



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

December 7, 2007

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. 3995. As organizations, we cannot overstate the negative impact this legislation would have on the lives of individuals with developmental disabilities and their families.

A regrettable part of the history of people with developmental disabilities, particularly those with severe cognitive or intellectual disabilities, is that too often the public and private systems that serve them do not serve them well – even engaging in neglect and abuse of individuals - while families guardians or “other legal representatives” remain clueless, relying on the very abusers themselves to assure them that all is well while, unbeknownst to them, their loved-ones suffer.

The most glaring example of this was the 1972 expose' of the horrendous abuse and neglect of people with mental retardation and other developmental disabilities at the Willowbrook institution in New York – abuse and neglect that was found to be common in institutional settings nationwide. Out of the outrage of the imprisonment and suffering of these individuals came federal efforts to ensure that such things never happened again.

However, such things continued to happen and most often in large and inappropriate institutional settings – far from the eyes of the community. Unfortunately, back in those days parents often were told to immediately institutionalize their children by doctors who had no training whatsoever in disability. There were no educational

programs for children with disabilities and no community supports to help them keep their children at home.

Things quickly began to change when many parents banded together in groups such as The Arc to begin to provide early intervention, educational, family support, and living arrangements in the community. These efforts – bolstered by the horror of Willowbrook – pushed the federal government in a new direction.

Since 1972, many things have changed. Federal legislation was enacted that ensured children with disabilities access to a free, appropriate, public education – thus providing them and their families with supports and services in the community where they were born and should grow up.

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 in the community. Medicaid law, which historically has had an institutional bias, has begun to focus more on the more cost effective and family-friendly home and community based services. 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.

Even more importantly, the philosophy of the disability community – ranging from consumers to parents and other family members to advocates and professionals in the field – is now completely focused on people with disabilities living in the community – with their families as children and as independently as possible as adults.

The *Olmstead* Supreme Court decision – based on the protections provided through the Americans with Disabilities Act -- requires that individuals with disabilities have access to supports and services in the least restrictive alternative – a definition that does not apply to large institutional settings.

The following statement from Self Advocates Becoming Empowered, the largest self-advocacy group for individuals with developmental and other disabilities makes it very clear what people want.

*If you are working with me and for me then do not disrespect me
We have been prepared enough,
ASK the people who are living in institutions
Would you trade places?
Close institutions
Get us real jobs
Close sheltered workshops*

It is essential that federally funded entities continue to have the broadest authority possible to pursue administrative, legal and/or other appropriate remedies or

approaches to ensure the protection of the rights of people with developmental disabilities. This includes enforcing their right to live full and productive lives in the community.

Our organizations informed you of our concerns with this bill as first proposed. We now would like to speak with you as soon as possible to discuss our very strong concerns with your revised and re-introduced legislation. Please contact Kim Musheno (301-588-8252).

Sincerely,

American Association of People with Disabilities

Association of University Centers on Disabilities

Autism Society of America

Bazelon Center for Mental Health Law

Disability Rights Education and Defense Fund

Easter Seals

Epilepsy Foundation

National Association of Councils on Developmental Disabilities

National Disabilities Rights Network

National Down Syndrome Congress

National Down Syndrome Society

National Rehabilitation Association

National Association of County Behavioral Health and Developmental Disability Directors

Mental Health America

Self Advocates Becoming Empowered

The American Association on Health and Disability

The American Association on Intellectual and Developmental Disabilities

The Advocacy Institute

The Arc of the United States

The American Network of Community Options and Resources

The National Spinal Cord Injury Association

The National Council for Community Behavioral Healthcare

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United Cerebral Palsy