

Office of Protection and Advocacy for Persons with Disabilities

At a Glance

CRAIG B. HENRICI, *Executive Director*

Gretchen Knauff, *Assistant Director*

Established – October 11977

Statutory authority – CGS §46a-7 et seq.

Central office - 60B Weston Street, Hartford, CT 06120

Average number of full-time employees - 39

Recurring operating expenses – \$3,972,729

Federal contributions - \$1,586,425

Organizational structure - Two operating divisions, Case Services and Abuse Investigation, plus an Administrative Unit.

Mission

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

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

Statutory Responsibility

A combination of federal and state statutory mandates requires the agency to:

- Safeguard the civil and human rights of people with disabilities in Connecticut;
- Provide information and referral services for persons with disabilities;
- Conduct investigations into allegations of abuse and neglect involving adults with intellectual disability, ages 18 through 59;
- Operate advocacy programs that are capable of pursuing legal and administrative remedies on behalf of people with brain injuries, as well as people with psychiatric, developmental and other disabilities;
- Advocate on behalf of individuals seeking assistive technology devices and services; voters seeking improved access to registration and the polling process; beneficiaries of Social Security; and clients of the vocational rehabilitation system looking for or attempting to maintain employment and/or independent living;

- Affirmatively reach out to traditionally underserved populations, conducting community development and public education activities;
- Conduct full independent investigations into the circumstances surrounding the deaths of Department of Developmental Services clients, especially when abuse or neglect is suspected to have contributed to the death;
- Review, in conjunction with the State Building Inspector, applications to install wheelchair lifts in non-residential buildings, and requests for waivers from the accessibility provisions of the Connecticut State Building Code;
- Review, in conjunction with the Secretary of the State, requests for exemptions from accessibility requirements for polling places;
- Review all deaths of individuals living in facilities run by the Department of Mental Health and Addiction Services;
- Staff and chair the Fatality Review Board for People with Disabilities, as required by Executive Order #42 of Governor M. Jodi Rell;
- Support the State's Accessibility Advisory Board;
- Receive reports of serious injury or death resulting from restraint or seclusion pursuant to Connecticut General Statutes §46a-150 et seq. and federal regulations - 42 CFR 483.374, Reporting of Serious Occurrences at Psychiatric Residential Treatment Facilities; and
- Receive reports of serious injury or death of a child receiving special education services in Connecticut pursuant to Connecticut General Statutes §46a-150 et seq., §10-76b and § 10-76d.

Public Service

During the 2015 fiscal year, the Office of Protection and Advocacy for Persons with Disabilities (P&A) received 2,976 requests for information and referral. The agency received an additional 635 requests that required a more intensive level of advocacy representation. P&A's Abuse Investigation Division (AID) received 1,446 allegations of suspected abuse or neglect of persons with intellectual disability. P&A staff investigated or monitored 1,256 of those cases. P&A's Fatality Review Board reviewed the deaths of 244 individuals who were served by the Department of Developmental Services. Fifty-eight (58) of the deaths received a more in depth review or investigation. The FRB also reviewed the deaths of 4 individuals who died in facilities run by the Department of Mental Health and Addiction Services.

P&A also sponsored or participated in 86 training opportunities that reached over 1,600 people with disabilities, family members, and others. Information was disseminated to more than 3,200 people at resource fairs, and more than 10,000 P&A publications and program brochures were distributed. The P&A website, which also posts all agency publications in accessible printable formats, received over 148,200 hits during the 2015 fiscal year and more than 52,000 publications were downloaded.

P&A continued to support disability-focused community advocacy and coalition building by:

- Continuing to provide in-kind support and training resources for AFCAMP (African Caribbean American Parents) and PAP (Padres Abriendo Puertas), two grassroots organizations of parents who have children with disabilities;

- Hosting a Spanish website with materials about the agency and disability rights.
- Providing special education training and technical assistance for parents of children with disabilities in Willimantic, Norwalk, Danbury, Hartford, and New Britain;
- Providing culturally-competent workshops on disability issues to underserved communities in both English and Spanish;
- Increasing the awareness of disability and disability issues of community-based grassroots organizations;

Improvements/Achievements 2014-2015

The Office of Protection and Advocacy for Persons with Disabilities continued to raise awareness about the civil and human rights of individuals with disabilities in vulnerable circumstances. The agency also protected the rights of vulnerable populations by:

- Continuing to advocate for the rights of persons with mental illness who are warehoused in nursing facilities. P&A attorneys continue to monitor the settlement that provides opportunities for people with mental illness to move from nursing facilities to community settings with support;
- Monitoring protective service plans for adults with intellectual disabilities who have been abused or neglected;
- Educating policymakers regarding harm caused by the use of restraint and seclusion as a routine component of a child's educational program;
- Participating in a project to close institutions for people with intellectual disability in Connecticut;
- Collaborating with other state agencies as a member of the Connecticut Restraint and Seclusion Initiative Partnership to eliminate the use of restraint and seclusion of children and adults with disabilities. The Partnership sponsored a statewide conference highlighting the experiences of people with disabilities who had been subjected to restraint and seclusion;
- Educating people with disabilities, family members, policymakers, advocates, and professionals about customized employment as a real option for people with disabilities.
- Addressing healthcare deficiencies at institutions run by the Department of Developmental Services resulting in new procedures and protocols including external monitoring to improve care.
- Translating P&A publications into Spanish and making them available in print and on the P&A website;
- Regularly meeting with representatives of the Department of Developmental Services to discuss, update and improve abuse and neglect investigation and reporting procedures and collaboration efforts between the agencies;
- Educating state and local emergency management professionals about emergency preparedness issues affecting persons with disabilities through participation in meetings with the Department of Emergency Management and Homeland Security, regional emergency planners, and the Red Cross;
- Interviewing and reporting on the experience of children and adolescents involved in incidents at psychiatric facilities that involve serious injury or death;
- Reviewing and reporting on deaths in facilities run by the Department of Mental

Health and Addiction Services;

- Educating policymakers on how legislative proposals would positively or negatively affect people with disabilities, including proposals concerning physician-assisted suicide; supportive housing for people with intellectual disability; strengthening the voting process; institutionalization of persons with intellectual disability and handicapped parking.

Other P&A systems change initiatives included:

- Reviewing deaths of persons with intellectual disabilities served by the Department of Developmental Services (DDS) and identifying trends to improve the health and safety of DDS residents;
- Representing people with disabilities at sterilization hearings to ensure all processes and procedures are properly followed prior to a final determination;
- Receiving and investigating reports of serious restraint-related injuries from public agencies pursuant to P.A. 99-210, “An Act Concerning the Physical Restraint of Persons with Disabilities”;
- Receiving and investigating reports of suicide attempts, serious injury, death, restraint, seclusion and serious occurrences at psychiatric residential treatment facilities.
- Educating people with disabilities, policymakers and voting officials regarding issues affecting the rights of voters with disabilities including accessible polling places and new voting technology;
- Ensuring the rights of voters with disabilities by assisting them with administrative complaints and by pursuing issues related to Election Day Registration and voting systems.
- Ensuring accessibility of Connecticut’s buildings and facilities by ruling on requests for 75 waivers from the accessibility provisions of the state building code and 33 requests for the installation of lifts. P&A staff defended appeals of these decisions through administrative hearings;
- Updating agency publications for distribution at resource fairs, workshops and other outreach events. The publications are also distributed to callers requesting information from the agency;
- Distributing more than 3,500 voter registration cards at outreach events and to callers contacting P&A for assistance;
- Ensuring physical accessibility of Connecticut’s polling places by ruling on requests for polling place accessibility waivers generated by Registrars of Voters;
- Addressing complaints from individuals who are deaf or hard of hearing involving effective communication in prisons, hospitals, doctors’ offices, lawyers’ offices, police settings and on college campuses;
- Continuously updating agency website (www.ct.gov/opapd) to provide accessible, current, comprehensive information on disability rights and resources. The site provides access to agency created self-help literature, information about P&A programs and services, and agency priorities and initiatives. The website also reports on the current developments in the field of disability rights and provides links to other relevant disability-related organizations.

Information Reported as Required by State Statute

By Connecticut Statute §46a-13, P&A is mandated to report annually on issues affecting services to Connecticut citizens with disabilities. Public input obtained from P&A sponsored forums, focus groups, specialized meetings, and widely distributed questionnaires was reviewed in conjunction with P&A information & referral statistics and advocacy case experience, resulting in identification of the following issues in the 2014 P&A Annual Report:

- **Children’s Mental Health, Autism Spectrum Disorder, Youth Assessment and Engagement** - The Office of the Child Advocate released a 114 page report concerning the December 2012 shooting at Sandy Hook Elementary School. The report lists 37 key findings and 19 key recommendations. Topics needing further action, according to the report include: screening for what the report terms “homebound children”; assessments, access and reception of early intervention for mental health and developmental concerns; care coordination and information sharing; support and engagement with families; education; increase expertise and services to support children with developmental and mental health challenges. The report stressed that mental illness and / or autism spectrum disorder (specifically Asperger’s) did not directly cause the shooter to act. The report highlights the availability of mental health and other services that were not accessed. Policy makers will address how to encourage individuals and families to engage in services, how to ensure school systems and health professionals work with individuals and families, and how to address the issue of screening individuals who may have mental health or developmental issues that need to be addressed.

- **Special Education.**

Schools continue to find themselves facing the same financial issues experienced by all governments. At the same time, they are obligated to provide quality appropriate programming for students with special education needs, creating friction in the delivery of school services. Some school officials express hostility toward parents who they describe as “unreasonable” “demanding” or “unrealistic”, and whom they blame for consuming disproportionate amounts of scarce resources. On the other hand, parents and advocates for special education students express frustration with schools that fail to recognize and observe sound, evidence-based professional practices and legally required evaluation and individual planning protocols. Areas generating particular concern include:

- 1) Inadequate (or non-existent) transition planning. Federal law requires that individualized plans be developed for each special education student, beginning at age 14, to ensure the student is adequately prepared for work or post-secondary education. In many cases, however, these plans are not based on an understanding of the student’s interests and preferences, or a vision of productive, contributing adult life. Rather, they reflect standardized program descriptions and vague references to eventual referrals to adult human service systems. In some instances, the law is simply ignored and no Transition Plan is developed. As resources for public support programs shrink, and life prospects for people with disabilities are becoming increasingly dependent on their own abilities to earn a living and independently

manage their affairs, preparing students for work and the realities of adult life is becoming increasingly important. Much more attention needs to be devoted to ensuring that relevant, effective transition planning is, in fact, occurring.

- 2) Frequent use of Restraint and Seclusion. Data amassed by the State Department of Education indicate that special education students were subjected to over 23,000 instances of seclusion and over 13,700 restraints during school year 2011-2012 (the most recent year for which data is available). The most prevalent use of these techniques occurred in approved private special education schools, but public schools also generated impressive numbers. The planned use of seclusion as a behavioral consequence is of particular concern: as the U.S. Department of Education has clearly stated, there is simply no evidence that placing students into seclusion rooms has any therapeutic or educational value or results in the acquisition of appropriate behavioral skills. It does, however, raise human rights concerns, create a risk of injury both for the student and for staff, contribute to psychological trauma and, ultimately, to a school culture that is inconsistent with the positive climate needed to support a learning community.
 - 3) Inadequacy of Evaluations to Identify Students' Specific Needs. Eligibility for special education and related services hinges on a finding by a Planning and Placement Team (PPT) that a student cannot learn adequately by simply following the general instructional curriculum; that the student needs an Individual Education Plan (IEP) in order to achieve satisfactory progress in school. To inform that decision, but even more importantly, to flesh out the contours of an appropriate IEP, the team is supposed to identify and arrange for whatever evaluations or assessments may be warranted for the individual student. To be of any value, these evaluations must be diagnostically comprehensive, and often must be conducted by experienced, well trained practitioners. Yet, too often, decisions about program content, possible use of assistive technology and placement plans are being justified by the minimal results obtained from general assessment instruments that have been administered by over-worked school staff. As a result, many students with specific learning disabilities, communications disabilities, autism spectrum disorders and significant emotional distress are being short-changed.
- **Barriers to Community Participation:** Full participation in community requires that people have choices about where to live, work, shop and participate in activities with others. People with disabilities who require services and supports should be able to choose community living over institutionalization. Historically, various "Catch-22" funding requirements have limited community living opportunities, particularly for people with significant disabilities. Over the past few years, Connecticut has taken apart some of those Catch-22s, and is making some limited but important progress toward becoming competent to support people's preferences and choices. The state publishes a Long Term Services and Supports (LTSS) Plan every three years to implement the overarching goal of rebalancing long term services and supports so that long term care dollars can support more people who choose community living options. However, there are still a number of issues that need to be resolved before this "rebalancing" can occur. Among these are:

- 1) Architectural Access. State and federal laws require that government services and programs be accessible to people with disabilities, and that places of public accommodation (e.g. theaters, restaurants, stores and other public spaces) remove barriers where doing so is readily achievable, and modify policies and take other steps to prevent disability discrimination. In addition, current building codes and the accessibility guidelines that regulate new construction and substantial renovations require design features and construction techniques that greatly facilitate access. However, reflecting compromises reached by drafting committees and governing bodies, those codes and guidelines sometimes fall short of ensuring full accessibility. For example, technical requirements do not require existing government buildings, or other public buildings to be retrofitted so as to assure that the main entrance is equipped with ramps and automatic doors. And, in many Connecticut towns, streetscapes that were built decades ago remain largely inaccessible. Until such these things change, people with disabilities and seniors who are trying to “age in place” will continue to experience problems.

- 2) Affordable, Accessible, Environmentally Safe Housing. The long-standing statewide shortage of affordable, accessible homes continues to thwart efforts by people who wish to move out of long-term care facilities. Accessible rental units for families are in especially short supply. While new housing starts are down, some efforts to rehab existing buildings are going forward. It is critically important that residential building code requirements continue to provide for percentages of new and rehab units to be made accessible and adaptable for individuals and families who have disabilities. It is equally important that environmental contaminants – particularly lead paint – be completely removed as part of this process. Legislation passed in 2012 created an “aging in place” task force. Housing, and community based services and supports, are key topics the task force will address.

- 3) Transportation. One of the earliest goals articulated by the disability rights movement was to resolve the problem of inadequate accessible public transportation. While some progress has been made on this front – most notably by transit districts operating fixed bus routes – it is still tremendously difficult to arrange to travel between different regions of the State without planning many days ahead. For people who use busses, moving about during evening and weekend hours is especially problematic. For people who do not live near fixed bus routes, the only solution is often to pay for expensive medical transportation services simply to get a ride to a meeting or for a doctor’s appointment. Another new option is accessible taxicab service. The good news is that wheelchair accessible taxis now serve 34 towns in the greater Bridgeport, Hartford and New Haven areas. While taking a cab for longer trips can be expensive, the convenience of using them for shorter distance travel (and the occasional trip to the airport) is greatly appreciated by people who want and need to get about in their communities. Some

limited funding to subsidize the cost of cab fare is available for people with disabilities in certain areas but it does not begin to address the need.

- **Physician Assisted Suicide**

In 2014, legislation to legalize doctor-assisted suicide was proposed and a public hearing was held. After the long public hearing the legislative Public Health Committee decided not to approve the bill—so the bill died right away. Advocates of legalizing doctor-assisted suicide have been clear that they will have the measure re-introduced in 2015. While not everyone in the disability community opposes this, there are grave concerns that persons who are elderly and persons with disabilities could be subject to pressure to commit doctor-assisted suicide or worse—they could have their lives ended without their approval. (Please note that the measure was reintroduced during the 2015 Connecticut legislative session. It failed to pass.)