

**Empowering Children,
Adolescents &
Adults with Disabilities**



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

Annual Report 2010



Eliot Dober
April 1936 – July 2010



Eliot J. Dober passed away on Friday, July 30th. With his passing we have lost one of the early leaders of the disability rights movement, the founder of the Connecticut P&A, and a good friend.

Appointed by Governor Ella Grasso in 1977, and subsequently reappointed by Governors William O’Neill and Lowell Weicker, Eliot served as Executive Director of the Office of Protection and Advocacy for Persons with Disabilities for 17 years. Beginning in borrowed office space with a staff of three, he built the agency into a multi-faceted, fully independent advocacy and safeguarding force of fifty advocates, investigators, lawyers and community organizers. Working with both state and federal elected officials to refine and expand the agency’s statutory mandate and its budget, he also made substantial contributions to the development of the national protection and advocacy system. He was a founder, and served as one of the first Presidents of the National Association of Protection and Advocacy Systems (NAPAS, now known as the National Disability Rights Network – NDRN).

Access is one of the primary goals of disability advocacy: access to buildings and places of public accommodation, to relevant support programs, to meaningful opportunities to work and contribute in communities. Eliot stood for all those things. But he specialized in a different kind of access – access to the corridors of political power. He understood the rhythms and relationships that drive governmental decision-making, and brought his skills as a master strategist to the disability rights movement. And he loved doing it. Even in retirement, he kept a watchful eye over events, ever ready to make a key phone call, to share his insights with a colleague, or just to lend a supportive ear. And when he called, he would always end by saying, “Be well.”

Be well, Eliot. Thank you for the opportunities you created, for accomplishing so much, for the way you shared yourself with us, for being a true friend. You will be missed, but your good works will live on.

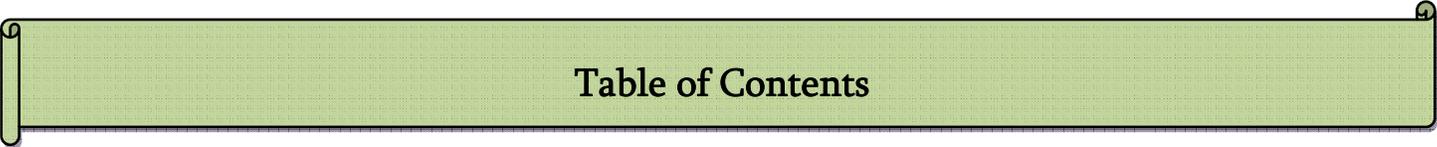


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A Message from the Executive Director and the Advocacy Board Chair

P&A

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Eileen Furey
Chair, Advocacy Board

Another year has flown by for P&A. As this report illustrates, 2010 has been busy and productive: We welcomed new members to our Advocacy Board, won important victories for our clients in court, continued to reduce repeat victimization from abuse, challenged unacceptable neglect of public school students with emotional and behavioral disabilities, led efforts to educate policy makers and the larger community about concerns with end-of-life decision making, continued to organize and inform families of children with disabilities from minority communities, and addressed barriers to equal access in health care facilities, attorneys offices and with law enforcement agencies. In fact, we have been so deeply immersed in these activities that we have had little time to stand back, take stock and appreciate either the breadth of issues that demand our involvement, or the intensity with which we must and do respond.

Preparing our annual report is an opportunity to take that step back; to assess our progress and double-check our navigation. There is both good and bad news here. Good news about the course we are following – as an agency and as a State we are headed in the right general direction, one that leads toward the goals of full citizenship, equal justice and true belonging. The bad news is that we still have such a long way to go. And, we are battling strong head winds.

Amidst the economic anxieties and severe budget problems that characterize these times, we need, more than ever, to focus on our core principles. Strategies may change with the times, but what is right and good does not change. The enduring principles around which the disability civil rights movement has formed are universal. At their most fundamental level, they are about fairness: full membership in the human community; equal opportunity to participate and contribute; freedom from unwarranted confinement and the tyranny of low expectations; genuine respect for individual rights; and, recognition that we all need each other and share far more in common than can ever be written in any listing of things that set us apart. These principles are our compass. If we hold them up, and then hold ourselves to them, we can weather the economic storms that surround us and help steer the course of progress.

As you read this report, we hope you will recognize both the good work of our exceptional staff members, the dedication of our all-volunteer Advocacy Board, and the commitment that together we bring to safeguarding the rights of all people with disabilities.

Person First Language

As both anthropologists and disability activists have long known, the words we use to refer to people can subtly, but powerfully influence how we see them. One of the first bumper stickers to emerge from the disability rights movement proclaimed a painful truth: “Sticks and stones may break my bones, but words can really hurt me.” That’s because, historically, disability has been described in terms that convey images of suffering, tragedy, illness and limitation. Referring to “the disabled,” or describing someone as “afflicted” or “suffering from” a disability makes it harder to see the real, individual, fully human people behind the labels – people for whom having a disability may be only one characteristic or factor in life.

In general, it is preferable to avoid terms that broadly label and categorize people, minimize expectations or evoke images of sickness, pity, charity and “holy innocence”. There are better alternatives. The basic principles are to refer to the person first, and avoid simply equating that person to his or her disability. Consider the following examples:

| Depersonalizing Language | Person First Language |
|---|--------------------------------------|
| Mary is disabled, handicapped or a brave sufferer. | Mary has a disability. |
| John is a victim of cerebral palsy; suffers from a disease. | John has cerebral palsy. |
| Katie is crazy, loony, nuts, insane or psycho. | Katie has a mental health diagnosis. |
| Bob is retarded, mentally defective or not all there. | Bob has an intellectual disability. |
| Sara is crippled, lame or deformed. | Sara has a physical disability. |
| James is wheelchair bound or confined to a wheelchair. | James uses a wheelchair. |
| Candy is afflicted by multiple sclerosis. | Candy has MS. |
| Dee is mute or dumb. | Dee does not speak. |
| Matt is a downs | Matt has Down syndrome. |
| Joan is slow, stupid or lazy. | Joan has a learning disability. |
| Bill is brain damaged. | Bill has a brain injury. |

Becoming conscious of the language we use is an important step towards overcoming habits of thought that unfairly limit opportunities for people with disabilities to achieve, contribute and participate as valued members of their communities. However, obsessively worrying about choosing politically correct terms is counter-productive. Relax. While some in the disability rights movement are very particular about language, most will value any genuine effort to be more respectful in words and actions. Language is important, and it can be a marker of attitude and sensitivity. But, it’s not everything.

Riverview Hospital Project

The Protection and Advocacy for Individuals with Mental Illness (PAIMI) program at P&A is authorized by federal law to investigate incidents of abuse and neglect of individuals with mental illness and pursue administrative, legal, and other appropriate remedies to ensure the protection of individuals with mental illness. Pursuant to Connecticut General Statutes §§46a-154 et seq. and a Memorandum of Understanding between P&A and the Department of Children and Families (DCF), P&A receives reports of all serious injuries and deaths resulting from restraint and/or seclusion at Riverview Hospital, the only state-administered psychiatric hospital for children in Connecticut. Since April 2009, P&A has been conducting interviews with the children involved in these incidents.



Through the course of these interviews, P&A learned several distressing facts. First, most of the children in the Riverview facility did not know that they have certain rights, and can advocate for what they need and want while at Riverview. We also learned that almost none of the children knew if they had a safety plan, never mind what their safety plan includes. P&A was and continues to be greatly concerned about the significant role of the police at the facility. With this in mind P&A took several steps.

P&A worked with Riverview Hospital and DCF leadership to establish a regular presence on each unit within the facility. P&A has developed two training curricula that offer the children opportunities to learn about advocacy, their rights, and how to develop their own safety plan. The first of these is "Self Advocacy 101", a four part training series that teaches the skills and strategies necessary to become a successful self-advocate. The second, titled "My Safety Plan", is a six part training series. The goal of this training is to engage the children in developing piece by piece, their own self-specific plan to use in times of crisis. The training culminates in the creation of an actual safety plan document for each child to present to his/her team. Children at Riverview are also given regular opportunities to privately meet with an advocate from P&A to discuss any concerns that they may have.

Although the training is still in its infancy, the children are finding the trainings to be valuable and useful. There is also increased participation by the children in their own treatment planning, more skillful self-advocacy interactions, and an increased confidence in dealing with the adults in their world.



Riverview Hospital Project

Marc's Story - Marc is an eleven year old boy who isn't sure how he came to live at Riverview Hospital. He just knows he has been there for a long time. More than anything else, Marc wants to be able to go home. When Marc is hungry or tired he sometimes acts out at the hospital. He doesn't know if he has a safety plan to use in times of crisis but he has his own ideas about what helps him. Taking a nap, eating a piece of fruit, or squeezing a ball helps him calm down, but he doesn't know how to ask staff for those things. Marc wishes that staff would simply ask him if he needs to take a nap when he is getting upset.

Andrew's Story - When the P&A advocates first met sixteen year old Andrew they were warned that he was "one of those kids" who is "just up and down". They were warned that he could quickly become very violent, and were asked if they wanted a staff member present for safety during their interview. They declined. When the advocates met Andrew, they found a very different child. Andrew struck the interviewers as not only bright but polite, thoughtful, and gentle. "Please", "thank you", and "ma'am" seemed to roll off his tongue naturally and without thought. Andrew expressed a deep respect for living things, and shared his dreams of becoming a veterinarian some day.

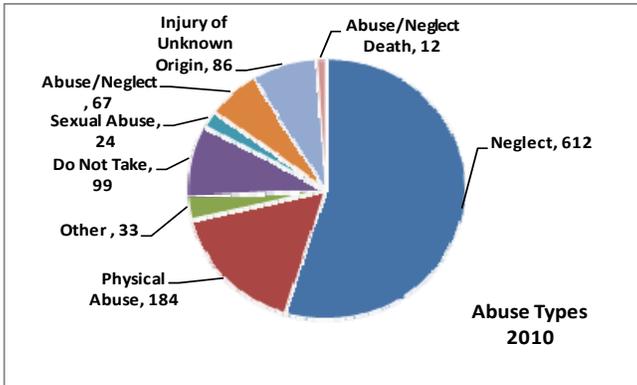


Andrew has been hospitalized at Riverview Hospital several times. During his last hospitalization, he tried to take his own life on three separate occasions. Every time Andrew has an outburst, the Connecticut State Police are called to intervene and he is usually physically restrained, mechanically restrained (strapped down to a bed by his arms, legs, and midsection), and/or placed in locked seclusion. Calling the police makes Andrew feel scared and disappointed. The police intervention, restraints and seclusion are not in the least bit helpful to him. He does not feel safe. Andrew knows what is helpful to him during a crisis; talking, listening to music,

drawing, and playing with Legos™, but no one asks him. Andrew has a safety plan but he doesn't know what's in it or how to use it. He feels that he isn't given the chance to make choices in his treatment or his life while at Riverview Hospital. Andrew is trying to find his way, but needs to be given the skills and opportunities necessary to succeed.



Abuse Investigation Division



P&A's Abuse Investigation Division (AID) was established in 1985 to investigate allegations of abuse or neglect by caregivers of adults with intellectual disabilities who are between the ages 18 and 59. Under the authority of Connecticut General Statutes §46a-11a et seq., AID conducts primary investigations for allegations of abuse and neglect involving people with intellectual disabilities living outside the mental retardation service system. Most reports involving clients of the developmental disabilities service system are directly investigated by the service agencies, with P&A monitoring the internal investigation. AID is also mandated to investigate the

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

Last year, AID received 1131 allegations of suspected abuse or neglect of persons with mental retardation, resulting in 1,117 cases. P&A staff investigated or monitored 1018 cases while 99 allegations did not meet the statutory requirements for a P&A investigation. The 1,117 cases involved 1,227 victims: 558 females and 669 males. Of the 1,112 cases accepted for investigation or monitoring, more than 48% of the alleged perpetrators were residential staff while 16% were vocational staff and almost 16% were family members. Other perpetrators included Community Training Home Providers (12), Nurses (34), Van Drivers (14), Step-father (8), Guardian/Conservators (7) and others (52). The identity of the perpetrator was not known in 124 of the cases.

Bob's Story - Bob, a man with an intellectual disability, lived with his brother. P&A's Abuse Investigation Division received a report that Bob's brother was verbally and physically abusive. He would lock Bob in his room for 5 or 6 hours every day after Bob got back from his day program. When Bob needed to use the bathroom, he had to beg his brother to let him out of the room.

P&A initiated an investigation. AID investigators met Bob at his day program, and immediately observed his hygiene to be poor. His clothing was dirty and his gums were red and swollen. Bob said that he was locked in his room by his brother and had to ask to use the bathroom. He also reported that his brother punched him and said that "it hurts to be hit and punched". Bob said his brother is always angry at him and he is afraid to be in his home. Because of Bob's fear of his home situation and the state of his physical care, AID initiated an immediate protective service request from the Department of Developmental Services, insuring that Bob received respite placement outside his home pending the outcome of the investigation. When the investigation was completed, AID substantiated both physical abuse and neglect. The investigation report was forwarded to the State's Attorney office for prosecution. AID issued a Protective Service Plan that included placing Bob in an appropriate residential setting outside his family home, providing necessary medical and dental care, and supervised visits with his brother, if Bob wants to have contact with him. Today, Bob lives in a place where he is free from abuse, has clean clothing and continues to receive appropriate medical and dental care.

Fatality Review Board

Fatality Review Board Members

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

Gerard Kerins, M.D.
Madison, CT

Patricia Mansfield
East Lyme, CT

Lt. David Rice
Department of Public Safety
Middletown, CT

Vacancy – Medical
Professional

Non-Voting DDS Liaison
Doreen McGrath, MSN, RN
Hartford, CT

The Fatality Review Board for Persons with Disabilities (FRB) was established by Executive Order 25 (February 2002) to bring greater independence and oversight to the fatality review process for people with intellectual disabilities who receive services from the Department of Developmental Services (DDS). The FRB is supported by P&A and operates independent of the DDS independent mortality review structure. FRB staff tracks all reported DDS client deaths and pursues preliminary inquiries and full, independent investigations into selected deaths. The Executive Director of P&A is the chair of the FRB. The FRB also has Governor-appointed members who are drawn from medical, law enforcement, and human service professions. The Commissioner of DDS or designee sits as a non-voting member. In April 2010, Governor Rell issued Executive Order 42, updating the FRB by adding an additional Board member who has expertise in teaching forensic investigation techniques.

In 2009, the Connecticut Legislature passed Public Act 09-67, requiring the Department of Mental Health and Addiction Services (DMHAS) to report the death of anyone receiving inpatient behavioral health services in a DMHAS-operated facility to P&A within 30 days after the individual's death. P&A and DMHAS staff met during this fiscal year and developed a protocol for reporting these deaths to P&A.

The FRB reviewed 176 deaths during the year. Forty-two (42) cases were subject to in-depth discussion, monitoring and review by the FRB. Additionally, the FRB investigated the circumstances surrounding 13 deaths where there was reason to suspect that abuse or neglect may have been a contributing factor. FRB staff also received reports of 11 deaths from DMHAS. Nine (9) of these deaths have been reviewed.

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A Pilot Study Analyzing Mortality of Adults With
Developmental Disabilities Residing in Nursing
Homes in Connecticut

FRB is Published! - In 2008, the FRB initiated a review of a sample of deaths of DDS clients occurring in nursing homes over the five-year period between January 1, 2002 and December 31, 2007. The primary purpose of this inquiry was to examine variables which might influence nursing home placement and the length of nursing home stay. The results of the study were published in the Journal

of Policy and Practice in Intellectual Disabilities (September 2010). The article, A Pilot Study Analyzing Mortality of Adults with Developmental Disabilities Residing in Nursing Homes in Connecticut, noted that 1) many individuals were admitted to nursing homes at an earlier age than for the non-disabled general population; 2) people with intellectual disabilities stayed in nursing homes longer, and died later than the general population of non-disabled individuals admitted to nursing homes; 3) about half of the individuals received case management on at least an annual basis; a third had no documented case management; and 4) a lack of appropriate alternate residential settings, lack of support services for families, and lack of case management resources for adults with intellectual disabilities residing in nursing homes in Connecticut were all apparent. The authors concluded that better standards of care and medical practices must be developed, more effective administrative and support services must be coordinated, and ultimately, family supports must be increased in order to prevent non-medical admissions to nursing homes.

Case Services Unit – Information and Referral

P&A and its subcontractors received requests for assistance from 4,918 individuals with disabilities, their family members, and interested parties. Of these, 3,419 were requests for information and referral, or short-term assistance. The remaining 779 requests received a more intensive level of advocacy representation.

P&A's advocates handled requests for information and assistance from callers, walk-in clients, legislators, e-mail contacts, letters and visitors to the P&A website. More than 560 requests related to Abuse or Neglect including inappropriate mental health treatment; excessive or involuntary medication; physical, verbal or sexual assault; inappropriate restraint; and financial exploitation. They also responded to questions concerning Housing (513), Government Benefits and Services (395), Rights Violations (288), Services (430), Employment (188), Education (178), Healthcare (105), Rehabilitation Services (105), Financial Entitlements (71), Transportation (52), Architectural Accessibility (48), Parental Rights (28), Assistive Technology (30), Guardianship (27), Post Secondary Education (20), Insurance (19), and Recreation (12). Advocates also responded to 335 requests for simple information like a copy of a publication or the name of a case manager. Callers also contacted P&A about voting rights and access to government programs.

DID YOU KNOW?

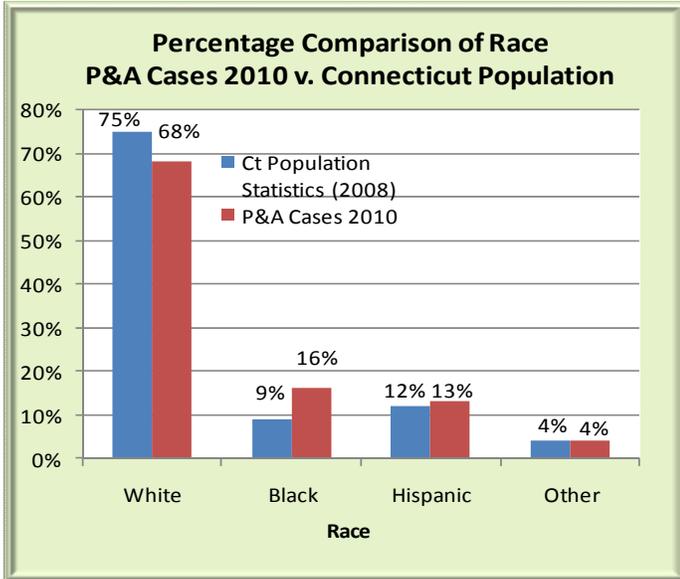
You can obtain information from P&A through a variety of sources including P&A's website (www.ct.gov/opapd), over the telephone, through the mail, by e-mail or by visiting the agency.

The YMCA started asking questions when Sara, the mother of 3 girls, attempted to enroll them in an after school program. Sara completed and submitted all the required paperwork for each child. When the YMCA staff person reviewed the paperwork, she noticed that 2 of Sara's daughters would be dropped off by their school bus after their day at a local public school. The 3rd daughter was also being dropped off by a school bus, but from a school outside the district. The YMCA staff person questioned the difference forcing Sara to explain that her daughter, Madison, has autism and her educational program is in a different school.

The Director of the YMCA immediately contacted Sara, informing her that before Madison could be accepted into the program, a copy of her school's educational plan would need to be submitted along with notes from her teacher and doctor saying that the after school program was appropriate for Madison. Sara explained that she was not requesting any accommodations for Madison, but was told that she had to submit the additional paperwork anyway. Sara contacted P&A.

A P&A Information & Referral advocate spoke with Sara and explained Madison's civil rights as a person with a disability. She also let Sara know that she was not required to submit the educational plan and notes from the doctor and the teacher. Sara relayed this information to the Director of the YMCA who then insisted that Sara bring Madison in for a meeting before she could be accepted into the program. Sara, exasperated, contacted P&A again. The case was assigned to a P&A attorney. (Continued on page 14, See YMCA).

Case Services Unit – Advocacy Representation Division



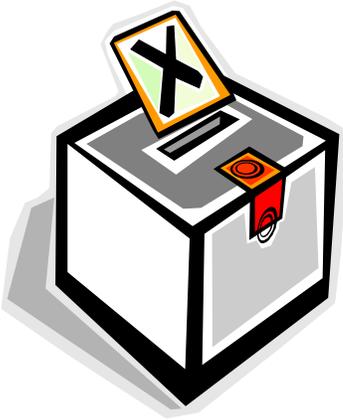
Advocates assigned to the Advocacy Representation Division protect the rights of adults and children with disabilities living in institutions and the community. In addition to providing advocacy representation and training on disability-related topics, advocates intervened on behalf of groups and individuals, including children with disabilities in need of appropriate planning and supports to meet their educational needs; and adults with disabilities needing assistance with becoming employed or resolving barriers to maintaining employment. They also represented people with disabilities seeking remedies for issues related to abuse; neglect; accommodations in housing; access to assistive technology; forced medication; parenting with a

disability; programmatic and structural accessibility; effective communication in hospital and law enforcement settings; and guardianship. Advocacy Representation Division staff attorneys seek administrative or judicial remedies involving discrimination based on disability. The Advocacy Representation Division of the Case Services Unit is composed of a number of distinct federally mandated advocacy programs for people with disabilities, as illustrated on the chart on page 21 of this report.

P&A advocates and attorneys provided representation to 704 individuals with disabilities. They requested advocacy in the areas of Education (179), Abuse (88), Rehabilitation Services (86), Neglect (65), Rights Violations (51), Healthcare (34), Government Benefits (32), Financial Entitlements (28), Quality Assurance (22), Employment (13), Housing (12), Services (12), Architectural Accessibility (10), Assistive Technology (8), Transportation (5), Guardianship (4), Unnecessary Institutionalization (4), and Voting (2). Thirty one (31) issues involved other problems such as childcare, recreation, and parental rights.

Upon disembarking from an airplane, George discovered that his highly specialized wheelchair had been damaged during the flight. The wheelchair was not returned to him but was taken to an undisclosed location. He was not given sufficient documentation or information about its location. Without his primary means of mobility or information about how to get it back, George called P&A in frustration. The P&A advocate contacted the airline and then the vendor who had the wheelchair. She informed them about the rights of air travelers with disabilities under federal law and negotiated for the quick repair and return of George's wheelchair. The advocate was assured that the repaired wheelchair would be returned within a reasonable amount of time; she also connected all parties so that George would be in the middle of, not outside, the loop. Two days later, the repaired wheelchair was returned.

Case Services Unit – Advocacy Representation Division



Everyone Counts! - Before the November 2010 election, the P&A received a call from Alice, a voter with a disability who discovered that the changes made to her polling place had significantly reduced the degree of accessibility. The Registrars of Voters were required to change Alice's polling place to a new location in the same building. The entrance to the new polling place was also in a new location, one that did not have accessible parking. Alice would be able to go to the polls but she could not make it to the polling place because the walk was too far. Alice wanted to vote on Election Day so she contacted P&A for assistance.

A P&A advocate immediately contacted the Town's Registrars of Voters to discuss the polling place problem. The Registrars arranged for an on-site visit with the Town's facilities manager. Several temporary solutions were negotiated and the ground was laid for permanent solutions to be implemented before the next election. The situation will be monitored by the client, the P&A advocate, and staff at the Secretary of the State's office.

Jen and her husband Pete are both deaf. Pete's doctor referred him to a specialist for an orthopedic issue. Jen contacted the specialist's office by relay to schedule an appointment. After providing insurance information and scheduling the appointment, Jen requested a sign language interpreter. She was told that the doctor's office would not provide one and that they were responsible for bringing someone who could interpret. Jen attempted to tell the Office Manager that it was the doctor's responsibility to schedule and pay for the interpreter but the Office Manager refused and disconnected the call. Jen called P&A.



Jen spoke with an Information & Referral (I&R) advocate and explained the situation. The Advocate contacted the doctor's office and spoke to the Office Manager, who repeated that it was the patient's responsibility to bring an interpreter. The advocate explained that healthcare offices have an obligation under the Americans with Disabilities Act to provide effective communication including sign language interpreters. It was not the patient's responsibility. She also faxed the Office Manager a copy of P&A's booklet entitled, "Healthcare Providers' Obligations under the Americans with Disabilities Act." They reviewed the booklet and the Office Manager agreed to discuss the situation with the doctor to see if they could change their policy. A short while later, the Office manager called P&A to say she had scheduled an appointment for Pete and their office had contracted with a sign language interpreter for the appointment.

Case Services Unit – Advocacy Representation Division

Fighting to be a Parent

Barbara, a mother with an intellectual disability, contacted P&A seeking assistance in gaining more rights with respect to her two-year old daughter. The Department of Children and Families had taken custody of her daughter, Anne, after her birth, a pattern familiar to P&A advocates. At that time, concerns had been raised that Barbara would not be able to provide safe care for Anne, who had serious medical issues at the time. To avoid the prospect of potentially losing her parental rights, Barbara eventually made a voluntary agreement allowing Anne to be placed with a relative.

Barbara expected that she would gradually have more opportunities to parent Anne, but this was not the case. Anne's situation improved; she was in better health. Soon, she was a healthy, typical three-year old and Barbara wanted to assume her parental role. The relative currently caring for Anne disagreed and told her that if she pursued her parental rights, she would not be able to continue to visit her daughter. She contacted P&A for help.

The P&A advocate worked with Barbara to develop allies who could help her gain custody of her daughter. They looked for people in Barbara's life who could speak credibly and positively about her parental skills and potential. Barbara's support staff from the Department of Developmental Services and the relative caring for her daughter were all very distrustful about her ability to parent a child. P&A helped Barbara connect with a new agency that had experience supporting parents with disabilities. This agency assigned a positive and supportive mentor who could supervise Barbara's visits with Anne. P&A also assisted Barbara as she navigated the court system to finally gain visitation rights with the supervision of her mentor. The visits served two purposes: they satisfied Barbara's immediate wish to have more quality time with Anne and provided neutral observers who could watch her interaction with her daughter. The mentor's observations revealed that Barbara was an exceptionally caring, responsible and cautious mother. The visits continued creating a significant body of positive evidence. This information was needed to support Barbara's argument that she should become Anne's primary caretaker.

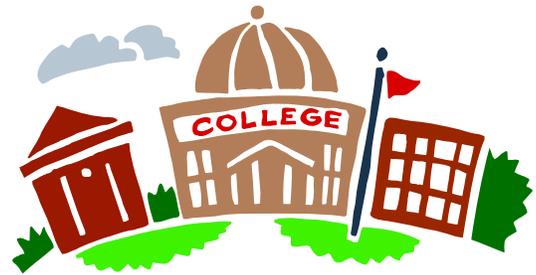


Barbara is still in the midst of the greatest and most important fight of her life. Even so, the experience has empowered her to help other parents in similar situations. With P&A support, she traveled to two national conferences to talk about the need to support parents with intellectual disabilities, and recently became a member of the Board of Directors for The Association for Successful Parenting.

Case Services Unit – Advocacy Representation Division

Jake is a college student with a bright future. He also has a hearing impairment and cerebral palsy. He was frustrated because the Bureau of Rehabilitation Services (BRS) would not agree to pay for classes at a college in another state. While BRS supported Jake's goal of getting a business management job, they would only pay the rate of tuition listed in the agency's policies. That rate is based on the tuition at Central Connecticut State University and does not take into account specialized services available at other colleges. Jake specifically requested an out of state college because it provided disability related services that he needed for success in his academic program, such as instructors who know sign language and access to related services such as captioning.

The P&A advocate reviewed all BRS case records and policies, and obtained information about the out of state college. She met with Jake to prepare him for the presentation of his case at BRS. Jake had tremendous advocacy potential in presenting his case but lacked confidence. The advocate, however, thought it would make a better impression on BRS personnel if Jake presented his own case.



Jake and the P&A advocate reopened communication with BRS, arguing that Jake's case met all the requirements for a waiver of the established tuition policy. Jake actively participated in the discussions and provided all information in a timely manner. BRS agreed to conduct a financial analysis of the case and made a new determination on fully funding Jake's matriculation at an out of state college.

This case was successful on many levels. Jake prevailed in his request for BRS to fund the out of state college. Most importantly, however, he gained confidence in his own advocacy skills. Jake sent a note to the P&A advocate indicating that he will never forget P&A as he learned how to effectively advocate for himself.

John, a resident of a residential care home, was hospitalized in the psychiatric unit of a local hospital. When he was preparing for discharge, the residential care home told the hospital that he could not come back. John, with the help of his social worker, contacted P&A. The case was assigned to an advocate who immediately intervened and advised the residential care home that they cannot simply refuse to take a resident back. The residential care home continued to refuse to allow John to return. The advocate advised them of their legal obligations, including pointing out that refusal to allow John to return is a violation of the law. The advocate also advised the manager of the residential care home that a complaint would be filed with the Department of Public Health if they refused to take John back. As a result of P&A's persistent advocacy, the residential care home readmitted John within a few days.

Case Services Unit – Advocacy Representation Division

An Appropriate Education

Matthew, age 14, and Michael, age 8, are brothers. Both boys have Down syndrome and intellectual disabilities. Despite receiving special education services, the boys had no way to effectively communicate with others, and neither child was experiencing academic success. Their parents had fought for years to obtain the kind of assistive technology and supports their boys needed, even seeking outside evaluations and treatment independent of the school system. Despite their best efforts, the boys remained without an effective way to communicate, did not develop intelligible speech, had minimal literacy skills, and made no friendships with peers their age. From year to year their Individualized Education Program (IEP) goals and objectives remained unmet and virtually unchanged.



After becoming increasingly frustrated with the services the school district was providing, the family contacted P&A. An educational advocate worked with the family to develop a strategy to address their disagreement with the self-contained program and insufficient services that the district had been offering. The advocate identified that the district had failed to provide a Free Appropriate Public Education (FAPE) in the Least Restrictive

Environment (LRE), and that neither boy had been provided with the full array of supplemental aids and services they needed in order to make meaningful progress, and derive benefit from their education. Although initial opposition to the family's requests was strong, the parents and P&A advocate succeeded in obtaining agreement to have independent evaluations conducted in all requested areas. The evaluations generated comprehensive and specific recommendations for a multi-modal treatment approach.

As a result of the parents partnering with P&A, both boys now have the assistive technology and supports they need to communicate, make educational progress, become included in their school community, and develop friendships among their peers. Their IEPs contain comprehensive goals and objectives, with meaningful supports and accountability regarding progress. The boys' parents have also benefitted, gaining knowledge and confidence in their ability to be strong and effective advocates for their sons. The educational team itself has become a functional and positive working partnership, conducting productive meetings with on-going, open, and respectful communication between the school, the family, and administration.

Case Services Unit – Legal Division

The Legal Services Division of the Case Services Unit provides legal advice and representation to selected agency clients. Staff attorneys also represent individuals and groups seeking administrative or judicial remedies for discrimination based on disability.

During the year, the P&A legal division provided individual and systemic representation and monitoring on a number of legal issues including, but not limited to: reasonable accommodation and discrimination in housing; eligibility for services from the Department of Developmental Services; proper treatment for prisoners with disabilities in prisons; sterilization of persons with intellectual disabilities; lack of effective communication by law enforcement; healthcare facilities and attorneys; rights under the Americans with Disabilities Act for

people with disabilities in nursing homes and other institutions; and employment discrimination. P&A attorneys also consulted with outside attorneys and the public on questions of disability law, working with staff to ensure quality responses to public inquiries and preparing comments on proposed state and federal regulations.



YMCA (Continued from page 8) - The attorney immediately contacted the YMCA. After many attempts to resolve the issue with registration staff and supervisors, she was finally able to speak with the Director of the YMCA. The Director reported that the information sought conformed to agency policy regarding the admission of any child with a disability to the program. P&A's attorney explained that those requests were discriminatory under Title III of the Americans with Disabilities Act because they create an additional burden for children with disabilities and their families before the children can participate in the program. After further discussion, the YMCA allowed all 3 children to register. Madison is now attending the program with her sisters and Sara did not have to submit additional paperwork or bring Madison in for a pre-admission meeting.



Julie had a successful heart transplant. Unfortunately, within days after her surgery she had a stroke, resulting in a severe brain injury. Six months after the transplant, P&A received a call from Julie's significant other who reported that Julie's parents/conservators decided to stop all treatment including follow up care for her heart transplant! Since the doctors at the rehabilitation hospital determined that Julie would make no further improvement, her parents decided that her life was not worth living; they would let "nature take its course."

A P&A attorney was assigned and immediately met with Julie to review the case and ask her what she wanted. Julie was adamant that she wanted to live, that she wanted her follow-up care and that she desperately wanted to be with her companion. P&A went to probate court on her behalf where the court ordered that she receive all necessary medical care including follow up treatment for her heart transplant.

Case Services Unit

Finally – A Home!

P&A has provided representation to Michael, a young man with a mild intellectual disability, for more than 10 years. He has a history of severe behavioral outbursts that are potentially dangerous to those around him. He has been in the custody of various state agencies most of his life and for many of these years none of these agencies were able to figure out how to support him other than to keep him restrained, secluded and away from people. P&A advocates and attorneys spent years trying to find solutions to the horrible conditions under which Michael was required to live.

When P&A first became involved with Michael, he was being kept in restraints 24 hours a day/seven days a week. He was transferred to the custody of the Department of Correction (DOC) because the Department of Children and Families had given up on him. P&A filed litigation to appeal the transfer to DOC, but it was eventually upheld by the Connecticut Supreme Court. At that point, Michael was 18 years old and DOC released him from its custody. His nightmare was not over.

P&A advocates worked to have the Department of Developmental Services (DDS) accept responsibility for supporting Michael. DDS developed a “program” for him that included placing him in a dungeon-like environment. His special cell had two chambers: the inner chamber, referred to as his bedroom, was an empty room with a mattress on the floor. The outer chamber, referred to as his “living” room, was a larger room that contained some basic unbreakable furniture. Michael’s living environment was separated from the rest of the facility by an iron door with a trap that was used to pass meals or other objects back and forth to Michael. The outer chamber had large Plexiglas observation windows.



P&A staff engaged in intensive advocacy with DDS, who eventually brought in experts to evaluate Michael. The result was a program that relaxed the rigid terms of his confinement and provided some guidance for a new living environment. After ten years, Michael was finally released from his prison and given his own house with staff support. He now lives in a comfortable home with a bedroom, living room and kitchen. The house is filled with real furniture and a front and back yard. Michael is now finally enjoying his home and spending time with staff who can help him live the life he deserves.

Legislation

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

During the 2010 Connecticut Legislative Session, P&A proposed two bills that did not pass. House Bill 5232 An Act Concerning Transfer or Discharge of Residential Care Home Patients would have ensured that people who live in residential care homes (RCH) are given proper notice of any transfer or discharge so they can appeal. Senate Bill 315, An Act Concerning the Sexual Assault of Persons whose ability to Communicate Lack of Consent is Substantially Impaired, would have improved the sexual assault criminal statutes by clarifying the conditions to be met for a person to be considered unable to consent to sexual activity. P&A collaborated with many agencies on this bill and is committed to continuing its work on both bills.

P&A testified on a number of bills that would impact the lives of persons with disabilities in Connecticut, including probate and competency to stand trial; issuance of emergency certificates by mental health professionals; visitable housing; education issues such as school suspensions, applied behavioral analysis and positive behavioral support strategies and expulsions; a task force to study the transfer of hospital patients who receive Medicaid benefits to nursing homes; state-wide expansion of the HUSKY Primary Care Case Management Pilot Program; and handicapped parking.



"Legal Perils of Assisted Suicide, the Disability Perspective" – In response to legislative proposals to legalize assisted suicide in many states around the country, P&A co-sponsored a forum on assisted suicide from the disability perspective. Not everyone in the disability community agrees on this subject. Some see legalizing physician assisted suicide as an extension of the concept of "self-determination"; others believe that suicide, itself, should not be illegal or the concern of the state. However, most leading disability-rights advocacy groups oppose this direction. The forum included a presentation by Diane Coleman, JD, MBA; and Stephen Drake of "Not Dead Yet". A panel of people with disabilities shared their differing perspectives on assisted suicide. For more information on the topic of Disability and Assisted Suicide, please visit the P&A website at www.ct.gov/opapd.

Community Outreach and Training

Every year, P&A staff participates in a variety of outreach events. This year, P&A sponsored or participated in 99 training events, including presentations, workshops, conferences, and resource fairs. Approximately 2,600 individuals received training on topics that included P&A programs and services; emergency preparedness and shelter accessibility for people with disabilities; the Americans with Disabilities Act; fair housing rights; special education including “least restrictive environment”, inclusion, the Individuals with Disabilities Education Act, transition and due process; voting rights of people with disabilities; employment rights and work incentives; vocational rehabilitation; assistive technology; physician assisted suicide; parent leadership; right to refuse medication and rights of people with mental illness; and abuse investigations. Information was disseminated to more than 6,300 people at 13 resource fairs. Over 13,200 publications and P&A program brochures were distributed to individuals and organizations throughout the year. More than 4,000 people were given the opportunity to register to vote. The P&A website is constantly updated and includes current news and a calendar of upcoming events; P&A program descriptions and agency publications; legislative updates; links to websites for disability rights and resources; and reports on developments in the field of disability rights. Last year, more than 200,000 visitors obtained information through the site. (www.ct.gov/opapd).

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

Disability Advocacy Collaborative Convention and Expo 2010 - In August 2010, P&A co-sponsored the 2010 Disability Convention and Expo organized by the Connecticut Disability Advocacy Collaborative. P&A staff also participated in planning the Convention which was scheduled to coincide with Connecticut’s gubernatorial and mid-term elections. The event drew over 800 people with and without disabilities. The highlight of the day was the appearance of five candidates for Connecticut state offices, including candidates for Governor, Attorney General and Secretary of the State. Each candidate spoke for 15 minutes and then took questions from the audience.

The Exposition portion of the event drew 81 vendors. Exhibitors included advocacy and family support organizations, accessibility-related businesses, community living programs, and a visual arts display by artists with disabilities. Participants were able to try a wheelchair accessible motorcycle and Connecticut’s first wheelchair accessible taxi. They also took home information about products, services and the rights of people with disabilities.



Major Issues Affecting People with Disabilities

The Office of Protection and Advocacy for Persons with Disabilities held public forums this summer and fall to see what members of the public were concerned about. The Office is required to do this by federal mandates, and responsible stewardship requires that we respond to those issues. The top four issues noted by people with disabilities and other interested parties are: employment, mental health, transportation, and housing.

This list of issues is not new. It is not surprising. As the economy continues its sluggish recovery these are the issues affecting all Americans—jobs, health care, transportation and housing. These issues are inter-related and hard to tackle one by one. P&A is not a health insurer, an employment agency, a transit service provider or a mortgage company. But P&A is an Advocate for people with disabilities who turn to us for help with these issues. P&A partners with other organizations and with more than thirty years of experience helping people with disabilities, P&A is able to get people help—either in-house assistance by a P&A Advocate or by referring individuals to the appropriate organization. Some examples:

Employment: People want to work. But everybody is having difficulty finding jobs during this economic downturn, especially people with disabilities. P&A Advocates can help people who are applying for employment services (including training and architectural modifications to their homes to allow them to work) from the DSS Bureau of Rehabilitation Services. We are also exploring ways to expand assistance to those who experience employment discrimination.

Mental Health / Health Care: P&A can assist individuals who are in psychiatric hospitals regarding the use of restraint and seclusion and forced medication. We also assist school children with emotional and behavioral disabilities who are at risk of restraint, seclusion and other restrictive practices. P&A Advocates can help individuals learn how to apply for Medicaid. If individuals with disabilities are employed but need health insurance, P&A Advocates help individuals understand how to pay for Medicaid. The premiums are based on income. In Connecticut, individuals can earn more than \$70,000 per year and still be eligible to buy into Medicaid.

Transportation: P&A has supported the availability of accessible taxis. Such taxis are available in New Haven and there is advocacy underway to expand this service across the state. Also, P&A is able to refer people with disabilities to paratransit and dial a ride services. P&A also helps people, when necessary, to file complaints against transportation providers. Some transportation providers simply need to be educated about the legal rights of people with disabilities or how to interact with people with disabilities. P&A is able to do this.

Housing: For too many years, the assumption has been that people with disabilities are single and have no children—that all that is needed is a one bedroom apartment. The reality is that people with disabilities

Major Issues Affecting People with Disabilities

are in all the different living arrangements as everybody else: single, married, with children, without children. People with disabilities do not always need architectural modifications; sometimes they have a service animal that prospective landlords say are not allowed because of “no pet” policies. Other times they simply need a reserved parking spot close to their unit. P&A often refers people to the Connecticut Fair Housing Center for these issues.

As the economy continues to be sluggish, funding for services and supports for people with disabilities and their families has been reduced. Both the State budget and other funding sources upon which many service organizations rely have been adversely affected. As a result, providers of direct services – already hurting from years of under-funding - are stretched very thin. In addition, advocacy and legal services organizations that serve low income people have reduced staffing and operating budgets. These organizations, some of which focus extensively on the needs of people with disabilities, have long been important safeguards against abuses and unfair treatment of vulnerable people. This is an especially important role when budgets are being cut and programs radically restructured. At times such as these, the identities and needs of people can easily get lost.

Through court decisions and public policy revisions, society is embracing the right of all people to leave institutions to live in the community with needed services and supports. A recent Settlement Agreement promises to present new, concrete community living options to people now living at Southbury Training School (STS). This institution was built in the 1930’s when segregated, congregate settings were the only locations available for people with intellectual disabilities seeking services. It is situated on 1600 acres in Southbury, Connecticut, and employs over 1,333 full time, part time and consulting staff. The staff provides “medical, vocational, residential, and therapeutic and facility support services” to over 400 residents. Offering those residents real opportunities to be considered for community living is a major step forward, both for them as individuals, and, hopefully, for Connecticut’s efforts to more effectively use precious resources.

Transitioning from institutions to community living is only part of the story, however. Sustaining the commitment to support people over time is equally important. This is especially so as people get older, and their care needs change. To ensure that people with intellectual disabilities, brain injuries and mental illness do not wind up in costly, inappropriate, prisons, hospitals and nursing homes, State service systems must sustain, and, in fact, prioritize their commitments to ensure relevant, adequate, flexible supports to people living in communities.

Federally Mandated P&A Programs for Persons with Disabilities

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

State Mandated P&A Programs for Persons with Disabilities

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

Fiscal Facts and Figures

In the fiscal year ending June 30, 2010, P&A had a total operating budget of \$3,764,958.56. Of this, \$2,483,919.04 (65.9%) was state funding and \$1,281,039.52 (34.1%) was federal funding. Personal services expenditures comprise 92% of P&A's General Fund Budget, with an additional 8% expended on contracts, outside services and necessary expense items, including supplies, equipment, telephone, postage, and printing.

P&A Federal Expenditures for Fiscal Year 2010 \$1,281,039.52

| | |
|--|---------------------|
| U.S. Department of Education, Rehabilitation Services Administration – Client Assistance Program (CAP) | \$120,068.56 |
| U.S. Department of Health and Human Services - Protection and Advocacy for Individuals with Mental Illness (PAIMI) | \$368,158.17 |
| Connecticut Department of Social Services - Social Services Block Grant (SSBG) | \$121,183.81 |
| U.S. Department of Health and Human Services, Administration on Developmental Disabilities - Protection and Advocacy for Developmental Disabilities (PADD), including a grant from Connecticut Council on Developmental Disabilities | \$260,362.94 |
| U.S. Department of Education, Rehabilitation Services Administration – Protection and Advocacy for Individual Rights (PAIR) | \$111,352.47 |
| U.S. Department of Education, Rehabilitation Services Administration – Protection and Advocacy for Assistive Technology (PAAT) | \$54,343.79 |
| Social Security Administration - Protection and Advocacy for Beneficiaries of Social Security (PABSS) Note: Includes funds for new Social Security Rep Payee Monitoring Program | \$129,529.17 |
| U.S. Department of Health and Human Services - Administration on Developmental Disabilities – Protection and Advocacy for Voting Access (PAVA) | \$48,736.03 |
| Health Rehabilitation Services Administration - Protection and Advocacy for Traumatic Brain Injury (PATBI) | \$67,304.58 |

Boards and Commissions Attended by P&A Staff

Advisory Committee for the Mashantucket Pequot Tribal Nation Voc Rehab

BESB Advisory Council

Birth to Three Interagency Coordinating Committee

Building Code Training Committee

Children's Behavioral Health Advisory Committee (CBHAC)

CRSE Concept for Positive Choices Grant Proposal

Connecticut Council on Developmental Disabilities

DCF Parents with Disabilities

DDS Focus Team on Aging

Disability Advocacy Collaborative Board

DOC/DMHAS CORP Steering Committee/CT Offender ReEntry Program

DPS 9-1-1- Accessibility Work Group

DSS - Brain Injury Steering Committee

Employability Committee (DAS)

Family Support Council

Fatality Review Board

Governor's Task Force on Justice for Abused Children

Independent Mortality Review Board

Long Term Care Planning Committee

MCC Disability Specialist Program Advisory Committee

Olmstead Coalition

Positive Choices Project - Center for Relationship & Sexuality Education

Special Education Advocates Network

State Mental Health Planning Council

State Rehabilitation Advisory Council (SRC)

UCE Consumer Advisory Group

Webmaster Portal Group



Contact Information:

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