

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 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 2007. 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 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.

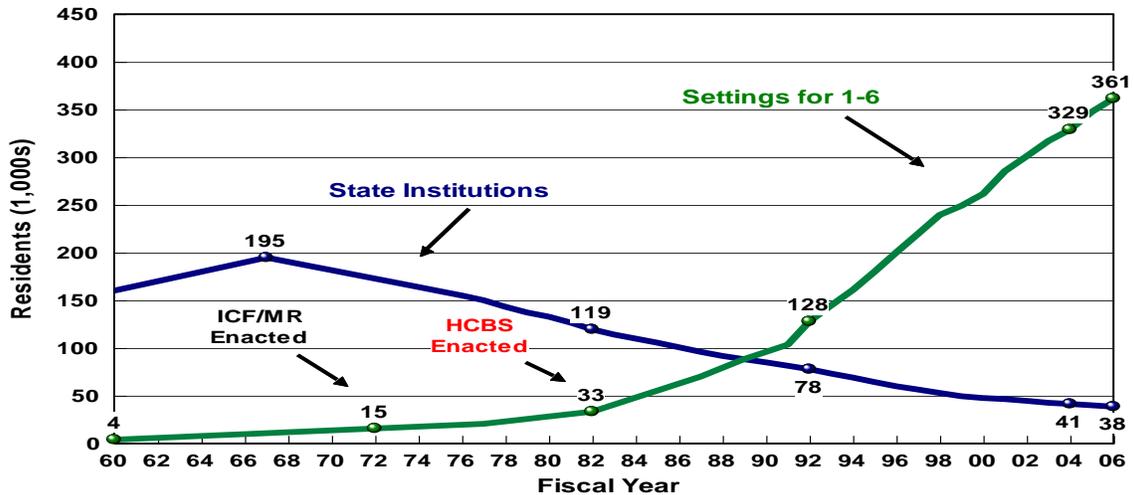
Since 1972, many things have changed. Federal legislation was enacted that ensured children with disabilities access to a free, appropriate, public education – thus providing them and their families with supports and services in the community where they were born and should grow up.

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.

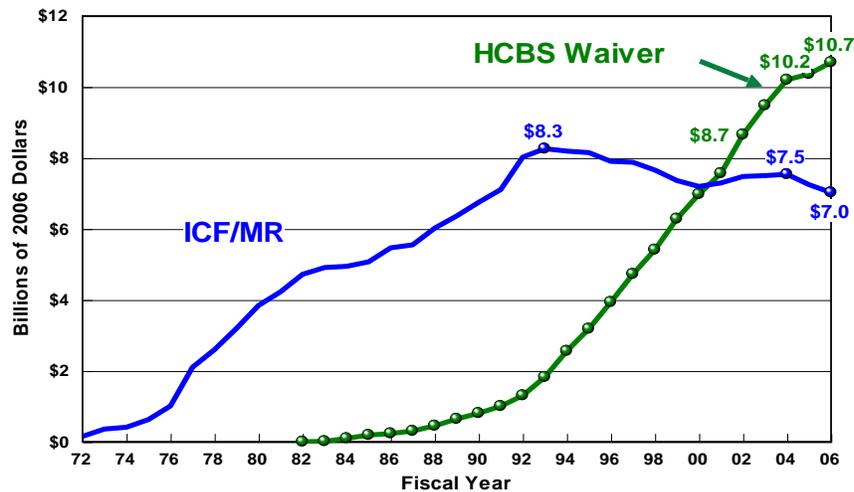
Even more importantly, the philosophy of the disability community – ranging from consumers to parents and other family members to advocates and professionals in the field – is now completely focused on people with disabilities living in the community – with their families as children and as independently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

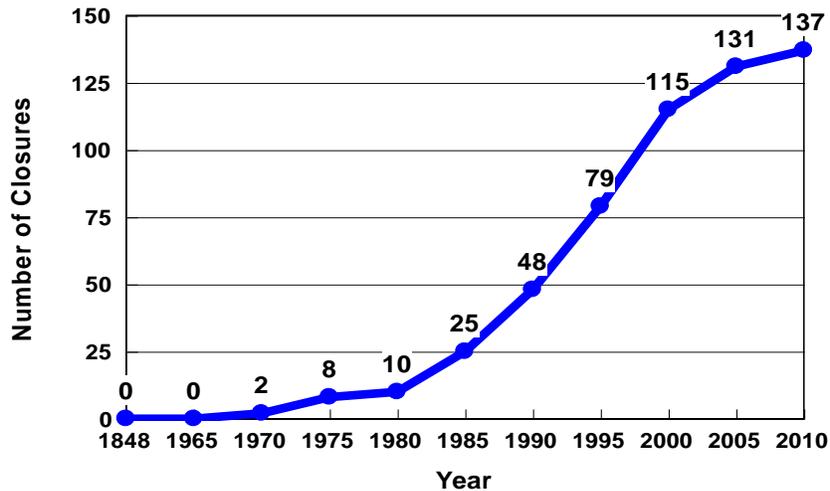
The chart below clearly demonstrates the move away from large institutional settings to smaller settings integrated into the community.



The second chart shows the move by the Medicaid program away from funding large institutional settings to funding supports in the community.



The next chart shows the cumulative closings of large institutions over history –obviously demonstrating that since the seventies, the movement is away from large institutions.



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.

Many have listened, some have taken action and we thank you.
But we have talked enough and waited too long!!!
We have told you what is important to us
Get rid of the infamous and hurtful "r" word, do not label us
We will not put up with
The "r" word continuing as part of an organization's name
even as initials
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
Give US the money to live OUR lives
Money follows the person means it is OURS not programs

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 limit the personal rights of individuals with developmental disabilities in favor of the rights of others who would prefer to speak on their behalf. In addition, this backwards legislation – legislation with no place in 2007 -- would jeopardize the well-being of many thousands of individuals with developmental and other disabilities.

- 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
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
TASH
United Cerebral Palsy
We need SABE on here and Mass groups I think

HOW THE PADD PROGRAMS HELPS INDIVIDUALS AND FAMILIES

This information is from the PADD 2006 Annual Program Report

The **Georgia P&A** assisted a 13-year-old boy who had been living in a nursing home since he was six. The P&A supported his mother to attend the Children's Freedom Initiative summit, where she spoke passionately about her desire to have her son live at home. A high-ranking official from the Department of Community Health (DCH) heard her story and pledged to help bring her son home. The boy was granted Medicaid funding to support him in the community, however, the boy's father had legal custody and opposed his move from the nursing home. The P&A assisted the mother to obtain pro-bono legal assistance to resolve the custody issue. Five months after telling her story at the Summit, the mother brought her son home with the support of the P&A, Georgia Legal Services, DCH, and the local community. The boy is being educated by the local school system and has friends in his neighborhood with whom he plays on a daily basis.

As a result of legislative advocacy by the **New Hampshire P&A**, New Hampshire created a central registry for caregivers who have a history of abusing, neglecting, or exploiting vulnerable adults, including those with developmental disabilities. The legislation passed in the 2006 session, with the P&A taking a lead role. The registry will mirror the one in place for child-care workers and will record the names of paid caregivers found guilty of abuse either through the courts or through internal investigations. It will detect workers who attempt to dodge detection by moving from system to system or from region to region. Agencies that receive funds from the state Department of Health and Human Services must use the database to screen potential workers.

A long-time resident living in a state resource center contacted the **Iowa P&A** requesting assistance with her release to a less restrictive living arrangement. The P&A began working with the woman and her social worker to ensure that a discharge plan was put into place and that the woman's desires were taken into consideration. Having to live with 10 roommates at the resource center, the woman's ideal living arrangement would be moving into a house with no more than two or three people. When a placement finally was agreed upon, a transition plan was in place. The woman enjoyed a shopping excursion, lunch with a peer, and a doctor's appointment so her medical needs could be addressed. Finally, the woman moved into an apartment where she has her own bedroom and bathroom, only one roommate, and a new job.

The **Massachusetts P&A** represented a 13-year-old girl with cerebral palsy who had received at-home occupational therapy twice a week since she was nine months old. As a result, she had made slow but significant progress in increasing her balance and the tone in her muscles. Although it took years, the girl is gaining more fine motor use in her hands and can now hold her head up for a short period, sit up, and chew. These have been crucial milestones that have enabled her to communicate with a computer, gain weight, sit in the tub and on the toilet, and brush her hair. The girl's parents sought the P&A's assistance with an appeal of a MassHealth decision to reduce the therapy from twice to once a week. At the end of the hearing, the MassHealth representative modified the decision and reinstated the therapy to twice a week.

The **Louisiana P&A** supported a 16-year-old student diagnosed with brittle bone disease (osteogenesis imperfecta) and other physical disabilities. She has a very small stature, must use a specially designed electric scooter for mobility, and sometimes needs to use oxygen. The school decided that if the student needed more than 1.5 hours on the oxygen concentrator daily, she is creating a danger to herself and others because of the volatility of oxygen. Therefore, they decided to place her in a homebound school program. The P&A negotiated with the school to allow the young woman to remain on campus, obtaining documentation from the manufactures of both the scooter and the oxygen concentrator indicating that the use of these did not create a danger. The P&A also obtained documentation from the student's physician reinforcing the manufacturers' documentation. The P&A further worked with the school to allow the young woman to take her oxygen treatments during a study hall instead of lunch so she could spend her lunch breaks socializing with peers.

The **New Jersey P&A** staff intervened on behalf of a 20-year-old individual with mental retardation and Prader-Willi Syndrome. The woman's father contacted the P&A complaining that his daughter had been sexually assaulted at her group home nine months earlier. He said the perpetrator was charged, prosecuted, and plead guilty to the assault. Since the assault, his daughter had been residing at her parents' home, where they cannot adequately care for her. The Division of Developmental Disabilities advised that the woman's room in the group home where the assault took place remained available and did not offer any other placement options. The psychiatrist treating the woman since the assault supported her parents that a return to her previous placement would be detrimental to her. Based on the information it

gathered, the P&A filed a complaint with the Department of Health and Human Services Office of Civil Rights on behalf of the woman. This action resulted in the Division offering the woman a new residential program, where reportedly she is adjusting well.

A school was restraining a 4-year-old boy during seizure activity because they did not believe the behaviors were due to the child's epilepsy. The school had placed the child in a behavior disordered kindergarten class. With assistance from the **Missouri P&A**, the parent was able to document the child's diagnosis for the IEP team and arrange for consultation with the Epilepsy Foundation. The P&A further pointed out that the restraint violated school policy and requested a behavioral evaluation, which determined that the child should be moved back to the regular classroom.

The **Rhode Island P&A** was contacted by a high school about a 21-year-old with developmental disabilities who was a part-time employee of the school cafeteria. This young man lived with his parents and reported to his employer that he had been locked in the basement of his parents' home and sometimes beaten with a coat hanger and belt buckle when he misbehaved. The P&A investigated and determined that – as a child the man received special education services in school – but that his mother failed to apply to the state for adult DD services, insisting that he was well taken care of at home. The P&A investigation indicated that there had been sporadic contacts with the police and revealed historical evidence of physical abuse, including hospital emergency room treatment. After being informed that he wanted to leave his parents' home, the P&A advised the young man of his rights as a self-determining adult and of the state services available to him. On an emergency basis, the P&A gathered his entire school record, police reports, and medical information, and arranged for an immediate eligibility hearing with the State Division of Developmental Disabilities seeking appropriate supports and services, up to and including removal from the family home and temporary placement.

The **Pennsylvania P&A** assisted a man who lived in northwestern Pennsylvania and had no funding for services. He was in his mid thirties, had mental retardation, and lived at home with his elderly parents. Both parents were in failing health and lived below the poverty level, frequently having to decide whether to spend their money on food or medications. Their son needed help with activities of daily living and could not live alone. The Waiting List Campaign met with the Office of Mental Retardation to discuss this situation. The young man attended the meeting to help demonstrate the need for funding for services. While the meeting was going on, his mother was taken to the local hospital and arrangements were made for both parents to be sent to a nursing home. Their son literally was without a place to live since his only caretakers were now in a nursing home. The P&A was able to secure emergency funding for this man and he now lives with a Family Living provider.