Speaking out for people
with intellectual disabilities

"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.).

CALIFORNIA:

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

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 <u>neediest</u>, <u>most fragile</u> and <u>most disabled</u> 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. Their lives include regular contact with peers, education and employment, and activities enjoyed by all California citizens both on and off campus, such as beach and amusement park trips, shopping, church services, picnics, etc.

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.

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

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: **Litigation**

Coffelt v. Department of Developmental Services was filed in 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).

Capitol People First et al v. Department of Developmental Service ("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," noting that "there is no well established right of parents to intervene in actions on behalf of even non-adult children . . ." The Court rejected P&A's challenge. (California P&A).

B. Organizational Priorities and Positions: **Legislative Advocacy**

The California P&A opposed SB 1337, a California bill pertaining to the right of an ICF/MR resident, conservator, parent, family member or other authorized legal representative to pursue a Fair Hearing when a disagreement arises over one's Individual Program Plan (IPP) relating to residence. P&A argued that rights of residency can only be determined by a Superior Court judge and should not be considered in a Fair Hearing. (California P&A, 2006).

II. DEINSTITUTIONALIZATION – ICFs/MR CLOSURE ACTIVITIES

A. Organizational priorities and positions

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

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).

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 mental retardation (*see*, http://www.vor.net/classactions.htm).

C. Legislative

The California P&A testified against appropriations to replace a kitchen at a developmental center that was inadequate to deliver meals to the residents, due to needed repairs and other health code issues, arguing that money would be better spent in a "less restrictive" setting. (California P&A, April 2008).

The California P&A testified in opposition to state legislation that would have required mandatory and low cost fire sprinkler systems to be installed in board and care homes, arguing that passage of the bill might decrease community beds and, thus, might cause some persons to remain in developmental centers. (California P&A, May 2006).

III. ACTIVITIES WHICH DISCRIMINATE AGAINST PEOPLE WITH SEVERE AND PROFOUND MENTAL RETARDATION 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.

In 2009, a mother sought placement for her son at Sonoma Developmental Center following the closure of Agnews Developmental Center. She approached the California Disability Rights Network (P&A) for assistance, but they would not help. She is now taking the matter to court. (California P&A, 2009)

In a similar situation, another mother secured admission for her son at Sonoma Developmental Center only after going to court several times in four months in her effort to secure placement. Again, P&A would not help because of her preferred placement for her son was Sonoma Developmental Center.

In another case, 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:

After forcing the closure of two ICFs/MR in California and the transition of 2,500 people to the community, the California P&A demonstrated a complete 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).

To the disregard of residents’ health, safety and nutrition needs, the California P&A testified against appropriations to address health code violations in a developmental center kitchen, arguing that money would be better spent in “less restrictive” settings. (California P&A, April 2008).

The California P&A testified in opposition to state legislation that would have required mandatory and low cost fire sprinkler systems to be installed in board and care homes, arguing that passage of the bill might decrease community beds and, thus, might cause some persons to remain in developmental centers. The message to advocates was clear: It is better to burn to death than to be in a “congregate” setting. (California P&A, May 2006).

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

Bob Hazard
5536 Modena Place
Agoura Hills, CA 91301
818-707-3719
818-707-1675 work
ra_hazard@att.net