

November 2012

Support H.R. 2032

H.R. 2032 Purpose

To protect the interests of each resident of intermediate care facilities (ICFs/MR) for people with intellectual and developmental disabilities in class action lawsuits by federally-funded entities on behalf of such resident, and in Department of Justice (DOJ) actions that could result in forcing such a resident from his/her facility home.

H.R. 2032 Summary

H.R. 2032 provides the following narrow and clearly defined rights to residents of Medicaid-licensed ICFs/MR or, where appointed, their legal representatives –

- (1) In federally-funded class action lawsuits involving ICFs/MR, the right to receive notice and a time-limited opportunity to opt-out of the lawsuit before it is filed; and
- (2) In DOJ actions involving ICFs/MR, the right, along with all interested parties, to be consulted during a DOJ investigation. If DOJ chooses to file a lawsuit, the residents would have a statutory right of intervention.

Why H.R. 2032 is Necessary

Class action lawsuits brought by federally-funded entities

- ✓ Advance notice and the right to opt out are not required under Rule 23(b)(2) of the Federal Rules of Civil Procedure because injunctive, not monetary, relief is being sought. The cases addressed here are unique in that they (a) involve only ICF/MR residents with profound developmental disabilities who cannot speak for themselves, (b) are brought on ideological grounds (for “community integration”) rather than to address safety, (c) involve one HHS program suing another, and (d) are authorized by federal statute. There are precedents for the Congress imposing special requirements in such cases, such as the Fair Labor Standards Act and the Age Discrimination in Employment Act, where Congress permitted collective action on behalf of only those who affirmatively chose to be part of the action. The bill applies narrowly to these cases; it does not amend Rule 23.
- ✓ These cases typically are brought without consultation with the families: “[P]arents and guardians were dissatisfied with the extent of P&A [Protection & Advocacy] communication with them before a settlement was proposed, citing problems such as not receiving notice of a family member’s inclusion in the class, which the parent or guardian opposed.” ([Protection and Advocacy Agencies: Involvement in Deinstitutionalization Lawsuits on Behalf of Individuals with Developmental Disabilities](#), GAO-03-1044 (2003)). This behavior is grounded in disrespect for the families. In one letter to Rep. Barney Frank, P&A referred to families as “clueless.”
- ✓ For more than a decade, all federally-funded class action lawsuits involving ICFs/MR have sought “community integration” and often closure, even when the vast majority of the hostage class of residents opposed closure and despite well-documented, tragic outcomes (*see e.g.*, “In State Care, 1,200 Deaths and Few Answers,” *New York Times* (Nov. 5, 2011) (reporting on 1,200 deaths from “unnatural or unknown causes” in group homes); *see also*, [Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities](#), VOR (rev. August 2012) .
- ✓ The rights proposed by H.R. 2032 respect Congressional intent. The Developmental Disabilities Act (DD Act), recognizes that “individuals and their families are the primary decisionmakers” regarding residential services” (42 U.S.C. 15001(c)(3)), and the legislative history states that “[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” (Statement of Managers, DD Act, March 21, 1994)].

Department of Justice actions

- ✓ DOJ also rarely includes residents, their families, and their legal guardians among stakeholders consulted during investigations, despite the fact these individuals are among the most informed stakeholders and are directly affected by DOJ actions (*see e.g.*, actions in Virginia, Illinois, Arkansas, and Georgia). Intervention is expensive, as attested to by the fact that Virginia families recently had to spend \$114,000 to intervene, successfully, in a DOJ lawsuit.
- ✓ In recent years, DOJ actions have been predominantly focused on community integration, calling these actions “*Olmstead* Enforcement.” Yet, the Supreme Court in its *Olmstead* decision did not mandate deinstitutionalization. Rather, the Supreme Court held that the Americans with Disabilities Act (ADA) requires consideration of individual choice in placement decisions, expressly cautioning against forced 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.”
Olmstead v. L.C. 119 S. Ct. 2185, 2187 (1993).

- ✓ When the families have been able to secure a seat at the table, the federal courts often have rejected DOJ’s attempts to deny choice and impose community placement on individuals:

“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*). (In this case, the families did not have to intervene because Arkansas opposed DOJ’s lawsuit).

- ✓ DOJ persists undeterred and with continued disregard for resident and family input and opposition. In the last three years, DOJ has been involved in more than 40 matters in 25 states.

H.R. 2032 will not affect existing Federal protections for the care of people with ID/DD in residential settings

- ✓ The Centers for Medicare and Medicaid Services (CMS) sets forth 378 standards of care for the residents of ICFs/MR. CMS prescribes a comprehensive system of enforcement of those standards.
- ✓ Over the past 16 years, not one federally-funded class action has contained allegations of abuse in an ICF/MR. Even so, H.R. 2032 would not restrict P&A from filing lawsuits on behalf of any alleged victims of abuse in an ICF/MR.
- ✓ H.R. 2032 does not in any way restrict DOJ investigations and lawsuits involving conditions of care in ICFs/MR. It merely affords the residents a statutory right to be heard in any lawsuit.
- ✓ CMS does not have comparable standards of care for people with ID/DD who reside in the community.