



**Office of Protection and Advocacy  
for Persons with Disabilities**

**2008 Annual Report**



Watercolor by Mary Irish  
of HARC's ArtSparks Group



Daisy Days  
by Kerri Quirk

## P&A Highlights the Arts

The artwork on the front and back cover of this 2008 Annual Report are pieces done by artists with disabilities. They, along with other works, have been featured in the Front Lobby of the P&A office during the past few years. The first OPART show highlighted the work of Mr. Henry Loomis, a talented and charming gentleman with mental illness. Since then, the OPART Committee has continually provided a revolving exhibit of dynamic, thought provoking and diverse pieces. A small group of P&A staff, with a passion and interest in art, comprise the OPART Committee within the Office of Protection and Advocacy for Persons with Disabilities. The members share the same vision: to support and promote art, in its many forms, that is either created by individuals with disabilities, or is particularly relevant to, and respectful of, the disability community.

Throughout the pages of this annual report, you will find photographs of some of the other pieces P&A has featured. We hope you enjoy these selections, and we welcome you to check the P&A website ([www.ct.gov/opapd](http://www.ct.gov/opapd)) for information on future shows and visit our office lobby to view the exhibits. The art featured in this report includes:

- Blue Ladder by Carol Clark (page 5)**
- Calico Cat by Mara Adlin (page 6)**
- Flagler Friends by Emmett Powers (page 7)**
- Frog Alone by Kerri Quirk (page 8)**
- Breakthrough by Jeff Bukowski (page 11)**
- On the Lake by Mara Adlin (page 12)**

## A Message from the Executive Director and the Advocacy Board Chair

### P&A

#### Advocacy Board

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Storrs, CT

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Plainville, CT

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**James D. McGaughey**  
Executive Director



**Eileen Furey**  
Chair, Advocacy Board

To the disability world, harsh economic realities are nothing new. Even during periods of relative prosperity, people with disabilities experience much higher than average levels of unemployment and poverty. Accessible housing, reliable transportation, healthcare and insurance are always in short supply. But, hard times bring an extra measure of frustration. Recent graduates of schools, colleges and rehabilitation programs have no place to market their diplomas and certificates. “Last hired, first fired” is more than a cliché and it applies to more than just jobs. Innovative human service programs and pilot projects, which often reflect best practices and offer hope for needed reform, are usually the first things to be eliminated when budgets are slashed.

Hard times test our commitment to concepts like equal access, person-based planning and community inclusion. They also exacerbate problems we have known about for a while but have succeeded in ignoring, such as chronic under-funding of community-based service providers upon whom so many depend. What will happen to the people those providers serve if their budgets are cut even further? Will staff and training levels slip to such an extent that vulnerable people are left at risk of harm? How many more people with intellectual or psychiatric disabilities will be institutionalized in nursing homes because community case loads grow unmanageable or are left uncovered? Who will take over if an agency collapses?

The P&A system is a product of hard economic times. P&As were established in response to scandalous conditions in state institutions like Willowbrook in New York. Willowbrook had been languishing for years when its budget was drastically cut in 1971. Thousands of people with disabilities were permanently confined in large, barren rooms without anything to do, many without regular meals, some even without clothing. Complaints raised by workers resulted in firings, while internal investigations whitewashed problems. The scandal broke in 1972. Congress acted, and the P&A system was born – guaranteeing that every state would have an *independent* safeguard capable of accessing people, investigating abuses and pursuing legal action.

As the Connecticut economy struggles and State government copes with enormous deficits, the Board and staff at P&A are refocusing on our core safeguarding mission. We cannot work miracles and we certainly cannot do it alone. But, especially in these hard times, we know we have important work to do.

## How Can P&A Help Me?

### What is P&A?

The Office of Protection and Advocacy for Persons with Disabilities (“P&A” or “OPA”) is an independent state agency established to safeguard and advance the civil and human rights of people with disabilities in Connecticut. Part of a nationwide network, P&A operates under both state and federal statutory mandates. In addition to conducting investigations, educating policy makers and challenging discriminatory barriers in court, P&A helps individuals with disabilities understand and exercise their rights. If you contact P&A, we can give you information about disability rights, refer you to experts and resources, and help you with your advocacy efforts.

In addition to advocating for disability rights, State statutes also require P&A to respond to reports of abuse or neglect of persons with mental retardation between the ages of 18 and 59. The agency responds to approximately 1,300 such reports every year. In addition, federal law authorizes P&A to investigate certain other types of abuse and neglect and to pursue remedies in court.

P&A gives information, advice and advocacy help to more than 8,000 callers each year. People call us with questions about a variety of topics, including:

- ◆ **Housing**
- ◆ **Special education**
- ◆ **Rights in treatment facilities**
- ◆ **Accessibility of buildings, programs and services**
- ◆ **Troubleshooting problems with human services**
- ◆ **Employment and vocational rehabilitation**
- ◆ **Transportation and handicapped parking**
- ◆ **Legal and human rights**

These are just examples. You can call P&A to discuss any disability-related issue or question. P&A also pursues community outreach projects, including training and consumer empowerment initiatives, and works with other disability groups on systems advocacy strategies, including efforts to educate legislators and other policy makers.

### What happens when you contact P&A?

Anyone can contact the office! You don’t have to be a person with a disability. Telephone calls (and e-mails, faxes, TTY calls, and letters) are directed to advocacy staff having professional expertise in the subject area of the call. Very often calls are taken immediately by the appropriate advocate, while sometimes you will receive a call back, usually by the end of the next business day. P&A tries to be

## How Can P&A Help Me?

accessible and welcoming to everyone. If you need a language interpreter or a particular accommodation, P&A will try to make appropriate arrangements.

Because resources are limited, P&A lawyers and advocates work on cases that meet specific mandates and priority criteria. Generally, these cases involve fundamental disability rights issues and have the potential to impact many people.

Unfortunately, P&A does not have enough resources to take action on every individual request for assistance. However, the agency is very aware that most people call because they are facing dilemmas, important decisions or unfair situations. Each person's issue is important and P&A will do the best it can to give you information and ideas that will help.

P&A accepts advocacy cases based on state and federal mandates, and on formally adopted priorities. Each case is reviewed on an individual basis to determine if it meets those guidelines and if the resources are available to provide advocacy assistance. P&A also collaborates with other agencies and other disability rights groups. If P&A is unable to provide direct advocacy representation, the agency will try to give the person information, coach them through the process and assist them with self-advocacy.

### How does P&A determine its priority issues?

Priorities for special projects and case selection are reviewed annually by the P&A Board. To be sure the agency's priorities reflect current needs, P&A staff analyzes data from thousands of constituent requests for assistance, identifies the issues that occur most often, and tracks the geographic locations of problems and the results of our advocacy efforts. P&A also provides the community with an opportunity to assist with priority setting by conducting public forums to listen to the concerns and experiences of people with disabilities, their families, friends and other interested persons. All the information is reviewed by the P&A Board, which recommends priorities for the coming year. Public comments on current or future priorities are welcome and can be submitted at any time by contacting the office by phone, e-mail or fax, or by completing a survey on the agency website at [www.ct.gov/opapd](http://www.ct.gov/opapd)

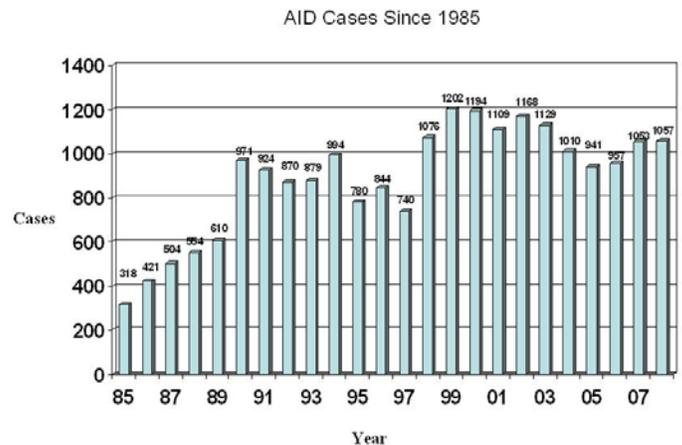
### P&A Does Not Discriminate

While P&A attempts to promote awareness of our common humanity, the Agency also respects the diversity of peoples' traditions, cultures and experiences. P&A does not discriminate in the basis of race, color, religious creed, age, sex, sexual orientation, marital status, national origin, ancestry, genetic information, or disability.

## Abuse Investigation Division

The Abuse Investigation Division (AID) was established in 1985 (Connecticut General Statutes §46a-11 et seq.) to investigate allegations of abuse or neglect by caregivers of persons with mental retardation, ages 18 through 59. AID has the authority to conduct direct investigations involving the Department of Developmental Services (DDS) or any other service provider. Most allegations involving clients of the mental retardation service system are directly investigated by the service agencies, with P&A's AID monitoring the internal investigations. AID conducts primary investigations for allegations involving people living at home or otherwise outside the scope of the mental retardation service system. In addition, AID is mandated to investigate the deaths of persons with mental retardation where the Department of Developmental Services has responsibility for direct care and oversight and there is reason to believe that the death may be due to abuse or neglect. There is no age limit for the investigation of these deaths.

AID received 1,182 allegations of suspected abuse or neglect of persons with mental retardation involving 1,250 perpetrators and resulting in 1,182 cases. P&A staff investigated or monitored 1,057 cases. One hundred and twenty five (125) allegations did not meet the statutory requirements for P&A investigation. The 1,182 cases involved 1,328 victims: 589 females and 739 males. Of the 1,057 cases accepted for investigation or monitoring, more than 53% involved neglect (564), while almost 21% alleged physical abuse (218). Case types also included Injury of Unknown Origin (100), Abuse/Neglect (65), Sexual Abuse (36), Abuse (8), Death (8), Willful Deprivation (1) and Other (57).



“Mary” - P&A’s Abuse Investigation Division (AID) investigated a case involving “Mary,” a young woman with physical and developmental disabilities who alleged through the use of a communication board that she had been sexually abused by her mother’s boyfriend. Mary told her mother of the ongoing sexual abuse, but Mary’s mother did not take any action to protect Mary from the boyfriend. Instead, her mother continued to allow the boyfriend to be alone with Mary. AID substantiated sexual abuse by the boyfriend and neglect by the mother. AID requested protective services to ensure the victim’s ongoing safety. The police also conducted an investigation and arrested the boyfriend on sexual assault charges. In February 2008, the boyfriend’s criminal trial took place. The prosecuting Assistant State’s Attorney equipped the courtroom with assistive technology enabling the victim to communicate directly to the court and jury through her communication board. The AID investigator also testified. The defendant was found guilty and sentenced to ten years in prison. Mary now lives in another town and receives residential supports. She consistently reports that she feels safe and happy in her home.

## Case Services Unit – Information and Referral

P&A and its subcontractors received requests for assistance from 11,803 individuals with disabilities, their family members, and interested parties. Of these, 10,323 were requests for information, referral, or short-term assistance. The remaining 1,480 requests received a more intensive level of advocacy representation.

P&A's advocates handled requests from callers, walk-in clients and visitors to the P&A website. More than 1,051 of these requests related to Services such as Personal Assistance, Program Access and Government Benefits/Services. They also responded to questions concerning Housing (578), Rights Violations (387), Neglect (297), Healthcare (228), Education (245), Employment (241), Abuse (210), Financial Entitlements (161), Rehabilitation Services (129), Architectural Accessibility (101), Assistive Technology (55), Transportation (29), Post-Secondary Education (24), and Non-medical Insurance (17). P&A also addressed concerns about Recreation, Voting, Childcare and Civil Commitment.

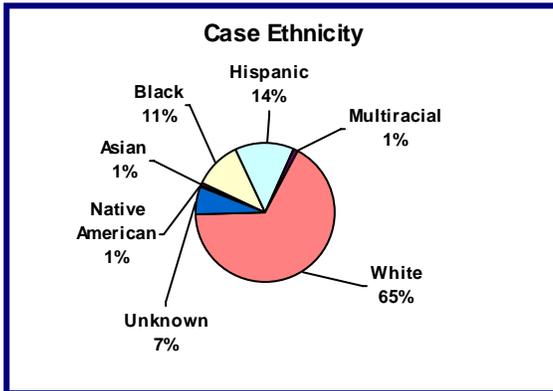
“John” - John lost his right hand at an early age. He was employed as a truck driver, but due to hard economic times, lost his job. As a single father, he needed to support his family and decided to go back to school and upgrade his Commercial Drivers License (CDL). John's instructor asked him if he had a medical waiver for his disability. When John reported that he was never required to get a waiver, the instructor contacted the Department of Motor Vehicles (DMV) and John had to immediately surrender his CDL. John had a clean driving record. He had renewed his license several times and nothing was ever mentioned about the waiver. John immediately obtained the necessary DMV documentation and submitted it but was told that it could take “some time” before he got his license back. John needed his CDL to work and after waiting a month for a response from DMV, he called P&A. A P&A Advocate was assigned to work on John's behalf. She reviewed his information and contacted DMV. His waiver was issued almost immediately and his CDL, including the upgrade, was re-instated. He could finally look for work to support his family.

“Jen” - Jen received a shut off notice in the mail for an outstanding electric bill. She called P&A concerned that her electricity was going to be shut off and that she would not be able use her oxygen machine, a constant necessity due to her respiratory disabilities. Jen tried to resolve this herself and the customer service representative from the company demanded that she make a large payment each month in an amount that she could not afford. The P&A advocate explained that there is a process to prevent utility shut-off in life threatening situations. Jen's doctor needed to complete a “Physician Certification” form, verifying that without electricity Jen would be in a life-threatening situation. Jen had the form faxed to her doctor and in a matter of hours the completed form was received by the company. Jen also arranged a reasonable payment for her utility bill and her oxygen use was uninterrupted, allowing her to continue to live independently in her home.



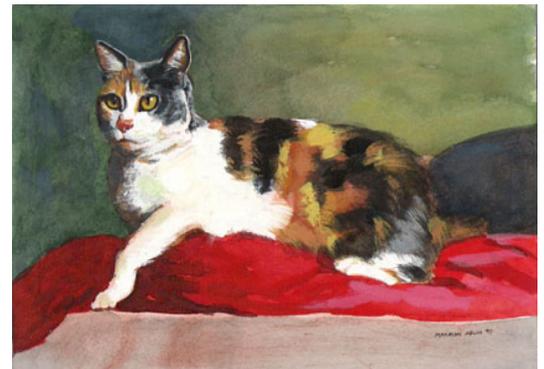
## Case Services Unit – Advocacy Representation Division

Advocates assigned to the Advocacy Services Division protect the rights of adults and children with disabilities living in institutions and community-based residential programs. In addition to providing training on disability-related topics, advocates also intervene on behalf of groups and individuals, such as adults with disabilities needing assistance with maintaining employment or resolving barriers to employment; children with disabilities needing educational supports; people with disabilities seeking remedies for issues related to housing; voting; programmatic and structural accessibility; abuse and neglect; effective communication; guardianship and personal decision making; and assistive technology. The Advocacy Services Division of the Case Services Unit is composed of a number of distinct federally mandated advocacy programs for people with disabilities, as illustrated on page 16 of this report.



P&A advocates and attorneys provided representation to 1,009 individuals with disabilities who had problems in the areas of Education (189), Rehabilitation Services (192), Abuse (158), Neglect (142), Rights Violations (95), Financial Entitlements (59), Services (31), Healthcare (29), Housing (23), Employment (21), Architectural Accessibility (13), Government Benefits (8), Assistive technology (7), Transportation (5), Voting (4), Guardianship/Conservatorship (4), Civil Commitment (3), and Recreation (3). Twenty-two (22) of the individuals had other problems, such as Childcare, and Program Access.

“Michelle” - Michelle, a woman with a brain injury, was discharged from a nursing home to a home her brother purchased for them to live in. She was able to move into the community and develop her independence with supports from the state’s Acquired Brain Injury (ABI) waiver program. Extreme sensitivity to touch and the effects of the brain injury caused Michelle to exhibit behavioral problems that were directed towards personal care staff. The resulting staffing issues created concern about the appropriateness of the community placement by ABI waiver team staff. Michelle requested assistance from P&A because she did not want to return to the nursing home. By challenging the decisions made by individuals in positions of authority and insisting on accountability from service providers, the P&A advocate was able to obtain additional services for Michelle, including specialized consultations, intensive in-home assessments, functional behavioral analysis, development of a strong behavioral intervention plan, in-home training to staff and family, and ongoing team participation. While these changes are still relatively new, she has displayed fewer behavioral outbursts, staffing issues have greatly diminished, and there has been no further discussion of her returning to any institution.



## Case Services Unit – Advocacy Representation Division

Theresa - Theresa was accepted at a private college and asked the Bureau of Rehabilitation Services (BRS) to pay for the college's specialized learning disability resource center. She contacted P&A when they could not agree on an employment plan. BRS objected to providing the resource center costs at a private university, offering instead the state supported university system and the disability resources it offered. Also, BRS found Theresa eligible for vocational services due to her psychiatric disability but determined she did not meet the eligibility guidelines for a learning disability and, therefore, they would not support the learning disabilities resources. P&A's Client Assistance Program (CAP) staff read Theresa's academic and case records, researched information about the private school program and comparable state university programs, and reviewed evaluations. The CAP advocate also assisted Theresa in gathering and organizing the documentation necessary to effectively present her case to the District Director. The meeting preparation emphasized self advocacy and having Theresa, not her parent or the advocate, talk about her case. At the meeting, the CAP advocate assisted Theresa in presenting her case, quietly providing organizational guidance. The meeting was successful, resulting in a creative outcome that meets Theresa's needs. BRS would not agree to support the specialized resource center at the private university because she did not meet BRS's learning disability guidelines, however, BRS agreed to remove the college funding limitation caps because the student would benefit from attending a private college in a small setting. BRS's monetary support would be recalculated and the additional monies could be utilized for whatever Theresa determined she needed to help her be educationally successful.



"Alice" - Alice, a woman with mental illness, was living in a residential care home (RCH). The owner of the home wanted to discharge Alice for perceived violations of house rules. Alice received an initial written document stating that she had to leave the residence in 30 days, so she called P&A. The P&A advocate determined that the document was not a valid notice of discharge because it neglected to include several requirements, including notifying the client of the right to an appeal, and agency contact information for the Department of Public Health (DPH). The advocate met with Alice and spoke with the owner and staff at the RCH. He explained that the administrator had to respect Alice's rights while the discharge process was pending, and negotiated with the owner to allow Alice to remain in the home as if there was not a discharge process under way. The P&A advocate and attorney also persuaded DPH that the discharge notice was not valid. After multiple communications, the advocate and attorney were able to negotiate a solution with both the owner and Alice. Alice was unhappy at the current RCH and was seeking an alternative residence. It was agreed that Alice would be able to remain in her current placement until she found another RCH that would suit her.

## 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 involving discrimination based on disability. During the year, the P&A legal division provided individual and systemic representation and monitoring on a number of legal issues including, but not limited to: proper treatment for prisoners with disabilities in Connecticut correctional system; violations of the employment and public accommodations provisions of the Americans with Disabilities Act, especially in hospital emergency rooms, prisons, and nursing homes; housing discrimination; forced sterilization of persons with developmental disabilities; educational placements and programs for children with disabilities; eligibility for services from the Department of Developmental Services; and guardianship/conservatorship for persons with disabilities. P&A attorneys also consulted with outside attorneys and members of the public on questions of disability law, working with staff to ensure quality responses to public inquiries and preparing comments on proposed state and federal regulations.



During the past 2 years, P&A handled many cases where the lives of individuals with intellectual disabilities had been threatened. These situations include medical orders withholding nutrition or dialysis and do-not-resuscitate (DNR) orders. P&A has been successful in persuading probate courts to reverse these orders and the individuals have gone on to live without the threat of loss of life. The following is a recent story about one such individual.

Chrissie, a 12 year old girl with a profound intellectual disability, was in the care of the Department of Children and Families (DCF). When she developed a highly treatable form of leukemia, the ethics board of the hospital determined that it would be ethical to refuse to treat her, a decision that would result in Chrissie's death. Their decision was based on Chrissie's inability to understand the reason behind the difficult treatment and the concern that she might not be able to maintain the same quality of life that she had enjoyed. DCF's ethical board was split as to whether, as the statutory parent, they would order treatment for Chrissie. A P&A attorney met with DCF and the doctors responsible for Chrissie's care and argued that to refuse to treat Chrissie would be a violation of the Americans with Disabilities Act. It was clear to P&A that the only reason that there was any question about whether to treat her was because of her intellectual disability, and that any other 12 year old child with her diagnosis would receive treatment. DCF decided, therefore, to order treatment, and the hospital reluctantly agreed. Chrissie is now doing well and is in remission.

These situations point out the pivotal role that P&A plays to remind medical providers that their obligation to treat individuals with disabilities is the same as their obligation to treat individuals without disabilities. P&A is seeking a way to inform medical ethics boards of this obligation, in order to bring a sense of disability awareness to these boards.

## Case Services Unit

### Edgar's Story

Edgar, a young adult with Cerebral Palsy, uses a wheelchair and a computer to communicate. He came to P&A for help in May of 2008. From the beginning, Edgar presented himself as a very determined and goal-oriented individual with enthusiasm for his life and his future. A member of P&A's information and referral unit met with Edgar and obtained basic information about his goals in seeking P&A assistance. Edgar shared that he attended East Hartford High School (EHHS) and that although he was a senior, the



school system was willing to provide transition services for an additional year. He and his family, including his conservator, had moved to an adjacent town and he could not receive the services unless he lived within the East Hartford town limits. Edgar's current conservator refused to allow Edgar to move, and would not agree to Edgar's choice to live independently, and work towards meeting his own goals. He came to P&A for assistance and was assigned an advocate specializing in the area of education and services for individuals with developmental disabilities.

Edgar told P&A that he wanted to change his conservator to an individual who would acknowledge his right to self determination and would allow him to pursue his goals to greater independence. Edgar communicated that his conservator was planning to move him again so staff could no longer locate him. Edgar's primary P&A advocate worked with other individuals who were also supporting Edgar in his goals and assisted him in working with the probate court to expedite the reassignment of a conservator of his choosing. Immediately upon appointment of a new conservator, Edgar's support network and the P&A advocate assisted him in moving from his relative's home to a temporary housing arrangement in East Hartford, and later to his own independent apartment. Police involvement ensured that the move was unhindered and Edgar's choice respected. Edgar was able to continue his education. After the move, P&A's Client Assistance Program advocate, who specializes in assisting clients who receive services from the Bureau of Rehabilitation Services, provided short term representation to assist Edgar in successfully working with BRS. She advocated for the necessary evaluations and services to assist Edgar in meeting his employment goals. Edgar now has access to transition planning services, daily living skills training, and opportunities for social networking. Edgar is supported by East Hartford High School and is currently enrolled at Manchester Community College, where he continues to pursue his dream of becoming a computer programmer.

## Community Outreach and Training

P&A sponsored or participated in 92 training events, including presentations, conferences, and resource fairs. Approximately 1,500 individuals received training on topics that included P&A programs, special education, voting rights, the American's with Disabilities Act, vocational rehabilitation, employment rights, work incentives, right to refuse medication, brain injury awareness, adult protective services, abuse investigations, and the rights of persons living in residential care homes. Information was disseminated to more than 5,900 people at 20 resource fairs. Over 12,500 publications and P&A program brochures were distributed. P&A also held 4 public forums and 2 focus groups to solicit information about issues affecting people with disabilities in Connecticut that P&A would use in setting its priorities for 2009.

**Disability Advocacy Convention and Expo** - P&A was a partial co-sponsor of the 2<sup>nd</sup> Connecticut Disability Advocacy Convention and Expo, one of the largest gatherings of people with disabilities in Connecticut. The event drew over 850 attendees to the Connecticut Expo Center in Hartford. Occurring just weeks before Election Day, the convention provided a timely opportunity for people from all over the state to hear from candidates for public office and to discuss critical disability rights issues. In addition to the political events, the booths displayed products and information about services and programs that serve people with disabilities. P&A staff participated on the convention planning committee, volunteered during the event and manned a large booth that displayed a wide range of literature for distribution, with an emphasis on voting rights material. P&A also arranged for staff from the Office of the Secretary of the State to provide voters with an opportunity to try the two voting machines now used in Connecticut.



The P&A website was reviewed and updated with current information. The site includes P&A program descriptions and self help publications, upcoming events, disability news, legislative updates, links to disability websites, and reports on developments in the field of disability rights. Last year, more than 125,000 visitors obtained information through the site.

Outreach and support to community based disability advocacy groups continued to be a priority for P&A. During the year, P&A staff provided training and technical assistance in diverse communities, including minority and under served communities. Staff also participated on the Family Support Council, Family Day Committee, Connecticut United Action Neighborhood, Help Me Grow, and the statewide Traumatic Brain Injury Advisory Board.

P&A continued its financial and staff support to African Caribbean American Parents of Children with Disabilities (AFCAMP) and Padres Abriendo Puertas (PAP), organizations that support minority parents of children with disabilities; the Americans with Disabilities Act Coalition of Connecticut; ADAPT; and Connecticut Kids as Self Advocates (CT KASA).

## Legislation



P&A's Legislative and Regulations Specialist (LRS) tracks legislative proposals that may affect the rights of persons with disabilities in Connecticut. During the legislative session, the LRS publishes a weekly Legislative Update that lists the status of bills currently being considered by the Connecticut Legislature. The Update is available by e-mail and on the P&A website. 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 previous legislative session. The 2008 Legislative Summary and other legislative information affecting people with disabilities can be found on P&A's website ([www.ct.gov/opapd](http://www.ct.gov/opapd)) under the "Legislative Information" section.

During the 2008 Connecticut Legislative Session, P&A supported a number of bills that would improve the lives of persons with disabilities in Connecticut, including expansion of the Autism Pilot Program within the Department of Developmental Services (DDS); modification of public school teacher education requirements to include preparation for teaching students with autism spectrum disorders; and mandating insurance coverage for autism-related services. P&A also supported authorization of a significant expansion in the Money Follows the Person program, including a component that applies to people who have not previously lived in a long-term care facility. P&A also testified before the Program Review and Investigations Committee regarding the Committee's report on Planning for the Needs of Aging Persons with Developmental Disabilities. The testimony included information gathered by P&A's Fatality Review Board about the conditions prior to the death of individuals under the care of DDS and supported a model where individuals with disabilities are allowed to age in place.

"Edward" - Edward's disability is a form of autism known as Asperger's Syndrome. His disability presents significant challenges to his understanding and functioning in the social world. To overcome barriers to employment and independent living and successfully learn the social rules of the "road," Edward needed services that would allow him to transition from school to work and adult life. The school system wanted to graduate Edward without providing him with these necessary services. The family objected and called P&A for help. The P&A advocate met with Edward and his family and reviewed the educational records. When the school system graduated Edward, the P&A advocate and attorney filed for due process to compel the school to provide the necessary services. During the hearing, the family and school system agreed on a settlement that will allow for an appropriate educational evaluation and transition services, including real life situations in the area of employment, post-school training, community life and independent living.

## Fatality Review Board

The Fatality Review Board for Persons with Disabilities (FRB) is supported by the Office of Protection and Advocacy for Persons with Disabilities (P&A). Established by Executive Order 25, the FRB, operating independent of the Department of Developmental Services (DDS), tracks all reported DDS client deaths. Staff also pursues preliminary inquiries and full, independent investigations into selected deaths. The Executive Director of P&A is the chair of the Fatality Review Board (FRB). The FRB also has five (5) Governor-appointed members who are drawn from medical, law enforcement, and human service professions.



The FRB reviewed or investigated 200 deaths during the year, 107 men and 93 women. Sixty (60) individuals were living in skilled nursing facilities or nursing homes at the time of their deaths. This number is followed by fifty-three (53) living in community living arrangements (CLA); thirty-seven (37) living at home with their families; twenty-seven (27) living at Southbury Training School; seven (7) living in a DDS-operated regional center; six (6) living independently in the community supported by self-determination funds and receiving case management support; three (3) living in the community supported by DDS or a private provider; three (3) living in community training homes; three (3) in the Hospital for Special Care; and one (1) living in a Hospice facility. One hundred and twenty-two (122) cases were subject to in-depth monitoring and review by the FRB. Additionally, the FRB investigated the circumstances surrounding nine (9) deaths where there was reason to suspect that abuse or neglect may have been a contributing factor.

**Aging in Place** - The FRB has become increasingly concerned about people with intellectual disabilities living in nursing homes when they died. Since the inception of the FRB, 32% of the reported deaths involved people who lived in nursing home settings. Part of the FRB's concern involves the quality of care in certain facilities, where neglect on the part of the nursing home contributed to an individual's death. The FRB is also concerned that even nursing homes that provide generally good care are not good places for people with developmental disabilities. The FRB has taken steps to address this critical issue: 1. Data Analysis - The FRB is gathering and analyzing data to determine why individuals are placed into nursing homes; where they lived prior to placement; their health prior to placement; why they weren't discharged; and how involved their families and providers were in their care. 2. Aging in Place - Based on FRB experience and interviews with individuals with developmental disabilities, family members, private and public providers, advocates and others, it seems fairly clear that most people prefer "aging in place." In order to promote program development to fulfill this desire for people who are aging, the agency is participating with our Developmental Disabilities Network partners in a symposium, *Including Our Elders With Disabilities: A Symposium on Aging in Place*, which will be held in Fall 2008 to explore and help develop a fuller sense of what "aging in place" may look like for people with developmental disabilities in Connecticut and help shape policy for the future.

## Fiscal Facts and Figures

In the fiscal year ending June 30, 2008, P&A had a total operating budget of \$4,336,215. Of this, \$2,587,433 (60%) was state funding and \$1,748,782 (40%) was federal funding. Personal services expenditures comprise 86% of P&A's General Fund Budget, with an additional 14% expended on contracts, outside services and necessary expense items, including supplies, equipment, telephone, postage, and printing.

### P&A Federal Expenditures for Fiscal Year 2008 \$1,748,782

U.S. Department of Education, Rehabilitation Services Administration – Client Assistance Program (CAP)	<b>\$101,673</b>
U.S. Department of Health and Human Services - Protection and Advocacy for Individuals with Mental Illness (PAIMI)	<b>\$532,514</b>
Connecticut Department of Social Services - Social Services Block Grant (SSBG)	<b>\$124,930</b>
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 Development Disabilities	<b>\$504,630</b>
U.S. Department of Education, Rehabilitation Services Administration – Protection and Advocacy for Individual Rights (PAIR)	<b>\$208,628</b>
U.S. Department of Education, Rehabilitation Services Administration – Protection and Advocacy for Assistive Technology (PAAT)	<b>\$52,229</b>
Social Security Administration - Protection and Advocacy for Beneficiaries of Social Security (PABSS)	<b>\$100,474</b>
U.S. Department of Health and Human Services -Administration on Developmental Disabilities – Protection and Advocacy for Voting Access (PAVA)	<b>\$80,602</b>
Health Rehabilitation Services Administration - Protection and Advocacy for Traumatic Brain Injury (PATBI)	<b>\$43,101</b>

## Major Issues Affecting People with Disabilities

### Economy Threatens to Worsen Chronic Unemployment and Underfunding of Community Services

Amid ever-worsening economic news, budget analysts are forecasting State budget deficits of \$2.6 billion in State Fiscal Year 2010 and \$3.3 billion in State Fiscal Year 2011. The State has not faced such large deficits since 1991, when the legislature and Governor Weicker wrangled over the budget throughout the Summer and into the Fall of that year. Agency budgets were slashed, staff were furloughed or laid off, and innovative programs were put on hold. That year a state income tax was adopted and, ultimately, the budget picture stabilized.

No similar resolution appears likely at this time; the global recession and the Connecticut economy's strong ties to the troubled financial sector foreshadow a period of significantly diminished State revenues. The bleak economic news is hitting people with disabilities especially hard. For those who are graduating from school or completing vocational rehabilitation programs, and even for those recently hired by employers who are now forced to downsize, rising unemployment rates create anxiety, frustration and, ultimately, threaten to perpetuate the cycle of poverty and dependence that has historically characterized much of the disability experience.

The situation is even worse for people with disabilities who need or rely on community-based services and supports. Over the past decade, community residential and day services, independent living programs, clinical services and other vital programs, most of which are operated by community-based non-profit organizations, have been chronically underfunded. Unable to keep up with rising operating costs and to provide competitive wages, benefits packages and realistic career paths for dedicated employees, many have lost promising staff members to other industries. This slow attrition has weakened the backbone of Connecticut's community service system, threatening service quality and depriving local organizations of both emerging leaders and the ability to innovate and keep pace with evolving needs. Amid the current budget crisis, there is much talk about re-examining the "core functions" of government. Let us hope that providing adequate support for community-based services is recognized as one of those core functions.

### Housing

The shortage of affordable, accessible housing is still keeping thousands of people unnecessarily institutionalized in psychiatric hospitals and long-term care facilities. Federally subsidized housing can be designated "elderly only" and non-elderly persons who need safe, affordable, accessible housing are not welcome. Affordable and accessible two and three bedroom apartments for families are very difficult to find.

### Corrections System as Default Service Provider

The Department of Correction is the largest housing provider for people with psychiatric disabilities. The settlement of a lawsuit against the Department of Correction put safeguards in place for prisoners with

## Major Issues Affecting People with Disabilities

psychiatric disabilities who were unable to adapt to prison and were at risk of inappropriate, increasingly harsh disciplinary actions. Although that settlement agreement has expired, the Department of Corrections is considering incorporating some of its provisions into its permanent policies. However, no amount of policy reform will ever make prisons into good places for people with psychiatric or intellectual disabilities. Too many people with these disabilities still wind up incarcerated. Although most are charged with relatively minor crimes, courts are reluctant to simply release them in the absence of coordinated support plans that include housing and realistic case management.

The situation is especially difficult for people with intellectual disabilities. Because services from the Department of Developmental Services are not “entitlements,” people who could successfully live in the community with minimal services and supports often receive no services. Some end up in jail for what could be considered nuisance activities. Driven by a need to protect resources intended for those on its “waiting list,” DDS will only become involved with an individual who is at risk of incarceration or re-incarceration if that person has been determined to be not competent to stand trial and then committed to DDS by a probate court. Because the legal standards for those determinations are quite exacting, most people with intellectual disabilities who run afoul of the criminal justice system receive no help from the service system.

### Use of Restraint and Seclusion in Schools

The Legislature passed landmark legislation in 2007 to prohibit the use of restraints and seclusion on students receiving special education services. These students can now only be restrained if there is a real danger that someone will get hurt, or, in the case of seclusion, as part of the student’s Individual Education Plan. While the legislation requires schools to notify parents when restraints or seclusion are used, more information about frequency and circumstances of restraint and seclusion use needs to be developed. In addition, requirements should be established for training in de-escalation techniques and positive behavioral supports that could prevent the need for restraint and seclusion use. In short, the legislation was a very good start. But more needs to be done.

### Nursing Home Placements

Over 2,000 people with primary psychiatric diagnoses remain stuck in Connecticut nursing homes. But there are also increasing instances where people with a primary psychiatric diagnosis who need skilled nursing care are denied nursing home admission because of their psychiatric disability. There is on-going litigation to address this issue. Money Follows the Person (MFP) is supposed to help individuals who have been in nursing homes for six months or more to move into community settings of their choice. MFP has faced continual delays and many people continue to languish in nursing homes because of the lack of community based services and supports. More needs to be done to prevent the initial placement into nursing homes for people who do not need that level of care and supervision.

## Federally Mandated P&A Programs for Persons with Disabilities

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

# State Mandated P&A Programs for Persons with Disabilities

State Program	Program Description
<b>Chair and Support Fatality Review Board for Persons with Disabilities</b> (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.
<b>I&amp;R Services</b> C.G.S. §46a-11(3)	Provides response to more than 10,000 inquiries/requests for assistance annually. Conducts limited research and provides individualized information.
<b>Case Advocacy Program</b> 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.
<b>Public Education</b> C.G.S. §46a-11(10)	Presentations and self-help literature; website and other publications.
<b>Fund or initiate litigation to secure rights</b> C.G.S. §46a-11(7)	Staff attorneys; sub-contracts with legal services provider.
<b>Investigate allegations of abuse and neglect of adults with Mental Retardation</b> 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 suspected. Recommends protective services (from DDS) or call for Immediate Protective Services where needed.
<b>Review and issue joint decisions or requests for exception to accessibility of building code; installation of wheelchair lifts</b> 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.
<b>Review and Rule on requests for waivers from polling place access requirements</b> C.G.S. §9-168 <u>et. seq.</u>	Applications forwarded by Secretary of State: 8-12 requests per election cycle.
<b>Ensure compliance with federal P&amp;A system requirements</b> Public Act 03-88	Requires director to operate agency in conformance with federal P&A system requirements.
<b>Annual Report to Governor and Human Services Committee</b> C.G.S. § 46a-13	Annual Report submitted 1 <sup>st</sup> of December. Report must include status of services for persons with disabilities and make recommendations regarding rights.
<b>Accessibility Advisory Board established</b> Public Act 06-56	Allows the director to establish an accessibility advisory board to be comprised of design professionals, people with disabilities, people whose family members have disabilities, and anyone else the director believes would provide valuable insight and input on matters relating to accessibility.



## **Contact Information:**

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