



**March 2008**

**PEOPLE WITH INTELLECTUAL AND OTHER DEVELOPMENTAL DISABILITIES  
WANT AND SHOULD LIVE IN THE COMMUNITY**

*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  
(Self Advocates Becoming Empowered)*

**Representative Barney Frank’s legislative proposal (H.R. 3995) to limit the ability of federally-funded entities to bring suits related to Intermediate Facilities for the Mentally Retarded rebuffs the desires and goals of individuals with disabilities. It is a bill that has no place in 2008. We urge you not to support this discriminatory and backwards thinking legislation.**

**Background:** A regrettable part of the history of people with developmental disabilities, particularly those with severe cognitive or intellectual disabilities, is that often the public and private systems designed to serve them did not serve them well – even engaging in abuse and neglect. At the same time, families, guardians or “other legal representatives” remained unaware of what is happening, often relying on the abusers themselves to assure them that all is well. 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. 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 developed family support programs. Medicaid

law, which historically has had an institutional bias, began to focus more on individual, family-friendly, and cost effective 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 individuals with disabilities to parents and other family members to advocates and professionals in the field – now is 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.

**NDRN Recommends that Members of the House and Senate oppose H.R. 3995 by not cosponsoring the legislation, opposing the legislation if considered in a committee or the full House, and not sponsoring a companion version of the legislation in the Senate.**

**Rationale:** By having broad authority to pursue appropriate remedies, the Protection and Advocacy (P&A) system has been instrumental in ensuring the rights of people with developmental disabilities. It has been documented by a Government Accountability Office report (03-1044) that the P&A system consistently follows the rules of legal procedure when it comes to bringing lawsuits related to institutional conditions or closure.

Disability policy has moved forward in the past 30 years, people with developmental disabilities want to live in the community – where they should – and families have options in the community – which they did not have in the past. By allowing those that would prefer to speak on behalf of individuals with developmental disabilities to have the final say, even if different than the individual's own desires, Representative Frank's bill restricts the civil and human rights of individuals with developmental disabilities.

Society, the courts, and the Congress have moved away from institutionalizing individuals with developmental disabilities to creating supports and services to allow these individuals to live full and productive lives in the community. For the wants of a few, Representative Frank's bill will step on the rights of many and stop the forward progress being made to ensure that individuals with developmental disabilities who want to live in the community can do so.

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. Representative Frank's bill would jeopardize the well-being of many thousands of individuals with developmental and other disabilities.

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