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WIDESPREAD SUPPORT FOR H.R. 2032

More than 100 local, state and national organizations support legislation to protect the rights of individuals with profound intellectual disabilities

The undersigned national, state and local organizations representing and advocating for the rights of thousands of people with intellectual disabilities and their families from across the country join together in support of individuals with intellectual and developmental disabilities (ID/DD) who rely on the life-sustaining supports provided in specialized, Medicaid-licensed facilities (ICFs/MR).

H.R. 2032, sponsored by Rep. Barney Frank (D-MA), Rep. Bob Goodlatte (R-VA), and Rep. Debbie Wasserman Schultz (D-FL), will protect the rights of thousands of people with profound ID/DD and their families in lawsuits that affect their choice of residency. Last Congress, similar legislation (H.R. 1255) was supported by the more than 100 national, state and local organizations listed below, as well as 90 cosponsors from both sides of the aisle.

H.R. 2032 will require that **before** federally-financed class action lawsuits against Medicaid-certified and funded Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR) can proceed, residents and their legal representatives must receive notice of the proposed class action and be given a time-limited opportunity to opt out of it. H.R. 2032 will also address similar actions by the Department of Justice that affect the choice of residency for our most vulnerable citizens. It does so by requiring DOJ to consult with the residents and their legal representatives in any DOJ action involving ICFs/MR and, when a lawsuit is filed, provide for a right of intervention for residents or, where appointed, their legal representatives.

This bill is desperately needed and supported by families of individuals with profound intellectual disabilities. It is opposed by the lawyers who bring these suits, as it would limit their discretion with regard to who they are allowed to represent. The undersigned organizations, however, submit that the decision regarding attorney representation should be made by individuals and their legal guardians, not by attorneys.

The problem is real.

Federally-funded attorney groups often pursue class action lawsuits against ICFs/MR, driven primarily by a bias against ICF/MR care, as evidenced by the number of closures due to these lawsuits – at least 15 ICFs/MR in 9 states, involving thousands of individuals with mental retardation (see, <http://www.vor.net/classactions.htm>). Families have good reason to be concerned. Closures sometimes result in tragic outcomes for the former residents (see e.g., http://vor.net/abuse_neglect.htm, listing examples of systemic abuse, neglect and higher death rates in community settings for people with mental retardation who have been moved out of ICFs/MR in many states and the District of Columbia).

Families, many of whom are also legal guardians, often object strongly and expressly object to the lawsuit and its objective of closure because they are pleased with the care their loved ones are receiving. Under current law, however, there is no requirement that legal guardians or residents be notified of a class action lawsuit and they do not have the right to opt out. Consequently, many residents of ICFs/MR are swept into these lawsuits and transferred from ICF/MR settings against their or their guardians' wishes (see, <http://www.vor.net/FamilyTestimonials.htm>).

Similarly, recent DOJ investigations and lawsuits in several states, if successful, will reduce significantly the population of or close all ICFs/MR in those states, without regard to resident choice and contrary to the Americans with Disabilities Act, as interpreted by the Supreme Court in the *Olmstead* case.

Please cosponsor H.R. 2032 today.

Contact Pilar Faló, Legislative Counsel to Rep. Barney Frank at 5-5931 to show your support and cosponsor H.R. 2032

Individuals with intellectual disabilities or, where appointed, their legal guardians should make the fundamental decision as to legal representation, not the federally paid lawyers. That's just good common sense.

Thank you in advance for your support.

- [ActionDD \(WA\)](#)
- [Advocacy Network, Inc. \(MA\)](#)
- Acadiana Region Supports and Services Center Parents Organization (LA)
- Alabama Voice of the Retarded (AL)
- [AFSCME Local 634 \(WI\)](#)
- Altoona – Cresson – Ebensburg Centers Association (PA)
- [American Health Care Association \(USA\)](#)
- [American Federation of State, County and Municipal Employees \(AFSCME\), AFL-CIO \(USA\)](#)
- [Area Seven Family Care Council \(FL\)](#)
- Association for the Mentally Retarded at Agnews (CA)
- Association of Hunterdon Developmental Center (NJ)
- [Autism Society of America – Butler County, Inc. \(PA\)](#)
- [Autism Society of America – Pittsburg, Inc. \(PA\)](#)
- [Autism Society of America – Pennsylvania, Inc.](#)
- [Autism Society of America – Westmoreland County, Inc. \(PA\)](#)
- Beatrice State Developmental Center Family and Friends Association (NE)
- [Billings Fairchild Center \(OK\)](#)
- [California Association of Psychiatric Technicians \(CA\)](#)
- [California Association of State Hospital Parent Councils for the Retarded \(CASHPCR\) \(CA\)](#)
- [Cedar Lake Foundation \(KY\)](#)
- [Cedar Lake Lodge, Inc. \(KY\)](#)
- [Cedar Lake Residences \(KY\)](#)
- Central Virginia Training Center Families and Friends (VA)
- [Civitan Club of Fairfax \(VA\)](#)
- Coalition of Families and Friends (MA)
- Coalition of Louisiana Supports & Services Centers (For Citizens with DD), Inc. (LA)
- [CCMR, Inc. \(MA\)](#)
- Concerned Families of Hazelwood ICF/MR (KY)
- [Conway Human Development Center Parents Association \(AR\)](#)
- [The Council on Mental Retardation, Inc. \(KY\)](#)
- [Developmental Disabilities Health Alliance, Inc. \(NJ\)](#)
- [Dever Association for the Retarded \(MA\)](#)
- Dixon Association for Retarded Citizens (IL)
- [East Central Georgia Family Council \(GA\)](#)
- [Eidetik, Inc. \(KY\)](#)
- Families and Friends of Care Facility Residents (AR)
- Families and Friends of North Lake Supports & Services Association (LA)
- Families and Friends of Tachachale (FL)
- Family & Friends Association of Arizona Training Program at Coolidge (AZ)
- Family and Friends of Central Wisconsin Center (WI)
- Family and Friends of Woodward Resource Center (IA)
- Fernald League for the Retarded, Inc. (MA)
- [Florida's Voice on Developmental Disabilities \(FL\)](#)
- Fox Center Families and Friends (IL)
- Frances Haddon Morgan Center Families & Guardians (WA)
- Friends of Choate (IL)
- [Friends of Fircrest \(WA\)](#)

<u>States Represented</u>
National – 4
AL
AR
AZ
CA
CT
FL
GA
HI
IA
IL
KS
KY
LA
MA
MD
MN
MO
NC
NE
NJ
OH
OK
OR
PA
SC
TN
TX
UT
VA
WA
WI

Friends of Jacksonville Developmentally Disabled (IL)
[Friends of Retarded Citizens of Connecticut \(FORConn\) \(CT\)](#)
Glavin Association for the Retarded (MA)
Gray Panthers California (CA)
Greater St. Louis Parent's Advocacy Group (MO)
Hamburg Center Family and Friends Association (PA)
Howe Family and Friends Association (IL)
Illinois League of Advocates for the Developmentally Disabled (IL)
[Kankakee Association for the Mentally Retarded \(IL\)](#)
[Kansas Neurological Institute Parent and Guardian Group \(KS\)](#)
[Lake Owasso Family Group \(MN\)](#)
[Lubbock State School Family Association \(TX\)](#)
[Maryland Association of Nonpublic Special Education Facilities \(MD\)](#)
[Maryland Coalition of Advocates for the Retarded \(MD\)](#)
[Massachusetts Coalition of Families and Advocates for the Retarded \(MA\)](#)
Mental Retardation Association of Nebraska (NE)
[Mental Retardation Association of North Carolina \(NC\)](#)
[Mental Retardation Association of Utah \(UT\)](#)
[Misericordia/Heart of Mercy \(IL\)](#)
Missouri Voice of the Retarded (MO)
[Mur-Ci Homes, Inc \(TN\)](#)
Murray Parents Association (IL)
National Disability Party (USA)
[Ohio League for the Mentally Retarded \(OH\)](#)
Oregon Voice of the Retarded (OR)
[ORI \(Opportunities & Resources, Inc.\) \(HI\)](#)
[Parents Association, Inc. of Bellefontaine Habilitation Center \(MO\)](#)
[Parent Association for the Retarded of Texas \(TX\)](#)
Parent Committee of Southern Wisconsin Center (WI)
Parent-Relative Organization for Oakwood Facilities, Inc. (PROOF) (KY)
Parents & Associates of the Institutionalized Retarded of Virginia (VA)
[Parents & Associates of Northern Virginia Training Center \(VA\)](#)
Parents and Friends Association of Selinsgrove Center (PA)
Parents and Friends of Lower Fairfield Regional Center and Associated Group Homes (CT)
Parents and Friends of Ludeman Center (IL)
Parents and Friends of Monson Developmental Center (MA)
Parents and Guardians of the South Carolina Coastal Center
[Parents Coordinating Council, Lanterman Developmental Center \(CA\)](#)
[Parents Planning Programs for the Developmentally Disabled of Florida, Inc. \(FL\)](#)
Parents, Relatives and Friends of Polk Center (PA)
[Parent's Hospital Association, Sonoma Developmental Center \(CA\)](#)
Patrons of Partlow (AL)
Pennsylvania League of Concerned Families of Retarded Citizens (PA)
Pinecrest Parents Association (LA)
Porterville Developmental Center Parents' Group, Inc. (CA)
RBS Consulting (FL)
Relatives and Friends Association of White Haven Center (PA)
Sacramento Association for the Retarded (CA)
South Carolina Parents and Advocates for the Developmentally Disabled (SC)
[St. Mary's Square Living Center \(IL\)](#)
[Southbury Training School Home & School Association \(CT\)](#)
Supporters of Residential Choices for the Developmentally Disabled/DSI Supporters (FL)
[Tennessee Family Solutions \(TN\)](#)
Umbrella Services for Advancing Autistic Children (PA)
Valley Association for Retarded Children and Adults (VARCA) (CT)
[VOR \(Voice of the Retarded\) \(USA\)](#)
[Washington State Democratic Disabilities Issues Caucus \(WA\)](#)
Waukegan Developmental Center-Association For Retarded Citizens (IL)
West Tennessee Parent Guardian Association (TN)
Wisconsin Parents Coalition for the Retarded (WI)
Wrentham Association for the Retarded (MA)