

A Rightful Place



Office of Protection and Advocacy
for Persons with Disabilities

Annual Report 2011

**Phyllis D. Zlotnick
1942-2011**

The 2011 P&A Annual Report is dedicated to the memory Phyllis D. Zlotnick, pioneering advocate, empowering presence, P&A Board Member, noted wit and caring friend.



As a young child, Phyllis was sent to the old Newington Children's Hospital on the advice of doctors. It was her first exposure to the fallibility of "professional" opinion, and to the massive injustice of institutionalization. Fortunately, her parents came to recognize the same thing and brought her home, where she pursued the very limited educational opportunities then available for young people with disabilities. Phyllis excelled academically. Because the building was inaccessible, she attended high school via speakerphone. Nonetheless, she graduated third in her class, and earned a national merit scholarship – the first of many awards she was to receive.

Unwilling to accept a marginal role in sheltered employment, Phyllis began her career as a receptionist for Hartford Easter Seals. She soon joined with a few others to form a self-advocacy group, which later grew into the Connecticut Coordinating Committee for Persons with Disabilities. Hired by Connecticut Easter Seals Society as a legislative liaison, and then by Speaker of the House, Ernie Abbate, she became an expert on navigating the legislative process. Later, she operated her own one-person business, tracking and analyzing legislative proposals for disability organizations. Over a career that spanned nearly 40 years, she became a knowledgeable and influential lobbyist on matters related to accessibility, human service programs and disability rights; published numerous articles; was a much sought-after public speaker; and made frequent media appearances. She was the key "go to" person on just about all disability issues, ranging from the mundane (self-service gas station accessibility) to the monumental (amending the Equal Protection Clause of the Connecticut Constitution).

Phyllis received many awards from state and national organizations during her career. She served on the National Council on Disability, and on the boards of many organizations, including two stints on the P&A Board. Widely respected for her political instincts, common sense and the skill with which she approached both those who held power and those needing empowerment, she brought grace and a formidable intellect to the task of opening doors and minds. And, through it all she mentored, counseled and supported many others. Quick to see the humor in things and keenly aware of the interdependence that defines the human condition, Phyllis Diane Zlotnick will be terribly missed and fondly remembered by all who knew her.

A Message from the Executive Director and the Advocacy Board Chair

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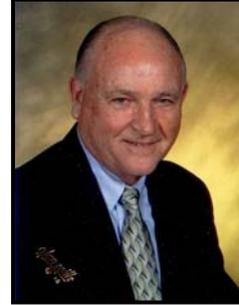
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Members of the Board and staff of the Office of Protection and Advocacy for Persons with Disabilities are pleased to be able to provide this report on our activities during 2011. In addition to affording a glimpse of the agency's safeguarding and advocacy operation over the past year, we have tried to capture some of the civil and human rights issues that have impacted people with disabilities and commanded our attention. In fact, the title we have chosen – *A Rightful Place* – says a lot about our work: we are very much about the business of helping people to secure their right to be present, participate in, and contribute to their communities.

Rights are powerful things in our culture. When we recognize that someone has a *rightful* place in the world, we are, in essence, acknowledging that person as having a legitimate claim to fair treatment, equal opportunity and common respect. Not because the person may have a particular characteristic, like a disability, but because he or she is a fellow human being, and we, as a society have a commitment to fairness.

People have a right to be free from abuse and neglect, to be included in the civic and cultural life of their communities, to live in a place they can call home, to learn in their public schools, to work and earn a living, to be listened to and have their choices respected by those who would help them. These things are not privileges extended by virtue of some benevolent, paternalistic impulse. They are not dependent on the availability of appropriations or the indulgence of charitable organizations. They are rights – things that, in a just society, must be respected. And yet, as several of the stories in this report illustrate, sometimes they are not. So the need for safeguards continues, just as the struggle for justice continues. But, the goal – *a rightful place* – is clear. We hope you will keep this in mind as you read this report.

Independent Death Review and Investigation

Why It's Important!

A recent article in the New York Times has focused attention on the deaths of clients of developmental disabilities service systems. (See *N.Y. Times*, "In State Care, 1,200 Deaths and Few Answers", 11/5/2011.) The Times reported that, in case after case where people receiving services in New York had died due to accidents or neglect, nothing was done to correct conditions or prevent others from suffering similar fates.

In Connecticut, the story is very different. One reason is that Connecticut requires an external, independent review of all deaths of clients of the Department of Developmental Services (DDS) and mandates independent investigations in all cases where abuse or neglect are suspected to have played a role. Both the reviews and the investigations are conducted under the auspices of the Office of Protection and Advocacy for Persons to Disabilities. Here are some examples illustrating why this system of independent review and investigation is important:

Choking Deaths – In 2006, P&A spotted a spike in the number of client deaths due to choking. In most cases, P&A found that the individuals who died had been identified as being at risk of choking on food or other objects, but that individual service plans, which addressed those risks, had not been consistently followed. P&A made protective services recommendations requiring systemic corrections: DDS reviewed its policies and training curricula, and organized a Safety Summit for department and provider staff. New assessment and screening tools were designed to identify specific, individual food preparation and feeding support needs, and a major educational campaign was initiated to raise awareness about the issue throughout the service system.

Burns and Deaths Associated with Scalding – In 2001 and again in 2004, P&A investigated the deaths of DDS clients who had been severely burned by scalding hot water while bathing. P&A found that water temperatures were dangerously high in the community residences where the individuals had lived – a condition that could have been prevented if the plumbing in those homes had been equipped with state-of-the-art anti-scald technology. At the conclusion of the second investigation, P&A sent DDS a formal request for Protective Services that included retro-fitting all licensed residential programs with anti-scald devices, ensuring that future DDS inspections include a water temperature check, and providing that all public and private service providers and residential staff throughout the state be specifically alerted to the necessity of checking water temperature immediately before assisting individuals into a bath or shower. Since these measures have been implemented, no one has died as a result of being scalded.

Medication Advisories – Over a three-year period beginning in 2003, P&A's Fatality Review Board (FRB) reviewed the deaths of several DDS clients who had died of necrotizing pancreatitis. All of the individuals had been taking the commonly prescribed anti-seizure medication Valproic Acid (brand name: Depakote), and all had complained of abdominal discomfort for several days prior to developing acute symptoms. Upon further research, P&A learned that the FDA had instituted a "black box" warning on package labeling for Valproic Acid precisely because data had emerged linking its use to an increased risk of pancreatitis.

Many DDS clients take anti-seizure medications, which are also sometimes prescribed to enhance behavioral control. P&A's Fatality Review Board formally informed DDS of its concerns. DDS responded by issuing a Medical Advisory, alerting practitioners to the risks associated with Valproic Acid and instructing that if anyone taking the drug exhibits any symptoms of abdominal discomfort, prompt and aggressive diagnostic follow-up is needed. In addition, DDS has begun reporting all cases of pancreatitis associated with Valproic Acid to the FDA.

Drowning Associated with Swimming – Between 2004 and 2007, P&A investigated two deaths due to drowning at recreational swim locations. In both cases, P&A found that the individuals were permitted to enter the water without proper flotation devices and staff support, even though attending staff were supposed to be aware of their inability to swim. As a result of P&A's findings and recommendations, DDS directed that an Aquatic Activity Screening, which identifies both the individual's swimming ability and the level of support they require, be completed for all individuals, irrespective of the type of residential program in which they are living. Staff is required to become familiar with the resulting information prior to pursuing any recreational swimming opportunity.

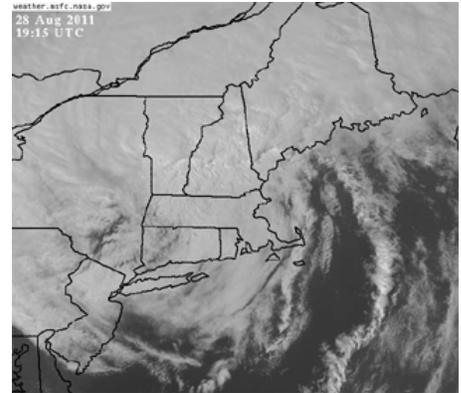
Inadequate Health Care Coordination – Between 2002 and 2005, P&A investigated a number of deaths where individuals' health care needs were not properly understood or adequately provided for by those responsible for supporting them. P&A pressed for comprehensive, proactive reviews of the healthcare needs of all DDS clients with chronic health conditions who live in their own homes and apartments. DDS responded by revising its Level of Need assessment tool, and including Healthcare Coordination as a Medicaid waiver service for which community providers can obtain reimbursement. In response to other cases where P&A investigations substantiated neglect on the part of both institutional and community providers or their nursing staff, DDS also clarified expectations for the active involvement of Registered Nurses in coordinating medical care for individuals. While some aspects of this issue remain unresolved, the discussions between DDS and P&A, and those occurring within DDS and its provider network, are moving things in a better direction.

Bathtub Drowning – Prior to 2002, two individuals who had significant disabilities, including seizure disorders, drowned in bathtubs in their group homes. In both cases, staff who were bathing those individuals had been called away to respond to other needs. In the relatively short time they were unattended, both individuals apparently experienced seizures, and their heads slipped below the water. Investigating those tragedies was less an exercise in blaming than it was an attempt to learn what could be done to prevent future deaths. In the end, the most important lesson involved simply getting people to recognize the serious risk involved in leaving individuals who have frequent seizures unattended in the tub. This information is now a component of training for all new employees, and an area of inquiry for quality assurance reviews.

Since February 2002, P&A's Fatality Review Board has reviewed 1,821 reported deaths of individuals with developmental disabilities, which occurred in Connecticut. Of that number, 144 or about 8% involved allegations of abuse or neglect. Since 2003, all such cases (except those arising in DPH licensed facilities) have received full, independent investigations by P&A's Abuse Investigation Division (AID). Abuse or neglect was substantiated in 59 of those cases.

Weathering Storms Irene and Alfred

Extreme weather events in August and October 2011 – a direct hit from a major tropical storm and an unprecedented early, heavy snowstorm – brought down much of Connecticut’s electrical and communications infrastructure for extended periods of time. While inconvenience and anger over the length of time required for power and telecommunication restoration were widespread, these events caused particular problems for people of all ages who rely on electrically operated technology to maintain their independence. People who need supplemental oxygen were unable to operate their home oxygen concentrators, people who use power wheelchairs and scooters could not charge them, people who rely on stair lifts or elevators were stuck where they were. Without power, refrigerated medications spoiled; well pumps could not supply water for drinking, bathing or flushing; and communications devices, suctioning devices and feeding pumps could not be plugged in or charged.



While Tropical Storm Irene caused residential evacuations in flood-prone areas, mass care sheltering operations were generally short-lived. Many people chose to “shelter in place” – a decision made easier due to an extended period of warm weather immediately following the storm. The aftermath of Snowstorm Alfred was a different story: as temperatures dropped, people flocked to congregate shelters, taxing municipal resources and challenging planning assumptions. For people with disabilities, the results were very much a mixed bag. In some towns, elected officials, emergency management staff and various service organizations and agencies embraced an inclusive approach, organizing ad-hoc solutions to particular issues as they emerged and encouraging expressions of neighborly concern and assistance. In other places, however, inadequate planning, lack of information and confusion about resource availability created needless problems.

In the wake of the storms, P&A surveyed the experience of people with disabilities and presented testimony before both the General Assembly and the Two Storm Panel appointed by the Governor. Based on the agency’s considerable experience working with State and local emergency preparedness planners, the results of its survey, and the situations presented by callers to P&A’s Information and Referral section, the agency is advocating the following steps:

1. Raise awareness amongst preparedness planners of the changing demographics of Connecticut communities and the implications of those changes for emergency preparedness. Just as there are many more large trees in Connecticut than there were in 1985, when Hurricane Gloria hit, there are many more people with access and functional support needs living independently and/or “aging in place” in Connecticut communities than was the case in 1985.

Weathering Storms Irene and Albert

2. Clarify the legal responsibility of all levels of government to ensure that people with access and functional support needs are included in preparedness planning, and are not treated as “patients”, are not thought of as a separate, “special needs” group, or seen as someone else’s responsibility. Good material and training opportunities are available on this topic, both from the U.S. Department of Justice, and from the FEMA. Let’s use them.
3. Identify and conduct thorough accessibility surveys of potential congregate shelter locations to ensure they can meet (or can be temporarily set up to meet) the access and functional support needs of the communities they will be serving. Emergency managers and shelter staff should also receive specific training on access and functional needs. Superficial or dated shelter checklists and training curricula are insufficient for this task. However, resources do exist that can assist municipalities and planning regions to conduct shelter surveys, and assure that people are trained in the competencies needed for inclusion – there is no need to reinvent these resources. What is needed is a clear understanding that these are basic, imperative steps that must be taken.
4. Improve communication and support strategies for “shelter-in-place” scenarios. Many of the weather/industrial/pandemic/terrorist events that could potentially affect Connecticut call for sheltering in place rather than evacuation and mass sheltering. It is especially important to recognize that the dimensions of time and temperature – the duration of an event and the season of year have a significant impact on the needs of those sheltering in their own homes. To date, too little attention has been paid to this area.
5. Ensure that warning communications are transmitted in multiple formats and by multiple means. (E.G. Televised warnings and instructions should be both interpreted by sign language interpreters, and closed-captioned; web-based material should be formatted so that screen readers can read it.)
6. Involve human service agencies (private as well as public), VNAs, home health agencies, equipment vendors, and disability organizations in municipal and regional preparedness planning and exercises. These agencies are community-based; have access to knowledgeable, experienced people; are able to access equipment, supplies and vehicles; and often know many of the individuals within particular communities who will need support in order to maintain their successful functioning. They are important resources. Many are also required to, or do have their own



disaster plans, but are not included in municipal or regional planning or training exercises. The best way to ensure coordination is to involve them in drills and exercises.

7. Develop a uniform, coordinated, one-stop “pre-registration” system that includes all possible emergency services and notification mechanisms. The goal should be to end the fragmentation across jurisdictions and confusion of multiple, uncoordinated appeals to sign up for this or that notification system, utility listing, etc., and give people a simple, clear, step-by-step process to follow across all jurisdictions.
8. Re-think personal preparedness messages and provide more detailed information about developing personal disaster plans. People with access and functional support needs should be encouraged to think about having plans “A”, “B” and “C”, rather than just having “a plan”.
9. Appoint a knowledgeable, full-time, senior-level leader to insure that all aspects of planning, training and public messaging for people with access and functional support needs are informed by good information and are consistent with legal requirements and best practices.

The day after Tropical Storm Irene hit, P&A’s Information and Referral Unit (I&R) received a call from a woman whose town had completely lost power. She was concerned about friends who lived in an elderly/disabled housing complex that had lost power. Most of the residents had gone to stay with family before the storm hit. But, another group of residents either had no family to go to, or chose to stay in their apartments. That remaining group refused repeated invitations from town employees and local clergy to go to a shelter. The caller had informed the residents that they could call Infoline and P&A for information and assistance, but they declined to do so.

While the complex did not sustain any physical damage, those remaining were without electricity and water, and it would stay that way for over a week. After a day they had exhausted the water supply they had saved prior to the storm and could no longer use bathroom facilities. By the second day all refrigerated food had spoiled and their non-perishables were running low. Again, however, the residents refused to leave their complex for a shelter.

The I&R Advocate stayed in contact with the original caller and with a local clergyman who visited the residents daily, bringing water and some minimal supplies. Each day they refused the shelter and banded together finding ways to meet each other’s needs. On the fourth day, the roads were cleared enough for a resident with a car to get to a neighboring town and obtain additional non-perishable supplies to sustain the community. That evening they had a cookout and served fresh water and food. They did this every day until the power came back on. Their determination and cooperation saw them through this storm. The I&R Advocate had a follow-up conversation with the clergyman who had been looking in on the group every day. He said that he was talking with one of the residents with a disability who had stayed and refused shelter repeatedly. That person eventually admitted that the reason no one would go to the shelter is because they thought they might end up in nursing homes and never return to their apartments. They felt that living without electricity, water and food was preferable to that option.

Restraint & Seclusion

A rightful place --- free from restraint and seclusion



Todd is an eleven-year-old boy with autism and a long list of psychiatric diagnoses. In October 2010, he suffered a broken tooth during a prone (facedown) restraint at one of Connecticut's Psychiatric Residential Treatment Facilities (PRTF). Casey is a twelve-year-old girl with diagnoses of mood disorder, metabolic syndrome, obesity, hypertension, sleep apnea and an enlarged heart. While being "physically assisted" to a seclusion room in the same PRTF, she suffered a fractured finger. Marcus is a thirteen-year-old boy who is diagnosed with Bi-Polar Disorder, Post-Traumatic Stress Disorder, and Attention Deficit Hyper-Activity Disorder. He, too, resides in the same PRTF. Earlier this year he lost consciousness for over ten minutes during a facedown restraint. 911 was called and he was rushed to a local Emergency Department. Following that incident, clinicians directed that he not be subjected to further prone restraint. But he was.

P&A investigated these incidents, and others, pursuant to authority assigned under the federal Protection and Advocacy for Individuals with Mental Illness Act (PAIMI). Detailed reports were written and supplied to both the Department of Children and Families, which licenses the residential components of PRTFs, and the Department of Education, which approves the school programs associated with PRTFs. In each instance, P&A investigators found that the children who were injured had hopes and dreams for their futures. They also had insights into how both they and their caregivers could have handled things differently. For the most part, however, input and feedback from the children had not been solicited by program staff. Significantly, the investigations also found that the "individual" treatment and educational plans for these children largely ignored their histories of past trauma, and seemed to feature generic, rather than individually appropriate, positive behavioral support strategies. In fact, certain routine practices at the program clearly violate its own policies, DCF directives, and the provisions of Connecticut statutes that regulate the use of physical and mechanical restraint.

Following those investigations, meetings were held with senior administrators at both the Department of Children and Families and the Department of Education. One of P&A's recommendations involved instituting a ban on the use of face-down, prone restraints. Over the past decade, evidence has been growing that prone restraint is an especially dangerous practice, as it is much more difficult to observe breathing difficulties and levels of consciousness. Both the Departments of Developmental Services and Mental Health and Addiction Services have banned its use, as have other agencies in other states. During discussions with DCF, however, it became apparent that costs were a significant consideration: Face-up floor restraints may be a safer alternative, but they require four people to accomplish, whereas, in most cases, a facedown prone restraint of a child can be accomplished by only two individuals. This is one of

those issues that challenges our values and should make us profoundly uncomfortable: Implementing a system-wide ban on prone restraint would require increasing staffing levels in programs where restraint is, or might be used. But, the additional expenditures might save a child's life.

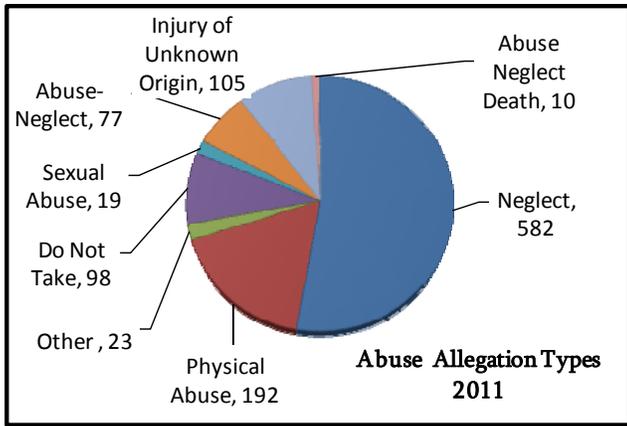
Perhaps the most significant lesson from these investigations involves the missed opportunities to intervene and teach positive behaviors and skills earlier in the students' educational careers - before placement in a PRTF or other segregated "therapeutic" school occurred. Many of the children who were injured while being restrained were sent to those settings by local school districts. In every instance P&A investigated, the injured child had family members who were concerned and involved, and had received some form of mental health intervention at the community level prior to being placed. And, in every instance, there had been opportunities, and repeated failures to involve input from those mental health professionals by the local school system in the process of developing Positive Behavioral Intervention Strategies as part of the student's Individual Education Plan.

Consider Nate's story: Nate is a 17-year-old boy with Asperger Syndrome and a significant anxiety disorder. During his junior year he had a great deal of difficulty functioning in the regular high school environment. The Principal of his school, who described his behavior as "unsafe and out of control", insisted that he be removed and placed into a PRTF or some other segregated setting. Because Nate had previously been placed in "special" programs that had failed to address his learning needs, his parents objected. Citing deficiencies in the way school staff had responded to Nate's behaviors, they contacted P&A for help. The P&A Advocate reviewed Nate's records, met with him and his parents and attended several PPT meetings, pointing out possible ways to include positive behavioral supports and real learning opportunities for Nate in the high school. But the school district remained adamant. They wanted Nate somewhere else. Nate's parents were equally committed to what they thought was right - that Nate get supports in his regular school, where he could learn from interactions with typical students and graduate with his classmates. They began to contact lawyers who could represent their son at a Due Process Hearing.

Ultimately, after conversations between the P&A Advocate and the School's Special Education Director, Nate's parents and the school district agreed to request mediation through the State Department of Education. The mediation agreement that resulted called for the school to hire a behavioral specialist as a consultant. The specialist completed a Functional Behavioral Assessment, developed a Positive Behavioral Intervention Plan and recommended a modified schedule for Nate with opportunities for vocational exploration and community-based mental health counseling as well as academic learning. It worked. Nate is now almost half way through his senior year, is on track to graduate with his classmates, and a Psychiatric Residential Treatment Facility placement was avoided.



Abuse Investigation Division



P&A's Abuse Investigation Division (AID) investigates allegations of abuse or neglect by caregivers of adults with intellectual disability who are between the ages of 18 and 60. AID conducts primary investigations for allegations of abuse and neglect involving people with intellectual disability living outside the service systems for people with intellectual disability. Most reports involving clients of the developmental disabilities service system are directly investigated by the service agencies, with P&A monitoring the internal investigation. AID is also mandated to investigate the deaths of persons with

intellectual disability for whom the Department of Developmental Services has responsibility for direct care or oversight and there is reason to believe that the cause of death may involve abuse or neglect.

Last year, AID received 1115 allegations of suspected abuse or neglect of persons with intellectual disability, resulting in 1,104 cases. P&A staff investigated or monitored 1006 cases while 98 allegations did not meet the statutory requirements for a P&A investigation. The 1,104 cases involved 1,253 victims: 575 females and 678 males. Of the 1,006 cases accepted for investigation or monitoring, more than 54% of the alleged perpetrators were residential staff while 15% were vocational staff and almost 12% were family members. Other perpetrators included Community Training Home or Independent Support Providers (13), Nurses (24), Van Drivers (10), Guardian/Conservators (9) and others (43). The identity of the perpetrator was not known in 123 of the cases.

A concerned community member contacted P&A to report that Bob was the victim of physical abuse and was not allowed to leave his home or use the phone. P&A's Abuse Investigation Division (AID) made a request for Immediate Protective Services from the Department of Developmental Services (DDS). A visit to Bob's home resulted in his removal to an emergency respite, a place where he would be free from abuse.

P&A Investigators interviewed Bob who stated that he has been living with a family for approximately two years. He reported that the living arrangement was initially successful but after a while the woman who lived in the home would shove him and that the man would punch him in the head and stomach. Bob was asked what was happening prior to the assaults, and he responded that his assailant would have had a bad day at work. Bob liked and felt safe in his respite placement and did not wish to return to his previous living situation.

P&A found sufficient evidence to substantiate physical abuse and issued a Protective Service Plan requiring DDS to provide Bob with a permanent placement in a DDS licensed program. The case was also forwarded to the States Attorney's Office for potential prosecution of the abusers. Bob currently resides in a Community Training Home and has a supported employment in his community.

Fatality Review Board

Fatality Review Board Members

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The Fatality Review Board for Persons with Disabilities (FRB) was established to bring greater independence and oversight to the fatality review process for people with intellectual disability who receive services from the Department of Developmental Services (DDS). The FRB is supported by P&A and operates independent of the DDS independent mortality review structure. FRB staff tracks all reported DDS client deaths and pursues preliminary inquiries and full, independent investigations into selected deaths. The Executive Director of P&A chairs the FRB. The FRB also has Governor-appointed members who are drawn from medical, law enforcement, human service and forensic investigation professions. The Commissioner of DDS or designee sits as a non-voting member. Since 2009, the Connecticut Legislature has required the Department of Mental Health and Addiction Services (DMHAS) to report the death of anyone receiving inpatient behavioral health services in a DMHAS-operated facility to P&A within 30 days after the individual's death. The FRB also reviews these deaths and investigates as necessary.

The FRB reviewed or investigated 200 deaths during the year. Forty-eight (48) cases were subject to in-depth discussion, monitoring and review by the FRB. Additionally, the FRB investigated the circumstances surrounding 12 deaths where there was reason to suspect that abuse or neglect may have been a contributing factor. FRB staff also received reports of 11 deaths from DMHAS. All the deaths were reviewed and two (2) were investigated by P&A staff.



Fatality Review Board (FRB) staff was invited to participate in training to share challenges experienced by people with intellectual disability in hospital and nursing home settings, which have surfaced as a result of the FRB's reviews over the past 10 years. The training, sponsored by the A.J. Pappanikou Center for Disabilities and The Kennedy Center, was called, "Improving Hospital and Nursing Care for Persons with Disabilities." Participants included medical professionals from a variety of disciplines who are interested in improving health care for people with disabilities. FRB staff and Board members shared real stories, with a focus on identifying how to improve services and outcomes for people with developmental disabilities, as well as how to avoid long-term nursing home placements. The evaluations from the training were so positive that FRB staff will continue to be involved in future trainings, with an eye towards informing caregivers by offering examples of best practices and practical suggestions to improve health care.

Case Services Unit – Information & Referral

In 2011, P&A advocates received requests for assistance from 4,078 individuals with disabilities, their family members, and interested parties. Of these, 3,287 were requests for information and referral, or short-term assistance. The remaining 716 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. The largest volume of calls (565) related to Abuse or Neglect including inappropriate mental health treatment; excessive or involuntary medication; physical, verbal or sexual assault; inappropriate restraint; and financial exploitation. They also responded to questions concerning Housing (514), Government Benefits and Services (352), Rights Violations (346), Employment (231), Education (200), Services (194), Healthcare (135), Rehabilitation Services (74), Financial Entitlements (97), Transportation (70), Architectural Accessibility (46), Guardianship and Conservatorship (42), Parental Rights/Childcare (28) Assistive Technology (27), Post Secondary Education (20), Insurance (14), and Recreation (8). Advocates also responded to 270 requests for simple information like a copy of a publication or the name of a case manager. Callers also contacted P&A about voting rights and access to government programs.

DID YOU KNOW?

P&A has a comprehensive Disability Resources Directory for Connecticut? It is available on the P&A website (www.ct.gov/opapd). You can also request a copy 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.



David contacted P&A because his town would not waive the registration fee for his service animal as required by Connecticut General Statutes. Despite the fact that David's service dog, Roger, was trained to help him perform everyday tasks such as picking items up from the floor, the town refused to recognize Roger as a service animal because he had not been trained by an organization. The town had been denying the registration fee for the past several years. Frustrated, Roger called P&A for assistance.

The P&A advocate consulted with a P&A attorney to confirm that under Connecticut General Statutes §22-345, a service animal can be trained by an individual with a disability to perform disability related tasks and does not need to be trained by an organization for the purposes of a fee waiver. The advocate contacted the Town Clerk to explain the David's right to a fee waiver. Despite documentation, the Town Clerk continued to refuse to recognize Roger as a service animal because the service animal definition given to the Town Clerks by the Connecticut Department of Agriculture incorrectly required training by an organization. A P&A attorney contacted both the Town Clerk and the Department of Agriculture, resulting in a clarification for Town Clerks statewide and a fee waiver for Roger's registration.

Case Services Unit – Advocacy Representation Division

Advocates assigned to the Advocacy Representation Division protect the rights of adults and children with disabilities living in institutional and community settings. In addition to providing advocacy representation and training on disability-related topics, advocates also intervened on behalf of groups and individuals, such as children with disabilities in need of appropriate planning and supports to meet their educational needs and adults with disabilities seeking assistance with barriers to becoming employed, including vocational training and discrimination. They also provided advocacy to people with disabilities seeking remedies for issues related to abuse, neglect, accommodations in housing; access to assistive technology, forced medication, parenting with a disability, programmatic and structural accessibility, effective communication in hospital and law enforcement settings, and guardianship. Advocacy Representation Division staff attorneys seek administrative or judicial remedies for cases involving discrimination based on disability. The Division is composed of a number of distinct federally mandated advocacy programs for people with disabilities, as illustrated on the chart on page 29 of this report.

P&A advocates and attorneys provided representation to 716 individuals with disabilities. They requested advocacy in the areas of Education (148), Rehabilitation Services (85), Abuse (81), Neglect (54), Rights Violations (52), Financial Entitlements (42), Healthcare (39), Government Benefits (35), Architectural Accessibility (34), Employment (24), Quality Assurance (22), Assistive Technology (17), Housing (14), Services (14), Unnecessary Institutionalization (9), Transportation (6), Guardianship (6), and Voting (3). Thirty-one (31) advocacy cases involved other problems such as childcare, recreation, and parental rights.



Juan is a 55-year-old man with multiple disabilities. For years, this vibrant, optimistic, people-loving man lived in a nursing home. He was visited there by various members of his extended family, five of whom shared responsibility for making decisions about his treatment and finances as Co-Conservators. Thanks to the State's Money Follows the Person (MFP) program, Juan he was able to move into his own apartment, which was made accessible by means of a bathroom expansion and the addition of an exterior ramp. However, when one of his co-conservators became embroiled in a dispute with his landlord, Juan's lease was allowed to expire and the co-conservators moved him into a different apartment – one that was not accessible. To make the new apartment accessible, they

wanted to remove the ramp that had been installed outside the first apartment, and re-install it at the second one. The conservators contacted numerous agencies in order to try to determine the actual ownership of the ramp, and to determine what would be necessary to have it moved to make the new apartment accessible. After encountering multiple roadblocks, they contacted P&A.

P&A assigned a Spanish-speaking Advocate to assist Juan with the ramp issue. However, once she met with Juan, ascertained his goals and examined the documents appointing the Co-Conservators, it became clear that more was involved than who owned the ramp. Over a period of many months, the Advocate worked with numerous agencies and individuals: the West Hartford Housing Authority; Money Follows the Person program; Independence Unlimited, the Hartford area Center for Independent Living; New Britain Social Services; the Hartford Probate Court; both the landlord of the old apartment and the landlord of the new apartment; one Conservator of Estate; and four Co-Conservators of Person on Juan's behalf. Following many phone calls and meetings, it was determined that, because Juan had already moved, and the MFP program had already located another nursing home resident in his old apartment, the best course of action was to leave the old ramp where it was, and to build a new ramp at his new home. However, the Advocate also took steps to ensure that the Probate Court had an opportunity to clearly instruct the Co-Conservators regarding the limits of their authority, and their need to ensure that Juan's preferences would be considered in any future decisions they made on his behalf. In the end, Juan is happy in his new home, and now knows he can contact P&A for assistance if he ever needs to do so. And, the world has gained one more accessible apartment.



Family values are alive and well in Connecticut. When Esther acquired disabilities, her adult daughter, Lucy, began making plans to modify her own condo so that her mother could move in. Part of the planning involved some modification to the condo, including construction of an exterior ramp. Problems arose, however, when the condo association placed restrictions on the construction that violated fair housing laws.

Condominium associations are often unaware of the rights of individual members with disabilities. In past years, P&A has had to file complaints and even pursue litigation in order to assert those rights. More recently, P&A has partnered with the Connecticut Fair Housing Center to address problems with condo associations and other housing issues. Fortunately, litigation was not necessary to resolve Esther's situation. After consulting with Fair Housing Center staff to obtain up-to-date legal information, the P&A advocate called the condo management company that had sent Esther letters on behalf of the association. After a long, informal process of mediation, the association agreed to recognize its member's right to install an exterior ramp. As part of the advocacy, the advocate provided an appreciative management director with documents that clearly explain the rights of tenants with disabilities to pursue accessibility modifications to their homes and to request reasonable modifications of policies and procedures.



Case Services Unit – Advocacy Representation Division



Darryel is a middle-aged gentleman who lived for many years at a large public institution for individuals with intellectual disability. For the past five years, he has been represented at Interdisciplinary Team meetings by an P&A Advocate. Although Darryel possesses limited ability to express himself verbally, he is well able to communicate his preferences to those who know him well, and amongst those who know him well are the staff and other participants in his off-campus day program. It was obvious by his eagerness to attend, and his enthusiastic participation that Darryel greatly enjoyed that program and that those relationships meant a great deal to him. In fact, they were so important to Darryel, that when an opportunity to live in a small, community-based group home was presented – an opportunity that was ultimately supported by his entire

Interdisciplinary Team - the most important caveat was that Darryel needed to continue to attend that particular day program.

The agency operating the group home Darryel moved into was informed about his need to continue in his day program, and voiced no concerns or objections. Happily, the day program was located only a short distance from the group home. The importance of maintaining the day program and the personal relationships Darryel enjoyed there was reiterated in written planning documents and at numerous meetings throughout the lengthy transition process. Accordingly, after Darryel moved into the community residence, he continued to participate in his day program. By all accounts, Darryel made a comfortable and smooth transition.

However, a short time after Darryel moved, the residential provider agency that operates the group home announced its intention to change Darryel's day program placement. The company wanted Darryel to attend its own day program. Its decision was based on the funding reimbursement structure the agency utilizes, a factor, which the agency had not mentioned to the sending team or the Advocate at any of the transition meetings. In response, meetings were convened. At first, the provider agency insisted it could not provide a home for Darryel unless it also provided his day program. There was a real threat that Darryel might even be returned to the institution. Darryel's Advocate participated in these meetings in an effort to protect both Darryel's right to live in the community, and his right as a DDS client to continue to receive the services recommended by his team in his Individual Plan. After several such meetings, which were attended by both DDS regional administrators responsible for overseeing the community provider, and team members from the institution, the issue seemed to be resolved. Darryel was to stay in his group home and attend his familiar day program. However, a short time later, the provider agency reinitiated the proposal to change Darryel's day program. Again, Darryel's P&A Advocate took action, making phone calls and writing letters. Fortunately, the proposal was finally abandoned. Darryel is now enjoying the numerous opportunities that both his residential and day programs afford him. He is actively and happily becoming a member of his new community, while continuing to enjoy longstanding friendships.

Case Services Unit – Advocacy Representation Division

“My friend has been crawling on the floor for two weeks. Her wheelchair is broken and she can’t get it fixed. Can you help?”

This was the chilling message P&A’s Assistive Technology Advocate found on her voicemail. Returning the call, the Advocate was told that the friend’s health insurance company was refusing to approve funding to repair the wheelchair. When the Advocate then called the client directly to discuss an advocacy plan, the despair was palpable. The Advocate understood. Losing the use of a personal mobility device can be difficult for anybody who relies on one. For many people who use them, a wheelchair is an extension of their person. It can spell the difference between living independently or submitting to the tyranny of dependence; between freedom and imprisonment. And when something so important is being arbitrarily withheld by an impersonal, intransigent power structure like a health insurance company, the world can close in on a person, and she can lose hope.

The Advocate quickly gathered the essential information and set to work. The vendor needed to be contacted; the insurer had to be convinced; the work order had to be put into motion. Less than twenty-four hours later, P&A’s advocacy began to pay off. The insurer had granted approval for an evaluation, and an appointment had been made with the vendor. Shortly thereafter, the wheelchair was removed for repair and a loaner chair was provided. A week later, the original chair was delivered to her home, fully repaired.

This was not the end of communication, however. Sensing that the client might be interested in meeting others who had shared some of the same experiences as she had, the Advocate referred her to individuals who live with similar disabilities and who are active in support groups. By the time the P&A case was officially closed, the client’s need for wheelchair repair had been addressed, and she was networking with others, forging empowering relationships, leaving behind the isolation with which she had lived.



In P&A’s 2010 annual report we introduced you to two brothers, Matthew and Michael, both have Down Syndrome and an intellectual disability. Despite receiving special education services for several years, the boys had no way to effectively communicate, and neither child was experiencing personal growth or academic success. After their parents partnered with P&A, independent evaluations were conducted, generating comprehensive recommendations for a multi-modal treatment approach. This approach

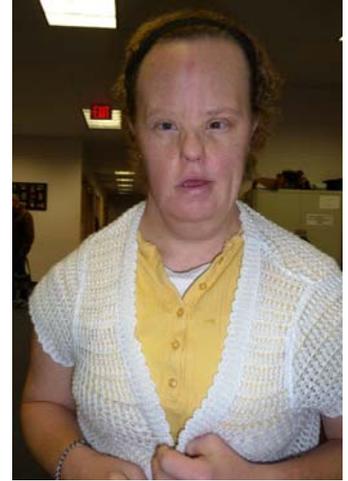
provided the assistive technology and supports that the boys needed to communicate, make educational progress, become included in their school community, and develop friendships among their peers. The parents gained confidence in their ability to be effective advocates for their sons.

Most importantly, the boys continue to thrive. They have made substantial progress using iPads™ in the classroom. They have been so successful that the school district has just purchased the newest version of this technology for both boys. Mathew and Michael are now truly benefiting from their education program, resulting in positive changes that continue and grow.

Case Services Unit – Advocacy Representation Division

For Deb, things had been going pretty well. In 2000, she had moved to Connecticut after her sister had visited her in Florida and became concerned with her living conditions. At the time, Deb was 35 years old. She has Down Syndrome. Ultimately, Deb moved into a group home, which she seemed to enjoy and where she gained friends and a positive sense of herself.

However, several years ago, the group home changed managers. It became run down, and more importantly, new residents moved into the house. One of these was a woman who was aggressive towards Deb, both physically and sexually. Deb was obviously upset, and began to exhibit “behavior problems.” Her sister reported these problems, but was frustrated by the lack of response from the provider agency. Not only did the aggressor stay in the home, but there were missed doctor’s appointments, lost personal items, and no more activities that Deb enjoyed. The sister noted mold growing in the bathroom, that the century tub used as an adjunct to physical therapy had become unusable, and that the heat in Deb’s room had been broken for two weeks before anyone noticed. When she reported these things, the new manager expressed resentment. Both the presence of her aggressive housemate and the escalating conflict between her sister and the house manager created stress for Deb. Her heart condition worsened, and she cried all the time. In desperation, Deb’s sister called P&A for help.



Initially, Deb’s sister wanted her to stay in the group home. She wanted help securing the removal of the aggressive resident, and wanted the provider agency to take responsibility for improving conditions and meeting Deb’s needs. After several meetings, however, she concluded that Deb just needed to move. Deb had also soured on the home and wanted to move. Deb’s Interdisciplinary Team (IDT) agreed, but moving within the Department of Developmental Services residential system is not always easy – it often takes years to arrange a new placement. Much depends on having an accurate understanding of an individual’s Level of Need (LON) – a comprehensive assessment of all aspects of the support assistance that an individual needs. Noting that Deb’s healthcare coordination needs had increased significantly, the P&A Advocate pressed the IDT for a reassessment of her LON. The new LON assessment ultimately translated into more funding being identified for Deb’s support. Fortuitously, just as Deb’s LON was changing, an opening arose in a group home run by a different provider agency. Deb went to visit and loved the atmosphere and the staff. A month later, on her second “trial visit”, Deb refused to go back to her old placement. As far as she was concerned, she had just moved to a new, much happier home.

There were a few more opportunities for advocacy regarding the old placement: a hassle getting Deb’s medical records from the old provider agency, resolving problems that arose because there was no accurate inventory of her possessions, and discrepancies were found in records about Deb’s personal funds. Resolving these issues required the Advocate to pursue persistent, sometimes intensive communication with the director of the provider agency, and resulted in reports to the DDS Quality Assurance Division.

Case Services Unit – Advocacy Representation Division

P&A received a call from the mother of a Hartford middle school special education student who was in trouble for fighting at school. Speaking only in Spanish, she explained that her son, Alberto, had been diagnosed with several types of emotional and learning disabilities. She requested assistance at what she thought was an upcoming Planning and Placement Team (PPT) meeting where decisions would be made about a possible alternative placement.



P&A's Education Unit staff contacted Alberto's school and reviewed his records. The records revealed that despite his several co-occurring psychiatric diagnoses, a clear history of difficulty coping in certain classroom situations, and his identification as a special education student with Emotional Disturbance, Alberto had never had a Functional Behavioral Assessment (FBA) and did not have a Positive Behavioral Intervention Plan (PBIP) as part of his Individual Education Plan (IEP). The Education Unit Advocate assigned to assist Alberto and his mom also learned that the upcoming "meeting" was, in fact, a "manifestation hearing" that could lead to Alberto's expulsion from school.

At the hearing, school officials initially questioned whether Alberto's mother had the right to bring an advocate from P&A with her. The proceedings were delayed while they checked. Once the hearing began, another problem surfaced: Instead of providing the mother with an objective interpreter, as required by regulations, the school social worker – who had a role to play in the hearing itself – began to act as the interpreter. The P&A Advocate (who is fully bi-lingual) had to make numerous corrections and point out several instances where the social worker was not interpreting, but rather offering her own opinions. (P&A staff has noted that utilization of unqualified staff to interpret for monolingual parents is a pervasive problem in the Hartford Public Schools. In this instance, the problem was exacerbated by the fact that Alberto's IEP and related documents had only been made available to his mother in English – another violation of law, and another pervasive problem in Hartford.)

After reviewing Alberto's history and diagnoses, the absence of required evaluations and a positive behavioral intervention plan as part of his IEP, and the frequency with which school staff had responded to behavioral outbursts by calling the police, the hearing concluded by agreeing that Alberto's behavior was, indeed, a manifestation of his disability. No doubt it was also a manifestation of his frustration with having to cope with an environment that only knew how to punish him.

The real story about Alberto began to unfold in the months following the hearing. At the urging of the Advocate, the PPT called in a behavioral expert who completed a FBA and helped team members develop a Positive Behavioral Intervention Plan. Just as importantly, the consultant provided training and feedback to school personnel as they attempted to break their habit of calling the police in response to outbursts. It took five PPT meetings to get Alberto's IEP into alignment with his learning needs, but he now has a good plan, and a real chance to succeed in school.

Case Services Unit – Advocacy Representation Division

A Rightful Place – Holding a Job: Bill is a young man with cerebral palsy who is employed at a major distribution center. He got the job – which pays good wages and provides a full benefit package – after successfully completing a training program that was supported by the Bureau of Rehabilitation Services (BRS). When he first landed the job, he was able to ride to and from work with someone who drove directly to the employees' entrance at the distribution center. However, that arrangement ended and he was unable to find another person who could drive him directly to the door. The best he could do was to get dropped off at a security station located at the entrance to the complex – over one-half mile away from the employee entrance to the main building where he worked.



This was a real problem for Bill. There are no sidewalks on the route between his drop-off point and the building where he reports to work, and the road is heavily traveled by large trucks. While Bill can walk, his gait is such that covering longer distances is quite difficult for him, and he can sometimes lose his balance. Nonetheless, seeing no alternative, Bill started walking. Soon that half-mile began to take a toll: Bill was so exhausted when he arrived at his workstation that his job performance began to suffer. It became clear to him that, unless he could do something about his transportation situation, he could be terminated from employment. Unable to negotiate a solution with his employer or the Bureau of Rehabilitation Services – both of which informed him that they were not responsible for employee transportation – Bill contacted P&A's Client Assistance Program (CAP).

The CAP Advocate reviewed Bill's vocational training records and spoke with both his employer and his BRS Counselor. They both reiterated that, as a matter of law and longstanding practice, neither was responsible for meeting the transportation needs of employees. Undaunted, the Advocate researched bus routes and other transportation resources and then requested a meeting with all parties at the work site.

At the meeting the Advocate assisted in negotiating a mutually satisfactory solution. As Bill had difficulty approaching other employees to ask for ride-share opportunities, the employer's BRS liaison agreed to assist Bill with this task. The employer also agreed to contact the bus company, CT Transit, to arrange to have the security station, where Bill was getting dropped off and picked up by his ride, recognized as an official bus stop. There already were established bus stops within the complex that housed the distribution center, including one that was just outside the employee entrance to the building where Bill worked. By adding the security station as an official bus stop, Bill could get on the bus close to where he was being dropped off by his ride, and then ride the bus for that last half-mile instead of having to walk. The employer even agreed to allow Bill to stand in the security station in inclement weather while waiting for the bus to come.

Now, Bill's job future looks bright. He arrives at his workstation rested and ready, and his work performance has returned to its previous levels.

Case Services Unit – Advocacy Representation Division

A Rightful Place – Respecting Choices

For ten years, Ed had been asking to move from the group home where he lived. He didn't like the community in which it was located, the people with whom he was living, or the house itself. In fact, before he was moved to the house, he had told people he did not want to live there. Instead, he asked for help moving to a different community – one that he considered to be his hometown. Ed is an articulate man who did not have, or need to have a guardian. Yet, despite his capabilities and obvious preference, his requests were ignored. Last year, at his annual Individual Planning meeting, Ed again voiced his protests about living in a house that he did not consider to be his home. When these comments were dismissed, he became so frustrated that he tried to dismantle his bed and move it out of the house by himself – quite a challenge for an older, somewhat frail man whose bedroom was on the second floor. It was at that point

that a concerned person decided to seek the assistance of an Advocate from P&A.



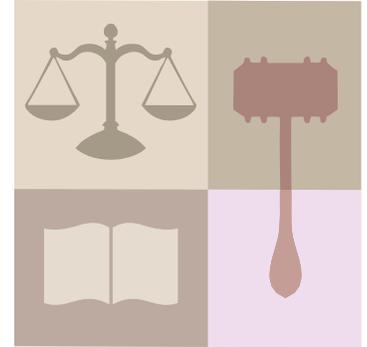
When the P&A Advocate assigned to represent him began to look into the situation, she was told that Ed has a somewhat cantankerous personality; that being happy and content was just not in his nature; that what he needed was a good behavior program. The Advocate was also told that even if a new home could be located, very little funding was “attached” to Ed – meaning that it was unlikely that a provider could be found that would be willing and able to meet his needs. Nevertheless, the Advocate pursued both the budget issue and Ed's request to live in a

community of his choosing. After the Advocate became involved, a thorough review of his needs was completed by his Inter-Disciplinary team and it became apparent that Ed qualified for a modest increase in residential funding. The agency that had been providing him with vocational support then put together an excellent proposal for Ed to live with just one compatible friend. They found a nice little house for rent in the part of the State that Ed still called “home”.

Ed, his friend and his cat are now a very serene and contented lot. No behavior program could have accomplished as much as this move did. Being respected and accommodated as a person has made all the difference. It's too bad he had to wait ten years, but he is too happy to be bitter. Ed has come home.

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: reasonable accommodation and discrimination in housing including inappropriate discharge from a residential care home; eligibility for services from the Department of Developmental Services; proper treatment for prisoners with disabilities; sterilization of persons with intellectual disability; lack of effective communication by law enforcement; healthcare facilities and attorneys; rights under the Americans with Disabilities Act for people with disabilities in nursing homes and other institutions; and employment discrimination. P&A attorneys also consulted with outside attorneys and the public on questions of disability law; prepared and reviewed amicus briefs; worked with staff to ensure quality responses to public inquiries and prepared comments on proposed state and federal regulations.



Over the past several years, P&A has represented a number of deaf people who have filed discrimination complaints against police agencies that fail to provide effective communication when the deaf individuals, or in some cases their children are being questioned. What happened to Mr. H, who is profoundly deaf and uses American Sign Language to communicate, is an example: Following a domestic dispute, the police were called to the home he shared with his wife, who is also deaf, and his 8-year-old daughter who is a hearing person. Mr. H was already outside when the police arrived. Using sign language and gestures he requested that an interpreter be provided and indicated a willingness to go to the police station to answer questions. He also requested that the police not use his daughter to interpret. Nonetheless, the police did use his 8-year-old daughter to interpret, and also questioned her directly even though neither of her parents could understand what she was being asked. Mr. H was arrested and brought to the police station, where, several hours later a qualified sign language interpreter was provided.

With P&A's assistance, Mr. H. filed a complaint with the Commission on Human Rights and Opportunities (CHRO). At the CHRO fact-finding session, P&A's Attorney obtained testimony from one of the responding police officers regarding several key facts. He acknowledged that there was no imminent danger or risk when they arrived at the scene, and that the responding officers could have waited to interview Mr. H. at the police station with an interpreter. He also acknowledged that they were aware that the caller was deaf when they responded, and that they knew an interpreter would be needed. He stated that they used the 8 yr old daughter to interpret because she was available; and admitted that they had also used the daughter to inform their "probable cause" determination to arrest Mr. H. Following the fact finding, CHRO issued its finding that there was "cause" to believe discrimination occurred. The case was subsequently scheduled for a conciliation session at which time the parties settled the matter.

Case Services Unit – Legal Division

A Rightful Place – Access to Justice

Over the past year, P&A’s attorneys submitted a number of amicus briefs before appellate tribunals in cases that raise significant issues of interest to the disability community. Among these was a case heard by the Connecticut Supreme Court concerning the jury trial of a man who was convicted of sexually assaulting a young woman with significant physical and communications disabilities, as well as mild intellectual disability. *State v. Fourtin*, Docket No. SC-18523.

State prosecutors charged Mr. Fourtin under a statute that relates to the sexual assault of a person who is said to be “physically helpless.” The jury convicted him based on the testimony of the victim, who used a communications board to respond to questions about what had happened to her. The Court had a closed circuit TV system installed so that jurors could directly watch her spell out her answers, which she did slowly and with great effort. She testified for no more than fifteen minutes at a time over a period of five days, as the effort involved greatly fatigued her. Following the jury’s verdict, the defendant appealed, and the Appellate Court reversed the conviction, holding that the young woman did not meet the definition of “physically helpless” largely because of testimony by her mother, who was Mr. Fourtin’s girlfriend, to the effect that the young woman was able to screech, scratch, kick and bite.



In its Supreme Court amicus brief, P&A argued that the Appellate Court’s reading of the term “physically helpless” placed an additional burden on individuals with disabilities in that it would require them to actively resist a sexual assault – something the law has never requires sexual assault victims to do. P&A argued that such a requirement is not only discriminatory, but, if it is allowed to stand, will discourage individuals with disabilities from reporting sexual assaults. Various expert analyses of crime statistics indicate that individuals with disabilities are twice as likely to become victims of sexual assault as people



who do not have disabilities, yet the current reporting levels are already low. Finally, P&A argued that the jury, which had heard the various witnesses testify, and had seen the testimony of the young woman herself, was in the best position to determine whether the victim was, indeed, physically helpless at the time of the assault.

The case was argued in the Supreme Court in October, 2011. A decision is expected within the next year.

Legislative Activities

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 Budget was the primary concern of the 2011 session of the Connecticut General Assembly. Actually, the term "concerns" is woefully inadequate to describe the scope and depth of the fiscal problems confronting the State. The budget proposed by the Governor, and ultimately passed by the Legislature in modified form, adopted a multi-pronged approach involving reductions in labor costs, enhancing revenues and effecting structural changes, including consolidation of certain agencies and programs such as the new Bureau of Rehabilitative Services, an important agency for people with disabilities.

P&A testified on a many bills that would impact the lives of people with disabilities in Connecticut, including access to the Department of Developmental Services Abuse and Neglect Registry by non-profit organizations; various changes to handicapped parking requirements; supportive housing initiatives; delays in evaluation of special education students; creation of a personal care attendant workforce council; and changes to the election statutes allowing for enforcement of new voting systems.

P&A also supported SB 918, An Act Concerning The Sexual Assault Of Persons Whose Ability To Communicate Lack Of Consent Is Substantially Impaired. This bill would have improved the sexual assault criminal statutes by clarifying the conditions to be met for a person to be considered unable to consent to sexual activity. P&A collaborated with many agencies on this bill and is committed to continuing its work on this issue.

For the past several years, members of the developmental disabilities community have been fighting to get rid of the term "mental retardation" from everyday terminology. They were successful in getting the Department of Mental Retardation changed to the Department of Developmental Services and since have continued to educate legislators about the negative connotations of the term.

During the 2011 Legislative Session, the Office of Protection and Advocacy for Persons with Disabilities (P&A) requested that the term "intellectual disability" be substituted for "mental retardation" in the Connecticut General Statutes that authorize P&A and its various programs. To reflect changes in the federal law and the developmental disabilities community, the Connecticut Legislature passed Public Act 11-16, creating those changes in terminology in the statutes for both P&A and the Department of Developmental Services. These changes were effective at the time of passage.

Community Outreach and Training

Every year, P&A staff participates in a variety of outreach events. This year, P&A sponsored or participated in 83 training events, including presentations, workshops, conferences, and resource fairs. More than 2,600 individuals received training on topics that included P&A programs and services; rights under the Americans with Disabilities Act and the Fair Housing Act; special education including “least restrictive environment”, inclusion, the Individuals with Disabilities Education Act, transition and due process; voting rights of people with disabilities; employment rights and work incentives; vocational rehabilitation; assistive technology; parent leadership; right to refuse medication and rights of people with mental illness; and abuse investigation. Information was disseminated to more than 3,200 people at 14 resource fairs. Over 13,500 publications and P&A program brochures were distributed to individuals and organizations throughout the year. More than 3,500 people were given the opportunity to register to vote. The P&A website is constantly updated and includes current news and a calendar of upcoming events; P&A program descriptions and agency publications; legislative updates; links to websites for disability rights and resources; and reports on developments in the field of disability rights. Last year, 38,380 visitors obtained information through the site. (www.ct.gov/opapd).

P&A staff supported community based disability advocacy groups across Connecticut, providing training and technical assistance on organizational development issues and disability rights. The agency continued its support for African Caribbean American Parents of Children with Disabilities (AFCAMP), Padres Abriendo Puertas (PAP); ADAPT and the Americans with Disabilities Act Coalition of Connecticut.

A Rightful Place – Educational Opportunity - Maria, the mother of a 5 year-old son, contacted P&A to thank the agency for a training series that she says changed her life. Here are her words: “My name is Maria. My son is 5 years old and he has beautiful green eyes, shining curly hair and a playful, mellow personality. He is the kind of child that when he comes into a room his smile is very contagious. My son also has autism, experiencing developmental regression in all areas. After 46 weeks in the school system, I was still living in darkness regarding his rights in the school system. I knew that there must be some kind of help for him although I did not know what it was or how to get it. Not having an appropriate educational program for him was like being in hell. Even worse, was the fact that the school has services and these were not made available to him.

There is a proverb that says: seek the truth; and truth will make you free. My son’s freedom came since I participated in a workshop series with the Office of Protection and Advocacy for People with Disabilities. At this educational workshop series, I learned about the laws and rights which protect my son's education; the importance for parents to be proactive with their child's school in educational decisions; and as a mother that I am the person who knows my son the best; this empowers my ability to advocate for my son's education.

If I need to put a title to my life it will be “after I found P&A”. My son and I are fortunate because our life has changed in the right direction.”

Major Issues Affecting People with Disabilities

Connecticut General Statutes §46a-13 mandate that P&A report annually on issues affecting Connecticut citizens with disabilities. The following issues were identified during this reporting year.

- 1. Disaster Preparedness.** During recent major storm events, it became clear that emergency preparedness planning for people who have access and functional support needs must be improved. Although some communities tried hard to include all their residents in support efforts, accessing resources from local service organizations and generating a true “we are all in this together” attitude, others tended to refer people with functional support needs to healthcare institutions – hospitals and nursing homes – or attempted to set up stand-alone regional “special needs” shelters. The later approaches violate the precepts of the ADA, misuse scarce healthcare resources, and on a practical level, represent poor community preparedness planning. People who think they might be sent to a nursing home or separated from neighbors and sent to a remote, segregated shelter will be less likely to evacuate or request assistance in the face of a widespread emergency. The demographics of Connecticut communities have changed over the past 30 years. The number of people of all ages who have support needs has grown significantly. So too must our mass care planning and response strategies. For a more detailed discussion and specific recommendations, please refer to the more extensive discussion on emergency preparedness planning elsewhere in this report.
- 2. Special Education.** As pressures increase on public schools to remedy poor performance, and all levels of government are facing significant financial problems, the institution of Special Education is coming under increasingly hostile fire. Amongst school officials, much of the hostility is being directed at parents who are being characterized as “unreasonable” “demanding” or “unrealistic”, and who are being blamed for sucking up resources by challenging the adequacy of programs being offered to their children. The most recent manifestation of this is a concerted effort by trade associations and law firms that represent school districts to reverse long-standing State rules that assign to school districts the “burden of pro[ving]” at a “due process” hearing that what they are proposing for a particular child is, indeed adequate. The proponents of this change seem to have forgotten something: special education law does more than establish a funding mechanism and attendant accountability requirements; it also defines a fundamental civil right – the right of all children with disabilities to a free, appropriate public education. Weakening the legal protections for that civil right (e.g. by shifting the “burden of proof” in due process hearings to parents) would significantly undermine our State’s commitment to that fundamental right, returning us to a time when schools were able to dictate terms of enrollment and marginalize students with disabilities. Due Process was written into special education laws precisely because it was understood that a disparate power relationship exists between school systems on the one hand, and individual students and their families on the other. Given mounting evidence of systemic deficiencies emerging in some districts’ special education programs, particularly for students with Emotional Disturbance,

Autism and Specific Learning Disabilities, it is becoming increasingly clear that changing the “burden of proof” will do little more than create a smokescreen to further obscure a general retreat from progressive standards and genuine expectations for successful learning .

3. **Transportation.** One of the earliest goals articulated by the disability rights movement was to resolve the problem of inadequate accessible public transportation. While some progress has been made on this front – most notably by transit districts operating fixed bus routes – it is still tremendously difficult to arrange to travel between different regions of the State without planning many days ahead. For people who use busses, moving about during evening and weekend hours is especially problematic. And, for people who do not live near fixed bus routes, the only solution is often to pay for expensive medical transportation services simply to get a ride to a meeting or for a doctor’s appointment. A recent proposal by two large taxi companies would have resulted in the acquisition of 70 additional accessible taxicabs. The taxis would have afforded people with mobility disabilities access to on-demand, accessible taxi service throughout the State. (Currently, Connecticut has a very limited number of accessible taxicabs.) Smaller, regionally based taxi operators objected to the proposal, and the Connecticut Department of Transportation denied the two taxi firms the licenses they had requested. Whatever the rationale for DOT’s denial, the fact remains that increasing the availability of taxi service would make an enormous difference for Connecticut residents with disabilities, and that the proposal from the two taxi companies is the only significant effort ever undertaken in that direction.
4. **Real Work & Expectations for Employment.** It is ironic that many school systems are attempting to minimize special education programming at the same time that governmental funding for adult services, including vocational rehabilitation and sheltered employment programs is beginning to dry up. Budgets associated with adult service systems for people with developmental, psychiatric and various other disabilities are not growing, and may in fact begin to shrink, depending on federal deficit reduction strategies. Waiting lists are growing, and there simply are no adult services available for people with many types of disabilities (e.g. autism spectrum disorders, acquired brain injuries, emotional disabilities that do not reflect major, persistent mental illnesses). More than ever before, to prepare students for a future where their own earnings will be a significant factor in how they live, special education will need to impart real, marketable vocational skills and expectations for on-going, life-long learning. Similarly, the vocational rehabilitation system will need to focus, as never before, on work. The days of sheltered workshops and traditional, low expectation tabletop assessment processes are coming to an end.
5. **Personal Care Services.** In Connecticut, a major controversy has developed concerning an Executive Order dealing with Personal Care Services (PCS). The Order created a new governmental structure, dominated by State agencies, to develop PCS policy and training for individuals employed as Personal Care Assistants (PCAs). It also effectively issues a speed-pass to the Union that is attempting to organize and represent PCAs across the country. PCAs are people hired, trained and supervised by individuals with disabilities to provide personal care. The role of the individual with

a disability as an employer is central to the concept of Personal Care Service, which, itself, is a critical component of the Independent Living Movement. However, the Executive Order creates an agency-dominated Personal Care Attendant Quality Home Care Workforce Council, which not only confuses personal care services with home health care, but is also charged with developing and sponsoring training for PCAs. Paralleling a twice-failed legislative proposal, the Executive Order also requires that the names of all individuals who are employed by people with disabilities as PCAs be made available for union organizing purposes. A similar executive order was recently vacated by court action in Pennsylvania.

6. **Affordable, Accessible Housing.** The long-standing statewide shortage of affordable, accessible homes continues to thwart efforts by people who wish to move out of long-term care facilities. Accessible rental units for families are in especially short supply. While new housing starts are down, some efforts to rehab existing building are going forward. It is critically important that residential building code requirements continue to provide for percentages of new and rehab units to be made accessible and adaptable for individuals and families who have disabilities.
7. **Loss of Experienced Leaders and the Lessons They Have Learned.** As State government downsizes and the baby boom generation ages, many experienced educators, advocacy leaders and human services workers are retiring. Just as the “Greatest Generation” which preceded them had unceremoniously gone about the business of saving the world from fascism, baby boomers have persistently pursued reform. They were the ones who taught the first special education students, staffed the first group homes, modified the first vans and busses, pioneered the Independent Living Movement, and first challenged the discriminatory assumptions the world makes about people with disabilities. Much of what they learned along the way is retiring with them, and much of that learning came the hard way – by trying things and making mistakes and then trying different things. One wonders if those who replace them will have to re-learn those same lessons. The odds that future generations will not stumble into superficially appealing, but fundamentally flawed models of support would significantly improve if there were to be a conscious effort to invest in leadership development strategies before even more veterans of the movement retire.

Did You Know?

Did you know that you can provide input about issues affecting persons with disabilities in Connecticut?

We want to hear from you! If you are interested, please complete the survey on the P&A website. The address is:

http://www.ct.gov/opapd/webforms/survey_blank.asp?s=CEFCACB83CDCFCD&d=CEC9CDCD83CDCFCC

Rather talk with someone or fill out a survey on paper? If so, please contact P&A at the numbers listed on the back of this Annual Report

Fiscal Facts and Figures

In the fiscal year ending June 30, 2011, P&A had a total operating budget of \$3,823,227.43. Of this, \$2,590,270.16 (67.7%) was state funding and \$1,232,957.27 (32.3%) was federal funding. Personal services expenditures comprise 92% of P&A's General Fund Budget, with an additional 8% expended on contracts, outside services and necessary expense items, including supplies, equipment, telephone, postage, and printing.

P&A Federal Expenditures for Fiscal Year 2010 \$1,232,957.27

U.S. Department of Education, Rehabilitation Services Administration – Client Assistance Program (CAP)	\$100,848.12
U.S. Department of Health and Human Services - Protection and Advocacy for Individuals with Mental Illness (PAIMI)	\$266,176.46
Connecticut Department of Social Services - Social Services Block Grant (SSBG)	\$139,312.99
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	\$182,784.95
U.S. Department of Education, Rehabilitation Services Administration – Protection and Advocacy for Individual Rights (PAIR)	\$141,627.47
U.S. Department of Education, Rehabilitation Services Administration – Protection and Advocacy for Assistive Technology (PAAT)	\$50,936.47
Social Security Administration - Protection and Advocacy for Beneficiaries of Social Security (PABSS) Note: Includes funds for Social Security Representative Payee Mentoring Program	\$132,451.31
U.S. Department of Health and Human Services - Administration on Developmental Disabilities – Protection and Advocacy for Voting Access (PAVA)	\$57,417.33
Health Rehabilitation Services Administration - Protection and Advocacy for Traumatic Brain Injury (PATBI)	\$61,402.17

Federally Mandated P&A Programs for Persons with Disabilities

Federal Program	Program Description
Protection and Advocacy for Individuals with Developmental Disabilities (PADD) <i>42 U.S.C. §15001 et seq.</i>	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) <i>29 U.S.C. §732</i>	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) <i>42 U.S.C. §10801</i>	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) <i>29 U.S.C. §2001 et. seq.</i>	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) <i>29 U.S.C. §794e</i>	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) <i>42 U.S.C. §15301 et. seq.</i> (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) <i>42 U.S.C. § 300 d. -51</i>	PATBI provides protection and advocacy services to individuals who have a 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, <u>et. seq.</u> 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 is 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 <u>et. seq.</u>	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:

**State of Connecticut
Office of Protection & Advocacy
for Persons with Disabilities**

**60B Weston Street
Hartford, CT 06120-1551**

Telephone - Voice: (860) 297-4300

TTY: (860) 297-4380

Toll Free (voice/TTY): 800-842-7303

Fax: (860) 566-8714

Website: www.ct.gov/opapd

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Upon Request