



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

July 13, 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 support for the federally mandated and funded Protection and Advocacy for Developmental Disabilities program (PADD) and our significant concerns about H.R. 2839. As organizations, we cannot overstate the positive effect that the PADD program has made of the lives of individuals with developmental disabilities and their families. The history of the PADD program is one of necessity, the necessary protection of human lives, human rights and human dignity. The PADD program was authorized as part of the Developmental Disabilities Assistance and Bill of Rights Act in 1975. It grew out of an 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. The original program goal was to ensure the rights of children and adults living in institutional settings and protect them from abuse and neglect.

Because of PADD, there are skilled personnel working in Protection and Advocacy organizations in 50 states, the District of Columbia and 5 territories to ensure that people with developmental disabilities are protected from harm, abuse, neglect and the denial of their human and civil rights and that those receiving publicly-funded services are receiving the best in quality supports that meet their individual needs. Protection and Advocacy (P & A) staff are often the ONLY resources in a state that can help people address the unique issues faced by individuals with developmental disabilities, wherever they live or work. Without the P & A, people would be left to fend for themselves in complex systems, often unable to address relatively simple challenges on their own and, more importantly, often unable to escape from abuse and harm when it occurs. P & A staff open doors, break down barriers, protect lives and rights and virtually make it possible for many thousands of people to survive and thrive in communities everywhere.

It is essential that Protection and Advocacy for Individuals with Developmental Disabilities programs 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 disabilities. We strongly believe that any effort to limit the ability of the PADD program to protect individuals with developmental disabilities would jeopardize the well-being of many thousands of individuals as well as negate the original intent of the program.

H.R. 2839 appears to limit not only the authority of Protection and Advocacy systems, but also the personal rights of individuals with developmental disabilities in favor of the rights of others who would prefer to speak on their behalf. 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. Without the PADD program and the authority of skilled P & A personnel to identify problems when they occur, investigate and act on behalf of the individuals themselves, the systemic abuse, that all-too-common part of the history of people with developmental disabilities, can emerge at any time and continue unabated. It simply makes no sense to restrict a P & A's ability to act to protect human lives,

Fortunately for our nation, disability policy has moved forward in the past 30 years -- with the norm now being children and adults with mental retardation and other developmental disabilities living in their home communities, just like everyone else. It is with this movement that PADD's mandate expanded and led to the major role PADD programs play in ensuring that people with disabilities are free from abuse and neglect in all settings and can access the necessary supports and services that make community living a long-term reality, such as education, health care, family supports, housing, employment, recreation, and transportation.

In 2006, the PADD program:

- Served over 20,000 individuals through information and referral services, training, advocacy services, and legal protection.
- Served individuals with developmental disabilities living in all settings, including individual's homes, family homes, provider-operated housing, foster care, and public and private institutions.
- Utilized a broad range of strategies to resolve issues consistent with the comprehensive approach of the P&A System, including short-term and technical assistance, investigations, negotiation, and mediation. Only five percent of cases resulted in legal action being taken.
 - In 2003 the Government Accountability Office did a study entitled *PROTECTION AND ADVOCACY AGENCIES Involvement in Deinstitutionalization Lawsuits on Behalf of Individuals with Developmental Disabilities*. This study was mandated in the 2000 reauthorization of the Developmental Disabilities Act and its results clearly demonstrate that P&As comply with the law related to proper notification when undertaking litigation.
- The Office of Management and Budget (OMB) PART report on the PADD program states that it has a clear purpose and complements other public and private efforts to support individuals with developmental disabilities in the community. In 2004, the number of individuals who had their complaints of abuse, neglect, discrimination, or other human or civil rights corrected was 88.7 percent – exceeding the goal of 88 percent. In 2005, this rose to 91 percent.

The examples on the attached fact sheet clearly illustrate the vital role played by the Protection and Advocacy for Developmental Disabilities program in the lives of individuals with disabilities.

The undersigned national disability organizations strongly support the federally mandated and funded PADD program and cannot emphasize enough the fact that any effort to limit the ability of the PADD program to protect individuals with developmental disabilities would jeopardize the well-being of thousands upon thousands of individuals and negate the original intent of the program. Because this is an extremely important issue to people with developmental disabilities, we would like to request an opportunity at your earliest convenience to discuss in person our grave concerns related to H.R. 2839.

We look forward to speaking with you soon about the importance of the Protection and Advocacy for Developmental Disabilities program. For more information, contact Developmental Disabilities Task Force Co-Chairs, Kim Musheno (301-588-8252), Karen Flippo (703-739-4400) or Janna Starr (202-783-2229).

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

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

The Consortium for Citizens with Disabilities is a coalition of more than 100 national consumer, advocacy, provider and professional organizations headquartered in Washington, D.C. (A list of members is available at www.c-c-d.org) Since 1973, CCD has advocated on behalf of people of all ages with physical and mental disabilities and their families. CCD has worked to achieve federal legislation and regulations that assure that the 54 million children and adults with disabilities are fully included in the mainstream of society.

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.