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**Organization Submitting Testimony:**

VOR, Speaking out for people with intellectual disabilities  
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**Testimony Prepared For:**

House Committee on Appropriations, Subcommittee on Commerce, Justice, Science and Related Agencies

**Regarding:**

Department of Justice FY 2013 Budget Request / Traditional Missions / \$31.8 million in Program Interests, including \$5.1 million and 50 positions (25 attorneys) for the Civil Rights Division

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**PROTECTING THE INTERESTS OF RESIDENTS OF INTERMEDIATE CARE FACILITIES FOR PERSONS WITH INTELLECTUAL DISABILITIES IN ACTIONS CONDUCTED BY THE DEPARTMENT OF JUSTICE’S CIVIL RIGHTS DIVISION THAT AFFECT THEIR CHOICE OF RESIDENCY**

VOR, a national advocacy organization for people with intellectual disabilities (ID/DD) and their families express gratitude to the Subcommittee on Commerce, Justice, Science and Related Agencies for this opportunity to submit testimony for the record of the hearing on March 22, 2012 in consideration of the Department of Justice’s FY 2013 request for appropriations, specifically relating to its request for \$5.1 million and 50 positions (25 attorneys) for the Civil Rights Division.

VOR’s members look forward to working with Representatives and their staff to ensure the civil rights of our most fragile citizens with ID/DD.

**Request that DOJ Meet its Choice Obligations under the Americans with Disabilities Act (ADA) in DOJ Actions Involving ICFs/ID**

To protect the interests of the residents of ICFs/DD and their families to be the primary decision-makers regarding where they reside, in response to the blatant and repeated disregard of the ADA requirement for individual choice of residency by the DOJ’s Civil Rights Division, VOR requests that the Subcommittee include the following language in the DOJ Civil Rights Division appropriations:

- (1) In any action taken by the Department of Justice, including investigations, that involves the residents of an ICF/ID, DOJ shall consult with the residents (or, if a

resident has a legal representative, the resident's legal representative) and families among all other interested parties before taking action.

- (2) If, after taking action, families wish to intervene on behalf of their family member with ID/DD in the DOJ action, DOJ is encouraged to support such intervention.

### **About VOR**

VOR is a national advocacy organization representing individuals with intellectual disabilities (ID/DD) and their families. VOR has thousands of members across the country, with representation in every state. Unlike other national advocacy organizations, VOR recognizes that individuals with ID/DD and their families are the primary decision-makers regarding services and supports. We recognize that legitimate choice and person-centered supports are only possible in a system that offers a full array of quality residential and support options, from small homes to Medicaid-funded and licensed Intermediate Care Facilities for Persons with Intellectual Disabilities (ICFs/ID).

### **Rationale: DOJ's Civil Rights Division has routinely ignored *Olmstead's* choice mandate.**

For FY 2013 United States Department of Justice (DOJ) has requested an additional 25 attorneys and \$5.1 million to enable the DOJ's Civil Rights Division to, among other activities, "strengthen civil rights enforcement efforts" as part of the Attorney General's ***Vulnerable People Priority Goal***. A portion of the requested increase will reportedly allow the Civil Rights Division to increase its enforcement of the Civil Rights of Institutionalized Persons Act (CRIPA). Presumably any additional funds and attorneys, in part, would also be applied to the Civil Rights Division aggressive enforcement of *Olmstead*. According to a recent statement by Tom Perez, Assistant Attorney General for Civil Rights:

The agreement with the Commonwealth [of Virginia] is part of a broad, nationwide effort to enforce the *Olmstead* decision. In the last three years, the Civil Rights Division has joined or initiated litigation to ensure community-based services in more than 35 matters in 20 states. We reached comprehensive agreements with the states of Georgia and Delaware that, like the agreement with Virginia, provide broad relief for thousands of individuals with disabilities. (Tom Perez, "*Department of Justice Transformative Olmstead Settlement*," February 6, 2012).

In DOJ actions in Virginia, Georgia, Illinois, Arkansas and other states, the legal "relief" for the affected individuals sought or supported by the Civil Rights Division has been the displacement of fragile individuals from life-sustaining, federally-licensed supports ("deinstitutionalization") without regard to choice and with little apparent concern for outcomes. These actions to enforce *Olmstead* are expressly contrary to the Supreme Court's decision<sup>1</sup>:

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<sup>1</sup> VOR contends that DOJ actions to close ICFs/DD contrary to resident choice also violates the federal Medicaid law which requires that ICF/DD residents be informed of alternatives under the home and

“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”).

Specifically, the Supreme Court held that community placement is only required when -

- a. The State’s treatment professionals have determined that community placement is appropriate;
- b. The transfer from an institutional setting to a less restrictive setting is not opposed by the affected individual**
- c. The placement can be reasonably accommodated, taking into account the resources available. *Id.* at 587 (**emphasis added**).

Increased funding for CRIPA or ADA enforcement for deinstitutionalization activities will undoubtedly result in expanded DOJ legal activities to undermine and ultimately eliminate the option of Medicaid-certified ICFs/DD.

Families and legal guardians of our country’s most vulnerable people with severe and profound ID/DD, who function at the level of infants and toddlers despite having the chronological age of adults, have strong objections to DOJ’s Civil Rights Division’s activities to “enforce the *Olmstead* decision.” Routinely, DOJ fails to seek or consider the input or protestations of the very individuals who have the greatest insights into the needs and desires of the affected individuals:

“. . . close relatives and guardians, both of whom likely have intimate knowledge of a mentally retarded person’s abilities and experiences, have valuable insights which should be considered during the involuntary commitment process.” *Heller v. Doe*, 509 U.S. 312 (1993)

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community-based services waiver and be given the choice of either ICF/DD or home and community-based services waiver supports. 42 C.F.R. 441.302(c).

“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*) (**emphasis added**).

The following examples exemplify the Civil Rights Division’s blatant disregard for *Olmstead’s* choice requirements:

**A) U.S. v. Georgia**

A Settlement Agreement reached between the United States Department of Justice / Civil Rights Division with the State of Georgia in October 2010, prohibits the admission of any individual with a developmental disability to a state hospital (ICFs/ID) by July 1, 2011 **and** requires the transition of ALL individuals with developmental disabilities already living in State ICFs/ID to community settings by July 1, 2015. Affected individuals were not afforded any choice and families and legal guardians expressly opposed the settlement: “[I]f everyone is forced to accept community living, then no one has choice.” (Resolution of the East Central Georgia ICF/ID Family Association Opposing Settlement Agreement, November 30, 2010).

Predictably, the one-year implementation report by the court-appointed Independent Reviewer has found problems associated with the health and safety of displaced residents with regard to access to health care, medication, nutrition, and safety. Reportedly, there have been at least four deaths.

**B) U.S. v. Virginia**

A January 2012 Settlement Agreement between DOJ and the Commonwealth of Virginia continues to display the ideological agenda of the DOJ’s Civil Rights Division in its relentless effort to eliminate the option of Medicaid-certified ICFs/DD. If approved by the court, it will result in the closure of four public ICFs/DD. Families who had no meaningful opportunity to provide input to settlement terms but who expressly opposed closures were not listened to. A Motion to Intervene on behalf of residents of all Virginia ICFs/DD has been filed in an effort to protect individuals from displacement and harm. The Motion to Intervene demonstrates that DOJ has ignored choice, as required by *Olmstead*.

An earlier court decision from Virginia points to a pattern and practice by DOJ to disregard choice contrary to *Olmstead*:

“Thus, **the argument made by ARC and the United States [DOJ] regarding 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.” (*Arc of Virginia v. Kaine* (December 17, 2009) (emphasis added) (see also, *Stanley Ligas, et al. v. Barry S. Maram, et al.*, 05 C 4331 (N.D. Illinois, July 7, 2009) (denying proposed settlement and decertifying class on finding that the named plaintiffs failed to meet the criteria set forth in *Olmstead* because class definition was not restricted to individuals who were eligible for, and desired, community placement.).

### C) Arkansas

In its CRIPA and ADA “civil rights” case against the State of Arkansas regarding its Conway ICF/ID, DOJ spent millions of federal dollars and lost soundly. In his ruling dismissing the case, Federal District Court Judge Leon Holmes, addressed squarely the complete disregard by DOJ of family/guardian input and choice:

“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.”

### **Conclusion: Please condition DOJ’s Civil Rights Division appropriations on respecting choice**

Choice is required by the ADA, as interpreted by *Olmstead*. Families and guardians of our country’s most vulnerable citizens seek relief from DOJ’s deinstitutionalization actions which are counter to the *Olmstead* choice mandate, counter to the best interests of the affected individuals who are displaced from life-sustaining services, and are pursued in complete disregard of the input of individuals and their families as primary decision-makers. VOR requests the Subcommittee to require DOJ to fulfill the ADA’s choice requirement by the following:(1) *In any action taken by the DOJ, including investigations, that involves the residents of an ICF/ID, DOJ shall consult with the residents (or, if a resident has a legal representative, the resident’s legal representative) and families among all other interested parties before taking action; and (2) If after taking action, families wish to intervene on behalf of their family member with ID/DD in the DOJ action, DOJ is encouraged to support such intervention.*

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