

Office of Protection and Advocacy For Persons with Disabilities

At a Glance

CRAIG B. HENRICI, Executive Director

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Established – October 1, 1977

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

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

Average number of full-time employees - 38

Recurring operating expenses – \$4,131,010

Federal contributions - \$1,689,260

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 and deaths of adults with intellectual disability of any age if abuse/neglect were a suspected cause in the death;
- 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

The Office of Protection and Advocacy for Persons with Disabilities (P&A) is submitting its last report for the Administrative Digest. The agency will be abolished on July 1, 2017 after proudly serving Connecticut citizens with disabilities for more than 39 years. Beginning July 1, 2017, the P&A functions will be handled by a non-profit entity that will be designated by Governor Malloy in the spring of 2017.

During the 2016 fiscal year, the Office of Protection and Advocacy for Persons with Disabilities (P&A) received 2,706 requests for information and referral. The agency received an additional 570 requests that required a more intensive level of advocacy representation. P&A's Abuse Investigation Division (AID) received 1,321 allegations of suspected abuse or neglect of persons with intellectual disability. P&A staff investigated or monitored 1,128 of those cases. P&A's Fatality Review Board reviewed the deaths of 257 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 four (4) individuals who died in facilities run by the Department of Mental Health and Addiction Services and one (1) individual in the custody of the Department of Correction.

P&A also sponsored or participated in 99 training opportunities that reached over 3,000 people with disabilities, family members, and others. Information was disseminated to more than 7,600 people at resource fairs, and more than 15,000 P&A publications and program

brochures were distributed. The P&A website, which also posts all agency publications in accessible printable formats, received over 129,486 hits during the 2016 fiscal year and more than 50,790 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 2015-2016

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 and advocate for persons with disabilities when those civil rights were violated. 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;
- Meeting with policymakers to clarify statutory language that excludes the use of restraint and seclusion as a routine component of a child's educational program;
- Participating in Campaign 2020, a project to close institutions for people with intellectual disability in Connecticut;
- Advocating for access to a private and independent ballot for voters with disabilities at polling places, Election Day Registration locations and referendums.
- 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;
- Celebrating the 25th Anniversary of the Americans with Disabilities Act (ADA) through a series of "Ask the Advocate" events and presentation. The agency also educated through "25 Facts for 25 Years," a question and answer series created to build understanding of the ADA over a 25 day period. This is still available on the website.
- Developing a Customized Employment Collaborative, inviting other agencies and

organizations to collaborate in educating the public and creating opportunities for providers to receive certification in customized employment.

- 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 emergency management exercises and 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 deaths in facilities run by the Department of Mental Health and Addiction Services (DMHS) and meeting with DMHAS officials when the deaths resulted from deficiencies of care;
- Educating policymakers on how legislative proposals would positively or negatively affect people with disabilities including proposals on notification of community residences for people with disabilities and modification of special education hearing procedures.

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 Connecticut General Statutes §46a-150 et seq.;
- 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;
- Ensuring accessibility of Connecticut's buildings and facilities by ruling on requests for 94 waivers from the accessibility provisions of the state building code and 38 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 3,200 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;
- Collaborating with other agencies to provide intensive leadership training for people with disabilities and family members resulting in a cadre of new disability leaders for Connecticut;
- 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

Under 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 2015 P&A Annual Report:

Frequent Use of Restraint and Seclusion: In Connecticut, people with disabilities of all ages are subjected to restraint and seclusion. For years, restraint and seclusion were routinely included in a child's educational plan, creating psychological and sometimes physical injury. Over the past several years, legislation passed that prohibits the use of both restraint and seclusion in educational settings. P&A, however, continues to receive calls from families whose children are being restrained or placed in time-out to handle behavioral issues. School systems worried about cost are not providing children with Functional Behavioral Support Plans and Behavioral Intervention Plans that focus on learning about situations that trigger behaviors in a child, de-escalating such situations and rewarding positive behaviors. These children are punished for behavioral incidents which can escalate behavior and lead to restraint and seclusion. Such incidents are also occurring at Connecticut's juvenile training school and residential treatment facilities.

Adults with disabilities are also subjected to restraint and seclusion. P&A receives calls from people with psychiatric disabilities who report that they are being medicated against their will. Some callers report spending extensive time in mechanical restraints while

others are placed in small bare seclusion rooms. None of these methods are therapeutic, and in the long run, only harmful.

Employment: In Connecticut, people with disabilities experience higher unemployment than the general population. They are also under employed, finding it difficult to find jobs and employers who recognize and are willing to pay for their skills. Employers often do not understand their legal obligations under state and federal disability law, leading them to fail to provide the job accommodations necessary for equal employment opportunity. Private providers are still allowed to operate sheltered workshops where people with intellectual disability are paid less than minimum wage. These workshops are based on low expectations about people with disabilities rather than their ability to work. As recent court decisions have upheld, they also violate the integration mandate of the Americans with Disabilities Act. Until these workshops are closed and the state adopts customized employment, workshops will continue to oppress and segregate people with disabilities.

Housing: Connecticut continues to experience a significant shortage of affordable, accessible housing for persons with disabilities. Existing accessible rental housing is extremely limited for families, tending to be structured as one or two bedroom units. Programs such as Money Follows the Person that are designed to move people from long-term care to community settings can't find accessible living arrangements hindering progress in moving people from institutional settings. Building codes must continue to require that a percentage of new housing units be adaptable and accessible for people with disabilities. They must ensure that that accessible features be maintained throughout the life of the housing and outdoor weather elements, such as ice and snow, be removed from ramps and paths of travel.

Additionally, people with disabilities are subjected to discrimination in the sale or rental of housing due to the assumptions made by landlords and management companies. Landlords and condo associations often refuse to allow residents with disabilities to make modifications to their homes that will allow them equal opportunity to use and enjoy the unit. Tenants with service or support animals often are told that they cannot have a pet or that their service animal must be limited in size.

Unnecessary Institutionalization: Connecticut currently maintains six state institutions, Southbury Training School and five Regional Centers, where approximately 500 individuals with intellectual disabilities reside. Connecticut chooses to maintain these six segregated institutions, even though in 1999, the United States Supreme Court, in the Olmstead v. L.C. decision, ruled that segregated institutions violate the Constitutional rights of individuals with disabilities to live in the community as fully participating members of society. State-operated institutions cannot be justified morally or legally. There are 15 states that no longer have institutions and people with the same type and severity of disability as those in Connecticut's institutions, live in community. Until the political will in Connecticut changes to come in line with current societal norms, people with disabilities will be subjected to institutional segregation rather than being valued members of their communities.

Education: P&A receives hundreds of calls each year from parents, and family members disappointed with the educational outcomes for their children and frustrated with the continuous struggle to obtain an appropriate educational program. Schools are obligated to provide each child who receives special education services with a “free, appropriate, public education” (FAPE) in the “least restrictive environment” (LRE). This obligation exists despite the cost of providing such an education, but this struggle causes school systems to fail in conducting required evaluations, and developing individualized services and implementing them in an inclusive environment. Areas of particular concern include:

- 1) Inadequate Evaluations: An inappropriate educational program often begins with an inadequate evaluation. Parents/guardians contact P&A when their child is not doing well in school and often P&A staff discover that the educational program is not based on evaluations or that the evaluation performed was not diagnostically comprehensive or was performed by an experienced professional. 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, communication disabilities, autism spectrum disorders, developmental disabilities, and significant emotional distress are being short-changed.
- 2) Lack of Appropriate, Effective Transition Planning – School systems are required to assist a student who requires special education services with planning for transition from school to work or post-secondary life. The federal law requires the planning to begin at age 14 and continue until the student leaves school or age 21. In some cases, the school does not provide any type of transition plan and in others, the student is sent to an already existing program that does not take into account his or her interests, preference, strengths and abilities. Students leaving school are not prepared to leave, to work and manage their own lives.

Architectural Barriers: State and federal building codes require structural accessibility for persons with disabilities. They also require that services and programs of state and local governments be accessible to people with disabilities. Places of public accommodation such as restaurants, medical offices and other public places, must remove structural and policy barriers to accessibility. These standards, however, often fall short because they are the result of compromises by drafting committees. Municipal building inspectors are often unfamiliar with accessibility provisions of the code and do not understand its nuances, resulting in dangerous structural features. Requirements for state and local governments do not require structural accessibility and, therefore, many public buildings and municipal pathways remain inaccessible for people with disabilities. Lack of resources for enforcement of these codes allows many places to remain unchanged.

Transportation: Connecticut's transportation infrastructure has always created difficulty for people with disabilities. While paratransit services required by federal law and the addition of accessible taxis in the New Haven and Hartford areas have improved transportation opportunities, travel to rural parts of the state remains almost impossible. Many towns have dial-a-ride services within their municipality, but it is still tremendously difficult to arrange transportation between different regions. This limits the choices for people with disabilities, choices of medical providers, choices of where to shop, choices of when or where to participate in community activities.

Mental Health Services: For the past several years, mental health services have come under increased scrutiny due to the number of shootings at schools and other public places around the country. In response, House Resolution 2646, Helping Families in Mental Health Crisis Act, was introduced by Congressman Tim Murphy of Pennsylvania. HR 2646, also known as the Murphy Bill, contains many provisions that would restrict the rights of persons with disabilities and discriminate against people with disabilities in housing, education, employment. Fewer people with mental illness will receive the treatment and supports they need. The bill offers states financial incentives to implement Involuntary Outpatient Commitment laws that would result in more people being forcibly medicated. The Murphy Bill also permits the release of an adult's diagnosis, treatment plans, medication plans and other information to family members even if the person objects to the release of his or records. Other provisions weaken "peer specialist services" and restrict the activities of the Protection and Advocacy for Mental Illness (PAIMI) programs across the United States including the PAIMI program in Connecticut. These regressive provisions and others in the Bill would significantly degrade the rights of people with mental illness.