



April 27, 2009

The Honorable Barney Frank
United States House of Representatives
Washington, DC 20515

Dear Representative Frank:

The undersigned member organizations of the Consortium for Citizens with Disabilities (CCD), representing consumers with disabilities, family members, and professionals in the disability field, are writing today to demonstrate our strong opposition to H.R. 1255. As organizations, we cannot overstate the negative impact this legislation would have on the lives of individuals with developmental disabilities and their families.

Having a full range of appropriate remedies, including the use of a class action, has been a keystone to protecting the civil and legal rights of individuals with developmental disabilities in all facets of their lives, including community integration. The Developmental Disabilities Act of 2000 reaffirmed the authority of the Protection and Advocacy systems to use any and all legal remedies appropriate to ensure the protection of individuals with developmental disabilities, including class actions.

There is also a misconception that H.R. 1255, which breaks new and dangerous ground by allowing class representatives to opt out of cases seeking injunctive relief, is somehow a needed legislative change. However, current Federal Rules of Civil Procedure provide guardians and family members with a number of protections, or “voice”, including appropriate notice, class certification requirements, the right to intervene, and a fairness hearing on the final outcome.

A regrettable part of the history of people with developmental disabilities, particularly those with severe cognitive or intellectual disabilities, is that all too often the public and private systems designed to serve them have not served them well – even engaging in abusive and neglectful treatment of individuals. At the same time, families, guardians or representatives remain unaware of the situation, often relying on the abusers themselves to assure them that all is well.

The glaring example that exposed the horrendous abuse and neglect of people with developmental disabilities in institutional settings nationwide was the 1972 expose of the Willowbrook institution in New York. However, such offenses have continued to occur

today, and most often in large and inappropriate institutional settings far from the eyes of the community. Just this month in Texas, it was discovered that staff that had been hired to care for the residents had been forcing them into “fight club” style battles.

Since 1972, many things have changed. Federal legislation was enacted that ensures children with disabilities access to a free, appropriate, public education. States, Congress, and the federal government have developed family support programs that allow families to have access to the supports they need for their children with disabilities to live in the community. All these changes have provided parents of a child with a disability with a much wider range of options than were available to parents in the 1950s and 1960s.

Enactment of legislation such as H.R. 1255 will jeopardize the well-being of thousands of individuals with disabilities by curtailing the ability to protect these individuals from systemic problems causing abuse and neglect, such as insufficient staff and lack of staff oversight in the Texas “fight club” example. By allowing those who would prefer to speak on behalf of individuals with developmental disabilities to have the final say, even when different than the individual’s own desires, this bill restricts the civil and human rights of individuals with developmental disabilities.

Protection and Advocacy systems must continue to have the broadest authority possible to pursue administrative, legal (including class actions), and/or other appropriate remedies or approaches to ensure the protection of the rights of people with developmental disabilities. This broad authority is critical to protect and advocate the rights of individuals with developmental disabilities and to insure the well-being of many thousands of individuals with developmental and other disabilities.

We would appreciate an opportunity to speak with you as soon as possible to discuss our very strong concerns with your re-introduced legislation. Please contact Kim Musheno (301-588-8252).

Sincerely,

American Music Therapy Association
American Association for People with Disabilities
Association of University Centers on Disabilities
Autism Society of America
Bazelon Center for Mental Health Law
Brain Injury Association of America
Disability Rights Education and Defense Fund
Easter Seals
Mental Health America
National Disabilities Rights Network
National Down Syndrome Congress
National Organization of Social Security Claimants’ Representatives
National Rehabilitation Association
Mental Health America
Self Advocates Becoming Empowered
The Arc of the United States
United Cerebral Palsy