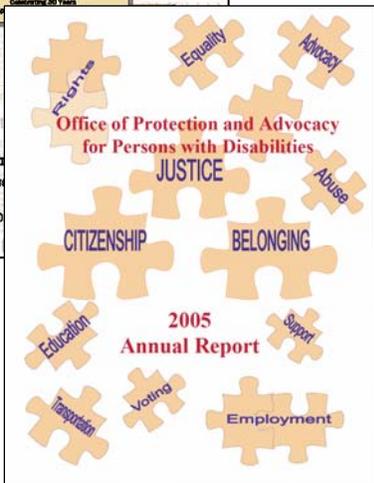
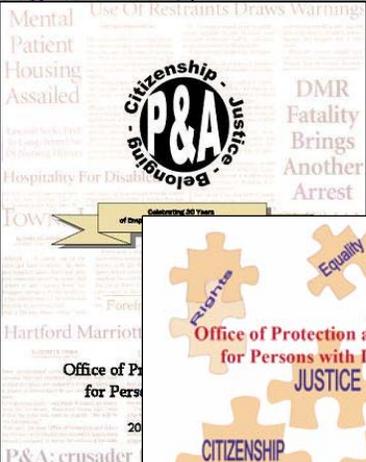
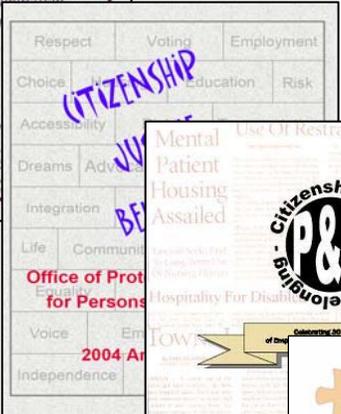
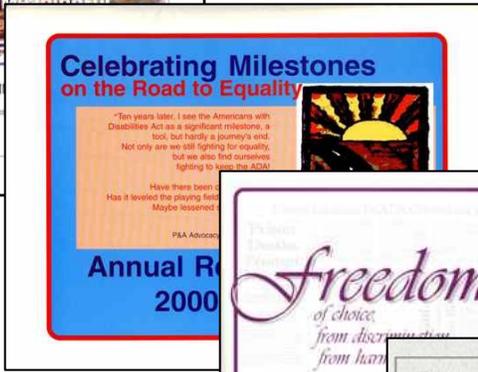
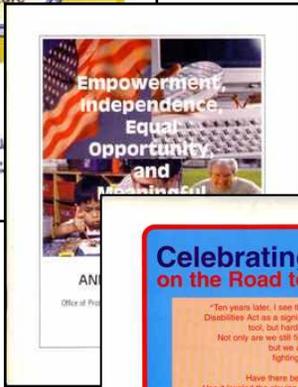
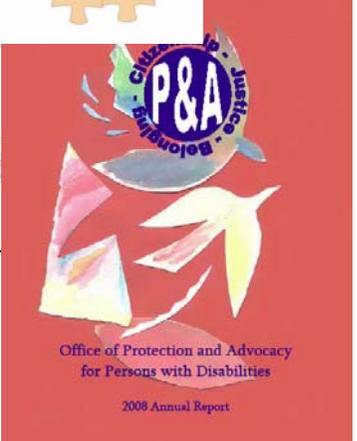


Updating the Past ~ ~ ~ Reporting on the Present



Office of Protection and Advocacy for Persons with Disabilities
2009 Annual Report





Updating the Past – Reporting on the Present

The recent economic challenges we have all faced have put a significant strain on many aspects of our lives. Our state government has been forced to make painful cuts, families are tightening belts, and businesses are struggling. We are all trying to do more with less. This is especially true within the disability community. Historically, individuals with disabilities and the service systems established to support them, have taken direct financial and programmatic hits in times of need. It is our job at P&A to identify these issues, to focus attention where others would ignore, and to minimize the impact on those we serve, to the best of our abilities.

P&A hopes that, through our outreach and advocacy, we leave the lives of those we advocate with and for, better. We hope that they remain free to make their own choices and that the supports that were hard-fought to obtain will work. As we watch for possible crises, and work to deflect them, P&A is taking an opportunity in this annual report to celebrate the successes of the past year while looking back and at the stories of previous clients. It is with this sense of looking back while looking forward, that we have included the stories you will see peppered throughout this report. “Where are they now” snapshots of those we have previously supported through adversity and discrimination are located in various sections of the report. Their stories, found in the shaded boxes, are as important now as they were then.

MISSION STATEMENT

The mission of the Office of Protection and Advocacy is to advance the cause of equal rights for persons with disabilities and their families by:

- ◆ increasing the ability of individuals, groups and systems to safeguard rights;
- ◆ exposing instances and patterns of discrimination and abuse;
- ◆ seeking individual and systemic remediation when rights are violated;
- ◆ increasing public awareness of unjust situations and of means to address them;
and,
- ◆ empowering people with disabilities and their families to advocate effectively.

A Message from the Executive Director and the Advocacy Board Chair

**P&A
Advocacy Board**

Rachel Bogartz
Danbury, CT

John Clausen
Storrs, CT

Eileen Furey, Chair
Ashford, CT

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James D. McGaughey
Executive Director



Eileen Furey
Chair, Advocacy Board

As required by our enabling legislation, the Board and the Office of Protection and Advocacy for Persons with Disabilities issue an annual report on the first day of December. For the past thirty years those reports have described our advocacy and investigation activities, identified barriers to the exercise of civil rights for Connecticut residents with disabilities, and listed issues affecting access to services. Whenever possible, we have also told the stories of real people we have worked with. Pulling together statistical information for the annual report is always instructive. But, it is the people whose lives we touch and who touch us that keep us real. Telling their stories is not only the best way to explain what we do, it is also a fair measure of how well we walk our talk.

Born in response to scandalous conditions in what were, at the time, almost exclusively institutionally-based human services, federally mandated protection and advocacy systems (P&As) developed different organizational forms in different states. In Connecticut, we are an agency of state government. P&As in nine other states and territories have similar structures. In a few states the P&A is a quasi-governmental agency, one that operates under state authority but is governed by an independent board or commission. Most P&As are not part of government at all, but are non-profit organizations that have been designated by their governors and/or legislatures to exercise the powers and duties mandated by federal P&A statutes. Irrespective of their governance structure, however, all P&As must be structurally and functionally independent, and must have authority to access people with disabilities and their records, to investigate, to educate policy makers and the public, and to pursue legal and administrative remedies on behalf of their constituencies.

Over the last thirty years P&As have seen mandates expand, strategies evolve and new issues emerge. However, the one thing that never changes – the thing that marks us as unique among public interest/watchdog entities – is the partnership we maintain with our constituents. Their needs inform our priorities, their goals determine the remedies we seek in the cases we bring, and their experience teaches us about what does and does not work. So their stories really are our story too – the story of what we are learning and how faithfully we are listening to the people who truly “own” the P&A system.

We hope that you will bear this in mind as you read the stories in this year’s report. Several of those stories are “updates” on people who were profiled in previous reports. We hope you find their experience as instructive as we have.

New Horizons Village



When Denise Laflamme moved into New Horizons Village (NHV) in 2004, she believed she had found an ideal new community. Denise, an individual with multiple disabilities, said “I really wanted to live at New Horizons because it gave me the chance to live in a community of people with disabilities and an accessible apartment”. A few months after moving into her new home, however, Denise became ill and had to go to a hospital. While she successfully recovered in the hospital, and discharge plans called for her to return to her home at New Horizons, she was shocked to learn that New Horizons did not want her back. Instead of the supportive community she thought she had found, New Horizons forced her to vacate her apartment. How could this have happened? It didn’t sound right to Denise, or to P&A.

New Horizons markets itself as an independent living community “designed for people who have severe physical disabilities. Tenants manage their own lives in a supportive and fully accessible setting.” However, as part of the application process, New Horizons required all prospective and current tenants to disclose private medical records and then used the information to make judgments about each prospective resident’s ability to meet independent living standards set by New Horizons. This process allowed New Horizons to screen out individuals they determined to be “too disabled” to live independently. The lease tenants signed imposed a similar, ongoing obligation to disclose medical records. Tenants who were determined to have become “too disabled” to live at New Horizons were subject to lease termination. So, tenants were at constant risk of eviction.

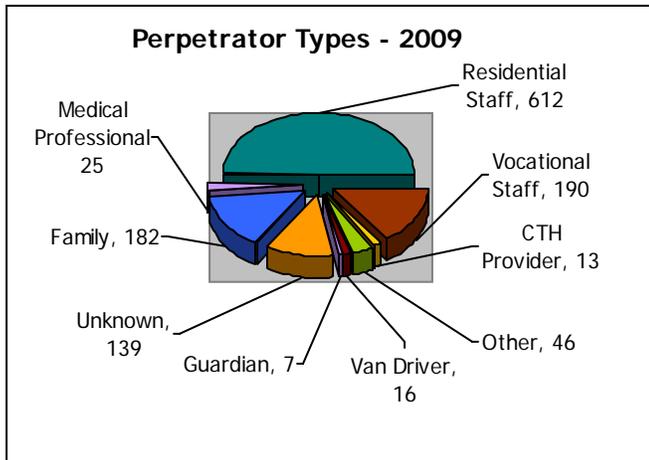
In 2005, P&A, in partnership with the Connecticut Fair Housing Center, filed a federal lawsuit on behalf of Denise, against New Horizons. The suit claimed that New Horizons’ policies subjected applicants and tenants to discriminatory scrutiny based solely on their disabilities, a violation of the Federal Fair Housing Amendments Act.

In 2009, four years after the lawsuit was filed, a federal court judge held that New Horizons had indeed violated the Fair Housing Amendments Act and the case was ultimately settled. Under the consent decree, NHV will completely revise its requirements for tenancy, evaluating each potential tenancy on a case by case basis; stop requiring tenants to provide them with private medical records; and pay damages and attorney’s fees totaling \$600,000. Individuals needing a higher level of personal assistance will not automatically be rejected for tenancy. Court-approved monitors will ensure that New Horizons complies with the consent decree, and will provide quarterly reports to the court for two years. This is the largest settlement in a case challenging independent living requirements in Connecticut.



Abuse Investigation Division

The Abuse Investigation Division (AID) was established in 1985 to investigate allegations of abuse or neglect by caregivers of persons with mental retardation, ages 18 through 59. AID has authority to conduct direct investigations and to oversee investigations conducted by service providing agencies. All staff, administrators, and professionals are mandated to report suspected abuse and neglect to AID. AID



conduces investigations for allegations involving people living at home or otherwise outside the scope of the mental retardation service system. AID is also mandated to investigate the deaths of persons with mental retardation for whom DDS has responsibility for direct care or oversight and there is reason to believe that the death may involve abuse or neglect.

Last year AID received 1126 allegations of suspected abuse or neglect of persons with mental retardation, resulting in 1,112 cases. P&A staff investigated or monitored 982 cases while 125 allegations did not

meet the statutory requirements for a P&A investigation. The 1,112 cases involved 1,223 victims: 584 females and 639 males. Of the 1,112 cases accepted for investigation or monitoring, more than 59% involved neglect (579), while almost 21% alleged physical abuse (207). Case types also included Injury of Unknown Origin (88), Abuse/Neglect (58), Sexual Abuse (22), Death (9), Abuse (7) and Other (12).

Update – The 2007 P&A Annual Report included a story about Mary, a woman with multiple disabilities who lived in a DDS licensed group home. P&A's Abuse Investigation Division received a call indicating that Mary was hospitalized after having difficulty breathing. Later it was learned she had choked on a large plastic bottlecap, leaving her unable to swallow food without aspirating. Her guardian would not approve insertion of a feeding tube. With his permission, doctors at the hospital ordered that she not be fed, and entered a Do Not Resuscitate (DNR) order in her chart. Without nutrition she was expected to die. When P&A investigators went to the hospital to investigate, they found Mary was very alert and smiling – hardly the picture of a terminally ill person.

A P&A staff attorney was immediately assigned to challenge the guardian's decisions. The probate court ordered the DNR removed and a feeding tube inserted. P&A assigned an advocate to make certain appropriate services were put in place for Mary to move into the community. Mary is currently residing in group home and attends a vocational program. She is now able to swallow food, and no longer needs a g-tube. According to her group home manager, Mary is very happy in her home and is always laughing and smiling, and enjoys listening to music and the television while hanging out with her housemates.

Case Services Unit – Information and Referral

P&A and its subcontractors received requests for assistance from 9,909 individuals with disabilities, their family members, and interested parties. Of these, 8,746 were requests for information and referral, or short-term assistance. The remaining 1,163 requests received a more intensive level of advocacy representation.

P&A's advocates handled requests for information and assistance from callers, walk-in clients, legislators, e-mail contacts, letters and visitors to the P&A website. More than 640 requests related to Abuse or Neglect including inappropriate mental health treatment; excessive or involuntary medication; physical, verbal or sexual assault; conditions in a facility; and financial exploitation. They also responded to questions concerning Housing (495), Government Benefits and Services (484), Rights Violations (361), Services (336), Employment (231), Education (184), Healthcare (137), Financial Entitlements (99), Rehabilitation Services (96), Transportation (61), Architectural Accessibility (63), Assistive Technology (53), Guardianship (30), Post Secondary Education (19), Insurance (18), Parental Rights (18) and Recreation (11). Advocates also responded to 292 requests for simple information like a copy of a publication or the name of a case manager. Callers also contacted P&A with concerns about Voting Rights, Child Care, Immigration, Privacy Rights and Access to Records.

DID YOU KNOW?

You can obtain information from P&A through a variety of sources including P&A's website (www.ct.gov/opapd), over the telephone, through the mail, by e-mail or by visiting the agency. Contact information is located on the back cover of this report.

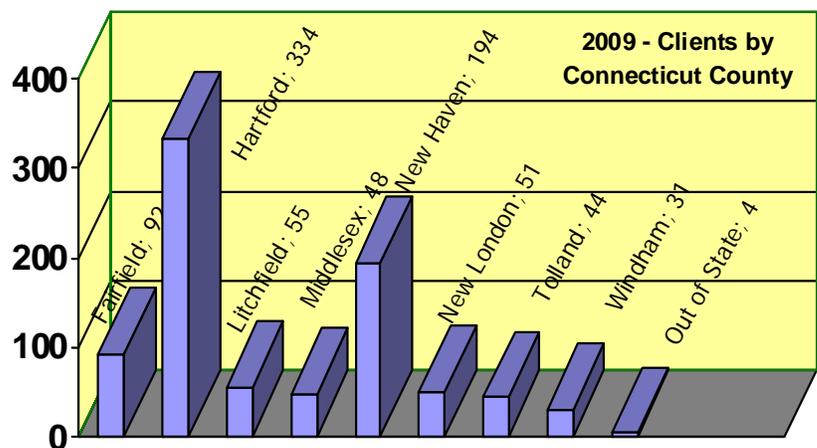


Mr. K needed his mail delivered to his front door because his disability prevented him from walking to the mailbox at the street. Mr. K works out of his home and the other individual in the home is often away on business making it almost impossible to get his mail for days at a time. He filed a hardship request with the local Postmaster, but was denied because another individual lives in the home and the street is heavily traveled, creating a possible safety concern for the mail carrier. At this point Mr. K did not know where to turn. He called P&A.

The P&A advocate contacted the Postmaster to try and resolve the issue. When the postmaster refused to reverse his decision, the P&A advocate researched Mr. K's appeal rights and suggested that he appeal to the next level and provide more documentation of his need. His appeal was initially rejected by the District Manager. The P&A advocate subsequently conferred with a P&A attorney about the next steps in the process and the information needed to appeal further. The advocate informed Mr. K about his rights and additional documentation for an appeal to the Regional Manager. Not long after filing his appeal with the Regional Manager, Mr. K. received a letter approving his request.

Case Services Unit – Advocacy Representation Division

Advocates assigned to the Advocacy Representation Division protect the rights of adults and children with disabilities living in institutions and community-based residential programs. In addition to providing training on disability-related topics, advocates also intervene on behalf of groups and individuals, such as adults with disabilities needing assistance with becoming employed or resolving barriers to maintaining employment; children with disabilities who are unable to obtain appropriate supports to meet their educational needs; people with disabilities seeking remedies for issues related to forced medication, accommodations in housing, access to the voting process; programmatic and structural accessibility; abuse; neglect; effective communication; guardianship and personal decision making; and assistive technology. Advocacy Representation Division staff attorneys seek administrative or judicial remedies involving discrimination based on disability. The Advocacy Representation Division of the Case Services Unit is composed of a number of distinct federally mandated advocacy programs for people with disabilities, as illustrated on the chart on page 17 of this report.



P&A advocates and attorneys provided representation to 853 individuals with disabilities needing assistance with 938 issues. They requested advocacy in the areas of Education (238), Rehabilitation Services (124), Abuse (110), Neglect (100), Rights Violations (67), Financial Entitlements (51), Quality Assurance (36), Healthcare (35), Architectural Accessibility (22), Government Benefits (22), Housing (17), Services (14), Assistive Technology (11), Transportation (8), Guardianship (5), Unnecessary Institutionalization (4), and Voting (4). Forty-one (41) issues involved other problems such as childcare, recreation, and parental rights.

Update - Adrienne was featured in P&A's 2006 Annual Report. At that time she was an 18 year old woman who needed assistance with special education and related services through her local school district. P&A advocates assisted Adrienne in obtaining a transition plan for her remaining years of high school.

Today, Adrienne lives in an apartment that she shares with another young woman. She works as a subcontract employee through a non-profit agency, but earns only \$30.00 per week. She is currently working with the Bureau of Rehabilitation Services, which funded a vocational evaluation. However, little seems to be moving on the employment front. Her family is grateful for the transition services that helped her learn more independent living skills. But they have been paying for transportation and rent, and have spent nearly the equivalent of four year's worth of college tuition on available, private agency transition programs – without much success to show for it. Adrienne needs a real job and some consistent coaching. She is not alone - many other young people with disabilities are finding it difficult to get started, and have to rely on their parents for survival.

Case Services Unit – Advocacy Representation Division

The Assistive Technology staff at P&A received a complaint from the Connecticut chapter of National Federation of the Blind because its members were being forced to accept assistance boarding and disembarking from paratransit vehicles. They didn't want this service and were upset at the connotation of incapacity that the service communicated. The paratransit company was perplexed: Isn't the ADA all about giving people the extra help they need? And what about liability concerns? P&A staff worked with both passengers and the company to re-think the issue and develop protocols that protect the autonomy and choice-making rights assured by the ADA. Riders can choose the level of assistance they receive based on their own needs and preferences.

Update - In the 2002 P&A Annual Report, John, a man with intellectual disabilities, contacted P&A because he wanted to leave the nursing home where he had been living with his wife of 27 years. After John's wife passed away, he decided to move ahead with his dream of living independently in the community. Two years after his wife's passing P&A assisted John with moving into his own apartment. Seven years later John is living in the same apartment. He puts flowers on his wife's grave every week and talks to her. The aging process has caught up with him and now he uses a walker. John's desire for independence continues and he is requesting assistance from P&A to help him move to a more accessible apartment in order to maintain his community living. John is very adamant that he is absolutely NOT going back to a nursing home. The time he spent there was more than enough.

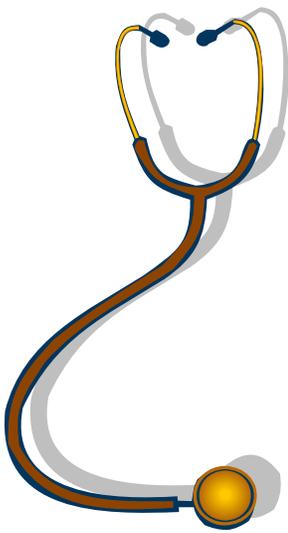
Mr. L., is a 60 year old gentleman with Downs' Syndrome and Alzheimer's disease. He lived in a group home and participated in a day program. Because of his increasing mobility impairment, staff determined that he could not continue to live in his home of 20 years. When Mr. L.'s team concluded that there was no other suitable residence for him except a nursing home, a family member contacted P&A for help with "keeping her brother out of a nursing home." The P&A advocate met with Mr. L and reviewed his records. She also met with several provider representatives and with staff of the Department of Developmental Services (DDS). Alternatives to a nursing home were not being sought and a document certifying Mr. L. for nursing home care had been improperly inserted into his official record. The advocate was able to have that document set aside, and a search for alternative group homes began. An alternative, accessible and appropriate group home opening was located within the same provider agency. Due to accessibility and familiar staff in the home, all parties agreed that this was an ideal conclusion. Financial support for this opening, however, seemed to be unavailable and therefore the P&A advocate worked with the agency and DDS to reach an acceptable settlement. Mr. L. moved two weeks later into his new home, supported by familiar staff and his family. A nursing home no longer looms in his future.

Case Services Unit – Advocacy Representation Division

Abby is the mother of two teenage children who have reached driving age. One of her teenage children is currently attending a local driving school and, as a parent, Abby is required by law to attend a two hour parent information session at the school. Because Abby is deaf, she requested that the driving school provide her with a sign language interpreter as an accommodation to her disability. When the driving school said no, Abby called P&A. The P&A advocate contacted the driving school to inform the owner of his obligation under the Americans



with Disabilities Act to provide effective communication for persons with disabilities who use his services. She also informed him of the process of requesting an interpreter through the Commission on the Deaf and Hearing Impaired. The owner reluctantly agreed to provide the interpreter and Abby was able to attend the required parent session of the driving class.



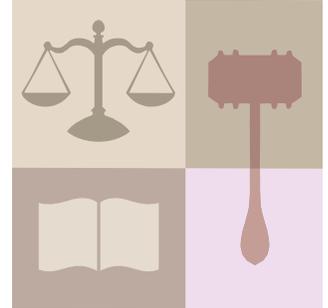
Dr. B., a gentleman with post polio syndrome, was a practicing chiropractor and chiropractic instructor whose license lapsed due to a long recovery from surgery. He worked with the Bureau of Rehabilitation Services (BRS) to develop an employment plan, however, he became frustrated at its slow implementation. Dr. B. needed to renew his chiropractic license by a specific date and present his case before the Board of Chiropractic Examiners, or he would have to start over, going through an entirely new licensing process again. Frustrated, he called P&A.

The P&A advocate requested a meeting with BRS to determine the exact steps that needed to occur to assist Dr. B. in licensure reinstatement. The advocate mediated the communication difficulties between Dr. B. and BRS by developing an action plan with a list of specific implementation deadlines. She also contacted the Department of Public Health (DPH) regarding acceptable classes, the number of courses needed, and inclusion of Dr. B's request on the agenda of the Board of Chiropractic Examiners meeting. P&A acted as a link between the DPH and BRS to assure that proper information was being shared among all parties and that all timelines agreed to and established were enforced.

Dr. B. finished the necessary coursework, completed the re-application process and had his case presented before the Board of Chiropractic Examiners. His license was reinstated and he is now able to teach at a local university.

Case Services Unit – Legal Division

The Legal Services Division of the Case Services Unit provides legal advice and representation to selected agency clients. Staff attorneys also represent individuals and groups seeking administrative or judicial remedies for discrimination based on disability. During the year, the P&A legal division provided individual and systemic representation and monitoring on a number of legal issues including, but not limited to: proper treatment for prisoners with disabilities in Connecticut's correctional system; violations of the employment and public accommodations provisions of the Americans with Disabilities Act, especially in hospital emergency rooms, prisons, nursing homes, and with the police; housing discrimination; forced sterilization of persons with developmental disabilities; educational placements and programs for children with disabilities; eligibility for services from the Department of Developmental Services; and guardianship/conservatorship for persons with disabilities. P&A attorneys also consulted with outside attorneys and the public on questions of disability law, working with staff to ensure quality responses to public inquiries and preparing comments on proposed state and federal regulations.



Housing Discrimination - In addition to prevailing in *Laflamme v. New Horizons Village* (see page 2), P&A attorneys represented many people with disabilities who were experiencing housing discrimination. In one case, Barbara, a woman with a disability, requested permission from her condo association to extend a handrail from her front entrance to an adjacent garage as an accommodation to her disability. Because of a neighbor's objection, the association denied Barbara's request, forcing her to consider moving from her home. The association also informed Barbara that she could have the railing installed for 6 months while she looked for a new place to live. Barbara contacted P&A for assistance. The P&A attorney reviewed the case and contacted the condo association to educate them about their obligation to provide reasonable accommodations for people with disabilities. The condo association agreed to grant Barbara's request, the handrail has been installed and Barbara does not have to move.

Update – The 2008 P&A Annual Report told the story of Chrissie, a 12 year girl with intellectual disabilities who was in the care of the Department of Children and Families (DCF). Chrissie developed a highly treatable form of leukemia, but doctors at the hospital where she had been admitted did not want to initiate the treatments. The hospital's ethics committee approved of the decision not to treat her, even though it meant that Chrissie's would die. Although the treatment could be uncomfortable, it was clear that if she did not have a disability, there would have been no question about treating her. P&A intervened, meeting with all parties and threatening to take action if Chrissie did not receive treatment. DCF and the hospital agreed and Chrissie received her treatment.

Today, Chrissie is doing very well. All signs of leukemia are gone, and she is a happy, healthy child who laughs, enjoys playing and loves music. Family members visit her regularly and she was recently featured on a program that promotes adoption. She is currently being considered for permanent adoption.

Case Services Unit

Kim's Story



Kim's mental health status was deteriorating. She had been placed in a group home on what she thought would be a temporary basis. Ten years later she was still there. Although she was living with five other women, some her own age, Kim had not developed friendships with any of them. She attended a day program over 30 minutes drive away, the travel back and forth exhausted her. Kim's demeanor and appearance were depressed, and she often sat slumped in her chair peering up at visitors from under her unkempt hair. She was becoming increasingly depressed the longer she lived in that setting. In November 2006, an anonymous caller contacted P&A and requested advocacy assistance for Kim.

The P&A advocate found Kim to be a bright young woman with various disabilities including cerebral palsy, seizure disorder and depression, who clearly wanted to move out of the group home. For more than 2 years, the advocate worked to remove barriers that prevented Kim from moving to a better living situation. Because Kim's parents could not agree on the best course for medical and psychiatric treatment, P&A worked with Kim's case manager from the Department of Developmental Services (DDS) and the probate court to identify a new medical guardian. The next step was working with the interdisciplinary team, a group that had experienced years of miscommunication and mistrust. Acting as a mediator, the P&A advocate got all of the team members to listen to Kim and work with her to create a new vision for her future, a vision that would make Kim healthy and happy at home.

Deciding to move Kim was easy - getting her there was much more difficult. The P&A advocate tirelessly worked with Kim's team. When a new home could not be found, the advocate and DDS case manager encouraged the team to think creatively. Soon a family friend invited Kim to live with her. A support plan and budget were developed but quickly rejected by DDS because of high administrative costs. Over the next six months, the P&A advocate attended numerous meetings, made many calls and sent many e-mail messages as the plan was reworked and a new budget was created. Other complications were addressed as they arose, always focusing on the goal to move Kim to a new healthy and happy home of her choosing.

Finally, in October 2008, Kim got the word! Her budget was approved. She could move by Thanksgiving! After two years, Kim's dream was finally fulfilled. She now spends her days at a horse farm run by Employment Options, Inc., and she just found out that she will soon be getting paid for her work contribution. At her most recent meeting, Kim said: "I'm growing up. I don't feel like an adult baby any more, I feel like a grown-up. I'm glad people are really proud of me, instead of saying "oh, she can't do that!"



Community Outreach and Training

P&A sponsored or participated in 85 training events, including presentations, workshops, conferences, and resource fairs. Approximately 1,500 individuals received training on topics that included P&A programs and services; special education including “least restrictive environment”, inclusion, the Individuals with Disabilities Education Act, transition and due process; voting rights of people with disabilities; the Americans with Disabilities Act; Parent Leadership; vocational rehabilitation and employment rights; right to refuse medication and rights of people with mental illness; abuse investigations; emergency planning for people with disabilities; and assistive technology. Information was disseminated to more than 4,650 people at 12 resource fairs. Over 11,500 publications and P&A program brochures were distributed to individuals and organizations throughout the year. The P&A website is constantly updated and includes P&A program descriptions and self help publications, upcoming events, disability news, legislative updates, links to disability websites, and reports on developments in the field of disability rights. Last year, almost 126,000 visitors obtained information through the site.

P&A staff provided outreach and support to community-based disability advocacy groups across Connecticut. They also provided training and technical assistance to diverse communities, often partnering with other P&A programs to create culturally competent presentations and workshops in English and Spanish. P&A also participated in many committees including Connecticut United Action Neighborhood, Help Me Grow, and the Traumatic Brain Injury Awareness Committee that planned and held a Symposium in fall 2009. Special education training was provided to parent groups in Bridgeport, Willimantic, Hartford, New Britain, New London, Danbury and other areas of Connecticut. P&A provided staff time to assist African Caribbean American Parents of Children with Disabilities (AFCAMP) and Padres Abriendo Puertas (PAP) with organizational development issues, training and support for a parent group. P&A also supported the Americans with Disabilities Act Coalition of Connecticut (ADACC) and ADAPT.

Several years ago, Milagros immigrated to the United States with hope and expectations for a better life. During the family’s second year in the US, Milagros’ son was diagnosed with Attention Deficit Hyperactivity Disorder. She didn’t know what that was but she knew the school was not providing the support that her child needed to be successful. She was not receiving the necessary information to navigate the educational system and help her son. She contacted community agencies seeking help and information.



Through the Danbury Hispanic Center she learned about the parent advocacy training provided by P&A. Milagros attended all the training sessions offered, becoming empowered and learning how to be a good advocate for her son. She also shared that knowledge and is helping other parents by telling her story, encouraging parents to learn and not give up. She also supports other parents by attending Planning and Placement Team (PPT) meetings and is currently the president of the Alumni chapter of People Empowering People (PEP) program in Danbury.

Legislation

During the Connecticut Legislative Session, P&A tracks legislative proposals that may affect the rights of persons with disabilities in Connecticut. The agency's Legislative and Regulations Specialist (LRS) publishes a weekly "Legislative Update" that lists the status of bills being considered by the Connecticut Legislature and provides information about public policy decisions and events important to the lives of people with disabilities and their families. The LRS also provides training and technical assistance on public policy and the legislative process, and develops proposals to protect the rights and advance the interests of persons with disabilities. After each legislative session, P&A also publishes an annual Legislative Summary of disability-related Public Acts passed during the legislative session. The Legislative Update, Legislative Summaries and other legislative information affecting people with disabilities can be found on P&A's website (www.ct.gov/opapd) under the "Legislative Information" section.

During the 2009 Connecticut Legislative Session, P&A proposed two bills that were successfully passed. Public Act 09-65, gives the Executive Director of P&A the authority to ensure that all aspects of the agency's operations comply with federally established confidentiality requirements and conform to federal protection and advocacy requirements for program independence and authority. Public Act, 09- 67, requires the Department of Mental Health and Addiction Services (DMHAS) commissioner to report to P&A the death of anyone receiving inpatient behavioral health services in a DMHAS-operated facility.

P&A testified on a number of bills that would impact the lives of persons with disabilities in Connecticut, including allowing information from E-911 emergency systems to be used to group notify members of the public in certain emergency situations; videotaping of interrogations; mental health parity in the Charter Oak Health Plan; notification requirements for halfway houses; mandating boards of education to provide behavior analysis services to students on the autism spectrum; and requiring all candidates for provisional and initial teacher certification to receive training in how to teach students with diverse learning needs.



The Promise of Olmstead: Past, Present and Future

This year marked the 10 year anniversary of the Supreme Court's historic *Olmstead* decision, which held that "unjustified isolation" inherent in institutionalizing people with disabilities who want to, and are able to live in community, "is properly regarded as discrimination based on disability," in violation of the Americans with Disabilities Act. P&A, in conjunction with a cross section of the disability community, participated in a commemorative event on June 18th at the State Capitol. Over 140 disability rights supporters attended, including Lois Curtis from Georgia, one of the plaintiffs in the *Olmstead* case. Preceding the event, thirty individuals, led by ADAPT, marched two miles in the rain from a Hartford nursing facility to the State Capitol to demonstrate the continued need to help people move out of institutional settings and into the community.

Fatality Review Board

Fatality Review Board Members

John DeMattia, Esq.
Supervisory Assistant
State's Attorney
Rocky Hill, CT

Gerard Kerins, M.D.
Madison, CT

Patricia Mansfield
East Lyme, CT

Lt. David Rice
Department of Public Safety
Middletown, CT

Vacancy – Medical
Professional

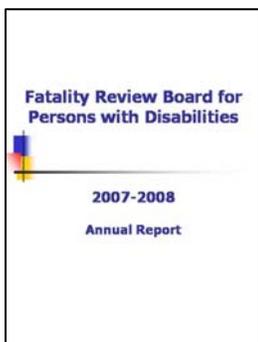
Non-Voting DDS Liaison
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The Fatality Review Board for Persons with Disabilities (FRB) was established by Executive Order 25 (February 2002) to bring greater independence and oversight to the fatality review process for people with mental retardation who receive services from the Department of Developmental Services (DDS). The FRB, supported by the Office of Protection and Advocacy for Persons with Disabilities (P&A), tracks all reported DDS client deaths and pursues preliminary inquiries and full, independent investigations into selected deaths. The Executive Director of P&A is the chair of the Fatality Review Board (FRB). The FRB also has five (5) Governor-appointed members who are drawn from medical, law enforcement, and human service professions.

The FRB reviewed or investigated 194 deaths during the year, 107 were men and 87 were women. The largest number of deaths, fifty-six (56), was attributed to cardiac arrest, cardiopulmonary arrest, cardiovascular disease, or congestive heart failure. Other causes of death include pneumonia (35); respiratory arrest or respiratory disease (21); cancer (14); sepsis (12); embolism or stroke (11); renal failure (6); five (5) each of Alzheimer's dementia, seizure disorder, and surgical complications; four (4) of internal hemorrhage; three (3) each of accidental trauma, bowel obstruction, and metabolic disorder; two (2) each of unknown cause and not otherwise specified; and one (1) each of acute illness, drug overdose, fire/burns, infectious disease, suicide, terminal illness process, and undetermined cause.

Sixty-eight (68) cases were subject to in-depth discussion, monitoring and review by the FRB. Additionally, the FRB investigated the circumstances surrounding 13 deaths where there was reason to suspect that abuse or neglect may have been a contributing factor.

FRB Annual Report (2007-2008) Issued - In addition to statistical information, the report includes findings and recommendations. Briefly, the recommendations include 1) supporting the recent recommendations made by the Legislative Program Review and Investigations Committee concerning the establishment of a quality assurance system by DDS to “systematically oversee the requirements for DDS clients in nursing homes”; 2) due to a notable increase in Do Not Resuscitate orders (DNR), DDS should ensure that proper mechanisms are in place to review and, if warranted, rescind a DNR order if a person's medical condition changes; 3) DSS should re-examine how funding can be directed to allow for the greatest flexibility of services and supports to DDS clients as they age and/or their health needs change; and 4) If placement in a nursing home cannot be avoided, every consideration should be given to placing people in geographic proximity to their previous residence, to facilitate the continuation of meaningful relationships with support staff, family and and friends.



Fiscal Facts and Figures

In the fiscal year ending June 30, 2009, P&A had a total operating budget of \$4,152,216. Of this, \$2,595,207 (62.5%) was state funding and \$1,557,009 (37.5%) was federal funding. Personal services expenditures comprise 89.2% of P&A's General Fund Budget, with an additional 10.8% expended on contracts, outside services and necessary expense items, including supplies, equipment, telephone, postage, and printing.

P&A Federal Expenditures for Fiscal Year 2009 \$1,557,009

U.S. Department of Education, Rehabilitation Services Administration – Client Assistance Program (CAP)	\$114,929.81
U.S. Department of Health and Human Services - Protection and Advocacy for Individuals with Mental Illness (PAIMI)	\$489,972.36
Connecticut Department of Social Services - Social Services Block Grant (SSBG)	\$147,546.07
U.S. Department of Health and Human Services, Administration on Developmental Disabilities - Protection and Advocacy for Developmental Disabilities (PADD), including a grant from Connecticut Council on Developmental Disabilities	\$339,154.07
U.S. Department of Education, Rehabilitation Services Administration – Protection and Advocacy for Individual Rights (PAIR)	\$183,653.82
U.S. Department of Education, Rehabilitation Services Administration – Protection and Advocacy for Assistive Technology (PAAT)	\$65,215.14
Social Security Administration - Protection and Advocacy for Beneficiaries of Social Security (PABSS)	\$131,522.24
U.S. Department of Health and Human Services - Administration on Developmental Disabilities – Protection and Advocacy for Voting Access (PAVA)	\$51,893.37
Health Rehabilitation Services Administration - Protection and Advocacy for Traumatic Brain Injury (PATBI)	\$54,122.11

Major Issues Affecting People with Disabilities

As the economy struggles, funding for services and supports for people with disabilities and their families has been reduced. Both the State budget and other funding sources upon which many service organizations rely (e.g. endowment portfolios, IOLTA, foundation support, private donations) have been adversely affected. As a result, providers of direct services – already hurting from years of under-funding - are stretched very thin. Many are unable to accept new clients, accommodate the changing needs of current ones, or invest in the types of staff training and innovation that maintain quality. Within State human service programs, case management positions have been eliminated or left unfilled; residential programs are being closed, consolidated or transferred to private operation; and funding flexibility (which often helped cover unanticipated emergencies) has been lost in an increasingly intense search for further budget reductions.

Direct services are not the only casualties: advocacy and legal services organizations that serve low income people have reduced staffing and operating budgets. These organizations, some of which focus extensively on the needs of people with disabilities, have long been important safeguards against abuses and unfair treatment of vulnerable people. This is an especially important role when budgets are being cut and programs radically restructured. At times such as these, the identities and needs of people can easily get lost. It is a testament to the dedication of the core staff of these organizations that they have accepted furloughs and, in many cases, significant salary reductions in order to help sustain the vital work of their organizations. Nonetheless, given the pressures and changes afoot, these reductions in advocacy capacity are deeply worrisome.

Some recent budget-driven changes in Title XIX (Medicaid) benefits are also worrisome. The new definition of “medical necessity” will likely increase difficulty in securing assistive technology devices for people with significant disabilities, and rules restricting availability of certain types of medications may complicate things for some people with psychiatric or neurological disabilities.

However, the budget crisis has also spurred some hopeful change. Having recognized that a number of patients do not require in-patient levels of care, the Department of Mental Health and Addiction Services (DMHAS) has proposed transitioning several hundred individuals to community based programs and then downsizing its long-term in-patient bed capacity. The reduction in beds will allow closure of one campus (Cedarcrest) and consolidation of certain specialized programs at Connecticut Valley Hospital. More importantly, this transition point offers an opportunity to better align the agency’s practice with its principles – to support peoples’ efforts to recover their lives in communities where they can acquire competencies, build relationships, make substantial contributions and find their places in the world. But it will only work if sufficient resources are made available to support them and community programs are able to expand and retool. To sustain their recoveries and realize their goals, people leaving in-patient settings will need housing and relevant, reliable help - both of which are currently in short supply. And, for those who are slated to be transferred from one facility to another, due attention must be paid to ensuring communication, continuity, and respect for preferences, rights and important relationships.

At the highest levels of DMHAS, administrative commitment to the concept of recovery is laudably high. Innovative models for recovery assistance are emerging, and some local programs are beginning to think beyond their traditional support configurations – to raise expectations and really “get it”. However, if people slated for

Major Issues Affecting People with Disabilities

community placement are to succeed, and if we are to avoid a repetition of the “dumping” that accompanied previous hospital closures, adequate resources must accompany their transitions. It remains to be seen whether that will happen.

Transitioning to community is only part of the story. Sustaining the commitment to support people over time is equally important. This is especially so as people get older, and their care needs change. Last year the Connecticut Developmental Disabilities Network sponsored a symposium on “aging in place”. Participants articulated a series of principles which recognized the importance of individualized planning, maintaining personal and community relationships, integrating generic supports and celebrating the experience and contributions of older people. Some providers and programs are doing a commendable job supporting people who are growing older; others are struggling with either the finances or architectural and programmatic adaptations that are necessary. A few larger, more traditionally oriented programs are still thinking in terms of moving people through a “spectrum of care”, which they see as inevitably including either nursing home placements or, possibly new, purpose-built mid-sized (e.g. 40 person) ICF-MR institutions. As increasing numbers of their clients grow older, State agencies that contract for services will need to step up their leadership on this issue. People should not have to be uprooted from their homes and important relationships and placed into congregate settings simply because their mobility and care needs are changing.

Another area needing attention involves coordination of medical care and health education for people who receive supports through Connecticut’s mental health and developmental disabilities systems. Coping with the fragmentation inherent in our contemporary health care system can be difficult for anybody. People who receive supports often do not get standard health screenings and counseling, and may not be able to navigate amongst the various specialists they are supposed to see, or understand what they are being told. Yet many of these people face substantial medical risks. Evidence is mounting, for instance, that some of the most commonly used psychiatric medications have significant implications for long-term health, as do dietary and lifestyle habits. Yet, support workers and case managers often lack knowledge about these subjects, and, sometimes even those agencies that employ nurses may not understand client education and coordination of health care as part of their responsibilities. Coordination does not take care of itself. Following a successful pilot project that proved the value of aggressive health care coordination for people with known medical risk factors, DDS recently amended its Title XIX Home and Community Based Waiver to allow providers to bill for healthcare coordination. While it is still too early to judge the results, this is a hopeful development.

In addition to these systemic service-system issues, P&A’s case experience indicates that perennial problem areas such as the scarcity of affordable, accessible housing and limitations in public transportation continue to present barriers. In fact, shrinking economic resources have reduced the availability of dial-a-ride services in some towns, and increased competition for subsidized rental housing. These are not the only chronic problem areas being made worse by the economy: disciplinary responses to special education students - even very young students - continue to reflect inadequate assessment, planning and programming on the part of schools. Budget-related deferral of in-school suspension requirements further exacerbates this problem.

Federally Mandated P&A Programs for Persons with Disabilities

Federal Program	Program Description
Protection and Advocacy for Individuals with Developmental Disabilities (PADD) 42 U.S.C. §15001 et seq.	PADD establishes basic requirements for all P&A programs. These include independence from service systems; access to client records; authority to conduct investigations and to pursue legal and administrative remedies on behalf of clients of the DD service system; capacity to provide information and referral services; and education of policymakers about issues of concern to persons with disabilities.
Client Assistance Program (CAP) 29 U.S.C. §732	CAP provides consultation and advocacy assistance to applicants and recipients of services provided under the federal Rehabilitation Act. CAP's primary focus is helping clients of the vocational rehabilitation service system, most notably the Bureau of Rehabilitation Services (BRS) and Board of Education and Services for the Blind (BESB).
Protection and Advocacy for Individuals with Mental Illness (PAIMI) 42 U.S.C. §10801	PAIMI investigates allegations of abuse and neglect and other complaints raised by people with mental illness who reside in supervised facilities and in the community. PAIMI also advocates for appropriate discharge plans, consumer choice, and respectful, relevant supports.
Protection and Advocacy for Assistive Technology (PAAT) 29 U.S.C. §2001 et. seq.	PAAT provides consumer education and representation in an effort to expand the availability of assistive technology devices and services for people with disabilities.
Protection and Advocacy for Individual Rights (PAIR) 29 U.S.C. §794e	PAIR is authorized to provide consultation and representation for people with disabilities who are not eligible for P&A services under one of the other federally defined P&A programs.
Protection and Advocacy for Beneficiaries of Social Security (PABSS) <i>42 U.S.C. §1320b-19</i> 20 CFR 411.635 (P.L. 106-170)	PABSS assists beneficiaries of Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) who need information, advice, advocacy or legal services to secure, maintain or regain employment.
Protection and Advocacy for Help America Vote Act (PAVA) 42 U.S.C. §15301 et. seq. (P.L. 107-252, Sec. 291)	PAVA is charged with expanding participation of people with disabilities in voting processes and protecting their rights.
Protection and Advocacy for Persons with Traumatic Brain Injury (PATBI) 42 U.S.C. § 300 d. -51	PATBI provides protection and advocacy services to individuals who have brain injury.

State Mandated P&A Programs for Persons with Disabilities

State Program	Program Description
Chair and Support Fatality Review Board for Persons with Disabilities (Executive Order #25)	Five members, appointed by Governor, chaired by P&A Executive Director and staffed by federally-funded investigator. The FRB conducts full, independent investigations into deaths of certain DDS Clients.
I&R Services C.G.S. §46a-11(3)	Provides response to more than 9,900 inquiries/requests for assistance annually. Conducts limited research and provides individualized information.
Case Advocacy Program C.G.S. §46a-11(4),(5),(8),(11)	Individualized case advocacy by Human Services Advocates. Individual advocacy plans developed with clients; specific outcomes sought.
Public Education C.G.S. §46a-11(10)	Presentations and self-help literature; website and other publications.
Fund or initiate litigation to secure rights C.G.S. §46a-11(7)	Staff attorneys; sub-contracts with legal services provider.
Investigate allegations of abuse and neglect of adults with Mental Retardation C.G.S. §46a-11a, <i>et. seq.</i> P.A. 03-146; P.A. 04-12	Monitors internal service system investigations and conducts primary investigations into allegations of abuse/neglect re: adults with mental retardation; investigates deaths of DDS clients where abuse/neglect suspected. Recommends protective services (from DDS) or calls for Immediate Protective Services where needed.
Review and issue joint decisions or requests for exception to accessibility of building code; installation of wheelchair lifts C.G.S. §29-269-271	Weekly meeting with representative of State Building Inspector to review approximately 75-120 waiver requests per year. Decisions based on showing of infeasibility or unreasonable complication to construction.
Review and Rule on requests for waivers from polling place access requirements C.G.S. §9-168 <i>et. seq.</i>	Applications forwarded by Secretary of State: 8-12 requests per election cycle.
Ensure compliance with federal P&A system requirements Public Act 03-88	Requires director to operate agency in conformance with federal P&A system requirements.
Annual Report to Governor and Human Services Committee C.G.S. § 46a-13	Annual Report submitted 1 st of December. Report must include status of services for persons with disabilities and make recommendations regarding rights.
Accessibility Advisory Board established Public Act 06-56	Allows the director to establish an accessibility advisory board to be comprised of design professionals, people with disabilities, people whose family members have disabilities, and anyone else the director believes would provide valuable insight and input on matters relating to accessibility.



Contact Information:

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