
VOR Request for the FY 2017 Labor HHS and Commerce, Justice Appropriations Bills

VOR is the only national nonprofit organization that advocates for a *full range* of high quality residential options and human rights for all persons with intellectual and developmental disabilities (I/DD).

Congressional disability policy supports both community integration and individual choice. These rights are primarily embodied in the Developmental Disabilities Act (DD Act), the Americans with Disabilities Act (ADA), and the Medicaid programs for both congregate and community-based care [the Intermediate Care Facilities for Individuals with Intellectual and Developmental Disabilities (ICF/IID) and the Home and Community-Based Services programs]. The ADA specifically requires public entities to provide services to individuals with I/DD in “the most integrated setting *appropriate to the needs* of qualified individuals with disabilities.” (emphasis added). At the same time, it recognizes the right of an individual to choose “not to accept” such an accommodation. The *Olmstead* decision interpreting the ADA upheld both rights. Regarding choice, it specifically says that “nothing in the ADA . . . 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., 2172, 2187 (1999).

Unfortunately, the DD Act programs funded by HHS and the Civil Rights Division of the Department of Justice have acted aggressively to eliminate the ICF/IID option, contrary to the plain language of these disability laws, and often with tragic consequences for our most disabled citizens. Therefore, VOR asks you to take the first steps towards protecting them. **We ask you to support inclusion of language in both the FY 2017 Labor, HHS and the Commerce, Justice Appropriations bills to require advance notice to the families of people with I/DD who reside in any federally- funded facility of any legal action to close the facility, and to require both HHS and DOJ to report to the Congress on how they are protecting the individuals’ right to choice under federal disability law and the *Olmstead* decision.**

Class Action Lawsuits funded by HHS: The Protection and Advocacy programs (P&As) funded by HHS have brought more than 24 class actions to close ICFs/IID “on behalf of” the residents, despite the opposition of the vast majority of the legal guardians. Most recently, the Ohio P&A has indicated its intention to file a class action suit to close Ohio’s ICFs/IID, despite the opposition of an overwhelming number of the guardians. Such actions ignore the clear choice language of not only the ADA and *Olmstead*, but of their own authorizing statute, the DD Act:

“Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, 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)(2000).

“[T]he 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” [H. Rep. 103-442 (March 21, 1994)].

Worse still, the results have too often proven tragic for the severely disabled persons forced to move into communities not equipped to meet their needs. (see e.g. up to an 88% greater risk of mortality in community settings in California (peer reviewed studies, 1996-2005) and [Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities](http://www.vor.net/images/stories/pdf/AbuseandNeglect.pdf) (<http://www.vor.net/images/stories/pdf/AbuseandNeglect.pdf>)).

Despite these tragedies, the committees of jurisdiction have failed to reauthorize the DD Act for 16 years, leaving the funding to the Appropriations Committees since the authorization expired in 2007. In response, the FY 2016 Labor, HHS Appropriations included a provision requiring advance notice of a suit to the families and language encouraging P&As to factor in the choices of the individuals and their families and to assure proper settings for care. VOR recommends that the Congress go one step further and require HHS to report on how the P&As are factoring in the needs of the individuals and assuring proper settings for care.

Enforcement actions by DOJ: DOJ utilizes a device analogous to the class action suit to pursue its ideological agenda of closing ICFs/IID. Since 2009, DOJ has filed some 50 *Olmstead* enforcement actions in 25 states, overriding the wishes of the individuals with I/DD and their families and legal guardians. The result has been that thousands of individuals with profound I/DD have been forced out of their ICF homes into communities that lacked the resources to care for them. Too often, these most vulnerable individuals have suffered significant harm, including death, and emotional hardship.

U.S. District Court Judge J. Leon Holmes recognized both the illegality and absurdity of such actions in his order dismissing DOJ'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.**” [*United States v. Arkansas* (June 8, 2011, dismissal order) (emphasis added)].

The most recent tragic consequences of DOJ's actions can be found in Georgia. A 2010 Settlement Agreement with the State called for the transition of nearly 1,000 individuals with I/DD and the closure of all state-operated ICFs/IID. On January 27, 2016, relying on State documents, the [Augusta Chronicle](#) reported that of 503 residents who moved from ICFs into the community, 79 have died. That rate is far higher than the mortality rate in the ICFs. Moreover, according to an independent consultant, Georgia only investigated 38 of the 79 deaths, and the cause of death for 29 patients was listed as “unknown.” (*Georgia faces contempt hearing in moving developmentally challenged patients to community-based care*). Thousands of hospitalizations and hundreds of reports of abuse, elopements, and interactions with law enforcement have also been reported in each of its [Annual Quality Management Reports](#) for 2013 and 2014.

The results should not have come as a surprise to DOJ. Samuel Bagenstos, former DOJ Civil Rights Division Principal Deputy Assistant Attorney General, 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, *The Past and Future of Deinstitutionalization Litigation*, 34 *Cardoza L. Rev.* 1, 21 (2012)].

The Fiscal Year 2015 Commerce, Justice Appropriations bill addressed this problem by including report language calling on DOJ to “factor the needs and desires of patients, their families and caregivers, and other caregivers, and other stakeholders, as well as the need to provide proper settings for care, into its enforcement of the Americans with Disabilities Act.” VOR recommends you take one step further and support inclusion of the same language as for HHS, requiring both advance notice of any DOJ action and reports on how it is meeting its legal obligations to protect choice and assure proper care.