VOR
Speaking out for people with
intellectual & developmental disabilities

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VOR, Speaking out for people with intellectual and developmental disabilities

Written Testimony for the House Appropriations
Subcommittee on Labor, HHS, & Education and Related Agencies

I. Agency, Program and Amount of Funding Involved in the Request

VOR has serious concerns about the activities of certain U.S. Department of Health and Human Services (**HHS**) agencies, including the Administration on Intellectual and Developmental Disabilities (**AIDD**), the National Council on Disability (**NCD**), and the Centers for Medicare & Medicaid Services (**CMS**). **We do not seek any funding, but instead seek language in the Labor, HHS, Education and Related Agencies appropriations bill** that expressly prohibits the use of HHS appropriations in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

VOR is a national 501(c)(3) nonprofit, non-provider organization advocating for high quality care and human rights for all people with intellectual and developmental disabilities (I/DD).

II. Concerns and Rationale for Bill Language Prohibiting HHS Agencies from Using Federal Appropriations in Support of Forced Deinstitutionalization

Forced deinstitutionalization is the elimination of specialized services for people with I/DD and is contrary to federal law and cause human harm. HHS-funded AAID, NCD and CMS pursue deinstitutionalization activities including advocacy, lobbying, class action lawsuits, and other tactics that result in the downsizing and closure of HHS-licensed and funded ICF/IID homes, some specialized group homes, sheltered workshops and day programs. **These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of federal funding.**

The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored and predicable tragedies are widespread when fragile citizens are removed from life-sustaining, specialized care [*see e.g.*, Hundreds of deaths (*Augusta Chronicle*, March 2015); 1,200 "unnatural and unknown" deaths in New York (*New York Times*, 2011-2012); a risk of mortality in community settings of up to 88% in California (peer reviewed studies, 1996-2005); more than 100 deaths in Connecticut (*Hartford Courant*, March 2013); 53 deaths in Illinois (*Belleville News-Democrat*, June 27, 2012); hundreds of deaths in the District of Columbia (*Washington Post*, reports since 1999); plus **many more reports of abuse, neglect and death** across the majority of all states (Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities (VOR, 2015)).

Bill language is desperately needed to prohibit these HHS-funded actions that lead to human harm and are contrary to federal law.

III. Examples of HHS Agencies Using HHS Funds to Eliminate HHS-Supported Homes, Resulting in Human Harm

A. Administration on Intellectual and Developmental Disabilities (AIDD): AIDD, within HHS, administers the DD Act programs: Protection & Advocacy (P&A), DD Councils, and University Programs. 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 Department of Justice and The Arc (2011). The national organizations for the three DD Act programs have referred to families who select HHS-licensed homes (ICFs/IID) as “clueless” and “unaware.” [June 14, 2010 and July 30, 2007 letters to Congress referring to families as “unaware” and “clueless,” respectively].

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. For example, Disability Rights Ohio (DRO), the P&A, cited *Olmstead* and threatened a class action lawsuit purportedly on behalf of thousands of Ohioans with I/DD who receive care and support in licensed state and private ICFs/IID, sheltered workshop, or day program settings (July 1, 2014 letter to state officials). In response to DRO allegations and threats, more than 19,000 families (and growing) signed a petition objecting to the budget proposals and many have testified prompting legislators to ask “who does DRO [P&A] speak for?”

In addition, since 1996, more than fifteen (15) P&A class action lawsuits for closure – *not* relating to conditions of care and over the known objection of residents and their families – and other deinstitutionalization tactics have been pursued. 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/IID.

B. The National Council on Disability (NCD): NCD is an HHS-funded, independent federal agency that advises the President, Congress, and other federal agencies on issues affecting people with disabilities. On October 23, 2012, NCD released a 230-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.

C. <u>Centers for Medicare & Medicaid Services (CMS)</u>: Last year, CMS finalized a new regulation ("rule") that very narrowly defined settings which qualify as "home and community-based" for the purpose of receiving Medicaid Home and Community-Based Services (HCBS) funding. Individuals living in settings deemed too "congregate" or too close to ICFs/IID may not be able to continue to receive necessary HCBS supports. According to CMS, "we seek to ensure that Medicaid is supporting needed strategies for states in their efforts to meet their obligations under the ADA and the Supreme Court decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999)." [79 FR 11 (Jan. 16, 2014)]. The ADA, however, forbids public entities from excluding or denying individuals with disabilities equal opportunity to receive program benefits and services, and must provide services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. [*Olmstead* at 592, *citing* the ADA, 28 CFR §35.130(d) (1998)]. The new CMS rule defines "community" so narrowly that it will disqualify certain community homes, essentially redefining them as "institutions" for the purpose of HCBS funding eligibility. In so doing, CMS has effectively denied individuals with disabilities access to the very services they want and need by disqualifying some community settings that are in fact "the most integrated setting appropriate to the needs of qualified individuals with disabilities," in direct violation of ADA.

IV. The Law: The *Olmstead* Decision, Medicaid Law, and the DD Act Protect Individual Choice Based on Need

HHS-funded organizations pursuing forced deinstitutionalization cite the landmark Supreme Court decision of ***Olmstead v L.C.* (1999)** as justification for its position to close HHS homes. However, the Supreme Court is clear in its holding that the ADA requires individual choice before community placement can be imposed and recognizes the need for specialized care: "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*, 527 U.S. 581, 601-02 (1999) (1999) (majority).

Medicaid law and regulation also require that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." [42 C.F.R. §441.302(d)(2)].

The **DD Act**, which authorizes funding for AIDD programs, and related Congressional history, support residential choice and recognizes that individuals and their families are the "primary decisionmakers" with regard to services, supports and policies (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")].

V. <u>Solution and Conclusion</u>

HHS-funded agencies must be *prohibited* from advancing a federally-financed ideological agenda in support of evicting eligible people from HHS-licensed homes, contrary to the ADA/*Olmstead*, the DD Act, and Medicaid law. Such actions are a cruel and absurd use of federal funding that is exacting great harm on our nation's most vulnerable citizens with I/DD, and contrary to societal values and laws which respect individual and family decision-making. Please support language to ***prohibit*** **HHS-funded deinstitutionalization activities.** Federal agencies must not define "choice" so narrowly and illegally as to disenfranchise the most vulnerable segment of our society.