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:
House Appropriations, Subcommittee on Commerce, Justice, Science and Related Agencies (CJ.Approp@mail.house.gov)

Regarding:
The U.S. Department of Justice (DOJ)

Requesting:
Conditions consistent with the *Olmstead* decision on federally-funded DOJ court actions that involve the residents of Medicaid-licensed Intermediate Care Facilities (ICFs/IID) or other specialized Medicaid-licensed facilities for persons with intellectual and developmental disabilities.

I. Introduction

VOR, a national nonprofit advocacy organization for people with intellectual and developmental disabilities (I/DD) and their families, expresses gratitude to Chairman John Culberson and members of the Subcommittee for this opportunity to submit testimony for the record in consideration of FY 2016 appropriations for the Department of Justice (DOJ). VOR's members look forward to working with Subcommittee and its staff to ensure the enforcement of the civil rights of our most fragile citizens with I/DD.

II. Summary: Legislative Language Needed to Enforce Individual Choice According to the U.S. Supreme Court's *Olmstead* Decision

As explained below, VOR asserts that the DOJ Civil Rights Division's legal proceedings and related actions to enforce the Americans with Disabilities Act (ADA) ("*Olmstead* enforcement"), directed at individuals with profound I/DD who reside in Medicaid-licensed facilities (e.g., ICFs/IID), have often caused human harm, including death, and financial and emotional hardship.

The concern is widespread: Since 2009, the Department of Justice (DOJ) has filed more than 45 "*Olmstead* enforcement" actions in 25 states. Yet, these actions often violate the letter and spirit of the *Olmstead* decision, especially with regard to the requirement of individual choice [*see, Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581 (1999)]***

In response to these very concerns, last Congress, this Subcommittee advanced this report language in H. Rep. 113-448 to accompany H.R. 4660 (May 15, 2014) at pp. 44-45:

> *Deinstitutionalization - The Committee notes the nationwide trend towards deinstitutionalization of patients with intellectual or developmental disabilities in favor of community based settings. The Committee also notes that in Olmstead v. L.C. (1999), a majority of the Supreme Court held that the Americans with Disabilities Act does not condone or require removing individuals from institutional settings when they are unable to handle or benefit from a community based setting, and that federal law does not require the imposition of community-based treatment on patients who do not desire it. The Committee strongly urges the Department [of Justice] to factor the needs and desires of patients, their families, and caregivers, and the importance of affording patients the proper setting for their care, into its enforcement of the Americans with Disabilities Act.*

In subsequent Conference negotiations, the Report language was changed, and Congress included this report language relating to DOJ actions in the Conference Report to accompany H.R. 83, Consolidated and Further Continuing Appropriations Act, 2015 (Division B, Commerce, Justice, Science and Related Agencies) (Pub.L. 113-235, December 16, 2014):

> *"Deinstitutionalization.-There is a nationwide trend towards deinstitutionalization of patients with intellectual or developmental disabilities in favor of community-based settings. The Department [of Justice] is strongly urged to continue to factor the needs and desires of patients, their families, caregivers, and other stakeholders, as well as the need to provide proper settings for care, into its enforcement of the Americans with Disabilities Act."*

This report language does not go far enough.

VOR urges the Subcommittee to build on this language and **adopt bill language** that conditions DOJ's appropriations, prior to bringing any court action, on (1) DOJ first consulting with residents, or their legal guardians, to determine residents' needs and choices with regard to residential services and supports and, (2) consistent with the *Olmstead* decision, not impose "community-based treatment on patients who do not desire it." [*Olmstead* at 602].

III. Rationale

A. Background on Forced Deinstitutionalization

There is a national trend towards deinstitutionalization, whereby individuals are encouraged and sometimes forced to move out of Medicaid-licensed care facilities (including Intermediate Care

Facilities for Persons with Intellectual and Development Disabilities, "ICFs/IID") and into residential settings.

However, there are significant well-founded concerns among the family members and legal guardians of individuals residing in state-run and private ICFs/IID regarding the adequacy of opportunities for residents to make their views and preferences known throughout the process.

B. Widespread, Well-Documented Human Tragedy

VOR and the families we represent are deeply concerned by the many reported outcomes of abuse, neglect and death of individuals with intellectual and developmental disabilities in community settings.

Higher mortality rates in Virginia, Nebraska, Tennessee, and Georgia, have been documented in the wake of DOJ's deinstitutionalization settlement enforcement.

In **Virginia** (*U.S. v. Virginia*), the risk of mortality for those individuals who left a state ICF/IID was double that of those who stayed.

In **Nebraska** (*U.S. v. Nebraska*), 94 (27%) individuals with profound I/DD who were transferred from a state ICF/IID pursuant to a DOJ settlement agreement subsequently died. A subset of "medically fragile" individuals died at a much higher rate, 43%, after transition from the ICF/IID.

In **Tennessee** (*U.S. v. Tennessee, 1992 and 1996*[1]), DOJ lawsuits resulted in the closure of Arlington Developmental Center (an ICF/IID) in 2010, and the downsizing Clover Bottom, Greene Valley, and Nat T. Winston developmental centers. **Deaths among people with intellectual disabilities released from institutions nearly doubled between 2009 and 2013.** Court-appointed monitors noted they are 'deeply concerned with the number of deaths, the age of the (individuals) at death, circumstances surrounding the deaths, and lack of comprehensive review and analysis.'" ["When disabled leave facilities, it's not all good," *Tennesseean* (Feb. 10, 2014) (**emphasis added**)]. A 2013 State Comptroller's audit also reported lack of access to adequate medical and dental care, incarcerations, hundreds of reports of abuse, and neglect and exploitation.

In **Georgia**, a 2010 Justice Department Settlement Agreement with the State in *U.S. v. Georgia* calls for the transition of nearly 1,000 individuals with I/DD and the closure of all state-operated ICFs/IID and the transition of 9,000 individuals with mental illness from facility-based care. Just last week, on March 21, 2015, relying on State documents, the *Augusta Chronicle* reported that **of the 499 individuals with profound I/DD who have been transferred from ICFs/IID pursuant to a DOJ "Olmstead enforcement" settlement, 62 (12%) have died unexpectedly.** Overall, there have been 1,000 deaths over two years (2013-2014) in community settings, 22% of which were "unexpected. Thousands of hospitalizations and hundreds of reports of abuse,

[1] These cases pre-dated the 1999 Olmstead decision; DOJ filed these actions under its Civil Rights for Institutionalized Persons Act (CRIPA) authority.

elopements, and interactions with law enforcement have also been reported in each of its Annual Quality Management Reports for 2013 and 2014.

Most tragic is that these deaths and other tragic outcomes (hospitalizations, abuse, neglect and injuries) were predictable. They've happened time and again in the majority of all states. ["Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities," VOR (Revised March 2015)]. In 2013, U.S. Senator Chris Murphy cited "the alarming number of deaths and cases of abuse of developmentally disabled individuals in group homes," and pointed to the "prevalence of *preventable* deaths at privately run group homes across this nation," in his request for an Inspector General investigation.

Even Samuel Bagenstos, a former DOJ Civil Rights Division Principal Deputy Assistant General and key litigator in "Olmstead enforcement" deinstitutionalization cases points to the inadequacy of community-based placements in deinstitutionalization actions:

> "It should not be surprising that the coalition of deinstitutionalization advocates and fiscal conservatives largely achieved their goal of closing and downsizing institutions and that deinstitutionalization advocates were less successful in achieving their goal of developing community services." [Bagenstos, Samuel R., *The Past and Future of Deinstitutionalization Litigation*, 34 Cardoza L. Rev. 1, 21 2012)].

C. The U.S. Department of Justice's *Olmstead* Enforcement is Contrary to Olmstead

DOJ's "*Olmstead* enforcement" actions seem to violate the letter and spirit of the *Olmstead* decision. [*Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581 (1999)*].

In particular, the Supreme Court in its *Olmstead* decision establishes the right to community-based housing and care *only* when the "State's treatment professionals have determined that community placement is appropriate", "transfer is not opposed by the affected individual" and "the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities" [*Id.* at 587].

The Court clarified its holding as follows:

> "We emphasize that nothing in the ADA [Americans with Disabilities Act] 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." [527 U.S. 581, 601-02 (1999) (*see also*, Justice Kennedy's concurring opinion, "It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that states had some incentive, for fear of litigation to drive those in need of medical care and treatment out of appropriate care and into settings with no assistance and supervision").

DOJ must not substitute its ideological view that all residents of ICFs/IID and similar facilities are better served in community placements for the Supreme Court's specific tests for community placement, which includes the judgments of the legal representatives of behalf of incapacitated residents.

Yet, *Olmstead* investigations and actions by DOJ against states have been pursued with the express intent of "Community Integration for Everyone" have rarely included consultation with families and legal guardians, and have led to settlements requiring deinstitutionalization without regard to assessments of individual needs and choices. As recognized by U.S. District Judge J. Leon Holmes in his order dismissing the Justice Department's case against the State of Arkansas:

> "Most lawsuits are brought by persons who believe their rights have been violated. Not this one. The Civil Rights Division of the Department of Justice brings this action on behalf of the United States of America against the State of Arkansas and four state officials in their official capacities alleging that practices at Conway [ICF/IID] violate the rights of its residents guaranteed by the Fourteenth Amendment, the Americans with Disabilities Act, and the Individuals with Disabilities Education Act. All or nearly all of those residents have parents or guardians who have the power to assert the legal rights of their children or wards. Those parents and guardians, so far as the record shows, oppose the claims of the United States. ***Thus, the United States is in the odd position of asserting that certain persons' rights have been and are being violated while those persons – through their parents and guardians – disagree***." [*U.S. v. Arkansas* (June 8, 2011, dismissal order) (***emphasis added***)].

In *United States v. Virginia* (2012), families and legal guardians were conspicuously absent from the long list of stakeholders interviewed by the Justice Department prior to settlement and families spent $115,000 to overcome Justice Department and Commonwealth opposition to secure intervention. [*U.S. v. Virginia*, *supra* note 2].

In *United States v. Georgia* (2010), the Department did not consult with families and legal guardians before entering a settlement that requires that the closure of Georgia's ICFs/IID and forces all residents from these homes. The Settlement does not provide families and legal guardians any decision-making authority except in the context of community transition. As discussed above, significant harm to affected individuals has followed transitions in Georgia and other states.

IV. Conclusion

Given these concerns, VOR urges the Subcommittee to adopt bill language that conditions DOJ's appropriations, prior to bringing any court action, on (1) DOJ first consulting with residents, or their legal guardians, to determine residents' needs and choices with regard to residential services and supports and, (2) consistent with the *Olmstead* decision, not impose "community-based treatment on patients who do not desire it." **[***Olmstead* at 602].

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