VOR
Speaking out for people with
intellectual & developmental disabilities

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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 the Senate Health, Education, Labor and Pensions (HELP) Committee Hearing, "*Olmstead* Enforcement Update: Using the ADA to Promote Community Integration," (June 21, 2012).

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

VOR respectfully submits this written testimony in response to the recent Committee hearing, "*Olmstead* Enforcement Update: Using the ADA to Promote Community Integration" (June 21, 2012).

VOR is a national, nonprofit, advocacy organization representing individuals with intellectual and developmental disabilities (ID/DD) 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.

Consistent with *Olmstead* and a myriad of federal laws, 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).

Individuals with ID/DD who rely on ICF/MR care do not have the capabilities of witness Ricardo Thornton, whose accomplishments since moving from Forest Haven Center more than 3 decades ago are impressive and heartwarming. His 34-year career working in the library, his happy marriage, his fatherhood, and his capable self-advocacy are all to be applauded. Years of aggressive deinstitutionalization have led to more appropriate, less-specialized services for former residents like Mr. Thornton. However, other affected individuals, as discussed below, have been met with preventable, predictable tragedy. The Supreme Court, in its *Olmstead* decision, expressly cautioned against interpreting its decision as a deinstitutionalization mandate, predicting such action would harm people:

> "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." *Olmstead v. L.C.*, 119 S. Ct. 2176, 2187 (1999). (*See also*, "As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk... 'Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution'[quoting VOR's *Amici Curiae* brief]." *Id.* at 2189

Despite the clarity of the Supreme Court's holding and its cautionary statement with regard to unjustified *community* placement, federal and state officials continue to mischaracterize *Olmstead*, treating it as a mandate to close facilities without any regard for how individuals will be served. As indicated in his statement to the HELP committee, Thomas Perez, Assistant Attorney General, Civil Rights Division, Department of Justice, "The Court's [*Olmstead*] ruling has often and properly been called the *Brown v. Board of Education* of the disability rights movement." One VOR Board Member responded:

> "'Appropriate' services, supports and placements are individualized and not necessarily 'equal.' My children would die if all that was available to them was what everyone else has available. With regard to level of disability, my children were not created equal. They need highly-specialized 24/7 care."

Mr. Thornton does not need 24/7 direct care supports. Imposing such care on him would not be appropriate, cost effective or even humane. Consider, however, Aaron Underwood. Providing Aaron care "equal" to the supports received by Mr. Thornton would be a death sentence:

> "**Aaron** was born 8 weeks prematurely in December, 1979. While he survived the birth, the lifelong effects from subarachnoid and pulmonary hemorrhages are devastating. A large portion of his brain was destroyed with the subarachnoid hemorrhage. Aaron is profoundly neurologically impaired to the point that mental retardation is not even an appropriate descriptor. His functional abilities are in the 2-3 month range. Seizures, respiratory insufficiency, frequent pneumonias, cortical blindness, spastic tetraplegia with ever increasing spasticity are just a few of the daily challenges for his caregivers. Aaron has no purposeful movement and does not reach for nor grasp objects. He will remain in the position he is placed until someone repositions him. He has no bowel or bladder control – undergarments will be required for the rest of his life. An incomplete swallow coupled with frequent aspirations necessitates a feeding tube for all nutrition and medications. He can, and has, choked on his own mucus, cutting off his airway. Aaron is non-mobile and when not in bed is positioned in a custom made wheelchair which accommodates the curvature of his body. Aaron is also non-verbal and cannot communicate his needs. Needs must be anticipated and proactively met." ("Meet Aaron Underwood," 2011 by parents Kevin and Rebecca Underwood)

People with disabilities have wide-ranging, diverse, unequal *needs*. Equal *rights* does not mean that individualized, person-centered, supports are to be ignored. "Equal rights" must relate to access to individually appropriate and necessary supports, no matter the setting.

I. Predictable Tragedies: The Present Day Deinstitutionalization Experiment

Advocates and policymakers are familiar with the failed deinstitutionalization experiment of persons with mental illness. Homelessness and incarceration, even today, are evidence of our ongoing failure to provide specialized treatment for persons with mental illness. Despite these lessons learned with regard to the mental health community, people with ID/DD continue to suffer from the same failed experiment.

As recently as November 2011, the *New York Times* reported that "One in six of all deaths in state and privately run homes, or more than 1,200 in the past decade, have been attributed to either unnatural or unknown causes" (November 6, 2011). The *Atlanta Journal-Constitution* found "Deficiencies in care, living conditions and record-keeping have piled up in scores of Georgia personal care homes [35,000 violations], with the state rarely shutting down violators or levying heavy fines [in just 544 cases]" (May 22, 2012). A *Miami Herald* investigation found a string of "deaths [that] highlight critical breakdowns in a state enforcement system that has left thousands of people to fend for themselves in dangerous and decrepit conditions" (May 1, 2011).

These tragedies, which are repeated in more than 25 states[1], amount to reckless disregard for people with profound ID/DD who have met with tragedy while federal and state officials figure out what went wrong. Consider these statements during the hearing by Thomas Perez and Zelia Baugh:

> "It is so important to learn from the past. The deinstitutionalization movement of the 70's - the profound mistake that was made was opening the doors of institutions when community infrastructure didn't exist." (Thomas Perez, Assistant Attorney General, Civil Rights Division, Department of Justice, June 21, 2012)
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> "If you look at our [settlement] agreements . . . we are building community infrastructure" so when someone is in crisis there are options other than jail or an emergency room. (Perez, June 21, 2012)
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> "ADMH [the Alabama Department of Mental Health] has experienced three main challenges in its efforts to shift services to community settings: securing stakeholder buy-in, identifying and developing resources within provider organizations to serve persons with significant behavioral challenges or multiple medical needs, and negative stigma. While ADMH has developed strategies to overcome these challenges, long-term efforts will be needed to ensure continued success." (Zelia Baugh, Commissioner, Alabama Department of Mental Health, June 21, 2012)

A careful reading of these statements signals a profound lapse between the reality of "community integration" and the promise of community living. Time and again, deinstitutionalization is aggressively pursued *before* a "robust community infrastructure," as described by Tom Perez, is in place. In the context of the mentally ill, Mr. Perez spoke about the support of some sheriffs' groups for more community placements for people with mental illness to keep them from inappropriate placements in the jails – 50 years after some pushed to close all the institutions for people with mental illness. **We must not repeat the same mistake for people with ID/DD.**

Mr. Perez says the Justice Department includes strong quality assurance provisions to prevent repeating this tragic mistake. For example, Justice Department officials have indicated that the proposed settlement agreement in Virginia includes a quality assurance provision modeled on best practices to include crisis centers and more. When pressed by VOR representatives, however, Justice Department officials acknowledged that this model community system is not in place in Virginia or anywhere, but is representative of a compilation of best practices from around the country. VOR and the members we represent do not dispute that is a well-intended plan, but it is only a *plan* and it is not in place for people to evaluate the results. Given the tragedies that have befallen fragile individuals with ID/DD who lack access to highly specialized care in communities around the country, there is little trust that a "robust community infrastructure" will actually materialize.

Consider, for example, Alabama. Partlow ICF/MR closed nearly two years ago, yet ADMH is still working on addressing care, safety[2], and funding challenges. By Commissioner Baugh's own admission, short-term funding is not assured (requests are pending), and financial sustainability beyond 2-3 years is of great concern:

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[1] See, Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities, Rev. June 27, 2012 at http://www.vor.net/images/AbuseandNeglect.pdf

[2] Commissioner Baugh also cites the State's quality assurance agreement with Alabama Disabilities Advocacy Program (ADAP) as evidence that former Partlow residents are being watched over. Yet, ADAP, which strongly supported closure even while identifying lapses in community care before Partlow closed, received a lucrative ($42,000) contract to oversee quality *after* it closed.

> “The challenge for Alabama is coming up with the match money for Medicaid. [We have applied for Affordable Care Act grants that would] assist us with a 90/10 match for next 2-3 years, but after that looking for sustainability is where we have great concern.” (Zelia Baugh, Commissioner, Alabama Department of Mental Health, June 21, 2012).

The mother of a former Partlow resident, who disputes Commissioner Baugh’s characterization of Partlow’s closure as a “success,” has tried desperately to remain in contact with the families of displaced Partlow residents:

> "I am in touch with several parents and the disturbing patterns of abuse and the lack of money for personal needs is so hard to handle. One family must now travel 1 ½ hours to visit their daughter each day to be sure she is doing well. I know of nine residents who have died and four who are in jail. ADAP [Alabama Disabilities Advocacy Program] is supposed to be monitoring former residents but when I spoke to ADAP they were only aware of 2 deaths, including one individual who died in a nursing home. All former 151 residents were very fragile upon their move from Partlow. Although I have encouraged families to contact ADAP if they have any problems, families don’t trust ADAP since they were instrumental in closing Partlow. It seems no one remembers that Olmstead stated on page 17 that residents, or their legal guardians, have the final say about the resident being moved to a community setting. We were totally ignored.” (Mother to M.M, former Partlow resident, June 25, 2012).

Unrealistic predictions of cost savings continue to contribute to community failings. We agree with Mr. Perez that “robust community infrastructures” are needed to serve safely and well people with ID/DD who are also multiply disabled, medically-fragile or who experience dangerous behavioral conditions. **Significant funding, on par with facility-based care or more, must be *in place* before transitioning people from facility-based care**. “Putting the cart ahead of the horse” - moving people before services are in place with false expectations of cost savings – has resulted in a poorly funded, ill-prepared community infrastructure leading to predictable tragedies and poor outcomes. As evidenced in statements by Mr. Perez and Chairman Harkin, jails continue be ad hoc “treatment” centers for people with cognitive disabilities in many states who have nowhere else to go. Justice Department settlement agreements require that “robust community infrastructures” be built (in the future) so that, according to Mr. Perez, jails and emergency rooms do not remain the crisis centers of last resort. Yet these same agreements mandate the displacement of a pre-determined number of ICF/MR residents (quotas) per year, without any regard for individual choice or need, as required by *Olmstead* (*see e.g.*, Virginia and Georgia settlement agreements).

VOR appreciates the questions posed by Senator Al Franken, who asked whether people with disabilities who chose home and community-based services should receive the same protections as people who receive facility-based care. The response by Rita Landgraf, Secretary, Delaware Department of Health and Social Services, was a “Resounding yes!” We agree completely.

II. Looking Ahead: *Olmstead* Enforcement Must Respect Different Needs

Until federal and state officials remove their “rose colored glasses,” tragedies will continue. The people at the center of the deinstitutionalization experiment are profoundly fragile individuals. Their right to receive appropriate and necessary care, based on their individual needs, continues to be ignored, contrary to the letter and spirit of *Olmstead*.

As discussed above, anything less than 24/7 highly specialized services would be a death sentence for some people with ID/DD. 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, like Aaron whose story is shared above, are thriving in ICFs/MR, specialized facilities designed to meet their long-term, complex care needs 24/7. Here are a few of their stories[3]:

- **David** has multiple disabilities including a ***profound*** level of intellectual disability (ID), total bilateral deafness, cerebral palsy and epilepsy. His teeth lack the normal enamel protective layer. David is 47 and has a mental age of 18 months. He is non-verbal and does not use sign language. He has had a hip replacement and is being treated for osteoporosis. His seizures have been under control with medication for five years. He has a history of aspiration pneumonia and has a diagnosis of moderate oropharyngeal dysphagia. Each meal consists of specially prepared blended foods and thickened liquids. David is at a high risk level for falls, diabetes, choking and dehydration. His bowel movements are monitored to avoid bowel impaction. David requires staff assistance with brushing his teeth, shaving, bathing, toileting, dressing, eating, transferring, and transporting himself. David uses a wheel chair. He can walk with staff assistance using a walker and a gait belt. He requires staff assistance to go from one location to another. He can't perform work activities in active day treatment without hand-over-hand guidance. David is aware of his surroundings. He is able to recognize people who are familiar to him and uses facial expressions (i.e., smiling) to greet others. He enjoys being in an area where other people are moderately active such as in his home living room, traveling in a car or van, or in mall or store. He enjoys watching people. His only method of communication is through eye contact and smiles. He does not have other communication skills. (May 2012, by parents D.P.and N.P.).

- My son, **Brian**, was expelled from four private facilities (two in Minnesota, two in Wisconsin), which do not have to keep difficult clients. When they expelled Brian because of dangerous aggression, he was sent HOME where we had little children. Out of structure, he broke hundreds of windows (we repaired them every weekend) and injured everyone in the family except the baby who was locked away from him. State-operated ICFs/MR in Illinois and many other states serve people with profound intellectual disabilities, and people with brain injury and physical aggression like Brian, but some even more extreme behaviors like sexual aggression, fire-starting, self-mutilation, etc. The most extreme cases need to have a stable environment and staff who are well-trained and well-paid. Brian who engaged in PICA while he was in and out of settings that could not handle him has had three surgeries to remove pens and pencils which perforated his stomach lining and infected his lungs. At Choate, a state-operated ICF/MR, that behavior was extinguished. Families who have been on the edge between life and death with their loved ones like we have or waiting for release of their severely disabled loved one who was inappropriately thrown into jail- we have those stories as well- do not want another tragedy in their loved ones' lives. What apartment building would be right for Brian and which McDonald's has an application with his name on it? (May 8, 2012 Letter from mother R.B).

- **R.S.** suffers from brain damage due to an oxygen deficiency at birth, epilepsy with uncontrolled mixed seizures, profound swallowing problems, brittle bones, optic atrophy with myopia, incontinence, stenosis of his neck and back, peripheral neuropathy and hyper-salivation. R.S. is non-verbal and completely non-ambulatory. He gets all nutrition, hydration and medication via a gastrostomy tube. (February 11, 2012 Letter from guardian A.S.)

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[3] As you read the stories of these individuals, consider how very different their disabilities and support requirements are from self-advocate Ricardo Thornton.

- **S.B.C.** suffered from spinal meningitis when she was seven weeks old and was left mentally and behaviorally disabled with “explosive-type” outbursts during which she kicks, screams, bites, and throws things requiring her to be separated from others for her safety and that of those around her. (March 12, 2012 Letter from parents, D.C. and L.C.)

- **K.M.** was born with severe brain damage resulting in many medical issues including a seizure disorder. K.’s father describes his son’s intellectual ability as being “that of a new born baby.” He is blind, a quadriplegic with little control of his limbs, and he receives nourishment through a feeding tube. See, March 9, 2012 Letter from father, D.M.

- **J.K.** has Angelman Syndrome and has the intellectual development of a six-month to one year-old. J.K. is not toilet trained; he is entirely non-verbal; he tends to place everything in his mouth and chew on items that become choking hazards; and, when excited and agitated, he is prone to grab and hold onto whoever is nearby. J.K. has an exceptionally high pain threshold as illustrated by his not showing even a whimper of pain after he broke his collarbone a few years ago. This condition poses a constant risk of accident or medical emergency. His mother described a recent situation in which J.K. ate eleven inches of his quilt, which has since been encased in parachute material, and another incident in which J. picked at a sore on his elbow to the point that he pulled tissue out of his arm requiring surgery. (February 11, 2012 Letter from his mother, J.A.)

- **T.K.,** who has been a resident of SVTC since the 1970s, is classified as moderately retarded with autistic tendencies. Her sister, J., states that T.K. has regularly exhibited violent behavior for most of her adult life including hitting, pushing, biting and breaking things. On one occasion, T.K. tried to put a piece of glass in her sister’s eye and, on another occasion, she turned her bed upside down and ripped a water fountain out of the ground. (March 15, 2012 Letter from sister, J.K.)

- **R.J.** is totally disabled, bed/wheelchair bound, tube fed, spastic with rigid muscles, diapered and medicated for seizures. (March 17, 2012 Letter from guardian L.J.)

The individuals’ *profound* disabilities and related needs are remarkable, but not unique. Their stories are repeated by the vast majority of families across the country whose loved ones receive life-sustaining supports in licensed Medicaid facility homes.

Mr. Perez and Commissioner Baugh’s testimony acknowledged family opposition, characterizing such opposition as a “challenge” to closing ICFs/MR. It’s no wonder. The deinstitutionalization experiment has not served people with profound ID/DD very well, nor have federal and state officials respected families as true partners in policymaking and service decisions. Over and over again we hear “We were totally ignored.” Promises have simply not met with reality. Inasmuch as it is their loved ones’ lives at stake, families are morally driven to challenge these life-threatening proposals.

Still, closure attempts have proceeded in spite of family opposition. Fortunately, some federal courts have noticed:

> “Furthermore, the 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."). (*U.S. v. Virginia*, May 9, 2012)(Order granting intervention to ICF/MR residents, as represented by their families/legal guardians, over objection of the Justice Department)

> "Most lawsuits are brought by persons who believe their rights have been violated. Not this one . . . 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 [Department of Justice] 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) (*case dismissed*).
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> "Thus, the argument made by Arc and the United States regarding the risk of institutionalization fails to account for a key principle in the Olmstead decision: personal choice. And here, where more residents desire to remain in institutional care than the new facility can provide for, there is little to no risk of institutionalization for those whose needs do not require it and who do not desire it." (*The Arc of Virginia v. Kaine*, December 17, 2009) (plaintiffs were represented by Virginia's Protection and Advocacy and supported by the Justice Department as Amicus) (*case dismissed*).

Yet, DOJ persists undeterred and with continued disregard for resident and family input and opposition. As noted in Mr. Perez's testimony:

> "[W]hen I became Assistant Attorney General in 2009, I identified enforcement of the Olmstead decision as one of the Division's top priorities. In the last three years, the division has been involved in more than 40 matters in 25 states."

Ann Knighton, VOR's President and the President of the East Central Georgia Regional Hospital (Gracewood ICF/MR), was not consulted as a stakeholder with regard to the Justice Department Settlement (October 2010) which calls from the closure of all Georgia ICFs/MR. In response, she stated:

> "The United States Department of Justice has undermined the U.S. Supreme Court's *Olmstead* decision by being forceful and aggressive with regard to community transitions and thereby omitting the element of resident choice, whether that be a community or ICF/MR setting. If everyone is forced to accept community living, then no one has choice." (November 30, 2012)

III. 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 12 years

The recent HELP hearing on "*Olmstead* Enforcement Update: Using the ADA to Promote Community Integration" 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 over 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, without regard to resident need and family input. For example:

> In a survey of all the people living in a Pennsylvania state operated ICF/MR and their family contacts were asked if they wanted a community placement. 1,013 of the 1,223 family contacts responded to the question and 97.24% of them answered "no." Of the 307 residents who were able to respond to the question 88.27% also answered 'no.' (*Source*: Survey, completed September 2011, as required by the **P&A-filed** *Benjamin v. PA Department of Public Welfare* Settlement Agreement. No attempt was made to survey all ICF/MR residents and their families before the settlement agreement).
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> Coffelt v. Department of Developmental Services was filed 1994 irrespective of the fact that 98% of the developmental center family/guardian survey respondents opposed P&A representation of their family members. As a result, 2 centers closed and 2,500 residents were transferred from developmental centers to community settings, resulted in well-documented higher mortality rates. One peer-reviewed study found risk of mortality to be 82% higher in community-based settings. Then, "Coffelt II" was filed in 2002. P&A challenged intervention efforts by parent/guardian representatives, arguing, "As a matter of substantive law, parents and guardians of institutionalized persons have different and potentially conflicting interests on matters pertaining to their child's or ward's constitutional or statutory rights to liberty and due process." The Court rejected P&A's challenge.
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> A survey of family members and guardians of residents in six New Jersey ICFs/MR asked recipients of the survey whether they were happy with the current placement of their loved ones, or would prefer community-based care instead. 61 percent of the families and guardians receiving the survey responded. 96% of respondents indicated support of continued ICFs/MR placement. The survey, sponsored by family advocates for residential choice, was an effort effort to respond to serious flaws in earlier state surveys and studies that have been used to justify downsizing and closure proposals, including a New Jersey P&A lawsuit.
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> The *Ligas* federal class action lawsuit was brought in 2005 by Equip for Equality (P&A), against Illinois "on behalf of" 6,000 severely disabled residents who live in the 240 privately-operated ICFs/MR with more than 9 residents, as well as those living at home with elderly parents awaiting placements. In the first four years of the case, families, on behalf of their loved ones, unsuccessfully tried to intervene. As feared, in 2009, after four years of litigation, the parties reached a proposed settlement that would have required the state to reduce private "institutional" beds for each community bed it added. In response, more than 2,000 families throughout the state for whom the settlement was supposed to help successfully objected to the settlement.

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 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

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 decision-makers:

> "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*)[4]; *see also*, *Olmstead v. L.C.,* 119 S. Ct. 2176 (1999) ("the transfer from institutional care to a less restrictive setting is not opposed by the affected individual").

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, as contained in the 1994 Conference Report, is as clear as *Olmstead* on this point:

> "First, the goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities may not be read as a Federal policy supporting the closure of residential institutions.
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> * * * *
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> "Third, Protection and Advocacy systems established under Part C of the Act shall use the resources made available under this Act in accordance with the purposes and statement of policy set forth in the Act and are authorized to pursue appropriate remedies to address the violation of rights under the laws in all settings, including community and ICF/MR institutions . . . . [(H. Rep. 103-442 (March 21, 1994)]

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.

IV. Conclusion

Contrary to the decision itself, "*Olmstead* enforcement" initiatives impose community placement on individuals, without regard for choice and the fundamental differences between individuals with physical or mild intellectual disabilities and those with profound intellectual disabilities. The ideology which drives the deinstitutionalization experiment (in the name of *Olmstead*) and the resulting outcomes are not critically scrutinized by Congress or the Administration.

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[4] In 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 affected individuals and their families deserve a hearing; they deserve a voice. Including family stakeholders in future Senate “Olmstead Enforcement” hearings and holding 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, with an opportunity to be heard. Their perspective matters. Choice matters.

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

Sincerely,

Sam Golden
Chair, VOR Government Affairs Committee

Peter Kinzler
Chair, VOR Legislative Committee

cc:
Members, U.S. Senate Health, Education, Labor and Pensions Committee
Eric H. Holder, Attorney General of the United States