

**Celebrating 30 Years  
of Empowering People with Disabilities**

Forefront of Fight for Rights of Handicap

# Office of Protection and Advocacy for Persons with Disabilities

## 2007 Annual Report

**P&A - a leader for the disabled**

# Office of Protection and Advocacy for Persons with Disabilities

## Celebrating 30 Years

### 1977-2007



The Office of Protection and Advocacy for Persons with Disabilities (P&A) is an independent state agency established in 1977 to safeguard and advance the civil and human rights of people with disabilities in Connecticut. P&A is part of a national network of protection and advocacy systems and operates pursuant to both federal and state mandates.

P&A systems were initially established in response to a series of scandals that erupted in the 1970s, revealing inhumane conditions in state institutions for people with developmental disabilities. As a condition of receiving funds under the federal Developmental Disabilities Assistance and Bill of Rights Act (the "DD Act"), states were required to establish an independent protection and advocacy system - a system that would be authorized to access information, conduct investigations, educate policymakers and pursue legal and administrative remedies to protect and advocate for the rights of people with developmental disabilities. Over time, the federal P&A mandate expanded to include people with mental illness and, eventually, other disability populations as well.

#### P&A Vision for the Future

The State of Connecticut will have a legally-based protection and advocacy system that is deeply rooted in the experience of people with disabilities and widely recognized, well respected and supported for its leadership, its commitment to community partnerships, equality and justice, and empowering approaches to defend and advance the civil rights of people with disabilities.

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

### P&A

#### Advocacy Board

Carrie Czerwinski  
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Ashford, CT

Christopher Knapp  
Plainville, CT

Suzanne Liquerman  
Stratford, CT

Heidi Mark  
Meriden, CT

Sheila Mulvey  
Plantsville, CT

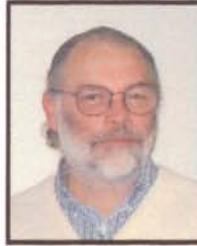
Anne Noble  
Burlington, CT

Walter Pelensky  
Bristol, CT

Jeffrey Simon  
West Hartford, CT

Peter Tyrell  
Middlebury, CT

Phyllis Zlotnick  
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James D. McGaughey  
Executive Director



Eileen Furey  
Chair, Advocacy Board

Thirty years. Three decades. By anyone's reckoning, it's a long time for an enterprise that began on a shoestring, surrounded by utterly unrealistic expectations about changing the world. In October, 1977, when our office first opened, Jimmy Carter was President, Watergate and Vietnam were still too fresh in the national consciousness to be called "memories", and tens of thousands of people with disabilities were still being routinely warehoused in large congregate institutions. The nakedness and despair that national magazines and television journalists showed the world from Partlow in Alabama, Willowbrook in New York, and Chattahoochee in Florida existed in every state, including Connecticut. It was an era when we had to grapple with scandal and colossal policy failure, when we had to confront our fallibility. We needed hope, and we needed to fight back. We needed to believe that we could set things right. We needed P&A.

We've come a long way in thirty years: Federal and State P&A mandates have expanded to include protecting the rights of people with all types of disabilities; the Connecticut Constitution has been amended to prohibit discrimination on the basis of disability; and major national civil rights laws like the Americans with Disabilities Act, have been enacted.

Service and support concepts now stress community participation, productive employment and independent living. Over the past thirty years, P&A has made solid contributions to this progress. We have exposed abuse and neglect, supported development of community advocacy groups, educated policy makers and influenced outcomes; and, fulfilling our mandates to pursue legal and administrative remedies, we have challenged discrimination and oppressive conditions in the courts. Through it all, we have stood alongside thousands of people with disabilities and their families in their personal quests for a rightful place in the world.

Taking time to recognize accomplishments and milestones – to reflect on where we have been and where we are going – is both clarifying and important. Despite our considerable progress, however, there is still so much to do: for many people genuine inclusion in schools, workplaces and community life remains an elusive dream; enforcement of accessibility requirements is still spotty; families raising children with significant disabilities are still being stressed, often beyond the breaking point, by financial and bureaucratic constraints; and cycles of rejection, poverty, abuse, homelessness, incarceration, institutionalization and long waits for marginally relevant services still trap too many people with psychiatric and cognitive disabilities. So we cannot pause too long to celebrate. We need to get back to the urgent business of changing the world.

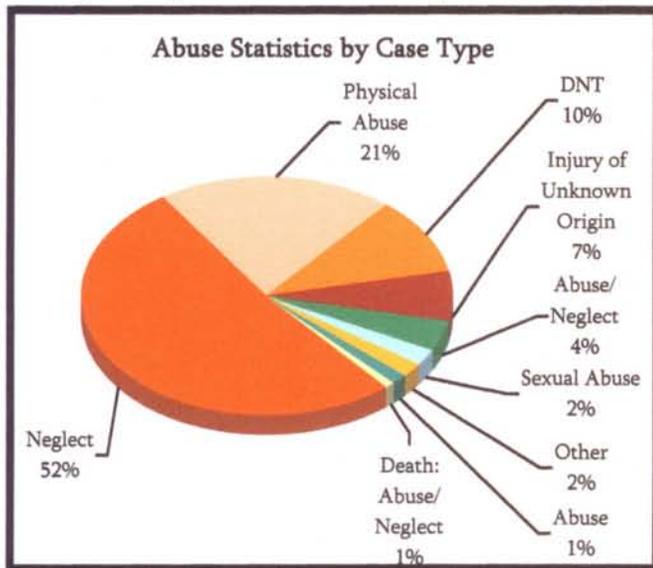
## A Brief History of P&A

### A Thirty Year Timeline of Empowering People with Disabilities

- 1977 Developmental Disabilities Assistance and Bill of Rights Act (the “DD Act”) was passed creating a protection and advocacy system in all 50 states. In response, Connecticut established the Office of Protection and Advocacy for Handicapped and Developmentally Disabled Persons to safeguard and advance the civil and human rights of all people with disabilities. (Public Act 77-589)
- 1984 P&A Client Assistance Program (CAP) was established.
- 1985 P&A Abuse Investigation Division (AID) was established to investigate allegations of abuse or neglect of adults who have mental retardation, ages 18-59.
- 1986 P&A Protection and Advocacy for Individuals with Mental Illness (PAIMI) program was established.
- P&A established a Citizen Advocacy Program, pairing volunteer advocates with residents of Mansfield Training School. P&A begins Transitions Project to advocate for people moving out of Mansfield Training School.
- 1990 P&A began organizing support for parent advocacy organizations for minority communities.
- 1994 P&A Protection and Advocacy for Individual Rights (PAIR) program was established  
P&A Protection and Advocacy for Assistive Technology (PAAT) program was established.  
P&A becomes the Office of Protection and Advocacy for Persons with Disabilities.
- 2001 Protection and Advocacy for Beneficiaries of Social Security (PABSS) program was established.
- 2002 P&A Fatality Review Board was established by Governor’s Executive Order No. 25 to provide oversight to the fatality review process for people with mental retardation.  
P&A began Every1Counts, voter accessibility project.  
P&A established an advocacy program at Southbury Training School.
- 2003 P&A Protection and Advocacy for Voting Access (PAVA) program established.
- 2005 P&A Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI) program was established.
- 2006 P&A Access Advisory Board was established.
- 2007 P&A celebrates 30 years of empowering people with disabilities, and launched a new campaign, “The Partnership for an Accessible Connecticut.”

## 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 Mental Retardation (DMR) 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 investigation. 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 (formerly Mental Retardation) has responsibility for direct care and oversight and there is reason to believe that the death may be due to abuse or neglect.

AID received 1,201 allegations of suspected abuse or neglect of persons with mental retardation, resulting in 1,176 cases. P&A staff investigated or monitored 1053 cases. One hundred and twenty three (123) allegations did not meet the statutory requirements for P&A investigation. The 1,053 cases involved 1,318 victims: 605 females and 713 males. Of the 1053 cases accepted for investigation or monitoring, more than 61% of the 1318 victims resided in group homes (810), while almost 17% (221) lived in the family home. Victims also resided in supervised living arrangements (84), regional centers (61), community training homes (43), Southbury Training School (21), medical facilities (17), independently (16), residential schools (7), board and care homes (3), community (3), foster homes (2) or with respite care providers (2). The residences of 28 victims were unknown.

"Partners in Protection" - P&A in collaboration with the Connecticut Department of Developmental Services (formerly Mental Retardation) and the Department of Public Safety sponsored "Partners in Protection", a conference for professionals who investigate abuse and neglect of persons with mental retardation. The conference featured a keynote address by Dr. Henry Lee; resource exhibits; and skill-building workshops that focused on different facets of investigating abuse and neglect of persons with mental retardation including Evidence Collection, Conducting Interviews, Computer Crimes and Internet Safety, and Risks and Safeguards for People who Direct and Manage Their Own Supports.



## Case Services Unit – Information and Referral

During the 2007 fiscal year, P&A and its subcontractors received requests for assistance from 12,486 individuals with disabilities, their family members, and interested parties. Of these, 10,936 were requests for information, referral, or short-term assistance. The remaining 1550 requests received a more intensive level of advocacy representation.

P&A's Information & Referral Advocates answered 600 housing questions related to fair housing issues, eviction, and provision of reasonable accommodations, including ramps, rental denial, and zoning. They also responded to questions concerning personal assistance services (517), abuse and neglect (459), education (381), rights violations (306), government services and responsibilities (304), healthcare (233) employment (263), financial entitlements (158), rehabilitation services (149), program access (125), transportation (88), architectural accessibility (76), and assistive technology (76). Callers also contacted P&A with concerns about issues including recreation, voting, childcare and benefits planning.

Danni, a woman with multiple sclerosis wanted a service dog to assist her around her condominium. She informed the condo association and was told that, according to the bylaws, only guide dogs for the blind were allowed. Danni called P&A to ask for information about her right to have a service dog at her condominium and assistance with obtaining permission from the condo association. The I & R Advocate explained the process of requesting an accommodation and offered to send several sample letters and other printed information that would guide her through the process. Danni called the Advocate back a month later stating that her request for accommodation was approved without any problems and she would be bringing her service dog home that weekend.



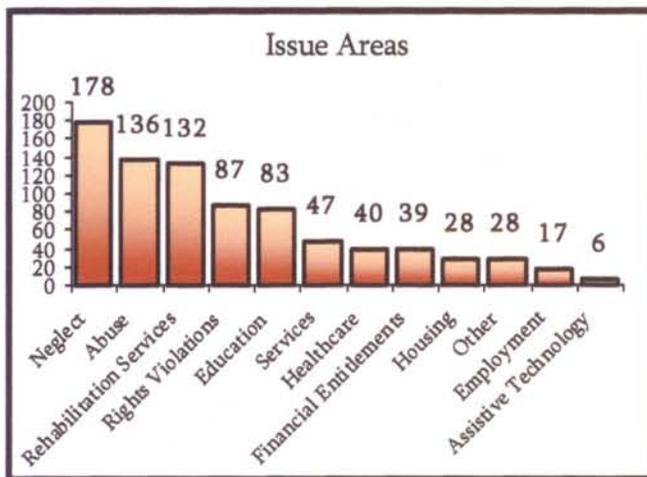
Janet, a sixty year old woman with a physical disability, called P&A's Information and Referral Unit to obtain assistance with an accessibility issue. Janet's Park and Recreation Department offers recreational swimming at the local high school pool, providing her with an opportunity to meet her need for water exercise on a daily basis. Janet was, however, concerned about how she was going to get in and out of the pool because she could not use the standard pool ladder. Janet called the local Park and Recreation Department to discuss other options for entering the pool and was informed that they have two means of accommodating her: with a chair lift that lowers an individual into the pool, or portable stairs that would enable her to walk into the pool. In an effort to maintain her independence, Janet selected the stair option, but was told that it was difficult and inconvenient for staff to install and remove the stairs. She would be required to use the chair lift. Janet wanted to maintain maximum independence and therefore contacted P&A for information and assistance. The I&R Advocate consulted with P&A's legal division about Janet's right to choose her accommodation under Title II of the Americans with Disabilities Act, which covers the obligations of state and local governments. The I&R Advocate explained to the Director of the Park and Recreation Department that Janet has the right to choose the accommodation that allows her the greatest level of independence and that she wanted to use the stairs. After the Director explained the problem with using the stairs, the Advocate and Director worked together to develop a solution to the problem. With the assistance of high school maintenance staff, the stairs would be made available to Janet whenever she wanted to use them, allowing her to maintain her independence and access recreational opportunities within her own community.



## 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 maintaining employment; children with disabilities who are

unable to obtain appropriate supports to meet their educational needs; people with disabilities seeking remedies for issues related to housing; voting, and programmatic and structural accessibility; abuse and neglect, effective communication; guardianship and personal decision making; and assistive technology. Advocacy Services Division staff attorneys seek administrative or judicial remedies involving discrimination based on disability. 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 the chart on page 16 of this report.



P&A advocates and attorneys addressed more than 821 issues while providing representation to 692 individuals with disabilities. Of the 692 individuals who received advocacy or legal representation, 322 had psychiatric disabilities and 123 had intellectual disabilities. Other disabilities of the individuals served include learning disabilities (50), physical/orthopedic impairments (38), traumatic or acquired brain injury (28), autism (26), deaf/hard of hearing (21), cerebral palsy (11), neurological impairments (12), blindness (7), auto-immune disorders, including HIV/AIDS (7) multiple sclerosis (5), diabetes (3), epilepsy (3), and other disabilities (9). The disabilities of 27 individuals were unknown.

Elizabeth, a woman with a long history of mental illness, was told by the residential care home where she lived that she had to leave. With no place to else to go, Elizabeth went to the emergency department of the local hospital. She was very upset and frightened at having to leave her home. Her caseworker called P&A and an advocate immediately intervened. The advocate notified the residential care home administrator that it is illegal to verbally tell residents that they have to leave. Elizabeth was allowed to return home, but was immediately given a written notice that she would be required to leave in thirty days. With the assistance of a P&A advocate, Elizabeth appealed the "Notice of Discharge" to the Department of Public Health, gathered her evidence and attended a fair hearing. The hearing officer found that there were no valid reasons for Elizabeth's discharge and ordered that she remain at the residential care home.



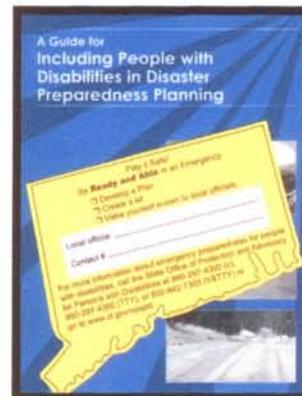
## Case Services Unit – Advocacy Representation Division

Two individuals called P&A because they were having difficulty in obtaining “joy stick” driver training through the Department of Motor Vehicles (DMV). Training on the use of a joy stick, rather than a steering wheel, is highly specialized and taught only by the DMV. The Bureau of Rehabilitation Services modified the clients’ vehicles as part of their approved employment plan, but they were unable to drive them because DMV did not have inspectors available to provide the necessary training. The P&A advocate contacted the DMV Handicapped Driver Consultant to discuss the issue. After several attempts, she still did not have a satisfactory response and was informed that DMV was not going to hire employees to provide “joystick” training. Since the DMV is required by Connecticut General Statutes to provide driver training for people with disabilities, the advocate asked P&A’s Executive Director to discuss the issue with the DMV Commissioner. A meeting between the Commissioner and Executive Director resulted in the hiring of a DMV employee to provide “joy stick” training to qualified individuals with disabilities. Both clients have been trained on the use of the “joystick” and are currently using their vehicles for school, work and play!



Barbara, a woman with a traumatic brain injury, contacted P&A for assistance to remain in her own home after she began experiencing problems with support staff who assist her in maintaining her home and independence. Barbara has lived in eastern Connecticut for several years and is a valued member of her community. She plays an active role in her local church, participates in several spiritual and social activities every week and enjoys spending quiet times in her home, with her cherished friend, her cat, Gracie Jean. Barbara receives support from the Department of Social Services’ (DSS) ABI waiver program. Because of her staffing problems, Barbara’s ABI waiver team began pushing for nursing home placement, stating that Barbara was not safe to remain in the community. She was notified by DSS that her ABI waiver services would be terminated. The P&A advocate requested a fair hearing, freezing the imminent termination of her services. Through intensive advocacy and representation, the P&A advocate was able to assist Barbara in maintaining and enhancing services, that provide her with reliable 24 hour personal care support, companions, and independent living skills trainers. Today, Barbara continues to retain her ABI waiver services, remains active in her community, and resides in her own apartment, with Gracie Jean.

P&A staff, in collaboration with other state and local organizations, developed and organized Playing It Safe, a traveling conference on emergency planning for people with disabilities and elders that is visiting each emergency response district in Connecticut. The conference, presented in both English and Spanish, is unique in the dual emphasis it places on personal responsibility and civil rights. Attended by emergency planners, public health staff, government officials and lay people, with and without disabilities, the conference is a five hour day that promotes interaction and conversation. Each conference includes a plenary session, “Ready and Able,” that focuses on personal emergency planning and afternoon workshops on planning for pets and service animals and planning issues for children with health care needs.



## 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, forced sterilization of people with intellectual disabilities; discrimination in housing; violations of the Americans with Disabilities Act and Connecticut General Statutes in prisons, recreational settings and nursing homes; educational programming for children with disabilities; proper mental health treatment for prisoners in Connecticut's correctional system; and appeals of building code waiver denials. Other legal division activities include consulting with outside attorneys and members of the public on questions of disability law; working with staff to ensure quality responses to public inquiries; and conducting presentations about disability rights at seminars and conferences; and preparing comments on proposed state and federal regulations and policies.

Jacob is 5 years old and lives with severe allergies to tree nuts and peanuts. If exposed to these allergens, Jacob is at high risk of anaphylactic shock, the consequence of which can be death. Before Jacob was scheduled to start kindergarten, his mother met with the school to provide them with information about Jacob's food allergy and its severity. While the school accepted the information, it took only minimal steps to ensure Jacob's safety in the school environment and on the school bus. Within a few days of school starting, Jacob's mom discovered that there were peanut/tree nut products in Jacob's classroom despite the classroom being labeled a "nut free" environment. The school refused to take further steps to protect Jacob and the family removed him from school.

Jacob's mom subsequently requested that the school find Jacob eligible for Section 504 services that would require modifications to the school environment so that Jacob could safely attend school with his peers. The school refused to find Jacob eligible for the services and the family contacted P&A. P&A advocates and legal staff successfully represented Jacob at meetings with the school and ultimately at a hearing where the Hearing Officer concluded that Jacob does have a disability and is entitled to the protections under Section 504. The school appealed that decision but the Hearing Officer again concluded that the severity of risk to Jacob's life as a direct result of his life threatening food allergies, coupled with the pervasive nature of allergens in the school and school bus environment, led to the ruling. This is the first time that a student with life threatening food allergies has been found eligible for Section 504 services in Connecticut. The school and Jacob's family are now working together to support Jacob's safe and complete education.



## Case Services Unit

### A Fight for a Valued Life

P&A received a call regarding Mary, a woman with an intellectual disability, who was in the hospital as a result of neglect. While conducting interviews into the allegation, P&A Abuse Investigators were informed that Mary's primary care physician, along with the guardian, had come to the conclusion that she had a terminal condition. They pursued what is called a "Do Not Resuscitate Order" or DNR, and the order was granted. A DNR is "an order written by a Connecticut licensed physician to withhold cardiopulmonary resuscitation, including chest compressions, defibrillation, or breathing or ventilation by any assistive or mechanical means including, but not limited to, mouth-to-mouth, mouth-to-mask, bag-valve mask, endotracheal tube, or ventilator." The Department of Developmental Disabilities requires that, before a DNR may be granted, an individual's condition is terminal, death is imminent and the individual and/or her surrogate decision maker consents to the DNR



P&A Abuse investigators visited Mary at the hospital and, to their surprise, Mary was alert and smiling. Her smile was bright and unforgettable. She was responsive to their voices and did not appear to be in any pain. She did not seem to be someone who was in the last stages of life. The investigators interviewed the nursing staff and discovered that she was not receiving nutrition or her prescribed medications because of her inability to swallow and because the guardian had refused administration of nutrition through a Nasogastric Tube. The nursing staff stated that she had been diagnosed with continuous aspiration and therefore was designated as terminal. The hospital's discharge plan was for Mary to be discharged to a hospice facility where she would die from starvation or dehydration.

Immediate action was needed. P&A investigators met with P&A legal staff to review the case and generate solutions. Review of the medical record revealed that there was no previous diagnosis of aspiration. P&A immediately intervened, filing a motion in the probate court to provide nutrition and hydration for Mary. P&A also submitted a request for a guardian ad litem, who would monitor the woman's condition. The hospital was ordered to provide Mary with nutrition until the probate court reached a final decision about the DNR.



P&A successfully challenged the DNR in Probate Court. The P&A Abuse Investigation Division issued an Immediate Protective Service Plan to further protect Mary and ensure that she was receiving appropriate medical care. In addition, P&A assigned Mary an advocate to make certain that she received the necessary health and safety supports, as well as to monitor quality of life issues. The woman who was once deemed terminally ill and fated to die is now living in a group home and is no longer in need of tube feedings. She is vibrant and her smile continues to shine.

## Legislation

P&A has a Legislative and Regulations Specialist (LRS) who 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. Each summer, P&A also publishes an annual Legislative Summary of disability-related Public Acts passed during the previous legislative session. The 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 2007 Connecticut Legislative Session, P&A supported self-advocates with intellectual disabilities by testifying in favor of legislation that authorized the renaming of the Department of Mental Retardation to the Department of Developmental Services. P&A also proposed or strongly supported legislation that creates an Autism Spectrum Disorder Division within the Department of Developmental Services ; tightens the rules about guardianship and conservatorship; requires conservatorship meetings and hearings to be recorded; requires "clear and convincing evidence" before a conservator may approve the use of psychotropic medications; and prohibits the Emergency Management and Homeland Security commissioner from approving any local emergency operations plan that he determines does not address the evacuation of pets and service animals.



The biggest legislative success in 2007 was passage of Public Act 07-147, An Act Concerning Restraints And Seclusion In Public Schools. – In late 2006, P&A advocates received an alarming number of calls from parents whose children were being either restrained or placed in seclusion rooms. School systems were routinely using restraint and seclusion as a method of handling children with behavioral problems often resulting in physical and emotional injuries to the children. Parents were not notified when their child had been restrained or placed in seclusion. P&A provided individual representation for families and in December 2006, held a public forum to educate legislators and the public about the issue and its pervasiveness. Several P&A staff also worked with legislators to educate them as they proposed statutory changes to address the problem. Public Act 07-147 regulates the use of physical restraints and seclusion on students receiving or awaiting eligibility determinations for special education services in public schools. Restraints and seclusion may only be used as an emergency intervention to prevent immediate or imminent injury to the person or to others, provided it is not used for discipline or convenience and is not used as a substitute for a less restrictive alternative, or as specifically provided for in an individualized education program. As regulations are developed and adopted, P&A will continue to educate and advocate to ensure that rights of children with disabilities are protected.

## Community Outreach and Training

P&A sponsored or participated in 135 training events, including radio/television shows, presentations, workshops, conferences, and resource fairs. Approximately 3,600 individuals received training on topics that included P&A programs and services, disability sensitivity, adult protective services, the Americans with Disabilities Act, legislative process, building code, emergency preparedness for people with disabilities, rights of voters with disabilities, special education rights, employment, vocational rehabilitation system, acquired brain injury awareness, investigation interviewing, and the rights of persons living in residential care homes. Information was disseminated to more than 3,800 people at 12 resource fairs. Over 12,000 publications and P&A program brochures were distributed.



The P&A web-site was reviewed and updated to include the current publications and information. The site includes P&A program descriptions, upcoming workshops and events, current disability news, legislative updates, P&A self-help literature, links to disability-related websites, and reports on developments in the field of disability rights. Visitors to the site can also obtain information about P&A's priorities and complete a survey about disability issues affecting people with disabilities in Connecticut.

P&A staff continued to provide community outreach and support to new and existing community-based disability advocacy initiatives in geographically diverse areas of Connecticut. During the 2007 fiscal year, P&A conducted outreach and training activities in minority communities and assisted grassroots organizations by providing training and assistance on organizational and membership growth, board development and self-advocacy strategies. Staff also continued to participate on the Connecticut Family Support Council; Connecticut Health Foundation's Health Care for Everyone; Connecticut United Action Neighborhood; and the Minority Outreach Committee of the statewide Traumatic Brain Injury Advisory Board. P&A also began its outreach to the Asian community in the Hartford area through connections with Asian Family Services.

Community Development staff provided training on special education for parents of children with disabilities in Norwalk, Danbury, Willimantic, Bridgeport, Hartford, Greenwich, and New London. The training focuses on teaching participants how to be the most effective advocates for their children by giving them information, basic skills and hands-on experience to allow them to navigate all phases of the special education system.

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 in Connecticut. The agency also continued to support the Connecticut Women and Disability Network (CWDN), the Americans with Disabilities Act Coalition of Connecticut (ADACC), ADAPT and Connecticut Kids as Self Advocates (CT KASA).

## 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 operates independently of the Department of Developmental Services (DDS) (formerly the Department of Mental Retardation) mortality review structure. The FRB tracks all reported DDS client deaths and pursues preliminary inquiries and full, independent investigations into selected deaths. The Executive Director of P&A is the chair of the Fatality Review Board (FRB). The FRB also has five (5) Governor-appointed members who are drawn from medical, law enforcement, and human service professions.

The largest number of deaths, or fifty (58), was attributed to cardiac arrest, cardiopulmonary arrest, cardiovascular disease, or congestive heart failure. Other causes of death listed, in rank order, include thirty-three (33) by pneumonia; twenty-seven (27) by respiratory arrest or respiratory disease; twenty-one (21) by cancer; twelve (12) by septicemia; ten (10) by renal failure; (5) as the result of a terminal illness process; five (5) by cerebral hemorrhage; four (4) by seizure disorder; four (4) by Alzheimer's disease; and four (4) by metabolic disorder. In addition to the major causes of death listed above, three (3) were attributed to gastrointestinal disease; two (2) to homicide; two (2) as a result of infectious disease; one (1) to accidental trauma; one (1) to acute illness; one (1) to diabetes; one (1) to drowning; one (1) to pancreatitis; one (1) to a stroke and one (1) to surgical complications. Six (6) causes of death are listed as "unknown" or "not otherwise specified".

Sixty-two (62) cases were subject to in-depth discussion, monitoring and review by the FRB. Additionally, during the period between October 1, 2006 and September 30, 2007, the FRB reviewed the circumstances surrounding twelve (12) deaths where there was reason to suspect that abuse or neglect may have been a contributing factor.

**Fatality Review Board for  
Persons with Disabilities**

2005-2006

**Annual Report**

The Fatality Review board made the following recommendations in its 2005-2006 Annual Report released in June 2007: 1) The Commissioners of the Departments of Developmental Services (DDS), Social Services, and Public Health should jointly issue a letter to all licensed nursing facilities in Connecticut reiterating the State and Federal mandates that require that DDS be notified of any significant change in the physical or mental condition of any nursing facility resident who has an intellectual disability; 2) DDS should clarify the responsibilities of Case Managers, Regional Health Services Directors, Regional Directors and Central Office personnel with respect to information received indicating that a nursing facility resident with an intellectual disability has undergone a significant change in condition; 3) DDS should pursue a process to develop more consistent standards regarding nursing support services for all residential programs; 4) State investigative agencies need to develop plans and resources to ensure that life support equipment can be tested when, in conjunction with a fatality investigation, the functioning of that equipment is called into question or when there may be a question of tampering or inexpert manipulation.

## Fiscal Facts and Figures

In the fiscal year ending June 30, 2007, P&A had a total operating budget of \$4,277,523. Of this, \$2,527,093 (59%) was state funding and \$1,750,430 (41%) was federal funding. Personal services expenditures comprise 85% of P&A's General Fund Budget with an additional 15% expended on contracts, outside services and necessary expense items such as including supplies, equipment, telephone, postage, and printing.

### P&A Federal Expenditures for Fiscal Year 2007 \$1,750,430

U.S. Department of Education, Rehabilitation Services Administration – Client Assistance Program (CAP)	\$171,198
U.S. Department of Health and Human Services - Protection and Advocacy for Individuals with Mental Illness (PAIMI)	\$437,523
Connecticut Department of Social Services - Social Services Block Grant (SSBG)	\$180,002
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	\$545,100
U.S. Department of Education, Rehabilitation Services Administration – Protection and Advocacy for Individual Rights (PAIR)	\$160,097
U.S. Department of Education, Rehabilitation Services Administration – Protection and Advocacy for Assistive Technology (PAAT)	\$56,165
Social Security Administration - Protection and Advocacy for Beneficiaries of Social Security (PABSS)	\$96,204
U.S. Department of Health and Human Services -Administration on Developmental Disabilities – Protection and Advocacy for Voting Access (PAVA)	\$59,840
Health Rehabilitation Services Administration - Protection and Advocacy for Traumatic Brain Injury (PATBI)	\$44,301

## Major Issues Affecting People with Disabilities

### 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 placed in restraints or seclusion if there is a real danger that someone will get hurt, or if they are included as part of the child's Individual Education Plan. However, the legislation does not require the State Board of Education and Education Department to compile a report of state-wide use of such restraint and seclusion. The legislation also did not require training in de-escalation techniques that should be used to prevent the need for restraint and seclusion use. In short, the legislation was a very good start. But more needs to be done.

### Forced Sterilization

There has been a significant increase in the number of sterilization petitions for women between the ages of 18 and 30 with disabilities. Most of these women have developmental disabilities, and some also have a psychiatric disability. State law requires that Probate Courts must give approval whenever a person has not given consent, or a physician has reason to believe a person is not able to consent, or when a person is under a guardianship or conservatorship. In such cases, the Probate Court can only permit sterilization "upon showing that such operation or procedure is in the best interest of the person." OPA will continue to represent individuals and continue to work to help guardians and conservators understand and respect the right of each individual to be involved in such major life decisions.

### Access to Oral Healthcare

Many people with disabilities have low enough incomes that they are eligible for Medicaid health and dental insurance. But many Medicaid recipients are unable to find providers who will accept Medicaid dental insurance. While reimbursement rates have gotten attention in the past year, dentists still lose money on many preventive procedures. The lack of oral healthcare providers who accept Medicaid is compounded by the lack of experience many providers have with people with disabilities.

### Emergency Preparedness

People with disabilities have the right to go to their local emergency shelter with their neighbors, friends and family. Architectural access, the availability of backup generators, accessible means of communicating, flexible administrative policies, and staff who are aware of disability issues are all important. Connecticut Red Cross shelter policy now embraces the concept of "universal access" at Red Cross shelters. Much work was done in the past year to educate people with disabilities and families with children who have disabilities about their rights and personal preparedness responsibilities. While these efforts are paying off in some towns, in many municipalities shelter facilities and emergency plans have not yet been assessed to ensure they will meet needs.

## Housing

The shortage of affordable, accessible housing is still keeping thousands of people unnecessarily institutionalized in psychiatric hospitals, long term care facilities and even in prisons. 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

As this report is being written, the Legislature’s Judiciary Committee is considering a proposal to build a 1200 bed medical and mental health facility within the Department of Correction as a way of addressing this issue. Advocates worry that such a facility will only encourage more judges and prosecutors to send people with psychiatric, developmental and cognitive disabilities to this “safe place” instead of working to improve community-based housing, services and supports.

## Nursing Home Placements

Over 2,000 people with primary psychiatric diagnoses remain stuck in Connecticut nursing homes. In addition, many people with physical and developmental disabilities who want to live in their own homes have no alternative but to live as nursing home “patients”. Efforts are underway to help some of these people transition to community living, but the lack of affordable, accessible housing is slowing progress.

## Employment

People with disabilities continue to have higher rates of unemployment and underemployment than people who do not have disabilities. There is a need for greater availability of information about both legal rights and workplace problem-solving resources. While vocational rehabilitation agencies help people acquire skills for initial employment and are educating prospective employers, more attention needs should be paid to helping people pursue promotional opportunities and career paths.

## Mission Statement

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

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

## 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, <i>et. seq.</i> P.A. 03-146; P.A. 04-12	Monitors internal service system investigations and conducts primary investigations into allegations of abuse/neglect re: adults with mental retardation; investigates deaths of DDS clients where abuse/neglect suspected. Recommends protective services (from DDS) or 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	Bi-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 <i>et. seq.</i>	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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