VOR
Speaking out for people with intellectual & developmental disabilities

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Testimony Prepared For:
Senate Appropriations, Subcommittee on Commerce, Justice, Science and Related Agencies

Regarding:
Department of Justice FY 2015 Budget

PROTECTING THE INTERESTS OF RESIDENTS OF MEDICAID-LICENSED FACILITY HOMES FOR PERSONS WITH INTELLECTUAL DISABILITIES IN ACTIONS CONDUCTED BY THE DEPARTMENT OF JUSTICE'S CIVIL RIGHTS DIVISION THAT AFFECT THEIR CHOICE OF RESIDENCY

I. Introduction

VOR, a national advocacy organization for people with intellectual and developmental disabilities (I/DD) and their families, express gratitude to Chairwoman Barbara Mikulski and members of the Subcommittee on Commerce, Justice, Science and Related Agencies for this opportunity to submit testimony for the record in consideration of FY 2015 appropriations for the Department of Justice.

VOR's members look forward to working with Senators and their staff to ensure the civil rights of our most fragile citizens with I/DD.

II. Summary: Legislative Choice Language Proposal

As explained in detail below, VOR asserts that legal proceedings and related actions, such as investigations, brought against states by the Department of Justice's Civil Rights Division under the Americans with Disabilities Act (ADA) have caused significant financial and emotional hardships, and sometimes harm, to individuals with developmental and intellectual disabilities and their families. **The concern is widespread: the Department of Justice has filed more than 40 actions in more than 25 states**. VOR views these "*Olmstead* enforcement" actions to violate the spirit and even, at times, the letter of the *Olmstead* decision, especially with regard to the requirement of individual choice [*Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581 (1999)]*. To correct for this injustice, VOR urges the Senate to adopt the following choice language relating to Department of Justice appropriations:

> "No funds appropriated for any Department of Justice program shall be expended to promote any law or policy that limits the choices of individuals with intellectual and developmental disabilities (or, if an individual has a legal representative, the legal representative), seeking living arrangements they believe are most suitable to their needs and wishes."

III. Rationale

A. Background on <u>Forced</u> 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 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. They are also concerned about whether state-run and private facilities are being closed before adequate community placements are available; whether Medicaid reimbursements rates are adequate to facilitate the services necessary in such community placements for residents to lead safe and fulfilling lives; whether, due to a lack of adequate local community placements, some residents are being placed in community facilities too far from family members sometimes to meet the goals of integration into the community; the pace of transfers; and the pressure being put on legal representatives to move residents from their ICF/IID homes and other specialized facilities.

B. The U.S. Department of Justice's *Olmstead* Enforcement

As stated above, legal proceedings and related actions, such as investigations, brought against states by the Justice Department's Civil Rights Division under the ADA have caused significant financial and emotional hardships, and sometimes harm, to individuals with I/DD and their families. VOR views these "*Olmstead* enforcement" actions to violate the spirit and even, at times, the letter 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" <u>and</u> "the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities" [*Olmstead* 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").

It is not the Justice Department's place to 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 the Justice Department against states have been pursued with the express intent of "Community Integration for Everyone" [DOJ Olmstead Enforcement website, 2014], 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 Human Development Center [a Medicaid-licensed 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***); *see also*, *Olmstead:* Community Integration ***for Everyone*** - Olmstead Enforcement, U.S. Department of Justice Civil Rights Division (website)(***emphasis added***): detailing the Division's *Olmstead* enforcement efforts in more than 40 matters in more than 25 states in the past 5 years].

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 $125,000 to overcome Justice Department and Commonwealth opposition to secure intervention of right [*see*, *United States v. Virginia*, Memorandum Order Approving Motion to Intervene (May 9, 2012): "[T]he Petitioners have a significant, protectable interest in receiving the appropriate care of their choice and protecting their rights under the ADA. See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 602 (1999) ('Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.")… The Petitioners are all [ICF/IID] Training Center residents who wish to continue receiving institutional care in their current settings. As such, their interests are certainly affected by a lawsuit alleging deficiencies in their care and a consent decree whose stated purpose is to prohibit the unnecessary institutionalization of Virginians with ID/DD…The parties' [Justice Department and Commonwealth] desire to phase out the residential Training Centers and transition all Virginians with ID/DD to community-based care is readily apparent."].

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 next, significant harm to affected individuals has followed transitions in Georgia and other states.

C. The Human Consequences

VOR is also deeply concerned by the many reported outcomes of abuse, neglect and death of individuals with intellectual and developmental disabilities in community settings [*see e.g,* Letter from U.S. Senator Chris Murphy to Daniel R. Levinson, Inspector General, U.S. Department of Health and Human Services (March 4, 2013): "I write to you today to request that you undertake an immediate investigation into the alarming number of deaths and cases of abuse of developmentally disabled individuals in group homes. In particular, I would like you to focus on the prevalence of preventable deaths at privately run group homes

across this nation and the widespread privatization of our delivery system."; "In State Care, 1,200 Deaths and Few Answers," *New York Times* (November 5, 2011): investigation finding that more than 1,200 deaths in state-run group homes in the past decade have been attributed to either "unnatural or unknown causes"; and Bagenstos, Samuel R., *The Past and Future of Deinstitutionalization Litigation*, 34 Cardoza L. Rev. 1, 15, 21 (2012), which raises serious questions about the adequacy of community-based placements; **notably, Mr. Bagenstos is a former Principal Deputy Assistant Attorney General in the Obama Justice Department's Civil Rights Division and was a key litigator in deinstitutionalization cases.]**

In Georgia, where a 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, the Georgia Department of Behavioral Health & Developmental Disabilities' Office of Quality Management released its Annual Quality Management Report (February 2014) finding that in 2013 there were 82 unexpected deaths, 1,200 hospitalizations, 318 incidents requiring law enforcement services, 305 individuals who were expectantly absent from a community residential or day program, and 210 alleged instances physical abuse of mentally ill and developmentally disabled individuals. Similar concerns, including some mortalities, were confirmed in a March 23, 2014 report from Elizabeth Jones, the Independent Reviewer in *U.S.v. Georgia.* In report, Jones cites an "urgent need to ensure competent and sufficient health practitioner oversight of individuals who are medically fragile and require assistance with most aspects of their daily lives." [*see*, "Report: Developmentally Disabled Need Better Care," Georgia Health News (April 10, 2014); *see also*, "Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities," VOR (rev. February 2014)].

IV. Conclusion

Given these concerns, VOR respectfully request that language be added to appropriations legislation to require individual choice, nothing more or less, as follows:

> "No funds appropriated for any Department of Justice program shall be expended to promote any law or policy that limits the choices of individuals with intellectual and developmental disabilities (or, if an individual has a legal representative, the legal representative), seeking living arrangements they believe are most suitable to their needs and wishes."

Thank you for your consideration. For more information please contact Tamie Hopp, VOR Director of Government Relations & Advocacy at thopp@vor.net or 605-399-1624.