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September 17, 2012

Kathy Greenlee, Administrator & Assistant Secretary for Aging Administration for Community Living  
U.S. Department of Human Services  
1 Massachusetts Ave., N.W.  
Washington, DC 20201

**Attn:** Office of Management and Budget (OMB) Desk Officer for the Administration on Community Living (ACL), Office of Information and Regulatory Affairs

**By facsimile: 202-395-6974**

**Re: VOR comment in response to Administration on Community Living Notice of Proposed Information Collection Activities: Submission for OMB Review; Developmental Disabilities Protection and Advocacy (P&A) Program Statement of Goals and Priorities**

Dear Ms. Greenlee,

Please accept these comments in response to the Administration on Intellectual and Developmental Disabilities (AIDD), Administration for Community Living's (ACL) proposed collection of information, as published in the Federal Register, Vol. 77, No. 161, page 50112 (Monday, August 20, 2012).

Specifically, ACL has proposed for Office of Management and Budget (OMB) review and clearance the collection of each State's Protection and Advocacy (P&A) System's annual Statement of Goals and Priorities (SGP) for the coming fiscal year for their Developmental Disabilities Programs (PADD). According to the notice for comment:

"Following the required public input for the coming fiscal year, the P&As submit the final version of this SGP to the Administration on Intellectual and Developmental Disabilities (AIDD). AIDD will aggregate the information in the SGPs into a national profile of

**Summary of VOR's Comment**

Independent oversight and an unbiased audit of P&A program outcomes are needed. People with profound intellectual and developmental disabilities who are being displaced from ICF/MR homes are being harmed. Tragedies are well-documented and predictable.

**Deinstitutionalization is a goal in most P&As' Statement of Goals and Priorities, yet VOR knows of no State P&A that has made any effort to determine if deinstitutionalization is a goal supported by those directly affected when ICFs/MR close – the residents and their families and legal guardians.**

AIDD, which shares and promotes an anti-ICF/MR bias, is in no position to provide adequate oversight, and certainly should not be permitted to formulate "technical assistance" when a State P&A is experiencing difficulty accomplishing a deinstitutionalization goal/target, as contemplated in this proposed collection of information. Furthermore, a formal mechanism for monitoring P&A and DD Act outcomes above AIDD – perhaps the Office of Inspector General – must be employed.

programmatic emphasis for P&A Systems in the coming year. This aggregation will provide AIDD with a tool for monitoring of the public input requirement. Furthermore, it will provide an overview of program direction, and permit AIDD to track accomplishments against goals/targets, permitting the formulation of technical assistance and compliance with the Government Performance and Results Act of 1993." Federal Register, Vol. 77, No. 161, page 50112 (Monday, August 20, 2012) (FR Doc. 2012–20418; Billing Code 4154–01–P).

As we have commented on several times in the past, VOR is gravely concerned about the lack of any unbiased review of the *outcomes* of P&A priorities and activities. Two recent comments are attached. Federally-funded P&As are operating unchecked, resulting in harm to many people with profound intellectual and developmental disabilities.

Most P&As have “deinstitutionalization” among their goals and priorities: the transitioning all individuals to community-based programs and the resulting *closure* of Medicaid-licensed Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR). **Yet, VOR knows of no State P&A that has made any effort to determine if deinstitutionalization is supported by those most directly affected when ICFs/MR close – the residents and their families and legal guardians.** Indeed, P&A actions speak to the level of disrespect for individuals who need and choose the ICF/MR option; and to a level of disrespect for family and legal guardian input – people who know the individual best and are morally and legally charged with ensuring their very best care. Consider these P&A actions:

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.*” (*emphasis added*)

"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).

A Massachusetts advocate contacted the Disability Law Center seeking advocacy for an individual who resides in an ICF/MR and was being pressured to leave. The Disability Law Center denied helping this individual. (**Massachusetts P&A**, 2011).

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**).

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 and legal guardians 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 and legal guardian decision-making authority, but taken opposing positions with regard to individual and family/guardian 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*, 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**).

When P&As include “deinstitutionalization” in their SGPs without any effort to ascertain the support of those affected, P&A must be held accountable for the outcomes. Instead, in support of total deinstitutionalization, P&As have failed to advance the cause of optimum, person-centered care for people with profound intellectual and developmental disabilities. In fact, P&A

activities have resulted in debasing care to the detriment of ICF/MR residents. Abuse, neglect and death following the closure of specialized ICFs/MR are predictable and well-documented.<sup>1</sup> A fair appraisal of the results of P&A's advocacy, which we have repeatedly requested,<sup>2</sup> would show that they have harmed individuals and failed to protect them. AIDD, which shares and promotes an anti-ICF/MR bias, is in no position to provide adequate oversight,<sup>3</sup> and certainly should not be permitted to formulate "technical assistance" when a State P&A is experiencing difficulty accomplishing a deinstitutionalization goal/target, as contemplated in this proposed collection of information.

The purpose of P&A, as set forth in the DD Act, is to protect the legal and human rights of individuals with developmental disabilities. Deinstitutionalization resulting in less than optimum care and resulting in harm is NOT protecting legal and human rights, NOT mandated by the DD Act, and is directly counter to the DD Act's requirement to respect the right of individuals with developmental disabilities and their families to be primary decisionmakers regarding services, supports and policies<sup>4</sup> and *Olmstead*<sup>5</sup>.

Independent oversight and an unbiased audit of P&A program outcomes are needed. Monitoring of P&A outcomes must include an assessment of complaints against them, particularly when they use DD Act funding contrary to the DD Act and *Olmstead* and to further an ideology that can lead to the violation of individual rights (the right to appropriate treatment and the right to choose). A mechanism above AIDD, perhaps through the HHS Office of Inspector General, must be employed to receive and act on complaints against P&A and other DD Act programs.

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<sup>1</sup> *New York Times*, "One in six of all deaths in state and privately run homes, or more than 1,200 in the past decade, have been attributed to either unnatural or unknown causes" (November 6, 2011). The *Atlanta Journal-Constitution* found "Deficiencies in care, living conditions and record-keeping have piled up in scores of Georgia personal care homes [35,000 violations], with the state rarely shutting down violators or levying heavy fines [in just 544 cases]" (May 22, 2012). A *Miami Herald* investigation found a string of "deaths [that] highlight critical breakdowns in a state enforcement system that has left thousands of people to fend for themselves in dangerous and decrepit conditions" (May 1, 2011). <http://www.vor.net/images/AbuseandNeglect.pdf>

<sup>2</sup> See, <http://www.vor.net/legislative-voice/vor-helps-you-understand/75-developmental-disabilities-assistance-and-bill-of-rights-act-reauthorization>

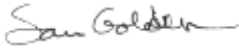
<sup>3</sup> VOR Federal Comments Urging Objective Performance - Not More Self-Reporting - of DD Act Programs (January 25, 2012) (VOR Comments in Response to ACF-OGM-SF-PPR-Form B-Program Indicators (OMB No. New Collection))

<sup>4</sup> "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 decisionmaking roles in policies and programs that affect the lives of such individuals and their families." DD Act, 42 U.S.C. 15001(c)(3)(1993) (*Findings, Purposes and Policies*).

<sup>5</sup> Community placement is only required and appropriate (i.e., institutionalization is unjustified), when "(a) the State's treatment professionals have determined that community placement is appropriate; (b) the transfer from institutional care to a less restrictive **setting is not opposed by the affected individual**; and (c) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities." *Olmstead v. L.C.*, 119 S. Ct. 2176, 2181 (1999) (**emphasis added**); See also, *Id.* at 2187 ("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.")

Thank you for your consideration.

Sincerely,



Sam Golden  
Chair, VOR Government Affairs Committee

**For more information:**

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cc:

Ann Knighton, President, VOR  
VOR Board of Directors

***Attachments:***

**VOR Federal Comments Urging Objective Performance Measures for State Protection & Advocacy Systems (June 28, 2012),**  
[http://www.vor.net/images/PAOMBCCommentJune\\_2012.pdf](http://www.vor.net/images/PAOMBCCommentJune_2012.pdf)

**VOR Federal Comments Urging Objective Performance - Not More Self-Reporting - of DD Act Programs (January 25, 2012),**  
<http://www.vor.net/images/VORCommentDDActEvaluationJan2012.pdf>

**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 (revised 2012),** <http://www.vor.net/images/DDActAbusesUS.pdf>

**ATTACHMENT:**

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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](mailto: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*."

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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**).

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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 8<sup>th</sup> 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**

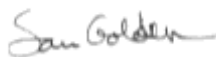
Without doubt, P&A Annual Reports will measure “success” based on the number of individuals transferred from ICF/MR settings and the number of ICFs/MR closed, without mention of outcomes.

**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](http://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](http://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](http://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](http://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](http://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>

**ATTACHMENT:**

**VOR Federal Comments Urging Objective Performance - Not More Self-Reporting - of DD Act Programs (January 25, 2012)**

<http://www.vor.net/images/VORCommentDDActEvaluationJan2012.pdf>



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January 25, 2012

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Administration for Children and Families  
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**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 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. 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”](#)

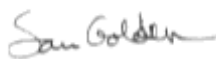
## **Conclusion**

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, Chair  
VOR Government Affairs Committee  
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Julie Huso, Executive Director

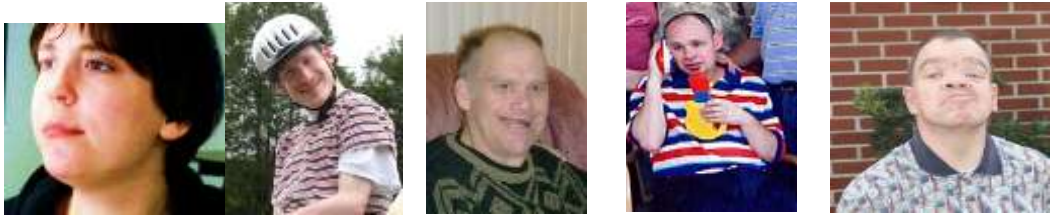
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**ATTACHMENT:**

**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 (revised 2012)**

<http://www.vor.net/images/DDActAbusesUS.pdf>



“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.” (U.S. Supreme Court, *Olmstead v. L.C.*)

**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 Developmental Disabilities Assistance**  
**and Bill of Rights Act (DD Act)**

The DD Act authorizes three primary grant programs designed to “assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life. . . .”

The three primary programs authorized by the DD Act are the state Developmental Disabilities Councils (**DD Councils**), state Protection and Advocacy (**P&A**) systems, and state University Centers for Excellence in Developmental Disabilities (**UCEDD**).

**Congressional Intent**  
**and the Role of ICFs/MR in the Continuum of Care**

As clarified by Congress, the DD Act's support for these goals is “not [to be] read as a Federal policy supporting the closure of residential institutions.” [House Energy and Commerce Committee Report No. 103-378, November 18, 1993 (to accompany H.R. 3505, the Developmental Disabilities Act Amendments of 1993)]. In the 1993 Amendments, in both statute and report language, Congress made it clear that individuals and their families, not the DD Act programs, are the “primary decisionmakers” regarding needed and desired services, “including regarding choosing where the individuals live.” Congress expressly cautioned, in the House Committee report explaining this language, “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.”

Why did the Congress support the continuation of residential institutions? The answer lies in the population who reside in such facilities and the care they receive. Residents of ICFs/MR are among the neediest, most fragile and most disabled members of our society. They need substantial support in every aspect of life including walking, communicating, bathing, eating and toileting. According to a 2007 University of Minnesota study, nearly 80% of the nation's ICF/MR residents experience severe or profound intellectual disabilities, functioning at an infant or toddler's level although fully grown; they also endure multiple disabilities, chronic medical conditions and/or behavioral challenges. Many also have seizure disorders, mental illness, visual or hearing impairments, or have a combination of these conditions.

ICFs/MR are often the best way to meet the needs of the most vulnerable of the population with intellectual and developmental disabilities, providing them with comprehensive around-the-clock supports to assure their safety and enable them to live their lives to the fullest.

Currently, the federal government helps fund and monitor 6,381 ICFs/MR that are home to 93,164 people.

### **Additional Resources And Legislative Recommendations**

The full report on which this document is based is available online at:

<http://www.vor.net/images/stories/pdf/TaskForceReport.doc>.

Recommendations for DD Act reform can be found at the end of this document.

### **All three primary DD Act programs pursue activities which violate Congressional intent**

So far, a volunteer VOR task force has identified over 90 examples in 20 states of the DD Act programs' disregard for Congressional intent. VOR is continuing this project to unearth examples in as many states as time and resources permit. The effort is in response to constant complaints from our members that the DD Act programs are not acting on behalf of their loved ones' best interests but, instead, are pursuing an ideological agenda to close all large ICFs/MR.

## **I. DISREGARD FOR FAMILY INPUT, IN VIOLATION OF THE DD ACT'S REQUIREMENT THAT INDIVIDUALS AND FAMILIES BE THE "PRIMARY DECISIONMAKERS"**

### **A. Organizational Priorities and Positions**

The national association for state P&As, the National Disability Rights Network, signed a letter to Congress which described families of ICF/MR residents as "clueless." (NDRN, 2007).

*The Blueprint for Systems Redesign in Illinois* 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.” (Illinois DD Council, Blueprint, p. 51).

The Florida P&A responded to a family member who expressed concern about a Florida P&A lawsuit that called for the closure of public ICFs/MR by writing that “Florida’s Developmental Services Institutions constitute a despicable way for government and society to treat people who happen to have a developmental disability.” (Florida P&A).

A Maine P&A advocate counseled her mentally ill client, William, who was receiving inpatient psychiatric care, that his parents were a “negative force in his life” given their efforts to keep him “institutionalized” due to his severe mental illness. Her subsequent “victory” in winning his release was followed shortly by William murdering his mother. (Maine P&A).

## **B. Litigation**

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 (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 8<sup>th</sup> 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).

Nelson v. Snider was filed in 1994, with the Pennsylvania P&A as a named plaintiff. Families strongly objected. Embreeville Center closed as a result of this lawsuit in 1997. (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. (Illinois P&A).

Lelsz v. Kavanaugh was filed in 1987. The Texas P&A intervened in support of the plaintiffs, who were State School residents. Families of these State School residents spent over \$500,000 and intervened in the Lelsz lawsuit in opposition to the lawsuit, which ultimately led to the closure of Travis and Fort Worth State Schools. (Texas 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).

### **C. Legislative Advocacy**

In a July 2007 letter to Rep. Barney Frank, the National Association of Councils on Developmental Disabilities (NACDD) and the National Disability Rights Network (NDRN, the national P&A association), with other organizations, wrote in opposition to H.R. 3995, a federal bill which would give individuals and their legal guardians an opportunity to be primary decisionmakers by giving them notice of a class action lawsuit and the opportunity to opt out. To explain their opposition to this family rights bill, NACDD and NDRN, in part, characterize families as "clueless" 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."

Opposition by the Florida Developmental Disabilities Council (FDDC) to a bill that would provide zoning allowance for planned communities for persons with disabilities, their families, caregivers, employers and friends. The bill was strongly supported by families of individuals with developmental disabilities who were seeking to develop planned communities, much like Florida's retirement communities, for their loved ones. 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).

Support by the Arizona DD Council for 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).

Several speakers who offered public comments at an Arizona Senate Committee hearing stated that the DD Council has "sold parents and family members down the river in favor of 'self advocacy' for the disabled." (Arizona DD Council).

## **II. DEINSTITUTIONALIZATION – ICFs/MR CLOSURE ACTIVITIES**

### **A. Organizational priorities and positions**

According to the Virginia Alliance for Community [the Virginia Office of Protection and Advocacy is a founding member], "Virginia has a unique opportunity to reform its historical focus on large, state institutions and fully transition to a true community-based system of support for its citizens with intellectual disabilities. Failure to establish a clear commitment to do so will compromise the state's ability to improve the service delivery system to one that is morally and fiscally responsible. The 'future' is community living. The time for Virginia to act is now." (Virginia P&A, November 17, 2008).

"Alliance Backs Closure of Southeastern Virginia Training Center." (Virginia P&A, December 17, 2008).

Calling for the closure of Partlow Developmental center, the Alabama Disabilities Advocacy Program called Partlow "a waste of taxpayer money," and said its residents could be better cared for at lesser cost in group homes and other community placements. (Alabama P&A, December 9, 2008).

“New admissions to Habilitation Centers should be eliminated” (Missouri DD Council, 2007).

“It is the position of the DDC that 1) the Legislature should pursue a policy on downsizing IMR/RHCs [ICFs/MR] with the goal of eventually closing institutions.” [Washington State DD Council, Policy No. 103 (1991)].

“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.” (Washington State DD Council, Legislative Agenda Brochure, 2006).

Goal to “end institutionalization” (PAI Advocacy Plan, 2008-2012, pp. 9 and 27) (California P&A).

“The Council supports the closure of Southern Center by June 30, 2007.” (Wisconsin Council, 2005).

“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.” (Maryland DD Council, Vision Statement, 2008).

The Maryland P&A is a member of, and provides office space for, meetings of the “Close Rosewood Coalition.” (Maryland P&A).

Collaborated with others to develop power point presentations which promoted the need for community care over ICs/MR. (Kentucky UCEDD, 2008).

In opposing a proposal to build small ICFs/MR on the campus of Hazelwood Center, the Kentucky P&A stated, “By clustering the smaller boxes with the bigger box, in a sort of disability ghetto, if you will . . . we oppose this proposal.” (Kentucky P&A).

“It doesn’t make sense to continue pouring precious dollars into an archaic system that isolates people based on disability labels and some unfortunate stereotypes and assumptions.” (Texas P&A).

The Pennsylvania P&A chaired the “Olmstead Committee” which developed “Community Integration Plan for People with Mental Retardation,” recommending that “within the next two years, the Office for Mental Retardation will ‘select two state centers for closure or merger’ and 2) ‘within the next five years, the Commonwealth should cease to directly provide services in public ICFs/MR.’” (Pennsylvania P&A).

*The Blueprint for Systems Redesign in Illinois* calls for closing 5 State Operated Developmental Centers over the objection and regardless of the concerns of legal guardians while acknowledging that “there are major shortcomings in the delivery of community services. (Illinois DD Council).

“Segregation or Community Integration” calls on Illinois to adopt a policy of refusing to admit people to existing ICFs/MR so that “combined with a plan for downsizing, there will be a natural attrition that shifts the balance of services and funding to the community.” (Illinois P&A, p. 6).

A representative of California Protection and Advocacy, Inc., told a newspaper reporter that, “the state is legally required to move people from institutions into community care. Her agency is suing the state for not moving people out of state institutions quickly enough.” (California P&A).

The Pennsylvania P&A listed as Fiscal Year 2006 Priorities, “Advocate for the movement of dollars from segregated facilities to integrated options,” “Close . . . state mental retardation centers and residential treatment facilities,” and “Provide consumer-to-consumer outreach at all state-operated mental retardation centers . . . in preparation for eventual closure of the centers.” (Pennsylvania P&A).

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.” (Wisconsin DD Council).

In 2008, the Kentucky UCEDD program collaborated with the ARC of Kentucky in distributing two PowerPoint presentations to policymakers using inflammatory, misleading language regarding ICFs/MR for people with profound developmental disabilities. These presentations promoted one system of care (“community” only) and encouraged the state to use its powers as public legal guardian to displace 52 public ICFs/MR residents to “community care.” (Kentucky UCEDD).

## **B. Litigation**

Since 1996, every P&A federally-funded lawsuit against an ICF/MR has been for the primary purpose of removing residents from their ICF/MR home (“community integration”); the condition of care at the targeted ICFs/MR was not at issue in any of these cases.

Fifteen of these cases have led to the closure of ICFs/MR, affecting thousands of individuals with intellectual disabilities (see, <http://www.vor.net/classactions.htm>).

In addition, DD Act programs in many states have misrepresented the Supreme Court Olmstead decision, characterizing it (incorrectly) as a mandate to close ICFs/MR (see e.g., Illinois P&A, Kentucky P&A, Utah P&A, Pennsylvania P&A, etc.).

## **C. Legislative**

Full page, full color advertisement in *St. Louis Post Dispatch* implying that ICFs/MR are like prisons by saying that ICFs/MR residents “who have committed no crime [are] locked away from society.” (Missouri DD Council, 2007).

“The truth is that institutional care is an out-dated service model.” (Maryland P&A).

“This tool kit provides: . . . 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.” (National Association of Councils on DD; New York UCEDD; Minnesota UCEDD).

Testimony in support of closing Rosewood, saying, “no one should have to live in an institution . . . the model of warehousing people . . . is an outdated relic of history.” (Maryland P&A).

In coalition with others, testified in support of closing Rosewood, a public ICF/MR (Maryland P&A and Maryland Council).

Lobbied the Texas Legislature to adopt budget policies that would cause “the immediate re-direction/re-allocation of resources from State Institutions to community living programs.” (Texas UCEDD).

Testified against additional funds for Arkansas’ developmental centers before legislative budget special language committee. (Arkansas P&A).

Testified against a Florida Senate Bill that would have required families be notified and have an opportunity to provide input before an ICFs/MR could be closed. (Florida P&A and FL Council).

Called for closure of Utah Developmental Center, calling institutional care “outmoded” before a legislative task force on Medicaid. (Utah P&A).

Sat on numerous policy making and policy influencing committees in state government, always articulating the same philosophy: that MR/DD citizens do not want ICF’s/MR or state operated developmental centers. (Ohio P&A).

Serves as contact office for the Texas Disability Policy Consortium which encourages letters to Texas legislators to support its recommendation for the “immediate re-direction/reallocation of resources from State institutions (including . . . state schools for the mentally retarded) to community living programs.” (Texas P&A).

Staff attorney for Wisconsin P&A chairs the Governmental Affairs Committee for Wisconsin DD Council. Committee recommends closure of “Southern Center by end of the biennium.” (Wisconsin DD Council and Wisconsin P&A).

Support for a bill that calls for the closure of five state ICFs/MR, even while noting that the bill is “incredibly ambitious” and questioning whether it is “logistically” possible. (New Jersey P&A).

### **III. ACTIVITIES WHICH DISCRIMINATE AGAINST PEOPLE WITH SEVERE AND PROFOUND INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, AND THE IMPACT OF THESE ACTIVITIES ON THESE PEOPLE**

Federal law requires that programs receiving federal funding must not discriminate against people with disabilities [Rehabilitation Act, Section 504 (1978)]. Yet, time and again, in apparent violation of Sec. 504 of the Rehabilitation Act, through lawsuits, lobbying, media outreach and other advocacy, many DD Act programs across the country have utilized federal funds to eliminate the federally created, funded and certified ICF/MR option, without regard to the needs and preferences of the ICFs/MR residents, often with disregard to the objections of family and legal guardians, and without apparent concern for the tragedies that sometime befall the individuals who are forcibly moved from their ICFs/MR homes.

#### **Examples**

##### **A. Some DD Act programs refuse to help someone gain admission to an ICF/MR.**

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 provide any services to individuals and their families, who may choose USDC [Utah 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).

A mother/conservator sought the help of the California P&A to gain admission for her son at Sonoma Developmental Center following the closure of Agnews Developmental Center. In October 2008, she received this response: “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)

52-year-old Roy Whitley was targeted for a move from Sonoma, where he had resided for 39 years, to a private facility in Fairfield which was too far away for his family to maintain regular contact and offered less adequate care than at the Center. Roy's sister and conservator filed an appeal with the California Court of Appeal after a trial court decision rejected her challenge to the planned move. California's Protection & Advocacy, along with a regional center and the state, challenged Roy's sister's decision that Sonoma was providing high quality care in the least restrictive environment for Roy. On appeal, Roy's sister/conservator prevailed. (California P&A, October 2007)

## **B. Some DD Act programs disregard problems in community programs:**

The Wisconsin Coalition for Advocacy (now called Disability Rights Wisconsin) was contacted for assistance regarding a resident of Northern Wisconsin Developmental Center who was suddenly scheduled to have all his teeth removed just before he was to be transferred to the community. It is believed that Larry's teeth were being removed because he had a habit of biting people and without teeth this behavior would not be an issue in his new community home. The Wisconsin Coalition for Advocacy refused to become involved or offer any assistance. (Wisconsin P&A).

After forcing the closure of two ICFs/MR in California and the transition of 2500 people to the community, the California P&A demonstrated a lack of concern for the health and safety of those individuals in the face of evidence of higher abuse and death rates. One 1996 peer-reviewed study found that the risk of mortality was 88% higher for those who were transferred from public ICFs/MR, as compared to those who did not move. The concern for those who were transferred was the subject of a separate lawsuit and an extensive, year-long, media investigation and expose by the *San Francisco Chronicle* (California P&A).

In response to the death of Donald Santiago, who died shortly after his move from Angews ICFs/MR, Ellen Goldblatt, executive director of the California P&A remarked, "It's tragic that he then died. It's also nice that he got to move after so many years of living in an institution," suggesting Donald was better off dead than in a licensed ICFs/MR. (California P&A).

The Governor of New Mexico authorized a private investigator to find former Los Lunas ICF/MR residents who had "slipped through the cracks." Los Lunas closed due to a P&A lawsuit (New Mexico P&A).

Families of former Western Center residents filed a lawsuit, alleging injuries among the residents transferred (Pennsylvania P&A).

A former social worker and incident data analyst with the Maryland Developmental Disabilities Administration, who oversaw some community placements during the closure of Great Oaks Center stated, "If Rosewood is closed in the fashion of the Great Oaks experience, medically fragile residents, and those individuals who are dangerous to themselves, will die in the community at a rate of 400 percent greater than if they stay at



Rosewood; 13.5 percent will die within the first 18 month” (Ron Coleman, Sept. 2006). Great Oaks was closed due to an Maryland Disability Law Center (P&A) class action lawsuit. (Maryland P&A).

Continued support for the closure of Rosewood despite repeated well-publicized concerns relating to Maryland’s community-based system (A failure to protect – Maryland’s troubled group homes, *The Baltimore Sun*, April 10-17, 2005; Safeguards meant to protect the disabled in Maryland group homes failed, *The Baltimore Sun*, August 1, 2004; Violence raises concerns over group homes, *The Baltimore Sun*, July 21, 2002; Md. concedes failings of group home system, *Washington Post*, May 8, 2002; State reports cited agency for poor living conditions, *The Herald Mail*, July 23, 2001) (Maryland DD Council and Maryland P&A).

*The Blueprint for Systems Redesign in Illinois* calls for closing 5 State Operated Developmental Centers over the objection and regardless of the concerns of legal guardians while acknowledging that “there are major shortcomings in the delivery of community services. [Community] Provider agencies are struggling to acquire and retain a stable competent workforce....workforce instability spawns major problems in assuring the quality of services and supports....In addition, there are gaps in the capacity of the community system to address the needs of individuals with especially challenging conditions.” (Illinois DD Council, Blueprint, P. 23).

Refusal to help a mother of an autistic adult son who was severely burned in a group home accident due to lack of supervision. During her son’s rehabilitation, at his mother’s home, her son’s former group home roommate died. (Utah P&A).

## **Recommended Reforms**

In light of these activities by DD Act programs – all of which violate Congressional intent and bring harm to the very constituents they are charged to advocate for and protect, VOR calls on Congress to take the following actions aimed at assuring that DD Act program recipients carry out the Act’s mandate to respect choice in residential settings and family decision-making:

- A. Schedule public hearings on the DD Act as soon as possible, providing opportunity for affected individuals and their families to testify.
- B. Amend the DD Act to enforce DD Act program adherence to residential choice, as is clearly supported by Congressional intent and the U.S. Supreme Court’s *Olmstead* decision:

“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.”
- C. Enact the provisions of H.R. 2032 to require DD Act programs to notify the residents of an ICF/MR or, where appointed, their legal representatives (defined to include legal guardians and conservators)

before filing a class action and provide them with a time-limited opportunity to opt out of the class action.

- D. Limit the reauthorization cycle to three years.

**For More Information**

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