

B. Federal law, including P&A's authorizing federal statute, requires individual and family decision-making regarding services, supports and policies, including residential choice

Lobbying, class action lawsuits and other destructive tactics by DD Act programs, including P&As, constitute an improper use of federal funds in violation of Congressional intent to eliminate the federally-created and funded ICF/MR residential option.

In 1993, Congress amended the DD Act to provide that DD Act programs, including P&As, 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.”)

C. P&A’s deinstitutionalization activities contrary to federal law have led to predictable human tragedy

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)).

III. Conclusion: OMB must insist upon an independent audit and solicit dissenting opinions

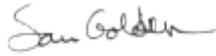
Without doubt, P&A Annual Reports will measure “success” based on the number of individuals transferred from ICF/MR settings and the number of ICFs/MR closed, without mention of outcomes.

A truly independent, unbiased review of DD Act grantee effectiveness, including State P&As, 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 attached.

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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ATTACHMENT

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
- VOR Federal Comments Urging Objective Performance Measures for State DD Councils (May 25, 2012), <http://www.vor.net/images/DDCouncilOMBCommentMay2012.pdf>