



Speaking out for people
with intellectual disabilities

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Please COSPONSOR H.R. 2032:

Federal legislation to protect the rights of people with profound intellectual disabilities

Introduced by Rep. **Barney Frank** (D-MA), **Bob Goodlatte** (R-VA), and **Debbie Wasserman Schultz** (D-FL), with these original cosponsors: Rep. **Culberson** (R-TX); Rep. **Payne** (D-NJ); Rep. **Moran** (D-VA); Rep. **Rush** (D-IL); Rep. **McMorris Rodgers** (R-WA); Rep. **Manzullo** (R-IL); and Rep. **Filner** (D-CA).

H.R. 2032 will help ensure that individuals with profound intellectual disabilities and their families benefit from their federally-established right to be the “primary decisionmakers” regarding the services and supports received, including where they reside (see e.g., the Developmental Disabilities Assistance and Bill of Right Act, Medicaid, and the landmark Supreme Court decision, *Olmstead*). More than 100 local, state and national organizations support H.R. 2032 (see, <http://www.vor.net/images/Signonletter.pdf>).

As with past versions of this bill (H.R. 3995 and H.R. 1255), H.R. 2032 will allow residents and their legal guardians (usually close relatives) to be notified in advance of a class action lawsuit involving their ICF/MR home, and given a time limited opportunity to opt out, before the lawsuit is filed. These important rights do not exist in current law, resulting in many residents being swept up into the suit, despite strong opposition by affected residents and their families.

H.R. 2032 includes new section addressing similar actions by the Department of Justice (DOJ)

The bill also includes a new section to protect the right to residential choice for people with profound intellectual disabilities in Department of Justice (DOJ) actions. Since 2009, the Department has issued investigative reports, filed suit, or presented briefs in cases alleging violations of the Americans with Disabilities Act (ADA), seeking or agreeing to settlements that would reduce significantly the population of or close all ICFs/MR in Virginia, Georgia, Arkansas, Pennsylvania, New Jersey, and Illinois.

In the most egregious actions – Georgia and Virginia – DOJ supported settlements with the State that will result in the closure of **ALL** public ICF/MR settings without any consultation with affected residents of their families and legal representatives. In Virginia, families are waging a legal battle in a desperate attempt to intervene in the action to have a voice, already spending tens of thousands to respond to the legal threats waged by DOJ and Virginia. In Georgia, more than 18 months after the settlement, people have been displaced and the court monitor has cited concerns with regard to the health and safety of residents because necessary supports were found to be lacking.

H.R. 2032 can help address these injustices by requiring DOJ to include the families’ perspective in any investigation and then provide a right of intervention if DOJ opts to file suit.

PLEASE COSPONSOR H.R. 2032!

Federally-funded attorneys should not be allowed to substitute their judgment with regard to ICF/MR living without any regard to the opinion of the affected residents, their families or guardians. ***Olmstead v. L.C.*, 119 S. Ct. 2176 (1999) does not mandate ICF/MR closures, but seeks a balance between encouraging community integration and preservation of facility-based care for those who require or choose the comprehensive services offered at ICFs/MR.** “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.” (*Id.* at 2187).

Contact Pilar Faló, Legislative Counsel to Rep. Barney Frank (5-5931), to cosponsor this critically important bill.

VOR (www.vor.net) is the **only** national organization advocating for the rights of thousands of people with intellectual disabilities and their families from across the country to choose from a full array of residential options, including community **and** facility-based (ICF/MR) care.

For more information contact Tamie Hopp at 877-399-4867; thopp@vor.net.