VOR
Speaking out for people with intellectual & developmental disabilities

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Organization Submitting Testimony:

VOR, *Speaking out for people with intellectual and developmental disabilities*
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Testimony Prepared For:

Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies
U.S. Senate Committee on Appropriations

Regarding:

U.S. Department of Health and Human Services (HHS) Agencies, including Administration on Intellectual and Developmental Disabilities (AIDD), National Council on Disability (NCD), and Centers for Medicare & Medicaid Services (CMS)

I. Introduction

VOR is a national nonprofit organization advocating for high quality care and human rights for all people with intellectual and developmental disabilities (I/DD).

VOR urges the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies Appropriations bill that expressly **prohibits the use of appropriations for any HHS program 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.**

Several HHS agencies use some of their federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including but not limited to AIDD and its programs, NCD, and CMS.

As explained below, we strongly believe such forced deinstitutionalization activities are contrary to federal law and cause human harm. These deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics by some HHS-funded agencies that result in the downsizing and closure of HHS-licensed 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.

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. **Bill language prohibiting the very actions that lead to human harm and are contrary to federal law is desperately needed.**

II. The Law: The *Olmstead* Decision, Medicaid Law, and the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) Protect Choice Based on Individual 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. Like many organizations that support deinstitutionalization, these federal agencies misread and misapply the *Olmstead* decision's requirements. The Supreme Court is clear in its holding that the Americans with Disabilities Act (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).
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> "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 605 (plurality).

Likewise, **Medicaid law** and regulation requires 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); see also, 42 U.S.C. §1396n(c)(2)(C) and 42 C.F.R. §441.303.

The **DD Act**, which authorizes for funding AIDD programs such as Protection & Advocacy Agencies, DD Councils, and University Affiliate Programs, and related Congressional history, support 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).
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> "[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" [H. Rep. 103-442 (March 21, 1994)].

III. Using HHS Funds to Eliminate HHS-Supported Homes Causing Human Harm: 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 15 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.[1] 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 ADA (as interpreted by the *Olmstead* decision) and Medicaid law, as outlined above.

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

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

national organizations for the three DD Act programs have referred to families who select HHS-licensed homes (ICFs/IID) as "clueless" and "unaware,"[2] a view not shared by the Supreme Court (*see*, *Heller v. Doe*, 509 U.S. 312, 329 (1993) (". . . 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.")).

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.

In a recent example, Disability Rights Ohio (DRO), the State's designated P&A, cited *Olmstead* and threatened a class action lawsuit purportedly on behalf of thousands of Ohioans with intellectual and developmental disabilities 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). Without consulting with what its authorizing legislation calls "primary decisionmakers" – the individuals and their families – DRO instead cites the experiences of three individuals with disabilities to make the case that "thousands" are equally unsatisfied with their present situations. DRO's allegations and threats of litigation, in part, prompted draconian budget proposals that will force thousands of individuals with profound disabilities from their homes, workplace, and day program settings.

In response to DRO allegations and threats, more than 18,000 families signed a petition objecting to the budget proposals and many have testified prompting legislators to ask "who does DRO speak for?"

Yet, as recently as March 26, 2015, DRO reiterated its threat, in spite of the families' petition and testimony which makes clear the widespread opposition to the budget proposals, writing, "Without the complete package of reforms laid out in the proposed budget, there would be no foundation for a future agreement and no alternative for class members but to pursue their claims in court." (March 26, 2015 letter to state officials).

Lawsuits have been a favorite tool of P&As over the years, so DRO's fear mongering comes as no surprise. 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/IID.

AIDD and its state-based programs persist in their ideological devotion to community placement despite **reports of hundreds of deaths** in Georgia (*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 (*see e.g*, Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities (VOR, 2015)).

IV. Using HHS Funds to Eliminate HHS-Supported Homes: National Council on Disability

The National Council on Disability (NCD) is an HHS-funded, independent federal agency that advises the President, Congress, and other federal agencies on issues affecting people with disabilities.

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

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. NCD has since received more than 350 letters from families opposing forced deinstitutionalization.

NCD's support for deinstitutionalization is contrary to federal law and reckless. ICFs/IID 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.

V. Centers for Medicare & Medicaid Services (CMS) Rule on Eligible Home and Community-Based Settings (HCBS) Narrows Options and Runs Counter to the Americans with Disabilities Act (ADA)

Last year, CMS finalized a new regulation ("rule") that defined settings which qualify as "home and community-based" for the purpose of receiving Medicaid HCBS funding. Individuals living in settings deemed too "congregate" or too close to ICFs/IID would not be able to continue to receive necessary HCBS supports. According to CMS, along with its overarching goal "to improve Medicaid HCBS, 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 6, *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.

VI. 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, and contrary to societal values which respect individual and family decision-making.

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 homes.** No federal agency should define "choice" so narrowly and illegally as to disenfranchise the most vulnerable segment of our disabled population.