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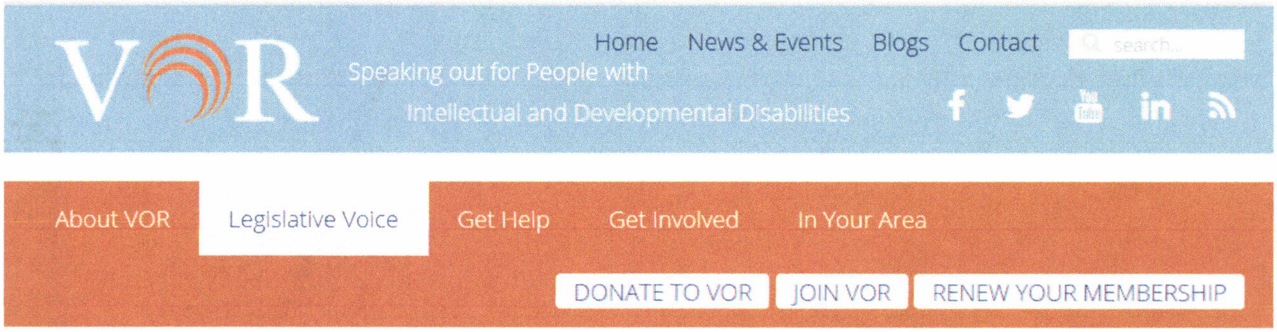

DD Act Program Abuse and Human Consequences

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

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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 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).

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'sMR 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).

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)

*Family advocates for ICFs/MR residents wrote to Utah's Lieutenant Governor with complaints about the Utah P&A noting in part, "The DLC refuses any help or provide any services to individuals and their families, who may choose USDC 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).

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 fact 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 MDLC (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.

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