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## TESTIMONY OF MARY REESE, VOR BOARD MEMBER

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### Before the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, House Appropriations Committee March 13, 2013

Mr. Chairman and Members of the Committee, thank you for the opportunity to meet with you today on behalf of VOR.

My name is Mary Reese.

VOR is a national organization advocating for high quality care and human rights for people with intellectual and developmental disabilities (I/DD). I am a VOR Board Member with over 50 years of experience working with and advocating for people with disabilities.

VOR respectfully requests the Subcommittee's support for language to ***prohibit the use of HHS appropriations in support of deinstitutionalization activities which evict vulnerable individuals with I/DD from HHS-licensed Medicaid facilities.*** Upon review of VOR's written testimony, and after listening to my comments today, I hope you will agree that HHS-funded closure activities which target HHS-funded and licensed homes are an absurd and cruel use of

federal funding: These closures often lead to human tragedy and violate federal law.

Like the vast majority of VOR members, my family member, Ginger, is my motivation. Ginger has profound intellectual disabilities and counts on me to be her voice.

Ginger recently moved to Holly Center, a state Medicaid Intermediate Care Facility. It took eight long years to secure the services she requires for her health and happiness. While we fought for admission, Ginger endured many health emergencies, inconsistent nursing care, and often neglect and injuries at the hands of poorly trained staff in her community setting.

Ginger is not alone in her past suffering. Headlines across the country tell of widespread tragedies in small settings serving people with I/DD. Reports 1,200 “unnatural and unknown” deaths in New York State, 100 plus deaths in Connecticut, 53 deaths in Illinois, and many more reports of abuse, neglect and death in a majority of states, are alarming.<sup>1</sup> Unconscionable is the fact that the very HHS-agencies that Congress has entrusted to protect people with I/DD rarely concern themselves with community-based tragedies and routinely dismantle the HHS-licensed and funded homes that provide highly-specialized care.

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<sup>1</sup> Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities (VOR, 2013) (<http://www.vor.net/images/AbuseandNeglect.pdf>).

Both the **Administration on Intellectual and Developmental Disabilities (AIDD)** and the **National Council on Disability (NCD)** are HHS-funded and pursue the closure of HHS-funded facilities, without regard to federal laws which require residential choice and individual and family decision-making.

AIDD oversees the federally-funded Developmental Disabilities Act programs, located in every state. These programs are Protection & Advocacy, DD Councils, and University 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. With virtually no independent oversight, AIDD and DD Act programs achieve deinstitutionalization through class action lawsuits, advocacy, and other tactics, routinely disregarding outcomes, individual choice and the legal right to appropriate services. The DD Act expressly recognizes that, “individuals with developmental disabilities and their families are the primary decisionmakers” with regard to residential care, supports and policies.<sup>2</sup>

HHS-funded NCD has also shown callous disregard for rights and outcomes. In October, NCD published “Deinstitutionalization: Unfinished Business,” a 300 page paper calling on advocates to engage in advocacy and file lawsuits to close all

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<sup>2</sup> DD Act, 42 U.S.C. 15001(c)(3)(2000).

homes with four or more people. Affected individuals and their families and legal guardians were not consulted. Instead, NCD unconscionably accuses caring families and guardians – parents like me – of violating our family members’ *civil rights* simply because we chose a care setting of four or more people.

Neither Medicaid law,<sup>3</sup> which expressly requires residential choice, nor *Olmstead*, the Supreme Court decision so frequently cited in support of deinstitutionalization, mandates or even allows these actions. In the *Olmstead* Court’s own words:

“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.”<sup>4</sup>

VOR implores this Subcommittee to take action. HHS agencies should not be filing lawsuits or pursuing advocacy against HHS programs. Please support language to ***prohibit the use of HHS appropriations in support of deinstitutionalization activities which evict vulnerable individuals with I/DD from HHS-licensed Medicaid facilities.***

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<sup>3</sup> 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.

<sup>4</sup> *Olmstead*, 119 S. Ct. 2176, 2187 (1999) (majority).

No federal agency should define “choice” so narrowly and illegally as to disenfranchise the most vulnerable segment of our disabled population. Such actions are a cruel and absurd use of federal funding that is exacting great harm on our nation’s most vulnerable citizens.

Thank you for this opportunity and for your consideration.