VOR
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

Wednesday, April 29, 2015

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 nonprofit, non-provider organization advocating for high quality care and human rights for people with intellectual and developmental disabilities. I am a VOR Board Member with over 50 years of experience working with and advocating for people with developmental disabilities.

Today, VOR is asking not for any money, but instead, we ask that the appropriated funding be used as intended, according to the law, and in support of family values and choice.

VOR respectfully requests the Subcommittee's support for language in the HHS appropriations bill to ***prohibit*** **the use of such appropriations in support of <u>forced</u> deinstitutionalization activities which evict vulnerable individuals with profound disabilities from HHS-licensed Medicaid facilities.** HHS-funded deinstitutionalization, which targets HHS-funded and licensed homes, is an absurd and cruel use of federal funding. Deinstitutionalization often leads to human tragedy and violates federal law.

Like the vast majority of VOR members, my family member, Ginger, is my motivation.

Ginger has profound intellectual disabilities. Two years ago she moved to Holly Center, a state Medicaid Intermediate Care Facility in Maryland. 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 profound disabilities. In Georgia, 500 people with developmental disabilities died in community settings in 2013, 62 of whom had recently been transferred from Medicaid facilities. Also in 2013, U.S. Senator Chris Murphy requested an Inspector General investigation,[1] due to what he called and "alarming number of deaths and cases of abuse of developmentally disabled individuals in group homes." There are many more such examples of increased mortality, abuse and neglect in small homes serving people with profound disabilities across the country, including in Tennessee, Maryland,

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[1] To our knowledge, this investigation is still pending.

Pennsylvania, Virginia, Connecticut and California.[2]

Unconscionable is the fact that the very HHS-agencies that Congress has entrusted to protect people with developmental disabilities rarely concern themselves with community-based tragedies and routinely dismantle the HHS-licensed and funded facility homes that provide highly-specialized care. Top level HHS administrators either encourage or are unaware of the resulting human harm by certain HHS-funded agencies. This was made clear in questioning by Vice Chairman Womack of Kathy Greenlee, the Administrator of the Administration on Community Living within HHS. At a February 26, 2015 hearing of this Subcommittee,[3] Rep. Womack asked Ms. Greenlee a series of questions about Protection & Advocacy's[4] deinstitutionalization tactics, including lawsuits and lobbying without regard to the choices of families and legal guardians, Ms. Greenlee's responses to Vice Chair Womack's questions were incomplete and worrisome.

Another HHS-funded agency, the National Council on Disability (NCD), has also shown callous disregard for rights and outcomes. NCD has published "Deinstitutionalization: Unfinished Business," calling on advocates to engage in advocacy and file lawsuits to close all homes with four or more people. Affected

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[2] Source: Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities (VOR, 2015) at http://www.vor.net/images/AbuseandNeglect.pdf or upon request by contact thopp@vor.net.

[3] The Vital Responsibility of Serving the Nation's Aging and Disabled Communities (LHHS Subcommittee), February 26, 2015, https://www.youtube.com/watch?v=Yy4Dtyeyg9o (at 1:33:37)

[4] Protection & Advocacy is one of the Administration on Intellectual and Developmental Disabilities' (AAIDD) programs. AAIDD is within Kathy Greenlee's Administration on Community Living in HHS.

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.

Very often, as Ms. Greenlee indicated during her testimony, the Supreme Court's *Olmstead* decision is *incorrectly* cited as justification for serving everyone in community settings. In fact, here is what Supreme Court in *Olmstead* said about deinstitutionalization:

> "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."[4]

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 forced deinstitutionalization activities which evict vulnerable individuals with I/DD from HHS-licensed Medicaid facilities.** VOR would be pleased to propose such language.

No federal agency should define "choice" so narrowly and illegally as to harm 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.