

Respect	Voting	Employment	
Choice	Housing	Education	Risk
Accessibility	Rights	Transportation	
Dreams	Advocacy	Freedom	Power
Integration	Diversity	Growth	
Life	Community	Relationships	Goals
Equality	Support	Ability	
Voice	Empowerment	Dignity	
Independence	Access	Values	

CITIZENSHIP
JUSTICE
BELONGING

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

2004 Annual Report

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Message from the Advocacy Board Chair



2004 has been an eventful year for both the Office of Protection and Advocacy for Persons with Disabilities (P&A) and its Advocacy Board. The Board has been especially pleased to follow the agency's progress in refining and using information in its new abuse investigation database. The ready availability of this information is proving useful both for program management purposes, and as an advocacy tool to secure relevant interventions to protect individuals in vulnerable circumstances. It is an example of the growing maturity and effectiveness with which the agency is discharging its responsibilities.

As we continue to watch over P&A's activities, advise on agency priorities and identify issues of concern to Connecticut residents with disabilities, we look forward to even greater progress in the future.

Sincerely,

Peter Tyrrell, Esq.
Chairperson, Protection and Advocacy Board

P&A
Advocacy Board

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Robert Wood
Trumbull, CT

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Manchester, CT

State of Connecticut
Office of Protection and Advocacy for Persons with Disabilities

Message from the Executive Director

Before trying to say our agency's full name, "The Office of Protection and Advocacy for Persons with Disabilities", you would be well advised to first inhale. It is quite a mouthful. No wonder we go by our initials – "P&A", or to some "OPA".

However you choose to abbreviate our name, the notion of an official source of "protection and advocacy" invites weighty and sometimes unrealistic expectations. Our statutory mandates focus on defending civil and legal rights, and quite deliberately avoid assigning us a "big brother" protective role. Yet we are often approached with expectations that we can intervene and impose a "rescue" on any person with a disability whose decisions and choices are troubling to others. Given our powerful sounding name, it is not surprising that some who call us also expect that we are standing guard, ever-ready to pounce on and punish human service evil-doers. When we explain that we do not, and, in fact, cannot do those things, the question is often asked, "So, what do you do?" This report is an attempt to answer that question.



As the information presented in this report demonstrates, we do quite a bit to defend civil and human rights, support community advocacy groups, address abuse and neglect, and to educate and empower. In a larger sense, however, questions about what a protection and advocacy agency does can never be finally answered. Needs change, new issues arise and opportunities to effect change present themselves. Part of our responsibility is to continually figure ourselves out, learning from and being guided by the experience of the people we represent.

I hope that you find the information in this report to be useful. If you have any questions or suggestions, please feel free to contact me.

Sincerely,

James D. McGaughey

WHO WE ARE AND WHAT WE DO

P&A HISTORY

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.

Connecticut’s P&A was established as a state agency, and, from its inception, provided advocacy services for individuals with all types of disabilities. Over the course of its twenty seven year history, additional federal and state mandates have added specific authority to:

- conduct investigations into allegations of abuse and neglect concerning adults with mental retardation (ages 18 to 59);
- advocate for people who are living in institutional environments;
- advocate for people with mental illness who live in the community and in public or private residential facilities;
- advocate for people who are seeking assistive technology devices and services;
- improve access to the voting process for persons with disabilities;
- provide information and referral services to individuals with disabilities;
- affirmatively reach to traditionally underserved populations, conducting community development and public education activities;
- conduct full independent investigations into the circumstances surrounding the deaths of Department of Mental Retardation clients, especially when abuse or neglect is suspected to have contributed to the death;
- advocate for Social Security recipients and vocational rehabilitation system clients;
- review (in conjunction with the State Building Inspector) requests to install wheelchair lifts and grant waivers from accessibility provisions of the State Building Code; and
- review (in conjunction with the Office of the Secretary of State) requests for exemption from accessibility requirements for polling places.

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Except for our more narrowly defined ministerial functions (e.g. building code waivers), all of these additional, specific mandates require essentially the same autonomy, access to information, and freedom to pursue remedies stipulated in the DD Act.

P&A STAFF

The cumulative experience and diverse backgrounds of the 47 people who work at P&A constitute the agency's principal assets. Staff backgrounds are rich in both personal and professional disability experience. Although some are new to the agency and to state service, current staff members have accumulated more than 440 years of experience at P&A, averaging more than 9 years of P&A service per staff member. Collectively, they have provided 540 years of service to the State of Connecticut and a total of more than 700 years in various human services capacities.

Disability issues have affected many P&A staff members in very personal ways. Some report that they are persons with disabilities while others report that their children, aunts, uncles, parents, and siblings have one or more disabilities. Like many other citizens, staff members also report their awareness of disability issues has increased through personal relationships with neighbors, friends and acquaintances made while participating in community activities.

During the past year, OPA staff effectively advocated for the civil and human rights of persons with disabilities in many areas including education, employment, housing, entitlements, physical and program accessibility, recreation, and healthcare. Two staff attorneys were recognized by the Connecticut Foundation for Environmentally Safe Schools with an "Indoor Air Quality (IAQ) Hero" Award for their work in assisting children and teachers with severe mold allergies in schools. AFCAMP, African Caribbean American Parents, a group of minority parents who have children with disabilities, recognized P&A for its continued support to the organization.

WHO DID P&A HELP IN 2004?

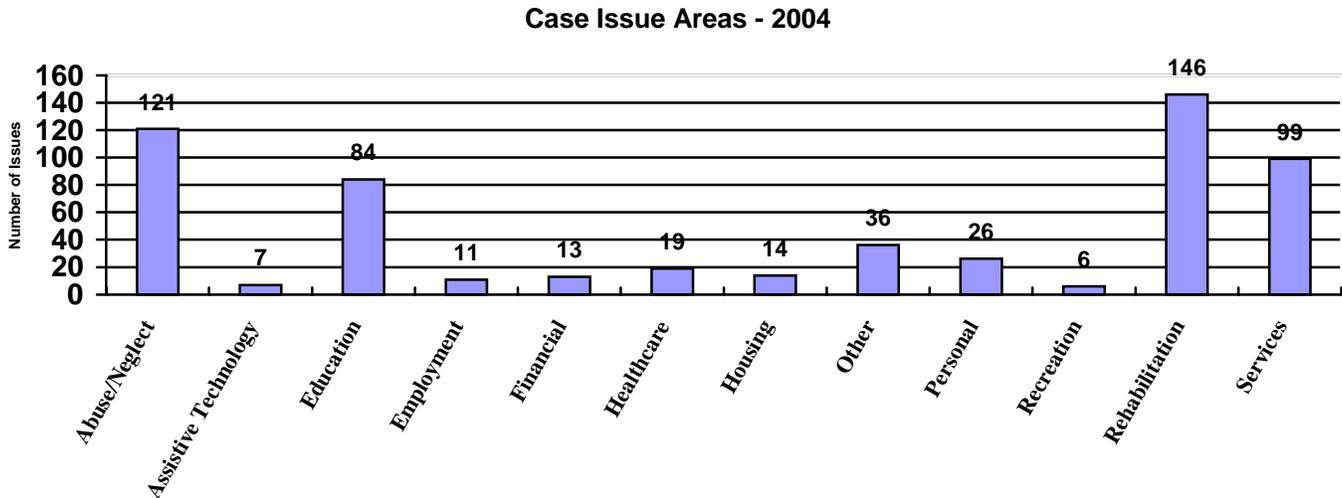
The following are statistics about the people with disabilities, family members, disability-related organizations and others who received assistance from P&A staff.

People with Disabilities

During the 2004 fiscal year, 8,432 individuals with disabilities, their family members, and interested parties contacted P&A or its subcontractors for assistance. Of these, 7,435 received information, referral or short-term assistance. P&A advocates and attorneys addressed more than 580 issues while providing representation to 512 individuals with disabilities. Of the 512 individuals who received advocacy or legal representation, 136 lived in a public or private institution, 151 lived independently, and 151 with family members. Individuals represented had a variety of disabilities including cognitive impairments (159), mental illness (142) and physical disabilities (84).

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The following is a graphic representation of the issue areas addressed by advocates and attorneys during the 2004 fiscal year.



P&A's Consumer Information advocates answered 633 inquiries related to fair housing issues, landlord/tenant disputes, accommodations, rental denial or termination, and zoning. They also responded to questions concerning access to services (660), personal decision making (605), education (431), employment (299), financial entitlements (275), healthcare (233), abuse and neglect (224), transportation (121), rehabilitation services (103), and assistive technology (64). Callers also contacted P&A with concerns about issues including the Americans with Disabilities Act (state and local government services and public accommodations), guardianship, recreation, voting, insurance, and daycare.

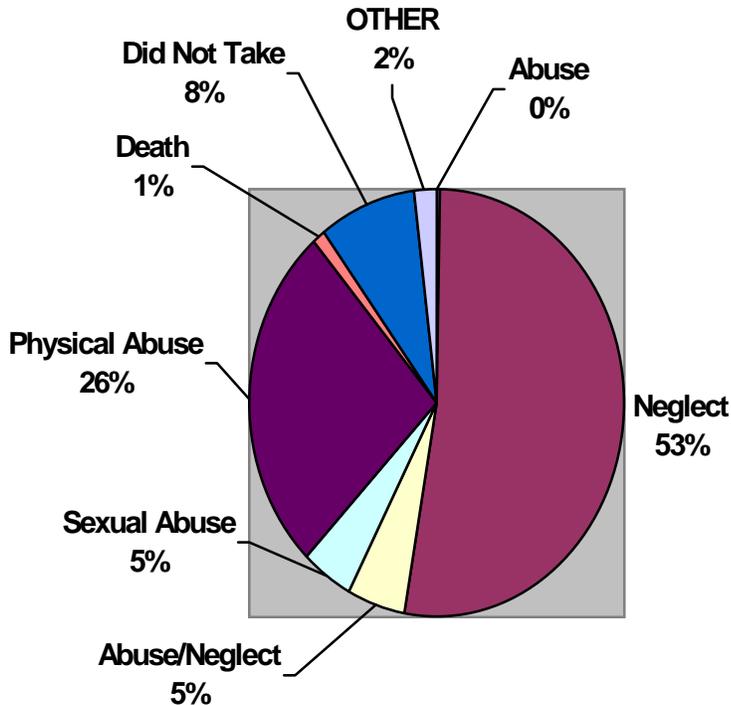
People Reporting Abuse and Neglect

P&A's mandated Abuse Investigation Division (Connecticut General Statutes Sec. 46a-11 et. seq.) received 1,159 reports of allegations of suspected abuse or neglect of persons with mental retardation, resulting in 1,093 cases. P&A staff investigated or monitored 1010 cases. Eighty-three (83) allegations did not meet the statutory requirements for P&A investigation.

Investigations often encompassed allegations for more than one victim. The 1,159 cases involved 1,248 victims: 541 females and 707 males. Over 55% of the victims resided in group homes (689) while 20% (250) lived in the family home. Victims also resided in supervised living arrangements (94), community training homes (59), regional centers (36), Southbury Training School (25), medical facilities (21), independently (15), schools (5), foster homes (2), correctional facility (1), and a board and care home (1). Three (3) individuals lived with respite care providers. The residences of 38 victims were unknown.

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The following chart represents case types for the Abuse Investigation Division:



**Abuse Investigation Division -
Case Types 2004**

Organizations Requesting Outreach, Technical Assistance and Training

During the past year, P&A staff responded to 30 calls for information and materials specific to community organizing, organizational management and fund development. Technical support, consultation and facilitation services were provided to 11 public agencies and non-profit organizations with missions of advocacy and service to persons with disabilities. P&A assisted community organizations in raising more than \$700,000 in grants, contracts and donations for self advocacy, parent support, educational programs, and new projects. In addition, P&A continued its financial and staff support to Padres Abriendo Puertas (PAP) and African Caribbean American Parents of Children with Disabilities (AFCAMP), organizations that support minority parents of children with disabilities in Hartford and other areas of Connecticut.

P&A staff members shared their knowledge with other groups by participating as presenters for 59 training opportunities including media events, workshops, conferences, fairs, and presentations. Approximately 1,478 individuals received training on topics including the Americans with Disabilities Act, special education and transition planning, vocational rehabilitation and employment, assistive technology, disability rights and resources, grassroots organizing, mental health and patient rights, entitlement programs, voting, P&A services and basic disability law. Over 5,500 P&A publications and other materials were distributed. For a complete listing of available P&A publications, please refer to the inside back cover of this report.

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The newly designed P&A website, www.ct.gov/opapd, received 146,102 hits during 2004. The site contains current disability news and information, P&A self-help literature, P&A program descriptions, reports on developments in the field of disability rights and allows individuals to ask questions or request information through an e-mail link on the site.

Client Stories

To help put a more human face on these statistics, here are some examples of the people our work has touched. The names are fictitious, but the people and their stories are real.

Mary's Story

Imagine being sent to a nursing home at the age of 21 because there is no place else for you to go. Now imagine turning 22 there... and 23. Soon you will be 24. You should be learning and experiencing life at its best, but you are still shuffling down the same long halls. The people you live with have their own problems, but most of them at least had the opportunity to experience life and become adults among their friends and loved ones.

Mary would like to live with people her own age, make friends, and learn new things. Like other people with mild mental retardation, she has the ability to set and achieve her own goals, but needs some support in order to do so. Mary has medical and behavioral needs that are relatively intense and she and her family have been told there are simply not enough resources to meet them in Connecticut's community service system. And so Mary remains in a nursing home with people who are three and four times her age.

Mary's advocate from P&A has attended meetings, filed administrative complaints, researched options, and educated DMR administrators and staff. A number of Connecticut residents receive from DMR the kind of services Mary needs. These individuals are thriving, in good health, and participating fully in community life. P&A will continue to work diligently and challenge Mary's placement so that her next birthday is spent in her own home with family and friends.

Daniel's Story

Every month, Daniel pays hundreds of dollars for medications that help him manage his bipolar disorder. His parents help him pay for the medications because he does not make enough money working part-time at the local supermarket. Working part-time is one of the ways Daniel manages his psychiatric disability, so he is unable to increase his work hours to assist in paying for his medication.

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At the age of 21, Daniel was not interested in sitting home and receiving Social Security benefits. Because his medications were so costly, however, it seemed like the only option. Daniel contacted Protection and Advocacy.

The P&A advocate explained to Daniel that Connecticut has a program, “Medicaid for Employed Disabled”, for individuals with disabilities who do not meet the income guidelines for Medicaid but because of their disability cannot find or afford private health insurance. Participants in the program pay a portion of the Medicaid premium based on their income. Daniel applied but was found ineligible. The advocate assisted Daniel in appealing the denial to the Department of Social Services (DSS). In preparation for the hearing, P&A researched the statute and definitions of qualifying disabilities, as well as supporting evidence about the severity and impact of Daniel’s disability.

DSS reversed its decision, and granted Daniel’s eligibility retroactive to the date of the original application. Many of his outstanding medication bills were covered by the program. Now, Daniel can keep his job and have his medications paid for while maintaining his independence.

Jim’s Story

Jim arrived in New York with no case record, no assessments, no educational record, and no plan for him to return to Connecticut. He had just aged out of the special education and Department of Children and Families (DCF) systems in Connecticut and had been sent to an institution, against his will, because plans had not been put in place for him in Connecticut.

This was not the first time Jim had felt abandoned. Born with a brain injury and multiple disabilities, DCF took custody of him before he even left the hospital. Neither of Jim’s parents attempted to assert their parental rights, so his childhood was spent shuffling from one foster home to another. When he turned 21, DCF determined that it would be best for him to go to New York, severing the few ties he had managed to create in Connecticut.

But the New York program could not provide Jim with services to meet his rehabilitation needs. He was also denied eligibility by the Connecticut Department of Social Services (DSS) for the Acquired Brain Injury (ABI) Waiver, so he could not get any funding to find a better place to live or work. Fortunately, he was referred to P&A. Jim worked with P&A advocates and lawyers to appeal decisions that had been made by DCF, its Unified School District, and the Department of Social Services, which administers the ABI waiver. He prevailed in all of the appeal hearings. DSS re-evaluated and found him eligible for the ABI Waiver, providing funding for a service plan. He also was awarded two years of compensatory education from a provider/consultant experienced in supporting people like him in integrated community settings. The Department of Education Hearing Officer found that Jim was subject to “gross and egregious” violations

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and that “without the intervention of the Office of Protection and Advocacy, the student surely would have fallen through the cracks.” Jim will return to Connecticut to live and work in a community that he can finally call home.

Ken’s Story

The school social worker was concerned because Ken, a student with mental retardation, repeatedly came to school appearing quite ill. He was very pale and thin and his behavior had changed significantly. When his attendance declined, she placed a call to P&A. The Abuse Investigation Division (AID) was informed that possible neglect was suspected in Ken’s home.

The investigator issued an Immediate Protective Service Plan from the Department of Mental Retardation (DMR) in an effort to secure immediate assistance for the young man. In the weeks that followed, P&A conducted a full investigation. Family members, school staff, DMR employees and the local police were all interviewed. The investigator substantiated neglect and Protective Services were requested from DMR.

Since the allegation was called into AID, Ken’s situation has improved. He now receives the services of a Home Health Aid and DMR is also working to secure additional services with an ultimate goal of obtaining a safe, supportive, and appropriate alternative residential setting.

Lynn’s Story

Lynn did not want to take the medications they were trying to give her on the psychiatric unit. She had had a very bad night, temporarily losing control, yelling and being verbally abusive toward her neighbor. The police had taken her to the Emergency Room and she was then placed on the psychiatric unit due to her continued agitation. Several hours after the incident, Lynn was completely calm and able to describe more appropriate ways of handling the situation. However, despite Lynn’s recovery, a doctor ordered a medication against the possibility that she would “react the same way again.” Lynn refused, and a forced medication hearing was scheduled (as required by Connecticut General Statutes §17a-543). The purpose of the hearing was to determine if the patient was able to give informed consent or refusal to the administration of the psychiatric medications.

A P&A advocate met with Lynn and supported her during the hearing. Lynn was questioned at length and a determination was made that she was competent and did not require medication. She was released from the psychiatric unit the same day.

Ann's Story

You can get breast cancer. Ann did. She had been putting off getting a mammogram, and was inconsistent with her monthly self breast exams. One day, Ann received a call from an organization known as ABACUS (Assessing Barriers and Creating Useful Solutions), whose goal is to improve access to mammography and educate women with disabilities about breast cancer and the importance of prevention and early detection. Ann was asked to become a volunteer peer educator, prompting her to schedule a mammogram and do a self exam. Ann found a lump. She acted quickly, and by the start of the volunteer training, she was three days post surgery. Now, Ann passionately spreads her message so that all women with disabilities know that they can and should get mammograms.

ABACUS is a collaboration that includes the Connecticut Women and Disability Network, Qualidigm and P&A, with funding from the Connecticut Race for a Cure® Susan G. Komen Foundation.

PROGRAM STRUCTURE AND EXPERIENCE

P&A is organized into two operating divisions, the **Case Services Unit** and the **Abuse Investigation Division**, and an **Administrative Unit**. By statute, governance and administrative functions are vested in the Executive Director, who is advised on matters of service priorities, policy and issues affecting people with disabilities by a fifteen (15) member Protection and Advocacy Advisory Board. The operating divisions house a number of discrete programs and oversee contracts and grants to local programs.

CASE SERVICES UNIT

The **Consumer Information Section** of the Case Services Unit provides information and referral services, and short-term advocacy assistance. The section is, in most cases, the entry point for new callers to P&A. Depending on the need presented, the Consumer Information advocates may provide information, connect callers to the appropriate P&A unit, or make referrals to relevant outside agencies.

Advocates assigned to the Case Services Unit provide **Advocacy Services** to protect the rights of adults and children with disabilities living in institutions and community-based residential programs. They also intervene on behalf of children with disabilities who are experiencing difficulty obtaining appropriate educational supports. Staff attorneys working with advocates represent individuals and groups seeking administrative or judicial remedies involving discrimination based on disability. The following federally mandated advocacy programs are located within the Case Services Unit:

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Federally Mandated P&A Programs for Persons with Disabilities

Federal Program	Program Description
<p style="text-align: center;">Protection and Advocacy for Individuals with Developmental Disabilities (PADD) 42 U.S.C. §15001 et seq.</p>	<p>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 to educate policymakers about issues of concern to persons with disabilities.</p>
<p style="text-align: center;">Client Assistance Program (CAP) 29 U.S.C. §732</p>	<p>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).</p>
<p style="text-align: center;">Protection and Advocacy for Individuals with Mental Illness (PAIMI) 42 U.S.C. §10801</p>	<p>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.</p>
<p style="text-align: center;">Protection and Advocacy for Assistive Technology (PAAT) 29 U.S.C. § 2001 et seq.</p>	<p>PAAT provides consumer education and representation in an effort to expand the availability of assistive technology devices and services for people with disabilities.</p>
<p style="text-align: center;">Protection and Advocacy for Individual Rights (PAIR) 29 U.S.C. § 794e</p>	<p>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.</p>
<p style="text-align: center;">Protection and Advocacy for Beneficiaries of Social Security (PABSS) 42 U.S.C. §1320b-19 20 CFR 411.635 (P.L. 106-170)</p>	<p>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.</p>
<p style="text-align: center;">Protection and Advocacy for Help America Vote Act (PAHAVA) 42 U.S.C. §15301 et. seq. (P.L. 107-252, Sec. 291)</p>	<p>PAHAVA is charged with expanding participation of people with disabilities in voting processes and protecting their rights.</p>
<p style="text-align: center;">Protection and Advocacy for Persons with Traumatic Brain Injury (PATBI) 42 U.S.C. § 300 d. -51</p>	<p>PATBI provides protection and advocacy services to individuals who have brain injury.</p>

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The **Legal Unit** provides legal advice and representation to a limited number of agency clients. Staff attorneys also represent individuals and groups seeking administrative or judicial remedies involving discrimination based on disability. Other Legal Unit activities include consultation with outside attorneys and members of the public on questions of disability law; presentations about disabilities at seminars and conferences; preparation of comments on proposed state and federal regulations and policies; and responding to requests for information from public officials and members of the public.

During 2004, staff in the Case Services Unit represented individuals who are clients of human services systems such as the Departments of Mental Retardation and Mental Health and Addiction Services. Advocates fought for improved conditions for persons with disabilities in institutional settings, received and reviewed reports of serious injury or death due to restraint and seclusion of persons with mental illness (Connecticut General Statutes §46a-150 et seq.) and provided support to individuals with mental illness in forced medication hearings. P&A attorneys continued work on a case that would require a local hospital to discontinue the use of pepper spray and were successful in settling a complaint that alleged failure by the Department of Corrections to provide adequate treatment for prisoners with mental illness.

P&A advocates and attorneys also addressed several systemic issues involving children with disabilities, including reforming special education deficiencies in the Hartford school system, while supporting the efforts of grassroots organizations to train minority parents who have children with disabilities. One P&A project was specifically designed to divert children with serious emotional illness and behavioral disabilities from the criminal justice system. Representation was also provided to children with life threatening allergies who were unable to attend school because of mold or were denied access to after school and municipal recreational programs because they require the use of an EpiPen.

Complaints from individuals who are deaf or hard of hearing were addressed in prisons, hospitals and nursing facilities resulting in improved access to assistive technology devices and sign language interpreters. The rights of voters with disabilities were enhanced through projects to improve accessibility to polling places and election technology. P&A advocates educated policymakers and supported self-advocates to successfully pursue a change in Connecticut's Hate Crime statute to include disability as a protected category.

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, ages of 18 and 59, who have mental retardation. Connecticut General Statutes §46a-11a establishes a list of "mandatory reporters", professionals and others in service providing roles who are

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required to report to P&A situations where they reasonably believe an adult with mental retardation has been or is being abused or neglected.

AID has the authority to conduct direct investigations involving the DMR or any other service provider. However, most reports involving clients of the mental retardation service system are directly investigated by the service agencies with P&A monitoring the internal investigation. P&A conducts primary investigations for allegations involving people living at home or otherwise outside the scope of the mental retardation service system.

When appropriate to do so, AID makes recommendations for protective services, refers cases of substantiated abuse to the State's Attorney, and takes immediate steps to ensure that emergencies receive an adequate response. In addition, division staff members conduct public education activities and advocate to change conditions that lead to dehumanizing treatment of people with mental retardation.

ADMINISTRATIVE UNIT

P&A's **Administrative Unit** implements the overall policy of the Agency, ensures accountability to state and federal funding sources, and coordinates and supports the activities of the operating divisions. It also supports the activities of the 15 member Protection and Advocacy Advisory Board.

The Administrative Unit also provides **Community Outreach** to a wide variety of new and existing community-based disability advocacy initiatives. Community outreach staff perform a number of functions, including monitoring grants; providing technical assistance and training on questions of organizational strategy and fundraising; board training and presentations on disability related topics; conducting outreach activities in minority communities; and assembling and distributing information about advocacy and disability rights.

In addition to providing training and support to numerous disability advocacy groups during 2004, Community Outreach staff focused on initiatives to improve access to mammography and gynecological health services for women with disabilities. With the Department of Public Health, P&A co-chaired a women's health workgroup that made recommendations to the Public Health Committee of the Connecticut Legislature. P&A was also an active participant in the ABACUS (Assessing Barriers and Creating Useful Solutions) Mammography Project and the Connecticut Initiative to End Violence Against Women with Disabilities. P&A staff were invited to speak about these initiatives at national conferences.

The Executive Director of P&A is also the chair of an independent **Fatality Review Board** (FRB) for persons with disabilities. Established by Executive Order 25, the FRB

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is charged with conducting investigations into the circumstances surrounding the deaths of DMR clients “which, in the opinion of the Executive Director, warrant a full independent investigation.” The board also has 5 Governor-appointed members who are drawn from medical, law enforcement and human service professions.

The FRB received reports of 187 deaths of persons with mental retardation during the 2004 fiscal year. All reports were reviewed and entered into a database. Eleven of these deaths warranted in-depth review and discussion by the FRB. Four deaths were referred for a complete investigation. P&A released a public report for one death, sent the results of another preliminary investigation to the Commissioner of the Department of Mental Retardation and is completing two reports that are scheduled for public release.

P&A’s **Legislative and Regulations Specialist (LRS)** tracks legislative proposals that have implications for the rights of persons with disabilities in Connecticut, provides training and technical assistance on the legislative process and develops proposals to protect the rights and advance the interests of persons with disabilities.

During 2004, P&A proposed or strongly supported legislation that further enhances protection for persons with disabilities by requiring more stringent timelines and expanded mandates for P&A’s Abuse Investigation Division; mandates a ten day stay on involuntary sterilization procedures ordered by probate courts; and adds disability as a protected class under Connecticut’s Hate Crimes statute. P&A also provided testimony and monitored additional legislation potentially affecting the lives of Connecticut citizens with disabilities.

In addition to the Executive Director, the unit also houses a Management Analyst, Personnel Officer, Business Office staff, Executive Secretary and support staff.

P&A TABLE OF ORGANIZATION

The illustration on page 21 describes the current organizational structure of the Office of Protection and Advocacy for Persons with Disabilities.

FISCAL FACTS AND FIGURES

In the fiscal year ending June 30, 2004, P&A had a total operating budget of \$3,389,834. Of this \$2,290,394 (68 %) was state funding and \$1,099,440 (32%) was federal funding. Personal services expenditures comprise 84% of P&A's General Fund Budget with an additional 11% expended on contracts and outside services. The remaining 5% was expended on necessary expense items including supplies, equipment, telephone, postage and printing.

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P&A Federal Expenditures for Fiscal Year 2004	
Total: \$1,099,440	
U.S. Department of Education - Client Assistance Program	\$104,961
U.S. Department of Health and Human Services - Protection and Advocacy for Individuals with Mental Illness	\$314,453
Social Services Block Grant	\$83,361
U.S. Department of Health and Human Services - Administration on Developmental Disabilities	\$315,524
U.S. Department of Education - Protection and Advocacy for Individual Rights	\$198,137
U.S. Department of Education - Protection and Advocacy for Assistive Technology	\$8,748
Social Security Administration - Protection and Advocacy for Beneficiaries of Social Security	\$74,256

MAJOR ISSUES AFFECTING PERSONS WITH DISABILITIES

State law requires P&A to report annually on the “status of services for persons with disabilities” and to “make recommendations, administrative and legislative, concerning the protection of the rights and welfare of persons with disabilities living in Connecticut.” This listing reflects problems presented by people who contact P&A for assistance, reports from public forums and other discussions between agency advisory groups and consumers, and the observations of agency staff who investigate and advocate on behalf of our clients.

Housing

The shortage of affordable, accessible housing is still keeping thousands of people unnecessarily institutionalized in psychiatric hospitals and long term care facilities. Federally subsidized housing can be designated “elderly only” and non-elderly persons who need safe, affordable, accessible housing are not welcome. Affordable and accessible two and three bedroom apartments for families are very difficult to find. As the State Building Code is amended in 2005, it is important to retain accessibility requirements for stand-alone and multi-family housing. Any efforts to reduce the accessibility requirements currently in place will cause a greater shortage of housing for families.

Transportation

The lack of reliable, affordable, accessible transportation prevents many people with disabilities from being able to seek employment, continue their education or receive adequate healthcare. Just as important, the lack of such transportation makes spontaneous trips to the mall or to the movies, the kinds of community interaction many people take for granted, all but impossible. The lack of transportation limits the ability of people with disabilities to truly integrate into the greater community.

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Education

The expectations for special education students, particularly in troubled urban school systems, remain dismally low, and inclusion is still not a reality for many children. Many schools have adopted a “zero tolerance” policy that results in children with behavioral and emotional issues being disciplined with suspensions, detentions and expulsions instead of receiving intervention, treatment and support to improve their behavior. Inclusion, and the expectation that all students will do the very best they can, should be adopted as official state policy. Zero tolerance should give way to a reasonable approach to behavioral problems. The state needs to formally recognize that sometimes the misbehavior of children is directly related to their disabilities.

Bullying

Bullying is a big issue for people with disabilities. In 2004, the state legislature amended the hate crime statute to add people with disabilities to the group of protected classes. People with various disabilities testified at a public hearing about the threats and violence they have received because they are “different” and the legislature acted to provide additional penalties for such crimes. But bullying behavior needs to be addressed before it rises to the level of being a crime. Schools are developing anti-bullying policies and must continue to insist every day that bullying behavior is not tolerated.

Employment

People with disabilities continue to have higher rates of unemployment and underemployment than the general population. Young people with disabilities, many of whom have never held typical part-time or summer jobs, often find the transition from school to work to be difficult. Even students who have achieved considerable academic success are often unprepared for workplace expectations. Employees with disabilities who encounter problems on the job are often unsure of their rights, or when and how to discuss their needs for reasonable accommodations with their employers. There is a need for greater availability of information about both legal rights and workplace problem-solving resources. Both the Board of Education and Services for the Blind (BESB) and the Bureau of Rehabilitation Services (BRS) need to continue to emphasize employability and help clients learn skills to become gainfully employed.

Nursing Home Placements

Placements into nursing homes seem to be increasing both for people with psychiatric disabilities and for people with mental retardation who are aging. Over 2,000 people with primary psychiatric diagnoses currently reside in Connecticut nursing homes. People with mental retardation who are aging but do not require extensive medical care should remain in the community with home care services. People with mental illness can live with more freedom and at less expense to the state in community-based supported housing.

Access to Community Infrastructure

Access is still limited. Many towns and cities are not fully compliant with state and federal accessibility requirements. Often, there is confusion about what is mandated

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because there are significant differences in state and federal requirements. Connecticut lacks a streamlined complaint and enforcement process that could ensure better accessibility. Connecticut should study the Massachusetts Access Board, which is an independent Executive Branch office, to see how it has streamlined the complaint and enforcement process. Also, Connecticut should consider ways to standardize definitions and requirements found in state statutes with those in federal law.

Abuse and Neglect

Requirements for reporting and investigating abuse and neglect are uneven across service systems. There are mandatory reporters regarding child abuse who must report to the Department of Children and Families and mandatory reporters regarding abuse and neglect of the elderly who must report to the Department of Social Services. But there is no mechanism to compel reports of suspected abuse or neglect of non-elderly adults with disabilities other than mental retardation. For example, if a person with mental illness is in a state hospital, there are no requirements for licensed healthcare providers to report suspected abuse and neglect to an outside agency for investigation unless the person is seriously injured or killed by the use of restraint or seclusion. The state should consider a reporting and investigation mechanism to ensure the safety of non-elderly adults with disabilities other than mental retardation.

Imprisonment of Difficult-to-Serve People Instead of Developing Relevant Programs

It has been the experience of P&A advocates that individuals with psychiatric and cognitive disabilities who have difficulty controlling their behavior or who may get into conflicts with neighbors are unnecessarily going to prison. Many of these individuals are on waiting lists for housing, or are significantly misfit into inappropriate settings where they do not receive relevant or adequate supports. The result is often minor but repeated confrontations with neighbors, or arrests for low level crimes such as shoplifting. While an increasing number of individuals with psychiatric disabilities are now being identified and screened out through court-based jail diversion programs, alternative options are limited for those who present as homeless or have co-occurring substance abuse problems. P&A is especially concerned about the increasing number of persons with mental retardation who are becoming involved with the criminal justice system and will be focusing additional attention on this issue during the coming year.

Need for Coordinated System of Services to Support People with Developmental Disabilities Other than Mental Retardation.

Despite the fact that incidence rates for Autism Spectrum Disorders (ASD) have been dramatically increasing, Connecticut has no coordinated system of services to address the needs of these individuals (unless they also happen to have mental retardation). Support needs for these people tend to vary considerably between individuals, and, in fact, many are or would be found eligible for some type of assistance from one or another educational or vocational agency. However, absent coordination of efforts by someone positioned to see the “whole person”, many never acquire the skills and environmental supports they need to successfully contribute in their families and communities.

LESSONS LEARNED THE HARD WAY

James D. McGaughey, Executive Director

The road to hell is paved with human service rationalizations.

Over the past 30 years, much of the progress in human service reform has involved abandonment of models and methods that we now recognize as not only unhelpful, but actually oppressive. Fortunately, lifetimes are no longer being wasted in back wards of huge state institutions, segregated special education schools are no longer the norm everywhere, and parents are no longer routinely counseled to institutionalize their children with disabilities. But hybrids of these old models have evolved, justified by many of the same rationales that protected their now discredited predecessors. Today, thousands of people with mental illness are languishing in nursing homes. While more people with disabilities are joining the workforce, unemployment and under-employment remain rampant, as structured (and expensive) day programs provide not opportunities for work and meaningful contribution, but rather the equivalent of congregate babysitting. And, in too many towns, segregated special education programs have simply been transplanted from remote buildings to isolated locations within public schools.

The “bad”, old, practices of yesteryear grew from fond visions of sunny uplands and social progress advanced by an earlier generation of reformers - earnest souls who, like ourselves, thought only to help. Unfortunately, they misjudged their own fallibility. And, together with the policymakers and professionals and community leaders who supported their efforts, they uncritically accepted a series of superficially appealing rationalizations that developed to explain away what, in retrospect, seem to be obvious shortcomings in their creations. These rationalizations obscured the realities in people’s lives, and led, not to a better day, but rather to abusive restraint practices, torturous aversive programming, widespread neglect of basic human needs, financial exploitation, massive drugging, wholesale sterilization, perpetual exclusion and the wasting of hundreds of thousands of lives.

Before we congratulate ourselves for taking these antiquated programs apart, we should be asking ourselves: What human service structures are we still tolerating, or even building anew that will trap future generations of children and adults in poverty, controlling bureaucracy, stigmatizing imagery and low expectations? How vulnerable are we to updated versions of the same sorts of excuses and justifications that obscured the harmful realities of yesteryear? How much of what we accept today will occasion regret tomorrow?

It is especially important that we ask ourselves these questions at this juncture. Emerging economic and demographic realities are signaling a sea change in the configuration of public funding mechanisms for health and human service programs. While there are many battles yet to be fought on this front, the most realistic long term planning

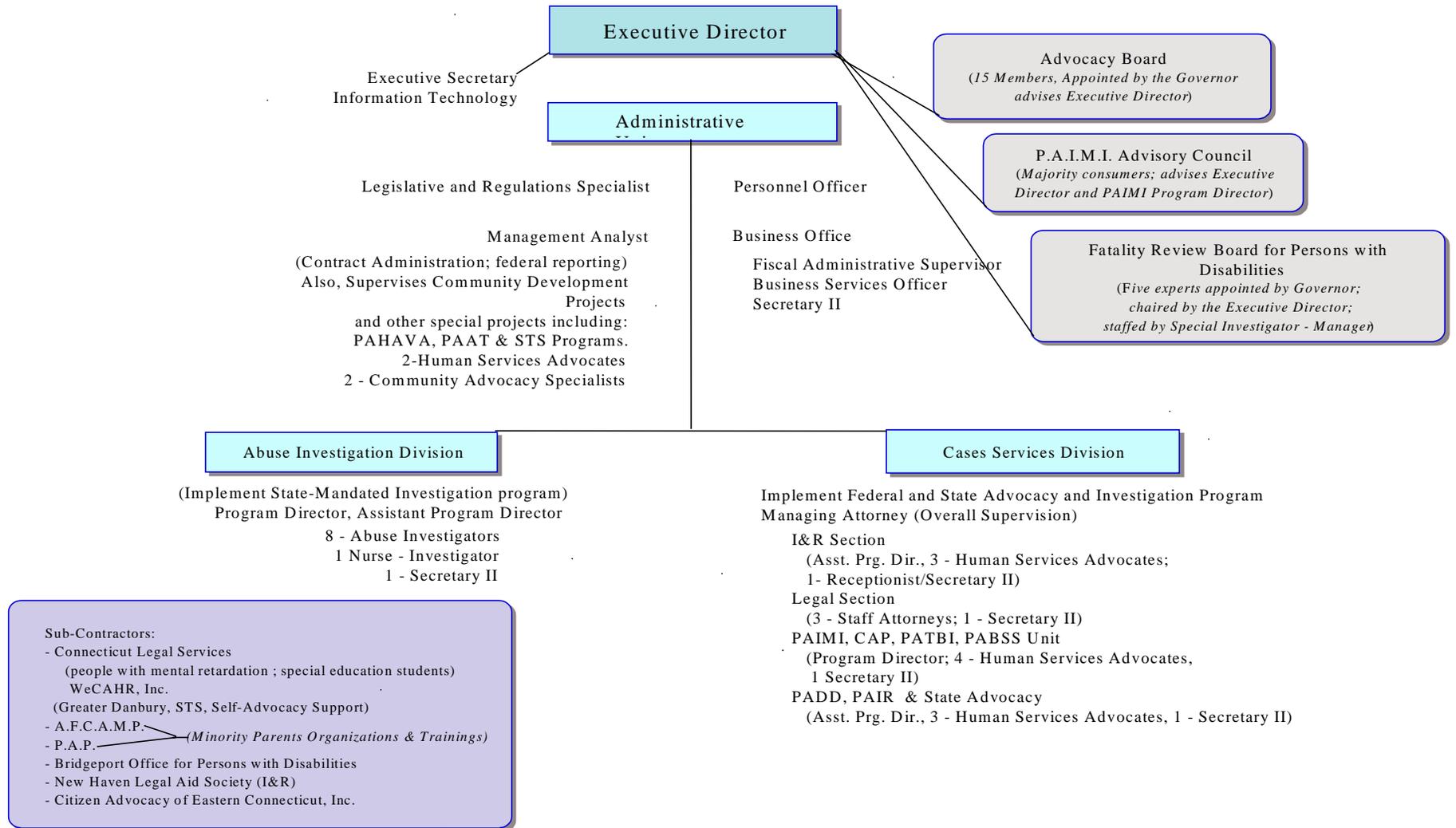
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assumptions involve increasing scarcity relative to demand. We have tasted a bit of this already when state agency budgets were recently reduced, however slightly, in response to economic pressures. The experience is worrying. Promising and innovative program initiatives – those that reflect the most forward thinking – tended to get put on hold, or were so underfunded that they may ultimately be judged to have failed. Budgets for training and leadership development (which function as incubators for renewal and innovation) were all but eliminated. Under even moderate fiscal pressure, lofty visions of respect, dignity, choice, recovery and support for meaningful, contributing roles in families and communities flickered and dimmed. More insidiously, forced by circumstance to adopt relatively harsh triage strategies, troubling rationalizations emerged amongst service systems to explain why certain clients or prospective clients were less worthy than others – rationalizations that consigned people who were difficult to serve to homeless shelters or the tender mercies of the criminal justice system.

If we learn any lesson from the history of human service reform efforts, it should be wariness of rationalizations purporting to explain why, in order to promote the greatest good for the greatest number, it is acceptable that certain individuals be deprived of fair opportunities to learn and grow and belong and contribute with the rest of us. Simply taking apart obsolete programs is not enough. As we explore new approaches, we have to do better, think harder and be less willing to uncritically accept justifications for why things are the way they are. Einstein said it best: “The significant problems we face cannot be solved at the same level of thinking we were at when we created them.”



P&A TABLE OF ORGANIZATION



Respect	Voting	Employment
Choice	Ho	tion Risk
Accessibility	ransportation	
Dreams	Advocacy	Freedom Power
Integration	Diversity	Growth
Life	Community	Relationships Goals
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Equality	Support	Ability
Voice	60 B Weston Street Hartford, Connecticut 06120 (800) 842-7303 (voice/TTY) (860) 297-4300 (voice) (860) 297-4380 (TTY) www.ct.gov/opapd	
Independence	Access	Values

