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Speaking out for people with intellectual & developmental disabilities

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TESTIMONY OF MARY REESE, VOR BOARD MEMBER

Before the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, House Appropriations Committee

March 13, 2013

I. Introduction

VOR is a national organization advocating for high quality care and human rights for all people with intellectual and developmental disabilities (I/DD). VOR is *not* requesting appropriations. Instead, VOR requests the Subcommittee's support for language to ***prohibit*** **the use of HHS appropriations in support of deinstitutionalization activities which evict eligible individuals with I/DD from HHS-licensed Medicaid facilities, in violation of federal law.** Deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics, by some HHS-funded agencies (discussed below) resulting in the downsizing and closure of HHS-licensed are a cruel and absurd use of federal funding.[1] These closures often lead to human tragedy. Medicaid-licensed facility homes, including Intermediate Care Facilities for People with Intellectual Disabilities (ICFs/ID), are uniquely suited to meet the residents' profound support, health care and behavioral needs. Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored.

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[1] The U.S. Department of Justice also investigates HHS-licensed, state-operated homes for people with I/DD, and files federal lawsuits against states, for the purpose of downsizing and closing these homes.

II. Using HHS Funds to Eliminate HHS-Supported Homes: The Administration on Intellectual and Developmental Disabilities (AIDD) and its state-based Developmental Disabilities Assistance and Bill of Rights Act (DD Act) Programs

It has been 13 years since Congress last reauthorized the DD Act. Authorizations for DD Act appropriations expired in 2007; however, Congress continues to fund these programs. DD Act programs, including Protection & Advocacy (P&A), DD Councils, and University Programs, operate in every state. AIDD, within HHS, administers the DD Act programs.

Independent oversight of federal AIDD and DD Act programs is nearly non-existent.[2] DD Act programs are using their public funds to achieve dangerous deinstitutionalization, evicting vulnerable people with I/DD from Medicaid-certified homes, disregarding individual choice and the legal right to appropriate services, as required by the Americans With Disabilities Act (ADA) (as interpreted by the *Olmstead* decision) and Medicaid law (both discussed below). The DD Act programs' own authorizing statute supports residential choice and recognizes that individuals and their families are in the best position to make care decisions:

> "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)(2000); *see also*, H. Rep. 103-442 (March 21, 1994) ("[T]he 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").

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[2] See, VOR Federal Comments Urging Objective Performance - Not More Self-Reporting - of DD Act Programs (January 25, 2012) (vor.net/images/VORCommentDDActEvaluationJan2012.pdf)

Yet, AIDD persists in its support for DD Act programs' deinstitutionalization activities and even proposed a recommendation to "[d]evelop and implement plans to close public and private institutions," and "[k]eep people with disabilities out of congregate institutions," in collaboration with DOJ and The Arc (2011). Hundreds of families and others objected; the recommendation has not yet been finalized. Likewise, the national organizations for the three DD Act programs have referred to families who select HHS-licensed homes (ICFs/ID) as "clueless" and "unaware,"[3] a view not shared by the Supreme Court.[4]

With AIDD directive, state-level DD Act program deinstitutionalization activities continue, exacting great harm on the very people Congress entrusted these HHS-entities to protect. Since 1996, more than fifteen (15) P&A class action lawsuits for closure (*not* relating to conditions of care) and other deinstitutionalization tactics have been pursued over the objection of residents and their families. The P&A class action lawsuits are a particularly egregious use of federal funds; they equate HHS suing itself because the targets of these HHS-funded lawsuits are HHS/Medicaid-licensed ICFs/ID. AIDD and its state-based programs persist in their ideological devotion to community placement despite reports of 1,200 "unnatural and unknown" deaths in New York, a risk of mortality in community settings of up to 88% in California, more than 100 deaths in Connecticut, 53 deaths in Illinois, 114 deaths in the District of Columbia, and more, plus many, many more reports of abuse, neglect and death across the majority of all states.[5]

III. Using HHS Funds to Eliminate HHS-Supported Homes:

National Council on Disability (NCD)

NCD is a small, HHS-funded, independent federal agency that advises the President,

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[3] June 14, 2010 and July 30, 2007 letters to Congress referring to families as "unaware" and "clueless," respectively.

[4] ". . . close relatives and guardians, both of whom likely have intimate knowledge of a mentally retarded person's abilities and experiences, have valuable insights which should be considered during the involuntary commitment process." *Heller v. Doe*, 509 U.S. 312, 329 (1993).

[5] Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities (VOR, 2013)

Congress, and other federal agencies on issues affecting people with disabilities. On October 23, 2012, NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. NCD spent nearly $150,000 in federal funds to prepare and publish "Deinstitutionalization: Unfinished Business," calling on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes. NCD did not consult with the individuals who could be evicted from their homes, nor their families and legal guardians. Instead, NCD accuses these caring families and guardians of violating their family members' civil rights for choosing a care setting of four or more people.

Like AAID, NCD cites the landmark Supreme Court decision of ***Olmstead v L.C.*** **(1999)** as justification for its position to close HHS homes. Like many organizations that support deinstitutionalization, AAID and NCD misread and misapply the *Olmstead* decision's requirements. The Supreme Court made it very clear that the ADA requires individual choice before community placement can be imposed, expressly recognizing an ongoing role for facilities:

> "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*, 119 S. Ct. 2176, 2187 (1999) (majority).

> "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 (plurality) (*see also*, *Id*. at 2191 (Kennedy, concurring) (it would be "unreasonable" and "tragic" if the ADA were interpreted to "drive those in need of medical care and treatment out of appropriate care and into settings," not capable or prepared).

Likewise, **Medicaid law** and regulation requires that ICF/ID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. §441.302(d)(2); see also, 42 U.S.C. §1396n(c)(2)(C) and 42 C.F.R. §441.303.

NCD's support for deinstitutionalization is contrary to federal law and reckless. ICFs/ID have an array of services not often available elsewhere (*e.g.*, on-site medical care, dental care, other specialties, and involvement in their broader communities). As discussed above, tragedies are predictable when residents are separated from life-sustaining supports.

IV. Solution and Conclusion

HHS-funded agencies should not be allowed to advance an ideological agenda in support of evicting eligible people from HHS-licensed homes, contrary to the DD Act, Medicaid law, and the ADA/*Olmstead*. Such actions are a cruel and absurd use of federal funding that is exacting great harm on our nation's most vulnerable citizens.

VOR urges the Subcommittee on Labor, HHS, Education and Related Agencies to act: Please support language to ***prohibit*** **the use of HHS appropriations in support of deinstitutionalization activities which evict eligible individuals with I/DD from HHS-licensed and funded facilities (e.g., ICFs/ID).** Federal law and policy supporting a full array of options reflect societal values which respect individual and family decision-making. No federal agency should define "choice" so narrowly and illegally as to disenfranchise the most vulnerable segment of our disabled population.

Mary Reese
VOR Board Member
Member, VOR Legislative Committee

Mary has over 50 years' experience serving on nonprofit county and state boards, and on committees representing individuals with intellectual and developmental disabilities (I/DD) and in leadership capacities encouraging volunteerism. She is the former Volunteer Services Director of a Maryland ICF/ID and the former Executive Director of Prince George's County Volunteer Center.

In 2012, Mary was elected to the Board of Directors for VOR, a national organization advocating for high quality care and human rights for all people with I/DD. Mary's advocacy is motivated by her step-daughter, Virginia, who has profound I/DD and medical challenges. Mary is Virginia's legal guardian and for years worked tirelessly to ensure adequate community supports while seeking admission to a state operated ICF/ID.

Recently, after a legal fight over many years, Mary secured placement at Holly Center for Virginia. Her story is featured on VOR's website (http://vor.net/images/VirginiasStory.pdf) and was recently the topic of WBAL 11 I Team report (http://www.wbaltv.com/news/maryland/i-team/Caretaker-fights-state-to-get-disabled-woman-needed-care/-/10640252/19003378/-/item/0/-/npe49ez/-/index.html).

Mary resides in Rockville, Maryland.