



Message from the Executive Director

2003 has been a difficult budget year for government agencies and human services programs across the country. In Connecticut, layoffs, early retirements and funding reductions have taken a toll, and P&A did not escape their impact. However, despite our reduced capacity, we continue to achieve great things.

During 2003, the Office of Protection and Advocacy for Persons with Disabilities (P&A):

- Provided information concerning disability rights and services to over 5,000 callers and delivered advocacy representation services to over 1,000 individuals.
- Received and acted on 1225 reports of abuse and neglect of persons with mental retardation, and 12 allegations of serious injuries resulting from the use of restraints on individuals with other types of disabilities.
- Implemented provisions of Public Act 03-146, requiring P&A to directly conduct investigations into the deaths of persons with mental retardation where abuse and neglect are suspected. P&A also supported investigations conducted by the Fatality Review Board for Persons with Disabilities (established by Executive Order #25), and published two major investigation reports concerning the deaths of individuals in state care.
- Completed compliance monitoring in Connecticut Association for the Deaf v. Middlesex Hospital et al., a class action brought by P&A to secure rights of deaf people to effective communications in hospital settings. The consent decree that settled the case was signed by every acute care hospital in Connecticut and the federal Department of Justice. Under the auspices of the Connecticut Hospital Association, the hospitals pooled resources to establish an on-call system that ensures the availability of sign language interpreters and other accommodations for deaf and hard of hearing persons.
- In collaboration with the Department of Health and the Connecticut Women and Disability Network, supported passage and launched implementation of Public Act 03-40, to develop recommendations concerning provision of gynecological services to women with disabilities, and ensure routine screening examinations for women served in state operated or funded facilities.

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- Provided ongoing support to organizing and education efforts of parent advocacy groups operating in Latino and African/Caribbean-American communities in the greater Hartford area.
- Prevailed in a federal court action to enforce P&A authority to access records of inmates who commit suicide in prison.
- Sponsored forums on “Eliminating Restraints and Seclusion”, and “Interrobust: Breaking Down Barriers to Genuine Community Inclusion”.
- In conjunction with the Council on Developmental Disabilities and the UCONN A.J. Pappinikou University Center for Excellence, formed the Connecticut Developmental Disabilities Network, a formal collaboration intended to foster leadership and communications amongst advocates and programs serving people with disabilities, and improve awareness of disability issues amongst policy makers and the general public.

While these accomplishments reflect significant progress in a number of areas, there is still much more to do. As required by statute, the last section of this report identifies a number of emerging issues that affect services and civil rights for Connecticut citizens with disabilities.

P&A MISSION STATEMENT

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

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

Introduction to the Office

The Office of Protection and Advocacy for Persons with Disabilities (better known as “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. Through its work, P&A aims to make people with disabilities and their families better informed, supported and equipped to advocate for themselves and others.

Part of a nationwide network of protection and advocacy systems, P&A’s federal mandates require organizational independence from service providing agencies and confer authority to access records, conduct investigations, pursue legal remedies, and educate policymakers.

P&A Programs -

Sections 46a-11 et seq. of the Connecticut General Statutes (C.G.S.) articulate the purpose of P&A under state law, and specifically authorize:

- advocacy, including legal advocacy, on behalf of individuals with disabilities;
- investigations concerning reports of alleged abuse or neglect of adults (ages 18-59) with mental retardation;
- investigations into general complaints made by, or, if in writing, made on behalf of people with disabilities;
- community development and public education activities, such as community organizing, training, technical assistance and support to community-based advocacy/disability/family support organizations;
- information and referral services, connecting callers to the appropriate P&A unit, and providing short-term advocacy assistance.

Other sections of the Connecticut statutes authorize P&A to review, in conjunction with the State Building Inspector, requests for exemptions from the accessibility provisions of the State Building Code (C.G.S. Section 29-269), and requests for approval to install wheelchair lifts in most types of buildings (C.G.S. Section 29-200), and to review, in conjunction with the Secretary of State, requests for exemptions from polling place accessibility requirements (C.G.S. Section 9-168d).

Executive Order No. 25 - P&A has recently been assigned additional investigation responsibilities under Executive Order #25, and Public Act 03-146. Executive Order No. 25 created the Fatality Review Board for Persons with Disabilities (FRB). The FRB is chaired by the P&A Executive Director and conducts full, independent investigations into the circumstances surrounding certain deaths of DMR clients. The FRB is comprised of representatives from health care, human services and law enforcement agencies. Its investigations, which result in public reports, are supported by a P&A staff member. In addition, Public Act 03-146 requires the P&A Abuse Investigation Division (AID) to conduct investigations into the deaths of DMR clients when abuse or neglect is suspected to have contributed to the death. These abuse/neglect investigations are conducted in accordance with the existing statutory requirements.

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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)</p>	<p>PABSS Program (Section 1150 of the Social Security Act) is the most recent addition to the federally funded P&A programs. 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>

New federal mandates for Voting Rights and people with Traumatic Brain Injury were added during 2003.

Support to Individuals and Families

The Office of Protection and Advocacy for Persons with Disabilities supports individuals and families through high quality, current information and representation related to disability rights and resources. The Consumer Information Unit responded to disability-related questions from individuals with disabilities, their families, legislators, municipal officials, employers, architects, advocates and other interested members of the public. P&A staff members also provided short and long-term advocacy interventions consistent with its state and federal statutory mandates.

During the 2003 fiscal year, P&A and two of its subcontractors responded to 5,573 requests for information and referral (I&R) services and short-term interventions. In addition to screening the 351 new cases accepted for advocacy representation, Consumer Information advocates answered 499 housing inquiries related to fair housing issues, landlord/tenant disputes, accommodations, rental termination, and zoning. They also responded to questions concerning access to services (440), education (388), abuse and neglect (322), personal decision making (244), employment (230), rehabilitation services (212), financial entitlements (196), healthcare (191), transportation (124) and assistive technology (93). 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 and daycare.

In addition to support provided through information and referral and short-term intervention services, 1,081 individuals with disabilities received advocacy representation from P&A advocates, attorneys and subcontractors. These individuals included 176 persons with psychiatric or emotional disabilities, 97 with mental retardation, 49 with learning disabilities, 37 with orthopedic impairments, 17 with neurological disabilities, 13 who are deaf or hard of hearing, 11 with blindness or visual impairments, 10 with autism, 9 with brain injuries, 5 with diabetes and 3 with substance abuse issues.

Individuals receiving advocacy representation services from a P&A advocate or attorney presented 625 distinct advocacy issues. One hundred sixty eight (168) of these issues involved abuse or neglect, 124 involved vocational rehabilitation, 112 involved access to services, 86 involved education programs and placements, 33 involved housing, 26 involved personal decision-making, 19 involved healthcare and 14 involved employment. The remaining issue areas included assistive technology, transportation, recreation, daycare, and financial entitlements. Fifty (50) percent of the individuals represented were Caucasian, 13% Hispanic, 12% African American, and 2% other. Twenty three (23) percent did not report ethnicity.

Tim's Story

It was late on a Friday before a long holiday weekend when an advocate from the state of Washington called P&A seeking advocacy for a gentlemen who recently moved to Connecticut (CT). Tim is a 34 year old man with quadriplegia who is dependent upon a ventilator to breathe. To maintain his health, he requires the services of nurses twenty four hours a day, seven days a week.

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Tim moved to CT to get married. Two days before the wedding, he received a notification from the State of Washington that the nursing services they had committed to provide him until he had fully transitioned in CT would be terminated on Saturday. This included compensation for the two nurses that provided him with the pulmonary and other health care he needs to safely maintain himself in the community. The advocate from Washington stated that she had exhausted all avenues to prevent the termination of services. If the nurses left, Tim would be in a life treating living situation in twenty four hours. Due to the lateness of the call and the pending holiday, all governmental agencies were closed. The P&A advocates desperately tried to locate services for Tim in CT, but without success.

After several conversations with Tim and telephone calls to Washington, I&R staff persuaded the advocate in Washington to pursue additional efforts in that state and negotiated with the nurses to stay with Tim through the weekend.

The following week, P&A advocates received a message from the advocate from Washington informing P&A that the Washington Social Services agency had its plan and was following through on their commitment to continue nursing services for Tim.

P&A also utilized a variety of methods to disseminate information to individuals and families:

- Training –
P&A sponsored or actively participated in 92 training opportunities including media events, workshops, conferences, fairs, presentations, and focus groups. Approximately 2,300 individuals received training on topics including, the Americans with Disabilities Act, special education, fair housing, employment, assistive technology, disability awareness, disability rights and resources, diversity, gynecological services for women with disabilities, community isolation of persons with disabilities, Ticket-to-Work, voting, P&A services, basic disability law, and current issues in disability. Over 5,000 P&A materials and other publications were distributed during these trainings.
- Internet site-
The P&A website, www.state.ct.us/opapd, continued to be an important resource for individuals with disabilities, their families and members of the general public interested in basic disability rights and information. The site is updated with a weekly posting of current disability news and information. The site also contains P&A self help literature, information about P&A programs, reports on developments in the field of disability rights on the state and federal levels, related sites of interest, and a summary of disability laws. Links to relevant bills and public acts are available during the Connecticut legislative session. Individuals may mail questions or request information or publications through an e-mail link located on the Internet site. During 2003, the P&A website received 56, 262 hits.

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- Publications –
During 2003, P&A staff have developed a series of self help booklets geared toward consumer empowerment. 3,295 booklets were disseminated. These publications answer basic questions about frequently asked disability issues. The booklet series currently includes a Disability Resource Directory; Building Accessibility; Access to Your Medical Records; Accessible Travel; How To File a Complaint with CHRO; Your Rights in a Psychiatric Facility; About SSI; Connecticut Fair Housing Laws; Your Rights and Responsibilities in Making Medication Choices; Your Rights to Vocational Rehabilitation; An Concerning Physical Restraint of Persons with Disabilities (PA 99-210); Conservatorship of Person and/or Estate; and Guardianship for People with Mental Retardation. All of these booklets are available at P&A, on the P&A Internet site and can be requested in alternative formats.
- The PABSS program recently completed work on two booklets designed to assist persons with disabilities gain or maintain employment. The first booklet is a question and answer publication concerning the Ticket-to-Work. The second booklet teaches Social Security beneficiaries how to approach employment networks once they have received a Ticket-to-Work.
- Special Education is Not a Place, a 79-page family resource manual, is designed to assist parents and other family members of individuals with disabilities in obtaining necessary educational supports for their children. Three hundred and thirty two (332) copies were distributed to individuals with disabilities, parents, and educators located in all areas of Connecticut. P&A continues to receive a high volume of requests for this resource.
- Organizing Parents: Building Family Advocacy Organizations, a 45- page parent organizing guide, includes chapters on "What is a Parent Advocacy Group", "How to Establish a Parent Advocacy Group", "Establishing a Non Profit, Tax Exempt Organization", "Fund Development", "Meetings and Decorum", and "Supporting Parents and Creating Systems Change". Fifty two (52) copies of this manual were requested and distributed to parents, self advocates and special education professionals.
- ADA Toolkit –
In response to employment related inquiries received by P&A, an expandable ADA Title I Toolkit is being created by the PABSS program. The toolkit will be used to train people with disabilities about their employment rights under Title I of the Americans with Disabilities Act. It will provide information about means of redress if such individuals experience employment discrimination. The basic information will include, but is not limited to, employment and disability related definitions; qualifications of who is covered under the ADA; reasonable accommodation; disclosure; confidentiality; employer rights to medical information; and sample letters.

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- Partners in Policymaking – P&A collaborated with its Developmental Disabilities Network partners, the University of Connecticut Center for Excellence and the Developmental Disabilities Council to complete the sixth year of Partners in Policymaking in Connecticut. The six month training is designed to provide self advocates and parents of persons with disabilities with information, training and leadership skills needed to access and effectively navigate community resources. Graduates of the program are community leaders, members of state and local boards and advocates for legislative and policy change.
- During 2003, P&A focused on responding to inquiries from individuals who are deaf or hard of hearing. The majority of the issues focused on access to interpreter services including the right to an interpreter in various settings such as educational facilities and places of public accommodation. Other issues also included access to appropriate services after discharge from an institution. P&A advocates provided information and technical assistance regarding the right to services and the procedures for filing complaints under the Americans with Disabilities Act and other applicable state and federal statutes.

Ed's Story

Ed is a 21 year old student who has hyperlexia, a disability that is manifested in significant problems in language, learning and social skills. As a student, Ed was placed in an internship that evolved into a full-time permanent position upon graduation from high school. This position required accuracy in processing numbers and checking for errors, all skills in which Ed was amazingly proficient. Ed successfully held this office job for two years until it was eliminated due to downsizing.

Ed applied for BRS services to receive additional office training that would enable him to expand his office and computer skills, thereby increasing his marketability. Ed contacted P&A's Client Assistance Program (CAP) when he encountered numerous problems with BRS eligibility. CAP attended meetings with Ed to advocate for the development of an appropriate employment plan based on Ed's abilities and interests. The BRS counselor would not approve any educational training programs for Ed that focused on working in an office environment. The counselor seemed locked into preconceived ideas about his client's disability as it negatively related to employment potential. CAP assisted Ed in requesting a new counselor. In the interim, alternative funding was located for a supported education training program for business office technology at a community college.

Ed has since graduated from the supported education training program. He was recently hired for a part-time position as a website consultant. He is responsible for making changes to a weekly website. His keen eye for any discrepancies and accuracy with inputting website material has made him a valuable asset to his company. His new BRS counselor has been very supportive in providing necessary services for Ed to maintain his new position.



Maureen's Story

Maureen contacted the PABSS program in March of 2003. She was having trouble getting her employer, a major supermarket chain, to reinstate her to her job. In January 2003, Maureen took a leave of absence because of an exacerbation of her disability. Maureen relied on her right to take a leave of absence under the Family Medical Leave Act. Her doctor gave her medical clearance to return to work as of March 2003, but the store refused to reinstate her to her former position. The PABSS advocate contacted Maureen's doctor who confirmed that Maureen was cleared to return to her job, provided certain accommodations were made to make the workstation accessible to Maureen. The manager of the store where Maureen was employed was contacted to assist her with returning to work. He stated that he could not provide any accommodations that would enable Maureen to return to her former position.

The PABSS advocate then contacted the supermarket chain's regional ADA Coordinator, a person whose assignments include coordinating accommodations under the Americans with Disabilities Act (ADA) for employees who have disabilities. There was a meeting to explore options. The chain agreed to bring in an expert to identify how Maureen's workstation could be modified to accommodate her disability. The expert determined that it was not possible to modify Maureen's workstation because of space constraints. The advocacy continued and a position at a near-by store was identified where modifications could be made to accommodate Maureen's needs. The workstation was modified so that Maureen could successfully perform all the duties of that job. Maureen was placed in that position and was reinstated to the company without a break in service.

Amy's Story

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Amy, a 37 year old woman who has a severe language processing disorder and dyslexia, which affected her ability to write. As a police officer for the past three years, she has been required to write reports for accidents, investigations, tickets, arrest and search warrants. Although she would take an additional four to five hours, without pay, to write reports, her supervisor had written her up for the poor quality and sequencing.

Amy requested assistance from her employer and the Bureau of Rehabilitation Services (BRS) for tutoring to improve her writing skills, and a laptop computer with related software to assist her with her job. Both BRS and the police department refused to provide these items. She was told by BRS that if her employer continues to refuse to provide the accommodations she should find a new job. Amy was also concerned about pushing the issue with the police department, as she was already felt pressure being a female in a male orientated profession. Amy did not want to change professions. Any assistance provided would have to be worked into her schedule naturally as not to draw further negative attention to herself.

Amy contacted P&A Client Assistance Program (CAP) for assistance. CAP arranged an informal meeting with the BRS counselor and supervisor. BRS agreed to pay for tutors. BRS also agreed to pay for a rehabilitation engineer to visit Amy's work site and make recommendations as to the type of assistive technology that would be useful in her position as a police officer. BRS stated they would not commit to paying for any assistive technology (AT) device but would consider possibly sharing the cost with the employer.

A rehabilitation engineer report was generated and recommendations were made that would assist Amy in the performance of her duties. A laptop computer proved not to be the best AT device available for her particular situation. It was recommended that she use a personal digital assistant (PDA) that had specialized software and sketch programs installed that were developed for patrol officers who are working in the field. The sketch program allowed her the opportunity to draw information regarding accident scenes she was investigating.

Amy was told by BRS to contact her employer, under the ADA, to request payment for this device. Amy did not want to draw further attention to herself or her disability by making this request of her employer. She contacted CAP for assistance in making this request of BRS. Through negotiations with the district director and supervisor, BRS agreed to purchase this device on condition that any further AT requests would be submitted to her employer. Amy agreed to these conditions and received this equipment to assist her with her job performance.

James' Story

James is a twenty one year old African-American man with physical and psychiatric disabilities. His paraplegia was caused by an accidental self-inflicted gunshot wound at age three. James was

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subsequently removed from his home by the Department of Children and Family (DCF). In DCF custody, James experienced constant change, moving between eight different placements.

During his developmental years, James accumulated a number of diagnoses including: Post Traumatic Stress Disorder (PTSD), Intermittent Explosive Disorder, Pervasive Developmental Disorder, Major Depressive Disorder, cognitive and language disorders, possible head trauma, seizures, personality disorder, and he engaged in self-injurious behaviors. Due to his challenging behaviors, he lived apart from his biological family with minimal contact from age three until age eighteen.

At the age of eighteen, DCF initiated the development of a group home for James in a rural town in CT. He lived there approximately one week. A hostile interaction between James and the staff resulted in hospitalization in a state psychiatric facility. This hospitalization changed from short-term to long-term when the provider refused to take James back into the group home. At the same time, noticing that James was now 18 years old, DCF sought to transfer responsibility for his care to the adult mental health system.

Neither DCF nor the Department of Mental Health and Addiction Services (DMHAS) could identify an appropriate placement for James. The state agencies turned to the Judge Rotenberg Center in Massachusetts. The Judge Rotenberg Center is the former Behavioral Research Institute which has historically used aversive stimuli to manage an individual's behavior. It is an extremely costly program, and did not afford James the opportunity to be reunified with his family in CT. State agency staff toured the center with the goal of placing James in the facility. However, at this point, James was referred to PAIMI. The PAIMI advocate met with James and immediately challenged this out-of-state placement plan by pressing the administration of the two state agencies to create a program in CT.

Successful in stopping the proposed out-of-state placement, James' PAIMI advocate continued to intervene over the course of almost two years. Monthly meetings were held involving all parties including James' mother. James and his family had begun the process of reunification. This reunification began to drive the outcome of James' need for a place to live. An outside behavioral consultation was sought and this consultant supported James' desire to live near his family.

Negotiations between DCF and DMHAS involving funding issues and provider selection slowed down the progress of James' move to a home in the community. A provider was finally selected based upon their plan to provide a home and all the services and programs needed by James. This provider purchased a home and made all the architectural modifications needed for accessibility. The provider also negotiated with James' mother and siblings to rent the second floor of the home.

James moved in July of 2003 to his own apartment on the first floor of a three family home. His mother and sisters live on the second floor. James attends a work exploration and daily living

skill program and is completing his high school diploma. As of November 2003, James remains living happily in his home next to his family.

Defending the Rights of Vulnerable Populations

The Office of Protection and Advocacy for Persons with Disabilities is required by state and federal statutory mandates to defend the civil rights of vulnerable individuals and groups. P&A staff investigate allegations of abuse and neglect; monitor reports of serious injury or death caused by restraint; and intervene on behalf of individuals whose fundamental rights are at risk.

P&A's mandated Abuse Investigation Division (Connecticut General Statute 46a-11et seq.) received 1,239 reports of allegations of suspected abuse or neglect of persons with mental retardation resulting in 1,225 cases. P&A staff investigated or monitored 1,129 cases. Ninety six (96) allegations did not meet the statutory requirements for P&A investigation. The majority of cases involved allegations of neglect (630) or physical abuse (248). Other case types included injury of unknown origin (98), abuse/neglect (50), sexual abuse (49), abuse (12), willful deprivation (1), abuse/neglect death (1) or other (40).

Investigations often encompassed allegations for more than one victim. The 1,225 cases involved 1,388 victims; 651 females and 737 males. Over 56% of the victims resided in group homes (786) while 17% (241) lived in the family home. Victims also resided in a supervised living arrangements (87), community training homes (56), regional centers (53), Southbury Training School (28), independently (11), foster homes (7), schools (5), and a board and care home (1). Three (3) individuals lived with respite care providers. The residences of 73 victims were unknown.

Beth's Story

Beth is an adult female with a diagnosis of Mental Retardation and Cerebral Palsy who resides in Connecticut. She is nonverbal and uses a wheelchair. At the time that the Abuse Investigation Division (AID) first became aware of Beth's situation, she was living with her brother, sister-in-law and their children. In January, 2003, it was reported that Beth was being sent to her day program with consistently poor hygiene (dirty hair, body odor, thrush, poor dental hygiene) and that her wheelchair was infested with cockroaches.

Five similar allegations relating to Beth were reported to P&A over the next several months. Additional issues were also reported, including a lack of consistent and appropriate supervision at home, excessive absenteeism from her day program and insufficient clothing as it relates to change in weather. Although Beth had a home health aide, involvement from her Department of Mental Retardation (DMR) Case Manager and the day program provider, the investigation indicated that Beth appeared to be residing in a neglectful and potentially dangerous situation.

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P&A Investigators conducted several interviews with Beth at her day program, visited her home environment and attended meetings with her support team in an effort to develop a support plan for addressing the issues of ongoing residential neglect.

AID issued several Immediate Protective Service requests to help deter further neglectful situations while evidence was being compiled. The lack of consistent cooperation on the part of Beth's legal guardian (brother) and sister-in-law, made it difficult to interview everyone in her home. AID was never able to interview the brother, who was said to always be "at work" whenever AID Investigators arrived at the home. The investigation revealed that Beth did not have a home health aide. Instead of receiving the services of a professional home health aide, Beth's sister-in-law was being paid by the Home Health Aide agency to be her caregiver and render hygiene services that she was not providing. Beth's situation was not good: her communication board had been thrown away, making it difficult for Beth to express herself and hindering her ability to learn. She was often being left in the care of adolescents who appeared unable to provide her with necessary services to maintain her mental and physical health, leaving her unclean and unattended. In addition to all this, Beth's home and wheelchair were infested with cockroaches.

As P&A Investigators were uncovering this evidence, Beth's Probate Court hearing for guardianship review was scheduled by her DMR Case Manager. P&A substantiated neglect on the part of Beth's brother and sister-in-law and requested Protective Services be put in place. This finding was presented to the Judge at the Probate hearing. As a result, it was determined in court that Beth was unable to provide for herself in a number of essential areas and that her brother and sister-in-law were no longer providing adequate care for her. The guardianship was changed and Beth was placed in a DMR licensed residential facility. It was later determined that Beth's brother had been incarcerated during the entire time of the investigation. Beth's sister-in-law never disclosed this information and appeared in Probate Court at the guardianship review to advocate for the continuation of the brother to serve as guardian.

In recent follow up, Beth is doing very well, enjoying all new clothes, progressing toward the acquisition of her new communication board and attending day program consistently.

Fatality Review Board for Persons with Disabilities -

In February 2002, Governor Rowland issued Executive Order No. 25 in an effort to bring greater independence and oversight to the fatality review process for people with mental retardation who receive services from the Department of Mental Retardation (DMR). Among the changes the Executive Order created was the establishment of an independent Fatality Review Board for Persons with Disabilities (FRB), which is comprised of experts appointed by the Governor, and is chaired by the Executive Director of the Office of Protection and Advocacy (P&A). The FRB meets once every two months. Its members include Major Timothy Palmbach, a law enforcement professional with a background in forensic investigations; Attorney John DeMattia, a representative from the office of the Chief State's Attorney; Patricia Mansfield, a mental retardation professional with a medical background; Doctor Gerard Kerins and Doctor Kirsten Bechtel, two medical professionals with backgrounds in internal medicine, geriatrics and

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pediatrics. Marcia Noll, the DMR Director of Health and Clinical Services represents the Commissioner of DMR on the FRB as a non-voting member.

The Executive Order also stipulates that the deaths of all persons who are clients of the mental retardation service system be reported to P&A. In accordance with the Order, DMR provides P&A with information on all deaths on a weekly basis, as well as any additional information as requested. In deaths where persons are minimally served by the DMR system, P&A makes contact with family members and DMR Case Managers in order to obtain additional information concerning the circumstances of the individuals' deaths.

Between July 1, 2002 and June 30, 2003, one hundred fifty seven (157) deaths were reported to P&A by DMR. Since its first meeting in September 2002, approximately twenty three (23) deaths have been subject to in-depth review, discussion and monitoring by the FRB. During the same time period, the Executive Director of P&A, in his capacity as Chairman of the FRB, referred four (4) deaths for full investigations.

In October 2003, the FRB issued its first report on the circumstances surrounding the death of a man with mental retardation who died following his admission to a Norwich nursing home. The report tells the story of "Philip Sampson" (a pseudonym), a highly personable and spirited man who lived in a group home run by a private provider, where his complex medical needs were very well managed. After being hospitalized for an acute medical condition, he entered a skilled nursing facility for short-term rehabilitation, which would enable him to return to the group home within a short period of time. Everyone assumed that his healthcare needs would be taken care of in a healthcare environment, but they were not. In fact, the FRB investigation uncovered a long list of problems and alarming oversights at the facility. The FRB made recommendations to the Department of Mental Retardation, Department of Social Services and the Department of Health, which are intended to prevent the recurrence of similar deaths and to effect positive change and improvement in the quality of care and treatment for individuals who are similarly placed. The national ARC distributed the story around the country, alerting member chapters not to assume that people will necessarily be well served in skilled nursing facilities.

Other major activities of the FRB during this past year include:

- P&A and DMR developed and implemented a Memorandum of Understanding, which provides P&A with information on all deaths, and allows P&A full access to client records and information as requested.
- P&A developed collaborative relationships with the Office of the Child Advocate and the Department of Public Health for purposes of sharing information and communicating care concerns.
- DMR provided FRB staff with access to data maintained on the DMR Connecticut Automated Mental Retardation Information System (CAMRIS).
- The FRB adopted by-laws, which were established in accordance with Executive Order No.25.

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- The Attorney General provided FRB members with information and advice on the Health Insurance Portability and Accountability Act (HIPAA), which became law in 1996.

In December 2002, findings and recommendations were issued, which resulted from an investigation conducted by the Legislative Program Review and Investigation Committee pertaining to client health and safety in community living arrangements operated or licensed by DMR. One of the Committee's recommendations was that all deaths where abuse and/or neglect is suspected should be investigated by P&A with appropriate resources. New statutory authority (Public Act 03-146) was passed during the 2003 legislative session, which requires a position to be transferred to P&A from DMR. P&A intends to hire a nurse investigator with these additional resources to support the P&A Abuse Investigation Division, which will be responsible for conducting these investigations.

Advance Directives –

PAIMI participates as a member of a work team including the Connecticut Legal Rights Project (CLRP) and the Department of Mental Health and Addiction Services (DMHAS), which has been initiating the use of advance directives in the mental health system. A manual and a video on advance directives have been completed to be used for public education and promotion of the use of advance directives in CT. The team has also drafted a model policy on advance directives which is now under review by the DMHAS Commissioner and the Office of the Attorney General. Once approved, a statewide initiative is planned including a training of mental health consumers who can assist others in developing an advance directive.

Connecticut (CT) Call to Action: Moving Toward the Elimination of Restraints and Seclusion –

The PAIMI Advisory Council, determined to heighten the awareness and accountability of state agencies and private providers to the dangers of restraints and seclusion, decided to host a CT Call to Action: Moving Toward the Elimination of Restraints and Seclusion. On September 23, 2003, Charles Curie, Administrator of Substance Abuse and Mental Health Services Administration was keynote speaker and presented his national agenda to end the use of restraints and seclusion. The status briefing included all the major stakeholders in CT including state agencies, private providers, family members, advocacy organizations, and most importantly individuals who have directly experienced restraints and seclusion. The full day event was broadcast over a cable station located at the State Capitol.

The day was also served as a tribute to the individuals who died in CT due to the use of restraints. Their pictures and stories were prominently displayed. A group of adolescents from a private residential program received recognition for their poster designs. These posters are currently being used to give other young adults advice on their rights regarding the use of restraints and seclusion.

Transitional Youth –

During the summer of 2003, employees within the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program were alerted to an action by the Department of Mental Health and Addiction Services (DMHAS) to close its transitional youth cottage program operated by

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Capitol Region Mental Health Center (CRMHC). PAIMI, in collaboration with the Connecticut Legal Rights Project sought to advise the nine young people on their rights and to advocate for their needs. Meetings were held with the administration of the program and the young adults to determine the most appropriate settings to meet their needs. Several of them chose to move to other parts of the state and into supported housing programs. With five young adults remaining, the program was targeted to relocate to a remodeled section of CRMHC in Hartford. As time passed, and the remodeling was occurring, plans drastically changed. The need for additional substance abuse beds for Blue Hills Hospital became a priority. The youth were displaced by this need, allowing them to remain in the current home for an indefinite period of time. Long-term plans involve relocating to a more community based supported housing arrangement.

Restraint and Seclusion Reports –

Under C.G.S. §46a-150 et seq., P&A receives reports of serious injuries and deaths from Department of Children and Families (DCF), Department of Public Health (DPH), Department of Mental Health and Addiction Services (DMHAS), Department of Education (DOE), and Department of Mental Retardation (DMR). During 2003, P&A received twelve reports of serious injury or death due to the use of restraint and/or seclusion. Nine children and three adults were injured. The majority of the reports of serious injuries came from the private providers in the DCF service system. No deaths were reports.

The Criminal Justice Collaborative –

In response to a growing concern about people with developmental disabilities in the criminal justice system, P&A was invited to participate in the Criminal Justice Collaborative sponsored by the University of Connecticut Center for Excellence in Developmental Disabilities. The goal of the Collaborative is to foster a better capacity for the criminal justice system to accommodate the needs of people with developmental disabilities. Other state and private participating agencies include: the Department of Mental Retardation, Department of Correction, Office of the Public Defender, Office of the State's Attorney, Department of Social Services, Office of the Child Advocate and Victim's Advocate, ARC CT, the Father Gengras Center for Justice, Friends of Retarded Citizens Connecticut, and the Sheriff's Association. Many interested individuals are also involved in the Collaborative.

Although the Collaborative is a new effort, working groups were immediately formed. Each group focuses on an aspect of the criminal justice system. Focus areas include juvenile issues, the courts, corrections, police and victims issues. Members of the groups are working together to develop an action plan.

Mario's Story

Staff at the hospital were frustrated. Mario was once again admitted for treatment due to behaviors relating to his mental illness. He was homeless and acting out in the community. Police were called and the ambulance took him to the hospital. His Department of Mental Health and Addiction Services (DMHAS) clinician shared her frustration; the hospital could treat him and help him recover but then he would be discharged back to the streets without services.

Mario had no benefits. His Social Security and Department of Social Service entitlements were abruptly discontinued because of an outstanding out-of-state warrant for his arrest. Under federal law Mario could not get services paid by entitlements until the warrant was removed. His conservator was unable to assist him in obtaining the supports he needed once he left the hospital.

The DMHAS clinician tried to resolve the problem and learned the nearly five year old warrant was for violating a misdemeanor conviction. The term of probation had been less than one year. She contacted the court that ordered the warrant and explained the tenuous situation. She was advised that Mario would have to return to that state and turn himself in. Even if MS was competent and able to decide to turn himself in, he had no means of traveling the one thousand plus miles. The court offered no assistance. The DMHAS clinician contacted the PAIMI program to advocate for Mario to regain the benefits he needed. After meeting Mario and the PAIMI advocate contacted the out-of-state court. The advocate also communicated with Mario's conservator, the Probate Judge in CT who ordered the conservator and the CT Judicial Department's Court Support Services. Connecticut probation officials responded that they could supervise Mario's probation if the other state requested it. While the conservator indicated he had limited responsibility concerning Mario's well being, the Probate Judge expressed a strong interest and scheduled a hearing to consider what could be done to resolve the matter. The probation office in the other state expressed interest in contacting their Connecticut counterparts. Despite this support, the response from the out-of-state Judge to the PAIMI advocate's letter identifying the seriousness of MS's mental illness was abrupt. Mario would have to return to that court and face charges on violation of probation.

In the meantime, Mario was discharged from the hospital. He disappeared for several weeks until he entered a homeless shelter. By that time, he had run out of medication and was having difficulties. The cycle repeated itself again. The police were called. Mario was hospitalized and the slow progress to recovery began. Fortunately, the DMHAS clinician arranged a temporary stay at the Local Mental Health Authority's Respite program. At the same time, the Probate Judge held a status hearing and made a commitment that he would contact the court and see if he as a judge could come to an understanding on the matter. This time the response was positive. The out-of-state judge vacated the arrest warrant and the DMHAS clinician helped reinstate the necessary entitlements.

Carlos' Story

Carlos is a 36 year old man who was severely injured in the mid-1980's when he was involved in a motorcycle accident that left him comatose for several days. Although Carlos regained his physical skills, his progress was blocked by an acquired brain injury (ABI) that contributed to poor impulse control and low tolerance for frustration. By the end of the 1990's Carlos was a regular user of alcohol and cocaine, was estranged from his family, had been arrested several times and was homeless. When he appeared at Superior Court for violating probation, the judge

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noted Carlos needed help and prison was not the appropriate place for him. Unfortunately, the Judge felt he had no choice but to sentence Carlos to time in jail. While he was in prison, Carlos' behavior was problematic, causing him to move to mental health units in different facilities and limiting the range of service he was offered.

As Carlos neared the end of his sentence, the social workers in the prison worried he was at risk of continuing his disruptive behaviors. He was referred to the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program to provide advocacy for the services and supports he needed upon release from prison. The PAIMI advocate helped Carlos plan for his future, get his entitlements reinstated and connected him with a program that could help support him. P&A also contacted the Department of Mental Health and Addiction Services ABI program and facilitated a collaborative effort between DOC and the ABI program. A private provider was contacted and a transition plan developed. Carlos was released from prison to a residential rehabilitation program. He has been living in an apartment with twenty four hour supports that will be available to him for many months. He is learning new coping skills, seeking employment and working toward his future.

- Pepperspray Case -
In September 2003 P&A and the Center for Public Representation in Massachusetts filed a case in Federal District Court on behalf of a client who had been peppersprayed in the emergency room of Middlesex Hospital. This client was known to the ER as a consumer of psychiatric services, yet on this occasion she was visiting the ER because of a physical problem. Nevertheless, despite her statements that her only problem was her knee, the hospital attempted to hold her in the ER until she could have a psychiatric evaluation by the Mobile Crisis Unit. When she decided to leave rather than wait for this evaluation, she was peppersprayed and restrained. Using its federal authority, P&A filed a lawsuit seeking damages on behalf of the client and a cessation to the use of pepperspray.
- P&A is also involved in efforts to ensure that prisoners with serious mental illness are not subjected to harsh disciplinary treatment because their disabilities create difficulty adhering to prison rules.
- OPA v. Armstrong –
On March 21, 2002, the District Court of Connecticut ruled that the failure of the Department of Correction (DOC) to grant P&A access to the records of prisoners who had committed suicide while in the custody of DOC violated the PAIMI Act. OPA v. Armstrong, 266 F.Supp.2d 303 (D. Conn. 2002). The court ruled in favor of P&A on all the issues raised by DOC, including the important question that P&A was not required to make a threshold showing that the prisoners in question had mental illness before accessing their records. The court accepted the P&A's argument that "evidence that a facility has previously housed individuals who are mentally ill, as well as evidence that some current residents may be mentally ill is sufficient under PAIMI to merit access by [P & As]." Id. at 314. The court also accepted P&A's argument that "even if an individualized assessment of each inmate was necessary--a requirement that the Court does not impose today--the fact that seven of these

eight inmates committed suicide certainly suggests that each suffered from some sort of mental illness or condition.” Id.

The court also agreed that prisons are facilities within the authority of PAIMI, that there is no requirement for P&A to seek permission from any legal representative of the deceased prisoners, and that P&A is the final arbiter of “probable cause” for investigation under PAIMI and that DOC may not seek to question P&A’s probable cause determination. DOC decided not to appeal this decision, and it stands as an important victory for P&A access. P&A attorneys litigated this case.

Sam’s Story

Sam has lived all but the first 5 years of his life at Southbury Training School. Now he is in his mid 50’s, and he’s starting to show a little of the wear and tear that goes with age. Most of the wear and tear in his life is probably of the sort that no one sees, and no one will ever even know. There must have been a lot of lonely days and scary nights for a little boy in the big, bustling institution, an institution that still provokes controversy amongst advocacy groups. Controversy aside, there is little dispute that the shifting, turning, and management needs of any bureaucracy can sever relationships abruptly, put a person under the care of strangers, or introduce meaningless “programs” that may make sense on paper to an outside reviewer but not to their intended beneficiary.

Southbury Training School is the world that Sam has known for many years. Much more is being done for him now than ever before: he sees every imaginable kind of doctor, there are behaviorists, psychologists, speech pathologists, physical therapists, dentists, neurologists...and the list goes on and on.

So what is this “advocate” doing now, appearing on the threshold after all these years? How can anyone attempt to be more than just another person from the State, a redundant member of his interdisciplinary team?

Perhaps the “advocate” in this case can best serve Sam by helping to remind all these other people of who Sam is and the common humanity we all share with him. His team members are well meaning. Many of them know more and care more about him than everyone else in his life. But the rhythms and rituals of planning and delivery of care sometimes capture the minds of caregivers as much as they define the lifestyle of their clients. The advocate can say, again and repeatedly, that it is not acceptable for an adult human being in his 50’s to just “wait out his days”. Don’t most people in there 50’s look forward to retirement soon, following life long dreams and renewing treasured relationships?

An advocate can remind others that it is not acceptable to center a man’s life around who is monitoring him day to day to try to prevent him from being physically injured; that the principal goal ought to be more than ensuring that there are no more embarrassing accidents or injuries; that keeping Sam in near isolation and wearing a helmet all day is not a great life.

Perhaps some of the things that are frustrating to staff are frustrating this man also; the opening and closing of cottages, interpersonal squabbles amongst staff, and changing institutional expectations. What would it take to free this man from all the baggage of the institution, and allow him to try another kind of life?

Support for Community Advocacy & Coalition Building

Community Development staff responded to 44 calls for information and materials specific to community organizing, including how to start and manage a disability nonprofit organization, grant writing and fund raising. Support and consultation services were provided to public agencies and nonprofit organizations with missions of advocacy, self-empowerment and representation of families and persons with disabilities. These groups include the CT Women and Disability Network, CT Lifespan Respite Coalition, CT ADA Coalition, Parents Available to Help (PATH), City of New Haven Office on Disability, CT Department of Public Health, People First of Connecticut, ARC/Padres Abriendo Puertas of Lower Fairfield County, Manes & Motion, and Boundless Playgrounds. P&A Staff helped grassroots disability organizations raise more than \$85,000 in grants.

Support for two parent advocacy groups from minority communities, and a citizen advocacy program in eastern Connecticut continued to be key elements in P&A's community development strategy. The parent advocacy groups – Padres Abriendo Puertas/Parents Opening Doors (PAP), and African and Caribbean-American Parents of Children with Disabilities (AFCAMP) provide outreach, training and advocacy support to parents from their respective communities, as well as helping to refer cases to P&A. The Citizen Advocacy Program of Eastern Connecticut, Inc., matches volunteer advocates on a one-to-one basis with people who need advocacy. It serves the greater Colchester area.

P&A co-sponsored a conference with the Connecticut Women and Disability Network, Southern Connecticut State University (SCSU) and the Disability Rights Center of West Haven. Revisiting Our Past and Planning for Our Future Conference is the first conference to focus on women with disabilities in more than 10 years. The conference, attended by ninety five (95) women including many SCSU students featured Harilyn Rousso, founder of the Networking Project for Disabled Women and Girls YWCA/NYC, and Ann Thompson, medical professional and wheelchair athlete.

P&A, in conjunction with the Connecticut Women's Health Campaign, Permanent Commission on the Status of Women and Connecticut Women and Disability Network, worked to educate policymakers concerning gynecology services for women with disabilities, resulting in Public Act 03-40, An Act Concerning Improved Access to Gynecological Services for Women with Disabilities. Since that time, staff from the Department of Public Health and P&A, along with advocates, consumers and medical providers, have been meeting to identify the barriers and

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obstacles that prevent women with disabilities from accessing women's health services and to include their findings and recommendations in a January 1, 2004 report to the General Assembly.

P&A staff also participated in the establishment of several reform and system enhancement initiatives including the Connecticut Lifespan Respite Coalition (CLRC). CLRC is a nonprofit coalition of families, public and private agencies committed to expanding respite services across the lifespan for Connecticut families, from children with complex medical needs to the elderly. They also work to raise respite funding levels.

P&A staff continued supporting Assessing Barriers and Creating Useful Solutions (ABACUS). The project, aimed at improving access to mammography services for women with disabilities, is a partnership between the P&A, the Connecticut Women and Disability Network, Qualidigm and the CT Society of Radiologists and is funded by the Susan G. Komen Foundation. This year, P&A staff worked with the project's newest partner, the Connecticut Chapter - American Cancer Society (ACS) to design a new curriculum component that targets women with disabilities to participate in the ACS Tell A Friend Program.®

P&A and the Connecticut Women and Disability Network assisted the Connecticut Coalition Against Domestic Violence (CCADV) with making shelter and program enhancements aimed at improving domestic violence services for women with disabilities.

Systems Change Initiatives

Legislation 2003 –

Many bills beneficial to persons with disabilities were passed this year, but due to the budget problems many programs and services have been eliminated or cut. A complete report on 2003 Legislation affecting people with disabilities is available on the P&A website at <http://www.state.ct.us/opapd>.

P&A successfully proposed HB 6517 AN ACT CONCERNING THE OFFICE OF PROTECTION AND ADVOCACY FOR PERSONS WITH DISABILITIES, which became Public Act 03-88. The act clarifies the agency's authority by adding to the director's existing powers the ability to ensure that all aspects of the agency's operations conform to federal protection and advocacy requirements for program independence and authority. This includes structural independence from other agencies that provide services to people with disabilities and authority for the director to:

- pursue legal and administrative remedies on behalf of people with disabilities;
- investigate allegations of abuse and neglect of people with disabilities who are receiving care, treatment, or services;
- have access to people who are living in facilities or are clients of service system and, with appropriate consent, to their care, treatment, or services records;
- educate policy makers, consumers, and the public about issues affecting people with disabilities;
- reach out to members of traditionally underserved populations; and

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- develop an annual statement of priorities and objectives and solicit public comment and input on this process.

Another Public Act which P&A was instrumental in passage of P.A. 03-40 (SB 1152) AN ACT CONCERNING GYNECOLOGICAL SERVICES FOR WOMEN WITH DISABILITIES. More information on this important law can be found under the “Support from Community Advocacy & Coalition Building” section of this report (see page 20).

P&A monitored and educated policymakers regarding the following legislation, passed in 2003:

- Demonstration project created for the use of electronic voting machines;
- 45 day time limit established on shock therapy ordered by Probate Court;
- Department of Mental Retardation (DMR) required to transfer an investigator position to P&A so that P&A can properly investigate deaths of DMR clients;
- Private sector employees able to use up to two weeks of accumulated sick time while on leave under the state's Family Medical Leave Act (FMLA) to attend to the serious health condition of a child, spouse, or parent of the employee or for the birth or adoption of a child;
- Person the governor appoints as the executive director of the Board of Education and Services for the Blind (BESB) required to have relevant skills and experience and to be approved by the legislature. Also, a fourteen (14) member BESB monitoring council is created to help BESB establish benchmarks concerning the agency's management, operations and services;
- Alternative Incarceration for People with Psychiatric Disabilities – allows judges to send criminal defendants who are incompetent to stand trial to a treatment program rather than Connecticut Valley Hospital's restoration unit;
- Medical insurance coverage extended to members of personal care assistance associations
- Health insurance policy changed to allow maximums for early intervention services.

Department of Mental Health and Addiction Services (DMHAS) Work Group on Integration of Physical Health Care into Behavioral Health Care - PAIMI participated as a member of an internal workgroup at the DMHAS. The work group is charged with the task of developing standards for the provision of physical health care to patients in the state psychiatric hospitals. Standards have been developed in such areas as women’s health care, including mammograms and gynecological exams, vision screening, dental care, etc. The standards remain under development and have not been released by the Commissioner of DMHAS to date.

The Residential Care Home –

This advocacy outreach pilot project began in July 2002 and ended in January 2003. Three peer educators were recruited and trained to conduct education and outreach activities in selected residential care homes. After initial struggles with gaining access into the facilities, there were a number of events conducted on rights with an emphasis on voting rights during the fall of 2002.

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PABSS – Exemption from Needs Testing for Persons on SSI/SSDI –

A young woman who receives Social Security Benefits was required by her vocational rehabilitation counselor to contribute financially toward the cost of her employment program. She contacted the Protection and Advocacy for Beneficiaries of Social Security (PABSS) program because she was unable to pay any portion of the program and could possibly lose vocational assistance. Historically, the Bureau of Rehabilitation Services (BRS) and the Board of Education and Services for the Blind (BESB) have subjected SSI/SSDI recipients to the financial aid processes in Connecticut and required the individual to contribute the amount determined by the educational institution.

The PABSS program has a role in ensuring that all social security disability beneficiaries receive what they are entitled to under the Rehabilitation Act. The PABSS advocate was instrumental in coordinating significant systems change with regard to vocational rehabilitation services in Connecticut.

During a regional training, which covered the Federal Regulations governing the 1998 reauthorization of the Rehabilitation Act, the PABSS advocate learned of a significant change to the Rehabilitation Act, which affected social security disability beneficiaries. Previous to 1998, the Rehabilitation Act provided an exemption, for eligible individuals, from financial participation with regard to certain categories of services. This meant that the designated state rehabilitation unit could not require a consumer to financially contribute towards these services which included rehabilitation counseling and assistive technology. The 2001 Federal Regulations governing the 1998 reauthorization of the Rehabilitation Act expanded the exemption for financial contribution to all individuals who received a social security disability benefit. This change meant that the designated state rehabilitation unit could not require individuals who receive social security disability benefits to financially contribute in order to participate in their rehabilitation plan known as the individual plan for employment.

In Connecticut the issue of financial contribution only occurs when an individual's employment plan has a training component that includes attendance at a college or university. In this situation, the individual is required to file with the Federal Financial Aid Program, which determines a person's student contribution.

Armed with new knowledge, the PABSS advocate argued with the local office of BRS that these individuals could not be required to financially contribute their social security disability benefit to participate in their employment plans. The advocate further argued that state policy needed to be change to reflect the change in Federal law. He was successful in resolving the financial contribution issue for the individuals he was representing, but the local BRS Director made no determination on the need for policy change stating that the matter was beyond her jurisdiction.

In preparation for the presentation at the State Rehabilitation Council (SRC) meeting, the PABSS advocate compiled an information package for each SRC member. The packet included a copy of the 2001 Federal Register indicating the change and copies of state vocational rehabilitation

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policies from three states who had changed their state policies to reflect the change in Federal law. This information was also provided to BRS Central Office for review.

The day before the issue was to be presented to the SRC, the BRS Bureau Chief agreed that state policy needed to be changed and indicated that he would support P&A's request. At the SRC meeting, a working group was formed to rewrite the state vocational rehabilitation policy to comply with Federal law. Additionally, the BRS Bureau Chief immediately sent a directive out to all vocational rehabilitation counselors detailing the change to the counselor manual and instructed the change to be immediate.

Everybody Works –

Everybody Works, a program of the Bridgeport Workforce Investment Board, is a two year grant to assess and improve physical and communication accessibility for persons with disabilities at One Stop Centers. It also provides opportunities for persons with disabilities to learn about their rights and resources. In 2003, P&A continued its work as a member of Everybody Works and its Americans with Disabilities Act (ADA) subcommittee.

Diversion Project Summary -

In 2002, P&A identified a need to protect the rights of children requiring special education in Connecticut. Of specific concern was the referral of juveniles to court for truancy based on the failure of local education agencies to evaluate and provide appropriate Individualized Education Plans (IEPs) with supplementary aids and support services.

Typically, these students have unmet mental health needs in addition to learning disabilities (LD) and Attention Deficit Hyperactivity Disorder (ADHD). As they are advanced through elementary grades, these students become increasingly aware that they are not learning as their peers are and often begin to exhibit behaviors that are not addressed by positive behavioral interventions. The behaviors, usually related to the unmet needs or unidentified disabilities, continue often resulting in multiple suspensions for the student. Frustration on the part of the students and/or families often surfaces in the form of chronic absenteeism. At this point, the schools contact the court system.

In an attempt to prevent this cycle, P&A began a pilot project in the Middletown/Meriden area. The region has an excellent Juvenile Public Defender who was very amenable to working collaboratively with P&A as a way of diverting juveniles from having court involvement due to truancy. Cities in the area routinely outplace juveniles who have been truant. A probation officer is usually assigned as an incentive to attend school. Yet, with a program that remains inappropriate, the students invariably continue to be absent, resulting in continued court referrals, and ever deepening legal difficulty.

The lack of an appropriate school based program results in further issues for some of these students. Spending time out of school without supervision creates idle time in which some juveniles engage in risky or illegal behavior, exacerbating their trouble with the law.

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The project aims to increase the coordination and availability of special education and related services for students with underlying learning disabilities and/or mental health needs that have penetrated, or are at risk of penetrating, the juvenile justice system. Team members have identified criteria for referral from the public defenders office, obtained records, and met with the families and students. Team members have also met with community stakeholders and coordinated meetings to identify and determine types and availability of services for targeted students and their families. P&A advocates also met with the juvenile public defender and social worker and developed recommendations for comprehensive service plans.

To date, three students with extensive and intensive “wrap around” needs have been represented by P&A advocates and attorneys. These students have been represented at numerous PPT’s, probate court and juvenile court matters. All three cases have had Due Process Hearings filed on the students’ behalf. Two cases are pending while awaiting final outcomes of independent evaluations. One student had been slated for residential placement due to long standing truancy matters, and his advocate successfully communicated to the judge that this student lacked an appropriate school based program, and that P&A involvement in this matter would help ensure appropriate evaluations and program. The judge agreed, and all court involvement for this student was discontinued.

Hartford Special Education Project -

In 2002, P&A special education advocates also initiated a project to identify and challenge patterns of inadequate evaluation, educational programming and related services for special education students in the Hartford Public Schools. The first phase of the project involved training a cadre of parents who can advocate for their children and support other parents’ advocacy. This was done in collaboration with two community organizations – Padres Abriendo Puertas (PAP) and African and Caribbean-American Parents of Children with Disabilities (AFCAMP). The next phase will involve formal inquiries into placement and programming practices, as well as ongoing advocacy on behalf of individual students.

Connecticut Association for the Deaf (CAD) v. Middlesex Hospital, et al. -

P&A completed its monitoring responsibilities of general hospitals pursuant to the CAD v. Middlesex Hospital consent decree. The consent decree addresses the lack of effective communication available to persons who are deaf and hard of hearing in Connecticut’s 32 acute care hospitals. During 2003, P&A:

- Completed inspection of all hospitals;
- Investigated individual complaints;
- Sent a final letter to the Connecticut Hospital Association, and the attorneys representing the hospitals regarding P&A’s findings and recommendations that will promote better services to the deaf and hard of hearing and their companions. These recommendations include the use of additional signage, door knockers to preserve a patient’s privacy, training on initiating a basic dialogue with a person who is deaf or hard of hearing and the development of a comprehensive communication assessment form.

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Deaf Prisoner Project –

P&A has been working cooperatively the Department of Corrections (DOC) in an effort to ensure that DOC's facilities become compliant with the Americans with Disabilities Act (ADA) for the deaf and hard of hearing inmate population. DOC's ADA coordinator has revised DOC's ADA Directive to be compliant with the ADA. It is patterned from New York DOC's Directive that was the result of a Consent Decree. The plan is for DOC to house inmates with disabilities in one facility, and make that facility ADA compliant. Another facility will be used for intake as well as screening and assessment for accommodation needs of inmates with disabilities. The Commission on the Deaf and Hearing Impaired (CDHI) is working with DOC to create an orientation program for incoming inmates.

Connecticut Youth Leadership Forum (CYLF) –

P&A continued its active participation in CYLF, a training experience for students with disabilities transitioning to post-secondary opportunities. It is designed to help develop their leadership skills, teach them about state and federal disability laws, and help them explore options for life after high school with a focus on transitioning to successful employment. The forum also provides opportunities to learn about programs, resources, and supports necessary for full community participation. Participants also experience time with their peers and often develop lasting relationships. Thirty high school students participated in the 2002 forum.

Library Inclusion for Everyone -

P&A continued to partner with the University of Connecticut's A.J. Pappanikou Center and the Connecticut State Library on "Library Inclusion for Everyone" (LIFE) - a project to improve the accessibility of Connecticut libraries for people with disabilities. LIFE seeks to provide information and technical assistance to librarians as they work to make their services and programs welcoming to all people, including patrons with disabilities. In addition to surveying libraries, LIFE staff presented a workshop about the project for Connecticut's Librarians at an annual library conference and training for students at Quinnipiac College.

Advisory Councils, Boards, Task Forces and Committees

P&A staff participate on the following councils, boards, task forces and committees in order to improve services, expand resources, and protect individual rights:

Lifespan Respite Coalition
Olmstead Coalition
Special Education Advocates Network
A.I.D.S. Initiative for Deaf Services
DMR's Investigation Division Advisory Board
DMHAS' Work Group on Advanced Directives
Birth To Three Interagency Coordinating Committee
Steering Committee of the Nursing Facilities
Transition Grant
Independent Mortality Review Board
Governor's Task Force on Justice for Abused Children

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Steering Committee of the Real Choice Grant
Connecticut Youth Leadership Forum
Business Leadership Network
Family Support Connecticut
Legal Services Training Coalition
DOIT Connecticut Portal Advisory Group
Children's Services Focus Team
Connecticut Building Code Training Council
Manchester Community College Disabilities Specialist Board
Specialist Program Advisory Board
BESB Advisory Council
Connecticut Developmental Disabilities Council
ADA Coalition of Connecticut
State Rehabilitation Advisory Council
Children's Mental Health Advisory Council
Fatality Review Board
UCE Consumer Advisory Group
Connecticut Coalition for Inclusive Education
Greater Hartford Local Interagency Coordinating Council
Learning Disabilities Association of Connecticut
PCSW First Congressional District Advisory Committee
Long-term Care Planning Committee
Advisory Committee for the Mashantucket Tribal Nation Vocational Rehabilitation Program
Connecticut Conference of Municipalities – Municipal ADA Coordinator's Group
State Department of Education Autism Advisory Review Committee

Fiscal Facts and Figures

In the fiscal year ending June 30, 2003, P&A had a total operating budget of \$3,711,769. Of this, \$2,511,507 or 68% was state funded and \$1,200,262 or 32% was federally funded. Personal services expenditures comprise 85% of P&A's General Fund Budget with an additional 10% expended on contracts and outside services. The remaining 5% was expended on necessary expense items including supplies, equipment, telephone, postage and printing.

P&A Federal Expenditures for Fiscal Year 2003 - Total: \$1,200,262

U.S. Department of Education Client Assistance Program	\$134,762
DHHS Protection and Advocacy for Individuals with Mental Illness	\$355,416
Social Services Block Grant	\$ 88,696
DHHS Administration on Developmental Disabilities	\$384,871
Protection and Advocacy for Individual Rights	\$100,175
Protection and Advocacy for Assistive Technology	\$ 12,930
Protection and Advocacy for Beneficiaries of Social Security	\$126,412

Issues Affecting People with Disabilities

Sec. 46a-13. Reporting requirements. The advocacy office and advocacy board shall report to the joint standing committee of the General Assembly having cognizance of matters relating to human services and the Governor no later than March 1, 1978, and thereafter annually on or before December first, and at any other time upon request of the Governor or the General Assembly, concerning the status of services for persons with disabilities and the operation of both the advocacy board and office and shall make recommendations, administrative and legislative, concerning the protection of the rights and welfare of persons with disabilities living in Connecticut.

Major Issues Affecting People 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.

Bullying -

Bullying is emerging as an important issue for people with disabilities. Bullying was a factor in the recent suicide of twelve year old Daniel Scruggs and also the beating and death of thirty-nine year old Ricky Whistnant. In 2002, the state legislature passed a law requiring schools to adopt anti-bullying policies and treat reported bullying behavior seriously. But this law applies only to behavior on school grounds and other school activities. It does nothing to help people with disabilities deal with neighbors who mistreat them. Awareness is the first step to solving the problem of neighbors who bully people with disabilities. Friends, family members and other neighbors cannot ignore bullying behavior and should speak out against it.

Supportive Housing for Individuals and Families -

Supportive housing can provide the services and supports individuals and families need to live as independently as possible and often rejoin the working world. Parents who can get in-home care for children with disabilities can continue to work, and pay taxes, and individuals with mental illness who need case management services and other supports can live with more freedom and self-determination in the community. Supportive housing is less expensive than other options (see below) and allows the state to spend its scarce resources for better care for more people.

Per Diem costs for various services and supports (1999 figures):

- Family support grant (DMR clients living in family homes): \$8.30
- Supportive housing (for people with mental illness): \$35.55
- Day support option (DMR clients, non-vocational programs): \$45.57
- Incarceration: \$70.49
- Residential substance abuse treatment: \$100

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- Community living arrangements (DMR clients): \$200
- Nursing home care: \$207
- Long term in-patient psychiatric care: \$660

The State should continue exploring Medicaid Waiver options to allow the state to receive reimbursement for community-based services and supports. Connecticut receives a 50% reimbursement for allowable Medicaid expenditures. Though the State would need to pay 100% of the costs and then seek federal reimbursement, the savings to the state would still be substantial.

Not all individuals with disabilities who live in nursing homes or other institutions would be able to live in supported community housing. But allowing just twenty percent of such individuals to live in the community would save enough money to be able to provide better care to all individuals. The total Medicaid-funded nursing home population is about 19,000. An estimated 2,000 individuals with primary psychiatric diagnoses live in nursing homes. If 400 of these individuals moved into supportive housing the total savings would be approximately \$25,000,000 in one year. If the state did not receive permission to bill Medicaid for supportive housing costs in lieu of nursing home costs, the state would still be saving \$12,500,000 per year (it would lose the 50% reimbursement from the federal government). The State will likely use some of these savings to mitigate the projected budget deficit. But a large portion of these savings should be used to provide additional services and supports to people with disabilities.

Health Care -

People with disabilities are affected by the same trends in health care as members of the general population. The shortage of nurses is hurting people with disabilities who need home care, especially families raising children with significant physical disabilities. Conventional nursing pools, often used to provide home care, cannot supply the kind of consistency and expertise that is needed by people with significant disabilities. The state must continue its efforts to increase the number of nurses in Connecticut, and should develop programs to train nurses to care for people with significant disabilities.

Family members become stressed from providing around-the-clock care and end up unable to care for their family member with disabilities at all. This results in emergency placements being needed - placements that are far more costly than respite care, personal care attendants and other home-based supports. Home-based nursing and other healthcare, as well as respite care, should be provided to families to prevent the total burnout of family members, which leads to expensive emergency placements.

Economic factors and the redefinition of mental illness as a “biological brain disease” are limiting treatment options for people with psychiatric disabilities. Most mental health care for people with “chronic” psychiatric disabilities still focuses on medication compliance and maintenance. Scarce state resources are being used to treat persons with severe mental illness and are not being used to assist people with mild mental illness - people who may present with severe mental illness later if they are not treated. The providers of mental health treatment must

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embrace the concept of recovery and must raise the expectation level of persons receiving treatment - people should be expected to succeed in life, not just survive. Medication may be an appropriate component of recovery, but it should not be the only focus. The emphasis should be on recovery itself.

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. Nursing homes should be used to provide care and treatment to people who need help with activities of daily living (eating, bathing, dressing) and skilled nursing care for serious, chronic medical conditions. 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 supportive housing. The State should seek a Medicaid Waiver to allow the State to receive federal reimbursement for less costly supportive housing, instead of nursing homes, and community based services. The savings could be used to mitigate the projected budget deficit and to provide more and better services to individuals in the community.

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. Prevalence of a not-in-my-backyard (NIMBY) mentality particularly thwarts development of supported housing programs for both youngsters and adults with psychiatric disabilities.

Affordable and accessible two and three bedroom apartments for families are very difficult to find. Developers must ensure that certain percentages of housing units built are accessible or readily adaptable for people with disabilities, but once they are built, there is no effective way to keep track of the locations of available units. Property managers should post information on the status of accessible and adaptable housing units on the Connecticut Accessible Housing Registry website. (<http://www.housingregistry.org/>). Funded through a contract with the State Department of Economic and Community Development, the listing is free to all participants, property owners and prospective tenants.

In addition, there is a push among some constituencies to remove or segregate “non-elderly disabled” people from elders living in state-funded housing that is designated for seniors and disabled people. Lawmakers have received complaints that younger persons with mental illness are causing disturbances and are making elderly persons feel unsafe. While there have been some problems of this nature, some housing authorities have developed successful intervention strategies that respect everyone’s rights. It is unfair and discriminatory to categorically label all persons with disabilities as a threat to the elderly population. Doing so ignores both the fact that elderly persons also can have mental illness or dementia and may also be causing problems, and the inherent benefits to both groups when they become neighbors and friends.

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While many people argue that non-elderly persons with disabilities do not belong in senior housing - they belong in the community with their peers - any legislation that bans people with disabilities from senior housing will worsen the housing shortage and penalize all persons with disabilities. The state should focus on preventing problems by having resident assistants on site to handle complaints and facilitate cooperation and to help all people - no matter their age - coordinate the services they need to live. Resident assistants have been used in the state and have received rave reviews from both elderly and non-elderly residents. Employing resident assistants is less costly in the long run than chronic homelessness and incarceration for persons with serious mental illness.

Education -

Municipalities continue to call attention to the impact of special education costs on school budgets. They point to the mandates and requirements associated with special education laws, and then ask where are the federal and state contributions that were promised when those mandates were established. While a fair question, the focus on costs and budgets ignores the fact that special education laws were enacted because large numbers of children with disabilities were being categorically denied any opportunity for education. Special education statutes were and are civil rights laws. If children with disabilities had been included all along with other children in public schools, as they should have been, the expense of educating them would be seen as simply part of the cost of operating a public school system. That said, policy makers clearly must continue to grapple with the mechanism for funding education. As the discussion continues, lawmakers should consider making all special education costs fully reimbursable by the state. There are many other policy options, but shifting the entire cost to the state would make state policy on the funding of special education comparable to the Education Cost Sharing (ECS) grant. The ECS grant is based on the notion that a decent education requires a certain minimum of dollars. Since it is generally accepted that children with special education needs often present unique requirements for assistive technology and special instruction, the state should be willing to pay for the reasonable costs associated with meeting the basic educational needs of students with special needs.

Funding is not the only issue. The expectations for special education students, particularly in troubled urban school systems, remain dismally low. Inclusion is still not a reality for many children. The use of disciplinary measures against students with special education needs is a growing concern. 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. Schools need to formally recognize that sometimes a child’s behavior is directly related to his or her disability, and that the school’s obligation is to help the child to learn, including the development of more appropriate behavior. Whether a child has a social or

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emotional disorder or simply is acting out because she or he is being teased or bullied, the school system needs to acknowledge the role the child's disability may have played.

Parents and guardians need to know their rights and how to work with the school system to get their child the education and supports needed. Parents and guardians need to be provided with a summary of their rights, and need information and support to go into meetings with school professionals - it can be very intimidating to deal with several "education professionals" who often have masters or doctoral degrees in education.

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.

Access to Information and Advice -

Callers to P&A often express frustration that other government and private agencies they deal with do not provide information to them about their rights and other possible sources of assistance. People say they feel unwelcome - either because they call an agency phone number to get information and get stuck in an endless loop of voicemail options or they talk to an agency employee who is not able or willing to help. Callers to P&A also complain that human service agencies are difficult to deal with because of fragmentation within the service system. Outreach and direct service delivery systems that reflect awareness of disability issues and that project thoughtful, welcoming messages could improve access to information and advice.

Access to Community Infrastructure -

Access is still limited. Many towns and cities are not fully compliant with state and federal accessibility requirements. And there is often confusion about what is required - 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 Architectural 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.

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Here are just some of the accessibility issues P&A deals with on a daily basis:

The laws regarding handicapped parking are a confusing jumble of inconsistent signage, layout and location requirements.

The accessibility provisions of the State building code receive uneven enforcement by local building officials.

Many towns and cities throughout the state have not fully met the requirements for accessibility.

The accessibility of sidewalks, parking and building entrances due to construction or wintertime snow plowing is frequently and thoughtlessly “temporarily” interrupted.

In rural areas and towns not served by public transportation, there is no reliable way for people with disabilities to get around.

Captioning, sign language interpretation and other accommodations (e.g. assistive listening devices) for deaf and hard of hearing people are still not generally available at public meetings or professional settings.

Finally, enforcement of legal requirements for reasonable modifications, accessibility requirements and non-discrimination is still largely a complaint-driven process. This implies that someone must assume the role of “complainer”, and creates the perception that changes and modifications are being made to satisfy a few individual “complainers” rather than being part of a global effort to create more inclusive communities for everyone.

Abuse & Neglect -

P&A has an Abuse Investigation Division that investigates mandated reports of suspected abuse or neglect of persons with mental retardation who are 18 to 59 years old. P&A’s Abuse Investigation Division is experiencing increasing difficulty obtaining relevant protective services from DMR for people with mental retardation who have been abused or neglected and would be unsafe if they remained in their current location. The principal problem involves finding residential placements. Some people with mental retardation who have been abused and neglected have been “placed” into homeless shelters (which are often closed during the day, leaving the person to wander the streets until evening). DMR must respond appropriately to requests by P&A investigators for immediate protective services.

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

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requirements for licensed healthcare providers to report suspected abuse and neglect to an outside agency for investigation unless the person is seriously injured by the use of restraints 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.

And, although deaths of DMR clients are subject to routine reviews, no systematic review process is in place to review the circumstances surrounding the deaths of non-hospitalized persons who receive publicly funded mental health services. The state should scrutinize the effectiveness of outpatient mental health treatment by tracking the outcome of services funded by the state. Such tracking could look at more than just deaths; it could look at whether individuals are repeatedly involved in the criminal justice system, if they have found stabilized housing and whether they are employed. Especially during times of scarce resources, the state should make every effort to see that treatment dollars are being spent wisely.

Summer camps for adults with developmental disabilities are not currently licensed by any regulatory agency. This makes it difficult for parents and other families members to be certain their loved ones are attending a camp that is safe and prepared to handle any medical or other emergencies that arise. The state should consider having DMR or the Department of Public Health license such camps - enforcing strict standards for staffing levels, medical care, and other health and safety issues.