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Health, Education, Labor and Pensions Committee
U.S. Senate
Washington, D.C. 20510

RE: VOR written testimony for the record for HELP Hearing, “ADA and *Olmstead* Enforcement: Ensuring Community Opportunities for Individuals with Disabilities,” (June 22, 2010).

Dear Chairman Harkin, Ranking Member Enzi and Members of the HELP Committee,

VOR respectfully submits this written testimony and related attachments in response to the recent Committee hearing relating to “ADA and *Olmstead* Enforcement,” held June 22, 2010.

VOR is a national, nonprofit, advocacy organization representing individuals with intellectual and developmental disabilities and their families. The vast majority of the people VOR represents are full grown adults with the mental age of a newborn or one year old. They cannot care for themselves, many have never spoken, and they are the most medically fragile of our citizens. VOR strongly supports a continuum of quality care options to meet the wide range of needs, ranging from family home, own home and other community-based options to Medicaid-licensed facility-based homes (ICFs/MR).

This hearing was a critically important opportunity for Senators to hear from advocates, professionals, and policymakers regarding opportunities for expanding community-based services for individuals with disabilities. The need for expansion of quality community programs is undeniable. As Tom Perez testified, more than 393,000 are waiting for home and community-based services.

I. *Olmstead* Enforcement: Respecting Different Needs

Despite the obvious need for expanded community options, however, the overriding theme for this hearing was “closing institutions.” As is often the case in the context of “*Olmstead* Enforcement” discussions, the diversity of the disability community was not adequately considered.

Mr. Perez shared the stories of Paul and Michele, two highly educated individuals with physical disabilities who understandably desire to be served in their homes and not nursing homes. As noted by Senator Harkin, why should Paul, Michele and others like them be served in nursing homes when they could be served for “8 hours a day of attendant services . . . or maybe even 4 or 6 hours, or maybe it is a small intervention in the work place.” We agree.

But for some other disabled people, anything less than 24/7 highly specialized services would be a death sentence. There are thousands of people with severe and profound intellectual disabilities who are also medically fragile and have multiple physical disabilities, or who experience significant behavioral challenges that render them dangerous to themselves or others. These individuals are thriving in ICFs/MR, specialized facilities designed to meet their long-term, complex care needs 24/7.

Too often, however, “*Olmstead* enforcement” initiatives disregard the fundamental differences between individuals with physical or mild intellectual disabilities and those with profound intellectual disabilities. Contrary to the *Olmstead* decision’s support for individual choice and its recognition that

some individuals' have needs that are so great that they may require institutional care¹, a typical "Olmstead enforcement" initiative benefits greatly people like Paul and Michele but, at the same time, by advocating for the closing of "institutions" undermines the services needed by the very fragile individuals being served in ICFs/MR. Senator Al Franken shared a story about a "delicate, vulnerable person" being forced from his group of 20 years simply because the state figured it would save money. After investigating the situation, Senator Franken realized that money was saved only because services were significantly cut. "This is why this individual's family was panicked." In response, Cindy Mann, Director of CMS, responded:

"How awful it is to be that person, to be that person's family . . . to be out of control, not being able to make that decision about what goes on in the most important aspects of their life . . . rethink . . . give back an ability to control and make their own decisions to the fullest extent possible."

We agree, and indeed that is exactly what Olmstead requires².

II. VOR urges the HELP Committee to hold hearings and reauthorize the Developmental Disabilities Assistance and Bill of Rights Act which hasn't been reauthorized in 10 years

The recent HELP hearing on "ADA and *Olmstead* Enforcement" is a perfect prelude to a long-overdue hearing: The Reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act). It has been a decade since the DD Act was last subjected to Congressional scrutiny and reauthorized.

We want to be clear upfront. VOR supports reauthorization of the Developmental Disabilities Act. We believe the DD Act programs play an important role in encouraging community integration.

However, we strongly believe that most federally-funded DD Act programs, including state DD Councils, state Protection & Advocacy groups, and University Centers of Excellence for People with DD, are harming the very people they are supposed to protect by subscribing to the incorrect notion that the DD Act and the Americans with Disabilities Act (ADA), as interpreted by the *Olmstead* decision, mandate the transition of *all* people from ICFs/MR to alternative settings. P&A, which files class action lawsuits for the sole purpose of forcing "community integration," are most guilty of operating as though *Olmstead* and the DD Act are mandates to close centers.

Furthermore, all three DD Act programs believe that families of ICFs/MR residents need to be "educated" about the community and are spending precious resources on propaganda to prove how successful some transitions are. Families whose children reside in ICF/MR homes do not need to be

¹ In addition to requiring individual choice ("the transfer from institutional care to a less restrictive setting is not opposed by the affected individual"), the Supreme Court cautioned against reading its decision as an endorsement of total 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." 119 S. Ct. 2176, 2187 (1999).

² Tom Perez testified to recent DOJ "Olmstead Enforcement" efforts in a number of states. These efforts were designed to move people out of ICFs/MR into the community despite the opposition of the families and guardians. In DOJ filings in Virginia and Tennessee, the court ruled against DOJ, noting that DOJ's Olmstead interpretation put too much emphasis on professional opinion, to the disregard of individual and family choice.

educated any more than families of those living in the community. They have simply made a choice that is deemed unacceptable to the policies of the DD Act programs, contrary to their authorizing statute and the ADA (*Olmstead*). Their original charge was not to do this type of work but with the long gap in federal oversight, these programs have wandered off their established path of advocating for people with intellectual disabilities into the role of telling the families and guardians of people with profound intellectual disabilities what is best for their loved ones. The result is to impose new limitations on people with intellectual disabilities rather than to expand those options to the maximum extent possible.

What the law really says: The DD Act and Olmstead

After our discussion of the DD Act below, we make recommendations for changes to the DD Act so that the programs can properly carry out the will of the Congress.

Like *Olmstead* in 1999, the DD Act in its 1993 amendments upheld the rights of individuals with developmental disabilities and their families to be the primary decisionmakers:

“Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive 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)(1993) (*Findings, Purposes and Policies*)³.

The “primary decisionmaking” clause was first added to the Act in 1993 due to an amendment by Congressman Henry Waxman. In 1999, the spirit of the clause was embodied in the *Olmstead* decision itself. Both the Act and *Olmstead* recognize that individuals and their families are in the best position to know what is best by way of services, supports and policies. Both the Act and *Olmstead* embrace individuality – recognizing that people with disabilities have very diverse needs.

Both also caution against forcing a community setting on someone who does not desire and could not handle a community setting. The legislative history of the DD Act is as clear as *Olmstead* on this point:

“[T]he Committee would caution that goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities not be read as a Federal policy supporting the closure of residential institutions. It would be contrary to Federal intent to use the language or resources of this Act to support such actions, whether in the judicial or legislative system.” [House Energy & Commerce Report, No. 103-378 (November 18, 1993)].

The parallels between *Olmstead* and the DD Act are unmistakable. Yet, many DD Act programs continue to work to counter to individual and family choice by proactively seeking the elimination of the ICFs/MR option.

Chairman Harkin noted during the ADA/*Olmstead* hearing that Protection & Advocacy groups are doing great work. In areas of transportation, accessible housing, education and other areas, we agree. But, when they engage in ideologically-motivated advocacy and lawsuits to close ICFs/MR, we believe they are violating both the DD Act and the ADA with tragic human consequences.

³In 2000, the following language was added to the “primary decisionmaking” clause, further strengthening the right of individuals and their families to choose from among an array of residential options: “. . . , including regarding choosing where the individuals live from available options, . . .”

The tragedies felt by individuals who are forced out of their long-time homes by a lawsuit or other DD Act advocacy are no different than that felt by the family whose pleas resonated with Senator Franken and whose story is, as Chairman Harkin recognized, multiplied many thousands of times over across the country.

The affected individuals and their families deserve a hearing; they deserve a voice. A hearing in conjunction with the DD Act would provide these individuals and their families, as well as other people with intellectual and developmental disabilities and their families, that opportunity.

Thank you for this opportunity and your consideration.

For More Information

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Attachments:

Summary (one page): The Reauthorization of the Developmental Disabilities and Bill of Rights Act: The Need for Immediate Reforms

Detailed, Annotated, Presentation (12 pages):
The Reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act: The Need for Immediate Reforms.