

The Protection and Advocacy for Individuals with Traumatic Brain Injury Program



Report of
2005 Activities

NATIONAL
DISABILITY RIGHTS
NETWORK

Protection & Advocacy for Individuals with Disabilities



Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI) – A Program that must be Saved

Background

When Congress authorized the Traumatic Brain Injury (TBI) Act as part of the Children's Health Act of 2000 (P.L.106-310), it included the Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI) program. Individuals with traumatic brain injury have an array of protection and advocacy needs, including assistance with returning to work; finding a place to live; accessing needed supports and services, such as attendant care and assistive technology; and obtaining appropriate mental health, substance abuse, and rehabilitation services. Very often, these individuals are the victims of stigma and discrimination because so little is understood about the effects of TBI. In addition, many people with TBI – including returning veterans – are forced to remain in extremely expensive institutional settings far longer than necessary because community-based supports and services they need are not available.

The President's FY 2006 budget recommended eliminating the PATBI program. Fortunately, Congress recognized the importance of this program and restored its funding. However, due to an across-the-board cut in most domestic discretionary programs for 2006, PATBI was only funded at \$2.97 million. This was a cut from \$3 million in 2005. **Unfortunately, the President's FY 2007 budget again recommends zero funding for this critical program. The Administration's ongoing attacks on this program fly in the face of the needs of the thousands of children and adults with TBI, and would make it impossible to address the needs of returning soldiers who are facing life-altering challenges because of TBI.** These attacks also go against the recommendations of a study of the TBI program by the Institution of Medicine (IOM) in March 2006. The study calls the programs serving people with traumatic brain injury (TBI) an "overall success," stating that "there is considerable value in providing ... funding," and "it is worrisome that the modestly budgeted HRSA TBI Program continues to be vulnerable to budget cuts."

As the IOM study suggests, this program must be continued and allowed to grow in order to ensure that each state has the resources necessary to maintain critical Protection & Advocacy (P&A) services for the estimated 5.3 million people currently living with disabilities resulting from brain injury.

- ➔ Each year in our nation 1.4 million individuals sustain a TBI.
- ➔ The leading causes of TBI are:
 - Bullets, fragments, blasts
 - Falls
 - Motor vehicle-traffic crashes
 - Assaults ¹
- ➔ More than one million children receive brain injuries each year. More than 30,000 of these children have lifelong disabilities as a result of the brain injury.²
 - Approximately 475,000 TBIs occur among children ages 0-14.
- ➔ Incidence is generally higher among males, Native Americans, and children less than five.

1 Defense and Veterans Brain Injury Center

2 National Dissemination Center for Children with Disabilities

- ➔ Military duties increase the risk of sustaining a TBI
 - As of the end of February -- almost 17,000 service members have been wounded in Iraq and traumatic brain injuries are one of the most frequent injuries,³ to the point of being called a “signature wound of the current war in Iraq.”⁴
 - Blasts are a leading cause of TBI for active duty military personnel in war zones.

**NDRN recommends a funding increase of \$3 million for a total
FY 2007 appropriation of \$6 million**

Effective protection and advocacy services for people with traumatic brain injury can lead both to reduced government expenditures and increased productivity, independence and community integration. However, advocates must possess specialized skills and the work is often time-intensive. Currently, due to the fact that this program is based on a funding formula, most state P&As receive approximately \$50,000 (except for the very large states like California, which receives approximately \$125,000) to address the growing and unique needs of children and adults with TBI. A \$6 million appropriation would trigger a formula that would increase minimum allotments to the states, send more money to the largest states, and help ensure that each state P&A can provide a significant program of brain injury protection and advocacy, with an appropriate level of staff time and expertise.

With limited current funds, TBI P&A advocates across the country are:

- Providing direct individual advocacy for children and adults with TBI in all the states and territories, including access to appropriate health care, community living, housing, education, guardianship, and employment;
- Providing individuals with TBI with the knowledge and skills to help them be effective self advocates;
- Challenging the failure of state hospitals, rehabilitation facilities, intermediate care facilities, and schools to provide appropriate supports and therapies to individuals with TBI who may require modifications to traditional supports in order for them to be effective;
- Working to ensure appropriate discharge planning and supports for persons with TBI leaving unnecessarily segregated settings and moving into the community.;
- Meeting with Emergency Room staff, clinics, health education centers, school personnel, social workers, businesses, state bars, voting officials, and rehabilitation hospitals to provide information about special needs of individuals with TBI and the role the PATBI program can play;
- Training police officers about the symptoms of TBI, as individuals with TBI are sometimes mistakenly identified as intoxicated and arrested inappropriately;
- Developing advocacy and legal rights training curriculum for use by leaders of brain injury support groups, and self-advocacy guidebook for TBI consumers, family members, and advocates; and
- Educating policymakers about the needs of individuals with TBI and the importance of supporting programs designed to address these needs and working on legislation to reduce the incidence of TBI, such as seat belt, helmet, and All Terrain Vehicle laws.

3 Iraq Coalition Casualty Count – U.S. Department of Defense

4 *New England Journal of Medicine*

Specific examples of individual advocacy for people with TBI follow:

A 36-year-old man working in northern Arkansas sustained a TBI limiting him to part-time work and also causing him to have problems with his balance and walking. He called the **Arkansas P&A** to complain about the inaccessibility of a number of courthouses in which he worked. As a result of the complaint, the P&A contracted out for Access Surveys. After receiving the results, demand letters were sent to county judges in all five counties. As a result, there have been removals of significant architectural barriers in four of the five counties.

The **California P&A** conducted an outreach event with 12 TBI survivors. These individuals were members of a TBI survivor support group which is facilitated at the San Francisco TBI Network, one of the seven California TBI Community Sites. The group included individuals from the Latino, Native American, and African-American communities. The group was given an overview of the PATBI program followed by a facilitated discussion on advocacy and service issues that TBI survivors face. The staff also conducted an outreach presentation to 20 staff members of the Fresno Independent Living Center. The presentation focused on an overview of the PATBI program and a discussion of issues the Independent Living Center staff had encountered in serving TBI survivors. Materials on P&A and PATBI services were provided for staff and TBI survivors who could benefit from such services.

A 41-year-old female who also has a variety of additional disabilities and illnesses sustained a TBI in 1996 in a motor vehicle accident. She began receiving services through the Home and Community Based Services Program for the Elderly, Blind and Disabled (HCBS-EBD) in 1999. She faced a number of obstacles to remaining at home and getting the supports and services she needed, such as having to appeal for continued waiver eligibility and the loss of home health services. The **Colorado P&A** provided her with assistance in understanding the HCBS-EBD regulations and advocacy for additional personal care hours that she felt she needed in order to continue to live at home and avoid institutionalization. The P&A determined that the Consumer Directed Assistance Services Program (CDAS) would better address her personal care needs because she had a large pool of care providers who didn't want to work for the home health agency, but would work independently for her. The P&A advocated for the maximum hours of personal care through the HCBS-EBD Program and for services through the CDAS Program. The woman recently contacted the P&A to report that she had been receiving services through the CDAS Program for several months, and that while she likes the program, managing it has been very tiring.

A man had been living in a nursing home for the past 13 years because of an acquired brain injury and physical disabilities caused by an automobile accident at the age of 21. He had lived at home with his parents for several years until they were unable to provide the care he needed. He desperately wanted to leave the nursing home, but he reported his social worker had become "more like [his] mother" and over time the social worker and his father/conservator were very protective and saw him as needing the care and services of the nursing home. This protective thinking thwarted any effort to move him into the community, which is what he truly wanted. The man repeatedly told the advocate from the **Connecticut P&A** that he was tired of living with older people and wanted more in his life. The advocate pushed for evaluations to determine the man's actual needs. A file review at the facility indicated that he needed minimal assistance with daily living skills and transportation. The advocate worked to educate those involved, and he was evaluated and referred to the Adult Brain Injury Waiver for determination of eligibility. Vigorous advocacy efforts resulted in his acceptance into the waiver. His discharge is now pending and he is anxiously waiting for a new home.

The **Delaware P&A** worked to help several people with TBI maintain their homes. One was a mobile home tenant with TBI and physical limitations due to a motorcycle accident. He had some support services, but his income (SSI) was insufficient to pay all of his bills. He secured roommates for short periods of time who provided personal assistance and funds toward rent. Unfortunately, his landlord pursued eviction based on unauthorized persons in the mobile home. The P&A collaborated with the Community Legal Aid Society, Inc. (CLASI) fair housing unit, and the landlord agreed to permit one roommate as a reasonable accommodation needed to assist with disability-related personal care needs.

The **District of Columbia P&A** assisted a 35-year-old male who sustained a TBI at the age of 23. He has been hospitalized for nearly five years for self-injurious behavior. The treatment team on his ward at the public psychiatric hospital is aware he has TBI, but continues to administer psychotropic medications in an attempt to control his behavior. The P&A advocated for the man and had discussions with the social worker and psychiatrist about the need for interventions appropriate for an individual with TBI. The P&A counseled the treatment team regarding the ineffectiveness of psychotropic medications on behaviors that are not caused by mental illness. The man's incidents of self-injurious and aggressive behavior have decreased as a result of this advocacy.

The **Georgia P&A** advocated for a young woman with TBI who was placed in a nursing home while her children were placed with their paternal grandmother. The woman spoke so softly that the nursing home staff assumed she only made incoherent mumblings. She was seldom moved from her bed, and was often neglected. Her children were abused by members of the household and placed in foster care. Visitation with their mother completely ceased. When the P&A began to advocate for the woman, an augmentative communication device was obtained; a friend was helped in being certified as both a host home for Medicaid waiver services and as a foster parent; and problems with Social Security, Medicaid, and the juvenile court were overcome, sometimes with legal intervention. The woman is now living in the community, and her children have been reunited with their mother.

The **Guam P&A** conducted presentations to the Guam Police Department patrol officers regarding TBI and TBI-related issues. Two presentations were made at each of the four different police precincts, with approximately 60 officers trained. The officers were provided with information on TBI and the importance of seeking medical attention immediately, especially when a person loses consciousness after an event where his/her head is struck. Also provided was information on the disability itself and its many symptoms.

An adult male diagnosed with traumatic brain injury and schizophrenia contacted the **Idaho P&A** with concerns that his scheduled discharge from Idaho State School and Hospital would not occur due to the lack of placement options and counseling services in his area of choice. As a result of P&A intervention, the man received a discharge to his community area of choice and was confirmed for extended counseling services.

A 10-year-old with traumatic brain injury and autism was placed on homebound services due to the frequency and severity of behaviors. He was receiving only two hours a week in homebound services, and the school had no plan in place to transition him back into the classroom. The **Indiana P&A** reviewed information on the Individuals with Disabilities Education Improvement Act (IDEA), as well as Indiana's law on special education, and determined that the current individual education plan (IEP) did not meet the child's needs, nor did it contain any transition plan. In addition, the school had failed to provide personnel with specialized training in regard to TBI, as required by law. The P&A began

attending case conferences with the young man and his family, and the school agreed to obtain additional assessment(s) in regard to his behavior and what was occurring in the classroom. Additionally, the school also began to develop a transition plan for the boy to re-enter the classroom.

The father and guardian of a man with a brain injury contacted the **Iowa P&A** to request advocacy assistance regarding the threat of his son being institutionalized. The father believed that his son, who at the time was living in a residential facility, was going to be placed in a nursing home due to the lack of essential services available for him at this current living program. He was working on an exception-to-policy request for the Home and Community Based Service Brain Injury (HCBS/BI) Waiver and wanted the P&A's assistance. The P&A assisted with developing an advocacy plan related to the services for the man with TBI and corresponded frequently with DHS regarding the status of the exception-to-policy request. The man was eventually granted the exception and started receiving in-home supports and services through the HCBS/BI Waiver program. He moved out of the care facility into an apartment of his own and obtained employment

A man with TBI due to an accident at home came to the **Kansas P&A** for assistance with a guardianship issue. Before the accident, he lived by himself. Afterwards, however, he needed assistance with some daily activities. An Independent Living Center was helping him find an appropriate place to live and to qualify for TBI waiver services. His caseworker found a group home and tried to get attendant services started. In the meantime, he went to a sheltered workshop during the day and the workshop contacted SRS to get guardianship over him. This guardianship was imposed over the individual's objections in 2004. The court decided to review his case after a year. The man wanted the P&A to represent him in terminating the guardianship. The P&A worked with him, the workshop, and his guardian to come up with a plan for moving him into his own apartment and providing him an opportunity to show he could make his own decisions. By the end of the year, his doctor agreed he did not need a guardian, and SRS agreed to dismiss the guardianship in November 2005. The man has moved to be closer to his family and continues to live on his own with minimal personal care attendant services.

The **Kentucky P&A** collaborated with the Brain Injury Association of Kentucky (BIAK) to develop an awareness among the brain injury community of the acute underfunding of services specifically for individuals with brain injuries. Although the University of Kentucky Medical Center's Injury Prevention & Research Project estimates that there are over 215,000 individuals in the state who have sustained a brain injury significant enough to affect work or education, the existing Medicaid waiver for TBI services has only 100 annual "slots." The state's Brain Injury Trust Fund has been capped by the Legislature at no more than \$3,250,000 annually, which has resulted in a significant waiting list for needed services. During this past year, the P&A and BIAK continued their joint Consumer Advocacy Training Team, which provides a structured framework to primary and secondary consumers about the three types of advocacy – self, public, and systemic. BIAK has consumer support groups in nine Kentucky communities, and P&A staff presented advocacy training in all of them. In addition, because Kentucky has the nation's highest number of deaths per capita, as well as significant head injuries, from ATV and off-road vehicles accidents, the P&A joined the ATV Coalition, which is attempting to get state legislation passed requiring safety equipment, especially helmets, for youth under age 16 who operate ATVs. Also active in the coalition is the Kentucky Farm Bureau, Kentucky Medical Association, and Kentucky Association of Health Plans, as well as several other statewide farming and youth organizations.

The **Maryland P&A** participated in legislative efforts passed in the 2005 session to create a TBI Advisory Board that reports directly to the Governor. The P&A is a member of the Board, which will

make recommendations to the Governor for effective ways to utilize existing funding streams for persons with TBI.

The **Massachusetts P&A** worked with a man who had been a marine sergeant. He was hit by a car and suffered partial hemi-paresis and TBI. He is now unable to speak, other than to utter three sounds. He communicates with gestures and with a special set of picture cards. He received counseling from Head Injury Community Services (HICS) and ultimately worked with Morgan Memorial Goodwill Industries to get a job. At first, he thrived. Then, unexpectedly he was suspended. Several women accused him of inappropriate, sexually suggestive noises and gestures. His inability to speak required that someone be present who was used to communicating with him and understood his gestures. Lacking this, his employer concluded that the charges against him were accurate and fired him. The P&A filed a complaint before the Massachusetts Commission Against Discrimination and negotiated a settlement to find another job within Goodwill.

A 25-year-old male was criminally charged for a stabbing incident. This young man called the **Minnesota P&A** from the county jail because he did not feel his public defender understood his brain injury and its impact on his understanding of the process. He also has vision and hearing loss related to his brain injury, and the public defender was not providing appropriate or effective communication. As is not unusual for people with TBI, he also had a chemical dependency problem. He wanted someone to explain his disability to the court at an upcoming hearing. The P&A contacted the public defender supervisor to offer technical assistance. Due to this consultation, the public defender was able to negotiate a dismissal of the charges with a placement at the Corrections Departments' brain injury program. The individual reportedly is doing very well in the program.

A woman with TBI was moving from a nursing home into the community, however, workers with the Medicaid program who were helping her were unable to get her into accessible housing. The apartment complex they approached did not want to accept her because of her disability. The **Mississippi P&A** became involved and contacted the apartment complex to let them know they had to accept her as they had others on the Medicaid waiver program and that, since they were HUD-subsidized, they could not discriminate on the basis of disability.

The **Nevada P&A** assisted a 42-year-old woman with TBI who had completed law school, but was denied her reasonable accommodation request for additional time to take the Nevada Bar Examination. The P&A helped her appeal the denial to the State Bar Examiners; the outcome of this case is pending.

The **New Hampshire P&A** assisted an individual with a head injury who was incarcerated in the Secure Psychiatric Unit (SPU) of the New Hampshire State Prison and was denied eligibility for the Acquired Brain Disorder (ABD) Waiver program. Through P&A advocacy, he was found eligible for the Waiver, placed on the waiting list, and transferred from the SPU to the New Hampshire Hospital, where he is currently in the process of being placed into the community.

The **New Jersey P&A** intervened on behalf of a 21-year-old with TBI. This individual, who has a history of substance abuse, had been confined to a developmental center for six months by order of a municipal court judge, with the expectation that he would receive appropriate rehabilitative services during his stay. After the six months, with only minimal services offered, he left the developmental center without any plans for community services. Without services, his substance

abuse problems recurred and he was sent to jail. He was interviewed by, and accepted into, a suitable rehabilitation program in Florida. However, without explanation, the Division of Developmental Disabilities denied funding for the program. The P&A met with the man and his family and engaged in extensive advocacy in support of his admission to the Florida program. Subsequently, he was released from jail to the rehabilitation program, where he is reportedly doing well.

In part due to extensive advocacy by the **New York P&A**, a cooperative agreement was arranged between the State Office of Mental Health and the State Department of Health's TBI waiver program to serve individuals with the dual diagnosis of brain injury and mental illness. As a result, regional coordinators from both offices were introduced to each other and trained in the dynamics of a dually diagnosed individual. These regional collaborations assisted in the placement of individuals into public and low cost housing. The housing providers were much more responsive once they realized that there was a joint clinical back-up service that would meet the need of the potential tenant in time of crisis.

The **North Carolina P&A** had two cases involving individuals with brain injuries whose rehabilitation therapy was being reduced by the state. P&A efforts resulted in these individuals continuing to receive appropriate rehabilitative services in FY2005. If their therapy had been reduced, it would have directly affected their ability to live in the most integrated setting possible.

A mechanic with a passion for race cars survived a severe brain injury as an adult about 15 years ago. Since his brain injury, no one had evaluated him in an auto repair shop. Instead, he had been asked to sort things into bins and assemble puzzles. The **North Dakota P&A** videotaped the person exhibiting physical skills that had not been seen in years. The treating physician was surprised to see his performance and agreed further vocational work would be therapeutic.

Upon meeting a socially isolated resident of a large TBI facility, the **North Dakota P&A** was also able to provide expertise and information on another P&A program specific to the person's employment needs and facilitate membership in the Head Injury Association of North Dakota, of which he is now a board member.

The **Ohio P&A** partnered with Columbus Children's Hospital in an effort to smooth the transition of children with TBI from hospital/rehabilitation to school. Through that partnership, the P&A trains hospital staff about the special education process and how they can advocate for a smooth transition for their patients. The collaboration also allows the P&A to reach parents of children with TBI, both to gather information from them about the needs of their children and family and to provide information to them about their rights in the special education system. Children's Hospital has incorporated the P&A's publication *Thriving Beyond Injury* into their informational packet provided to parents, and modified their transition process to incorporate information learned through this collaboration.

The **Pennsylvania P&A** brought a lawsuit against the owner of a mobile home park in Lycoming County alleging he violated the Fair Housing Act by refusing to allow installation of a ramp at the front entrance to a trailer owned by the family of a young man with TBI who uses a wheelchair for mobility. After the family installed a temporary ramp, the defendant threatened them with eviction. The young man secured funding through a Medicaid Waiver for a permanent ramp that likely would satisfy the defendant's aesthetic concerns, but the defendant continued to insist that any wheelchair

ramp must be installed at the rear entrance. After the P&A filed the lawsuit and prepared a motion for preliminary injunction, the defendant entered into a settlement agreement to allow installation of the ramp at the front entrance and the case was dismissed.

The **Pennsylvania P&A** also assisted a family member whose son with TBI was in jail in a small rural county where proper TBI rehabilitation services were not provided. The family member requested PATBI staff assistance in providing documentation for the judges and jail personnel about TBI. The individual was released from jail to a community-based TBI rehabilitation provider.

The **Rhode Island P&A**, in collaboration with the Brain Injury Association of Rhode Island ("BIARI") and the Governor's Commission on Disabilities ("GCD"), was involved in the development and introduction of legislation in the Rhode Island General Assembly that would have created a state TBI fund. Prior to hearings in committees of the state Senate and House on this legislation, the P&A conducted a total of six trainings on legislative self-advocacy for individuals with TBI, their family members, and professionals who work with TBI survivors.

The **South Carolina P&A** received a call from the social worker in a local hospital regarding a man with TBI, who wanted to return to his apartment to live. The P&A worked with the Head and Spinal Cord Injury service coordinator to achieve this goal. Because of the P&A's involvement, this individual secured appropriate supports and services in the community and was able to return to his apartment.

The **South Dakota P&A** provided an overview on the PATBI program and available TBI resources within the state to 21 professionals of the Veterans Services Officers/Congressional Forum. Administration Directors; Veterans Administration Directors from Ft. Mead and Hot Springs; and representatives from the county Veterans Administration and the offices of Senator John Thune and Congresswoman Stephanie Herseth attended. Presentation topics included information on the PATBI Program, state funding for TBI services, TBI-related available resources, and the Brain Injury Alliance of South Dakota.

A 24-year-old was attending a state university when he contacted the **Texas P&A** because of extreme difficulty passing a math class (failed nine times) needed for graduation. After testing, the Texas Rehabilitation Commission determined he would not be able to pass the class. After P&A negotiations with the university's disability office and, the school offered a philosophy of math class as a substitute. The man could not pass this class either. His family asked the school to adjust his grade as an accommodation, but the school refused. After further negotiation with the P&A, the school agreed to waive the course. The man graduated with a degree in Physical Therapy, and is now pursuing a career as a physical trainer.

In a case referred from the Vermont Long Term Care Ombudsman, the **Vermont P&A** represented a 55-year-old with paraplegia and TBI who had been living in a nursing facility for the last 15 years, and was seeking discharge back to his home in the community. Discharge was being blocked by his sister who was his guardian. The sister's daughter was living in the man's home while he was in the nursing facility. The P&A provided advocacy to assure that appropriate services and supports were accessible in the community, then represented him in guardianship proceedings to challenge his guardian's actions in preventing his discharge. After a half-day hearing, the court ordered that the man be discharged. He then went back to his home.

Brain injury awareness and identification are virtually nonexistent in the U.S. Virgin Islands. Therefore, there is a critical need to develop an understanding of TBI and how to prevent such injuries from occurring. As a result, the primary role of the **Virgin Islands P&A** is the dissemination of information on TBI so the community can become better educated and equipped. The P&A released a 30-second public service announcement (PSA) on dangerous vehicular behaviors that can cause TBI. The PSA has aired extensively over the radio and is narrated by a well-known local radio personality. It simulates the sound of an automobile crash with a passenger riding in the back of a pick-up truck.

The **Virginia P&A** represented a man in his mid-forties who suffered a TBI when he was 23. The man was residing in an assisted living facility that primarily housed seniors. Although he had lived at the facility for two years, it had grown tired of his disability-related behaviors and wanted to discharge him. However, the facility failed to engage in discharge planning at the same time that they intimidated the individual's sister saying that if she would not come and get him at the end of 15 days, they would drop him off at a homeless shelter. The sister, who also has a disability, was not able to house the man or aware of anywhere he could live. The P&A met with the administrators of the facility, the individual, and his family, and explained to the facility they would be guilty of neglect if they dropped the man off at a homeless shelter. The facility denied it ever said it would drop the man off at a homeless shelter, but admitted that it told the sister about the plan to discharge the man in 15 days. The P&A told the facility administrators that they failed to engage in discharge planning and that this action was unlawful. The P&A also informed the facility that it was discriminating against the man due to the nature of his disability. The facility stopped the discharge.

An individual with TBI reported great difficulty navigating various bureaucratic entities. In particular, he wished to work, but a 10-year-old conviction was standing in his way. He needed assistance in getting this conviction dismissed in order to pursue his goal of employment. The **Washington P&A** posted a summary of this situation to the Seattle Area Pro Bono Attorney network, and a private attorney with a large Seattle law firm agreed to assist the man. As a direct result of P&A advocacy services, this individual obtained legal representation to assist him with pursuing his goal of having an old felony conviction dismissed, which enabled him to pursue his employment goals through the Division of Vocational Rehabilitation.

The **West Virginia P&A** received a call from a doctor concerned about one of his patients who is a TBI survivor. This individual had been living in a rented mobile home in the same location for 11 years and was now threatened with eviction. He had several pets, which he had had for years, but now neighbors were complaining to the landlord. The landlord, who did not understand the man's disability, had started formal court proceeding to evict the tenant. The P&A met with the man and found he did not have a copy of his lease; did not understand the eviction notice; had no support system; and would be homeless if the eviction order was issued. He also was not able to recognize the seriousness of his predicament, or the possible consequences of the situation. The P&A worked with the man to get and explain the lease and his situation. The P&A also negotiated successfully with the landlord and got a physician's order to make at least three of the animals support animals (this number was permitted in the lease). The consumer and the P&A located homes nearby for the three other animals, and the man was not evicted and still got to keep at least some of his treasured animal companions.

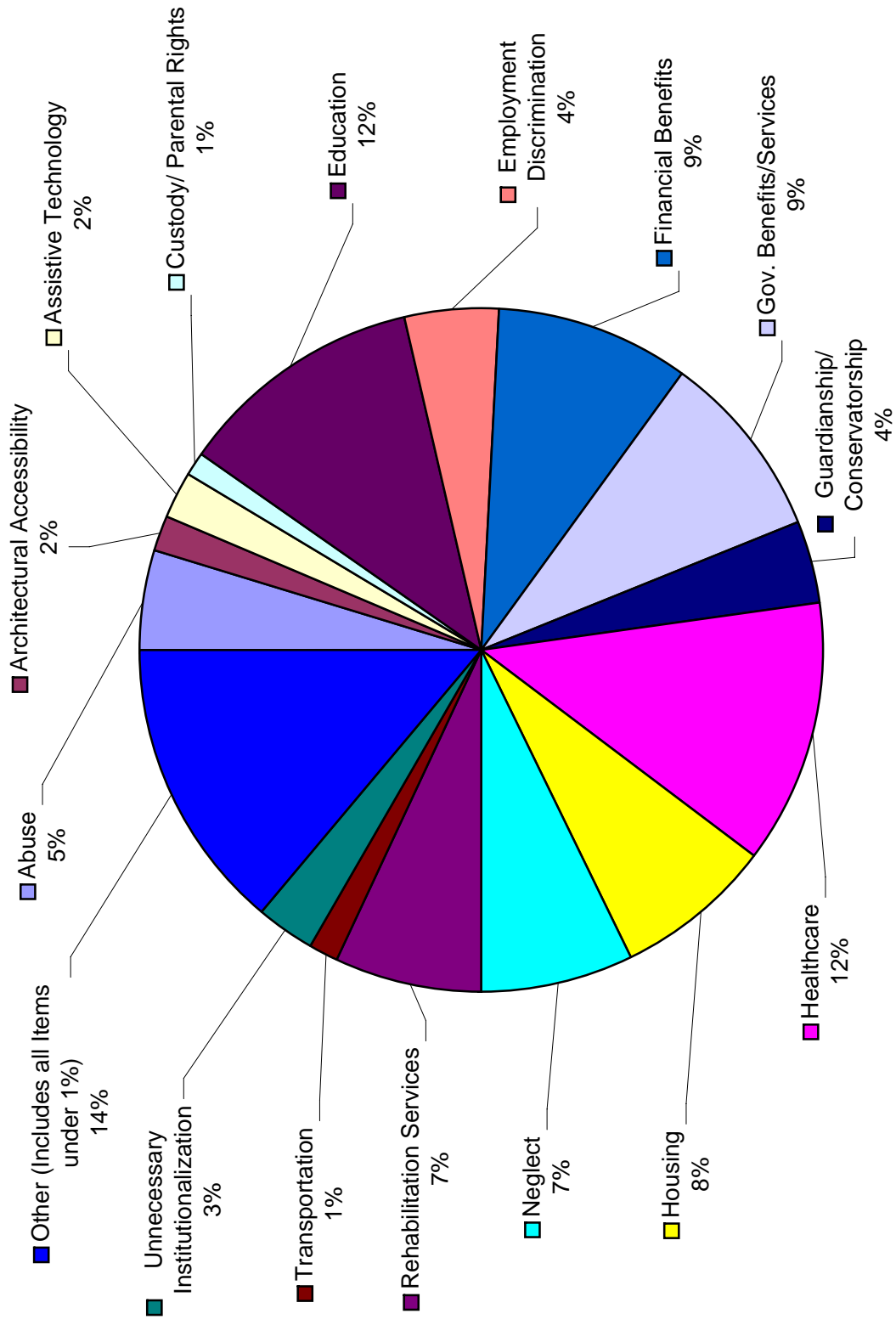
A 32-year-old experienced a TBI during a motor vehicle accident over eight years ago. He had minimal rehabilitation and returned to his rural community with no support system. He was often

homeless and wandered in his small town. His guardian is in very ill health and unable to engage in advocacy for his ward. An aunt contacted the **Wisconsin P&A** and asked for help. Working with the man, the P&A was able to help him gain admission to a rehabilitation center to increase his independent living skills. Upon discharge, he still failed to receive the funding needed for supports so he could successfully live in the community. With continued advocacy by the P&A, he received county funding to pay for him to live in the group home he wanted and he will also receive employment services.

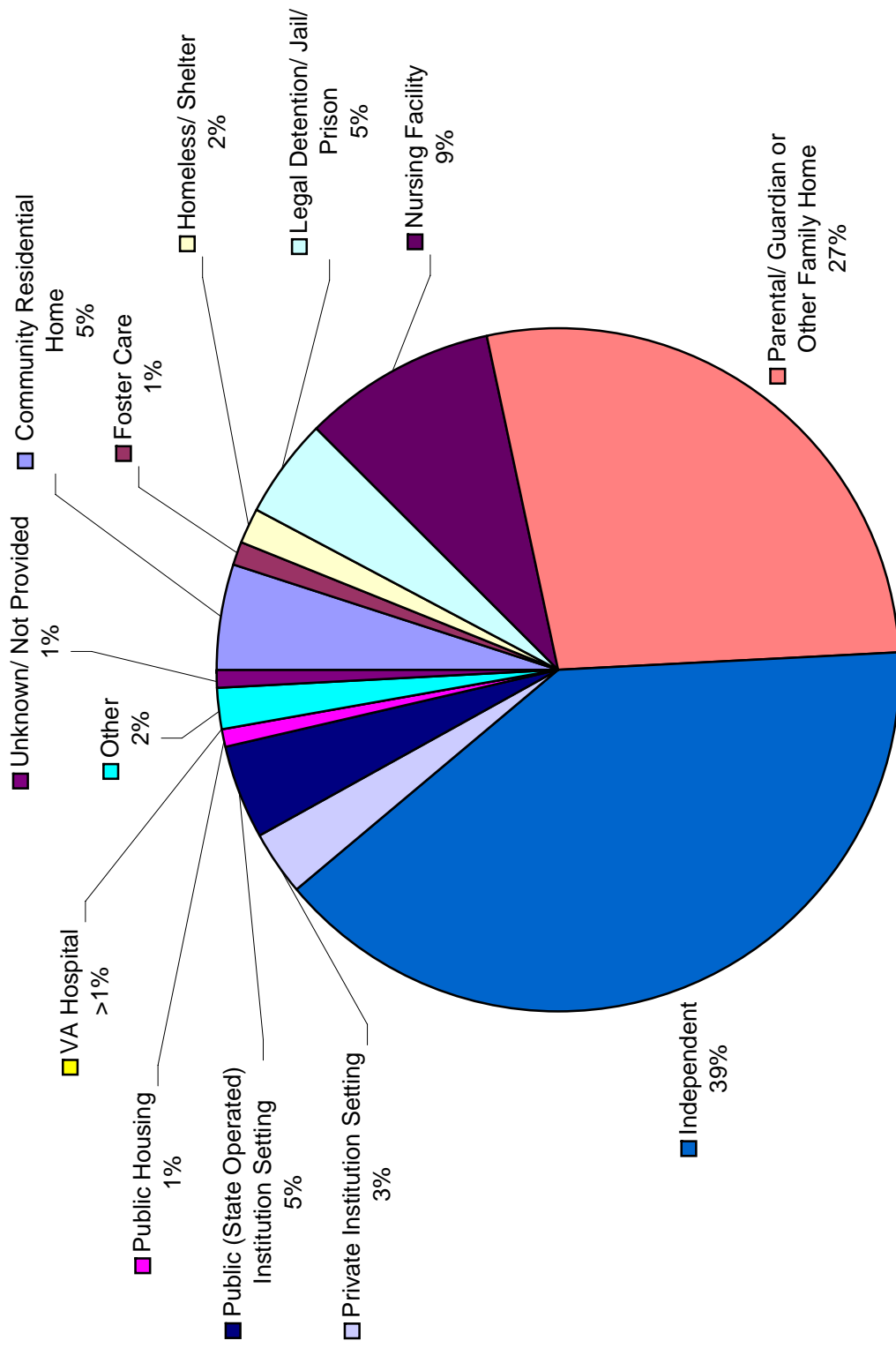
The **Wyoming P&A** assisted an 8-year-old boy who received his brain injury when a metal cattle gate fell and crushed the right parietal side of his skull. His parents came to the P&A after the school's resistance to considering qualifying the young man for services for Section 504 or IDEIA and paying for related services of occupational and physical therapy. The special education director at first told the parents that the district believed a TBI is a "health condition rather than a disability." After the P&A attended a meeting, the boy was qualified for services. Two months later, however, the school changed its mind. After additional P&A advocacy, the issue was resolved and the young man received the needed modifications.

For more information contact NDRN at 202-408-9514.

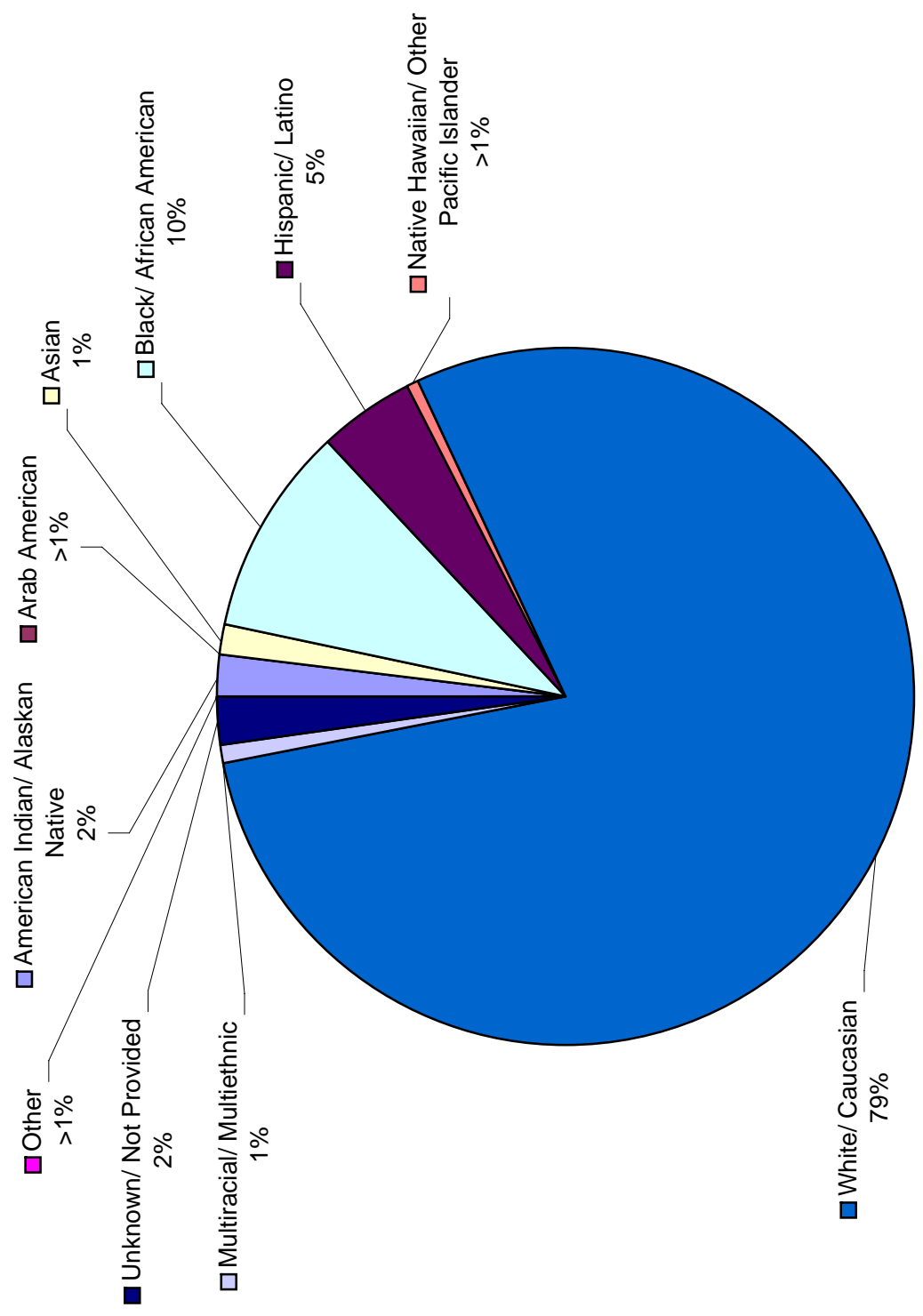
PATBI Problem Areas



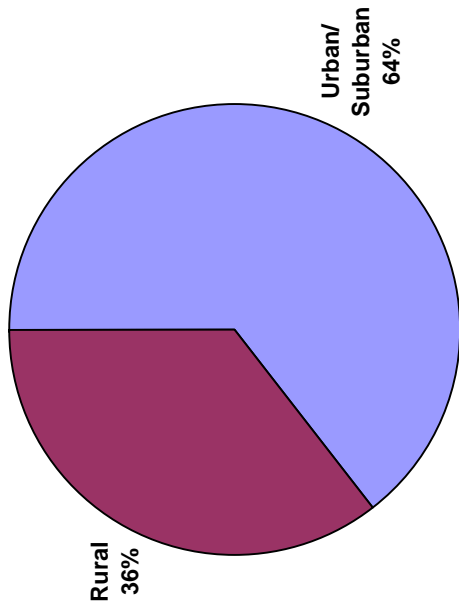
Living Arrangements of Individuals Served by PATBI



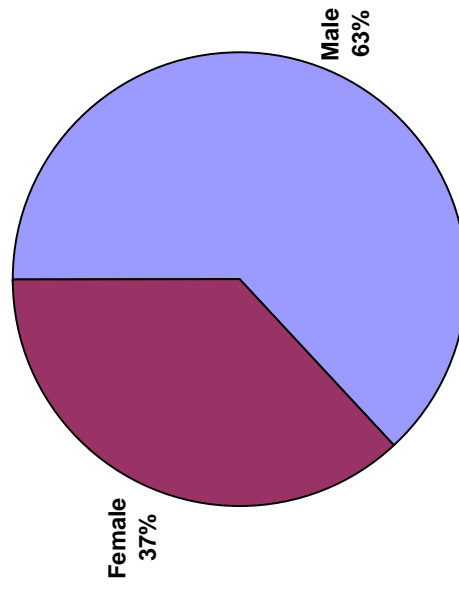
Ethnicity/Race of Individuals Served by PATBI



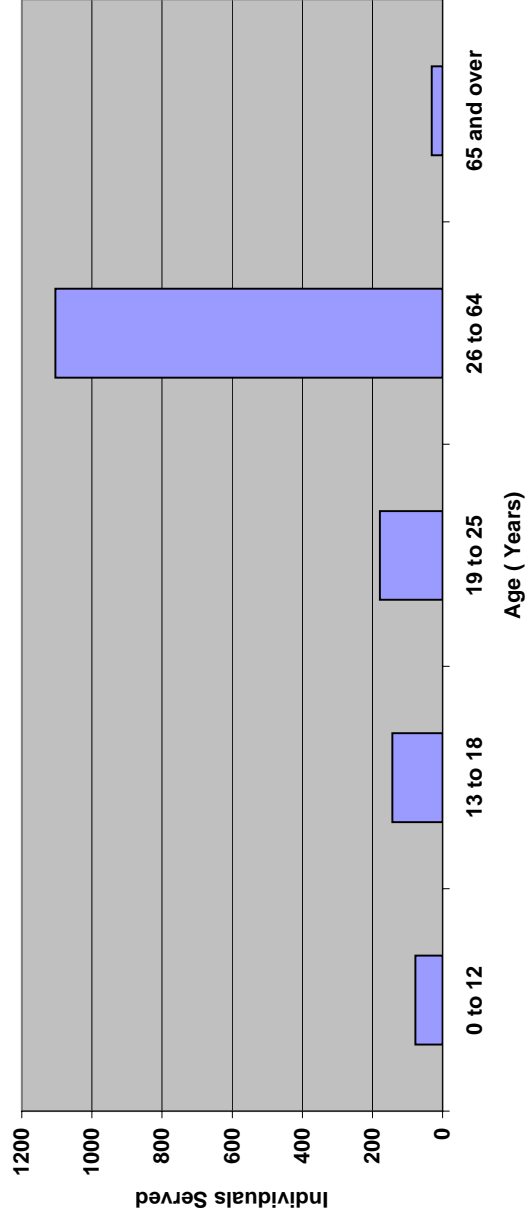
Geographic Location of Individuals Served



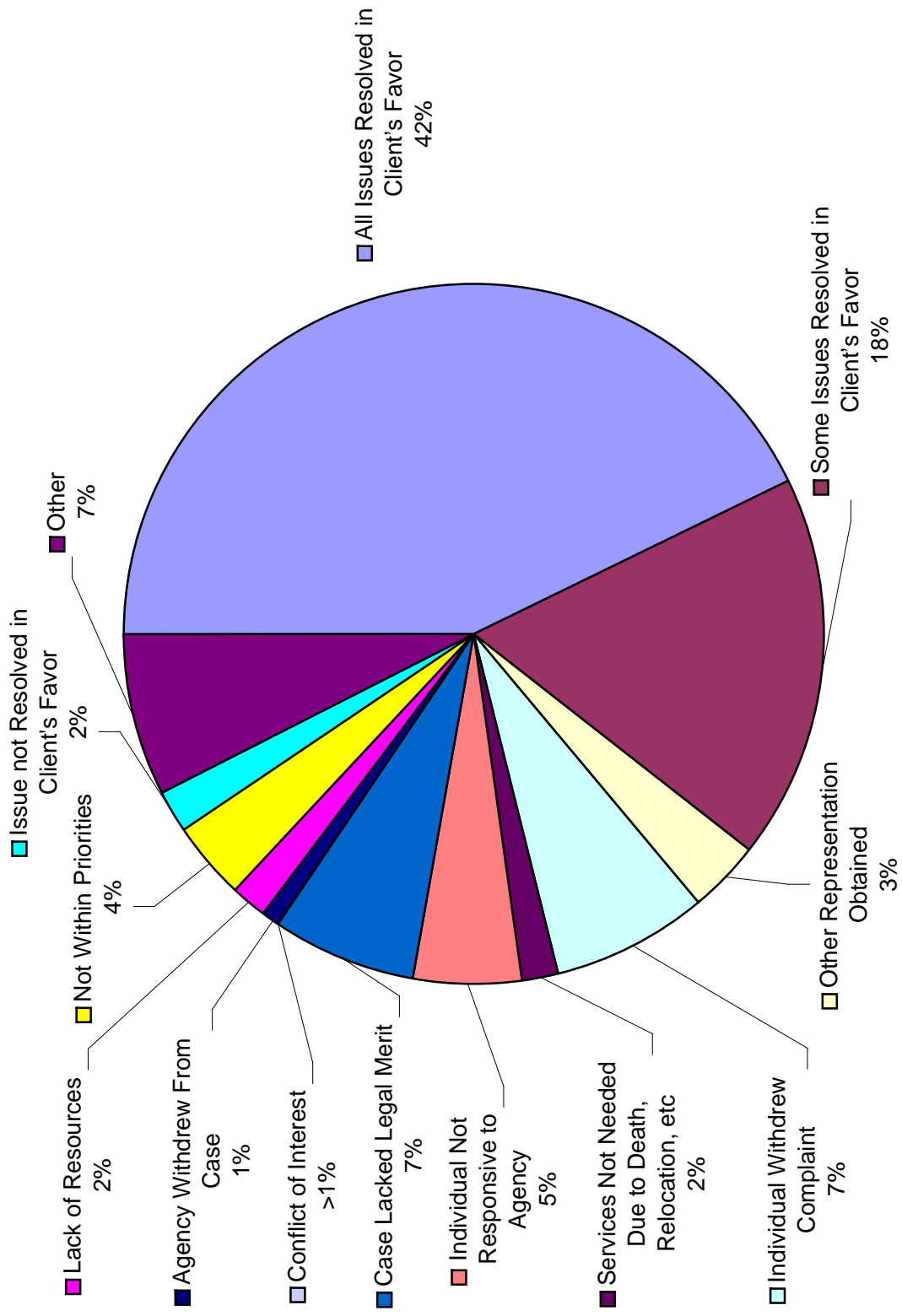
Gender of Individuals Served



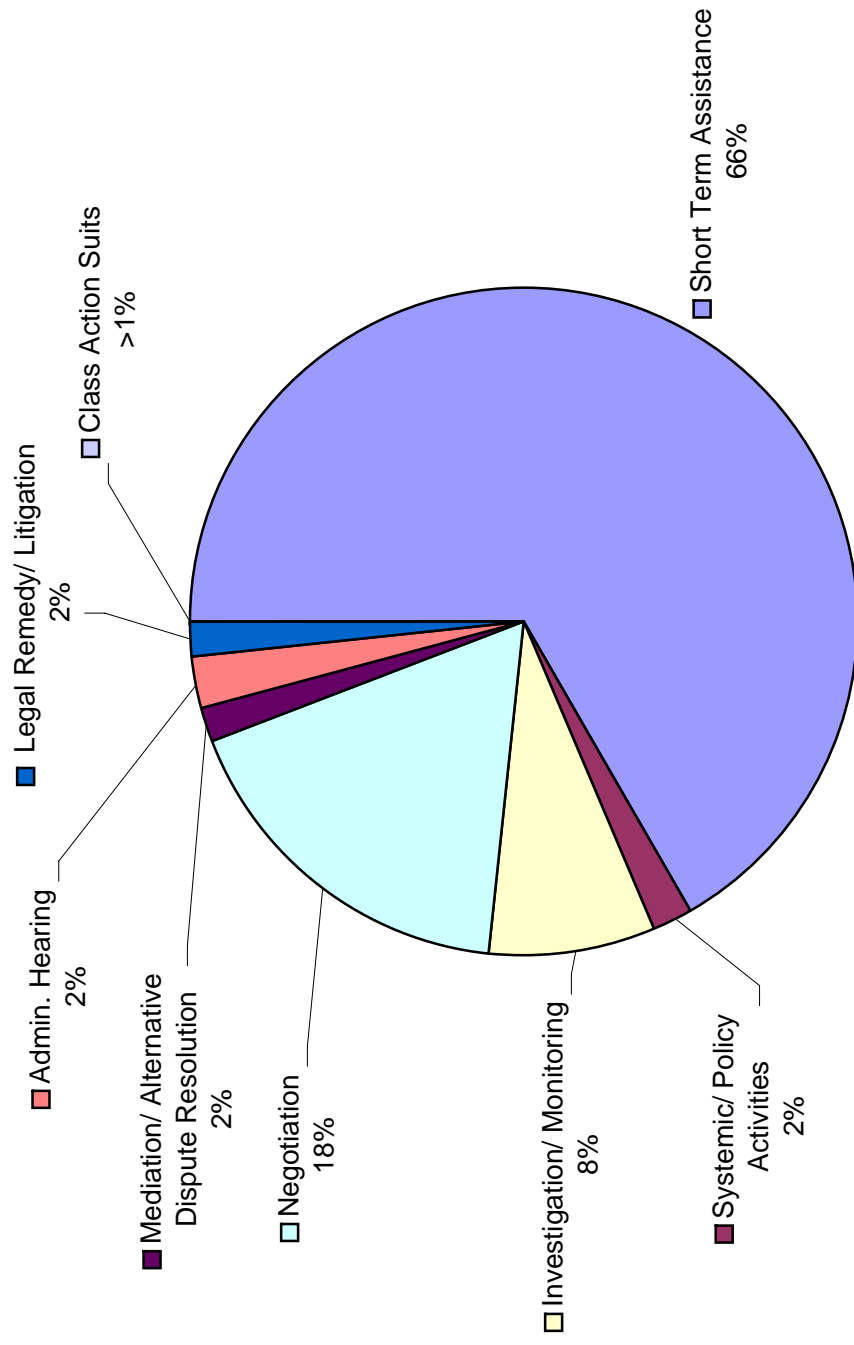
Age of Individuals Served



Reasons for Closing Case Files



Highest Intervention Strategy



NATIONAL PATBI PROGRAM STATISTICS (FY05)

PART I: NON-CASE SERVICES

A. INFORMATION AND REFERRAL SERVICES (I&R)

1. Total Individuals Receiving I&R Services	8030
2. Total Number of I&R requests during the Fiscal Year	8577

B. TRAINING ACTIVITIES

1. Number of Trainings Presented by Staff	1163
2. Number of Individuals Who Attended These Trainings	61210

C. INFORMATION DISSEMINATED TO THE PUBLIC

1. Radio and TV Appearances by Agency Staff	127
2. Newspaper/Magazine/Journal Articles Prepared by Agency Staff	427
3. PSAs/Videos Aired by the Agency	57
4. Website Hits	8069289
5. Publications/Booklets/Brochures Disseminated by the Agency	136920

6. External Media Coverage of Agency Activities

Radio/TV Coverage	Newspaper/ Magazines/Journal	PSAs/Videos	Publications/ Booklets/Brochures
69	284	18	227

PART II: CASE-SERVICES

A. INDIVIDUALS SERVED

1. Individuals	
a. Individuals Served Receiving Advocacy at Start of Fiscal Year (carryover from prior)	510
b. Additional Individuals Served During Fiscal Year (new for fiscal year)	1206
c. Total Number of Individuals Served During Fiscal Year (a + b)	1716
d. Total Number of Individuals with Cases that Were Closed During Fiscal Year	1070
e. Total Individuals Still Being Served at the End of the Fiscal Year	646

2. Services	
a. Number of Cases/Service Requests Open at Start of Fiscal Year (carryover from prior)	518
b. Additional Cases/Service Requests Opened During Fiscal Year (new for fiscal year)	1409
c. Total Number of Cases/Service Requests During Fiscal Year (a + b)	1927
d. Total Number of Cases/Service Requests that Were Closed During Fiscal Year	1173
e. Total Number of Cases/Service Requests Open at the End of the Fiscal Year	754

B. PROBLEM AREAS/COMPLAINTS OF INDIVIDUALS SERVED

Complaint	
1. Abuse (total)	89
a. Inappropriate Use of Restraint & Seclusion	16
b. Involuntary Treatment	1
c. Physical, Verbal, & Sexual Assault	24
d. Other	48
2. Access to Records	6
3. Advance Directives	3
4. Architectural Accessibility	31
5. Assistive Technology (total)	38
a. Augmentative Comm. Devices	5
b. Durable Medical Equipment	13
c. Vehicle Modification/Transportation	2
d. Other	18
6. Civil Commitment	10
7. Custody/Parental Rights	19
8. Education (total)	215
a. FAPE: IEP/IFSP Planning/Development/Implementation	92
b. FAPE: Discipline/Procedural Safeguards	16
c. FAPE: Eligibility	7
d. FAPE: Least Restrictive Environ.	28
e. FAPE: Multi-disciplinary Evaluation/Assessments	11
f. FAPE: Transition Services	11
g. Other	50
9. Employment Discrimination (total)	82
a. Benefits	2
b. Hiring/Termination	23
c. Reasonable Accommodations	23
d. Service Provider Issues	3
e. Supported Employment	6
f. Wage and Hour Issues	1
g. Other	24
10. Employment Preparation	18

11. Financial Benefits (total)	169
a. SSDI Work Incentives	4
b. SSI Eligibility	67
c. SSI Work Incentives	6
d. Social Security Benefits Cessation	8
e. Welfare Reform	0
f. Work Related Overpayments	9
g. Other Financial Entitlements	75
12. Forensic Commitment	5
13. Government Benefits/Services	165
14. Guardianship/Conservatorship	74
15. Healthcare (total)	227
a. General Healthcare	60
b. Medicaid	106
c. Medicare	3
d. Private Medical Insurance	14
e. Other	44
16. Housing (total)	139
a. Accommodations	18
b. Architectural Barriers	1
c. Landlord/Tenant	16
d. Modifications	5
e. Rental Denial/Termination	20
f. Sales/Contracts/Ownership	6
g. Subsidized Housing/Section 8	15
h. Zoning/Restrictive Covenants	0
i. Other	58
17. Immigration	0
18. Neglect (total)	134
a. Failure to Provide Necessary or Appropriate Medical Treatment	34
b. Failure to Provide Necessary or Appropriate Mental Health Treatment	29
c. Failure to Provide Necessary or Appropriate Personal Care & Safety	27
d. Other	44
19. Post-Secondary Education	16
20. Non-Medical Insurance	8

21. Privacy Rights	6
22. Rehabilitation Services (total)	130
a. Communications Problems (Individuals/Counselor)	9
b. Conflict About Services To Be Provided	40
c. Individual Requests Information	7
d. Non-Rehabilitation Act	0
e. Private Providers	4
f. Related to Application/Eligibility Process	12
g. Related to IWRP Development/Implementation	6
h. Related to Title I of ADA	0
i. Other Rehabilitation Act-related problems	52
23 Suspicious Death	2
24. Transportation (total)	23
a. Air Carrier	1
b. Paratransit	4
c. Public Transportation	8
d. Other	11
25. Unnecessary Institutionalization	55
26. Voting (total)	2
a. Accessible Polling Place / Equipment	0
b. Registration	2
c. Other	0
27. Other	178

C. REASONS FOR CLOSING CASE FILES

1. Reason for Closing Case Files

Reason	
a. All Issues Resolved in Client's Favor	503
b. Some Issues Resolved in Client's Favor	210
c. Other Representation Obtained	38
d. Individual Withdrew Complaint	86
e. Services Not Needed Due to Death, Relocation, etc.	18
f. Individual Not Responsive to Agency	62
g. Case Lacked Legal Merit	77
h. Conflict of Interest	1
i. Agency Withdrew from Case	8
j. Lack of Resources	21
k. Not Within Priorities	43
l. Issue Not Resolved in Client's Favor	23
m. Other	87

D. HIGHEST INTERVENTION STRATEGY

Interventions	
1. Short Term Assistance	864
2. Systemic/Policy Activities	25
3. Investigation/Monitoring	103
4. Negotiation	228
5. Mediation/Alternative Dispute Resolution	23
6. Administrative Hearing	30
7. Legal Remedy/Litigation	22
8. Class Action Suits	1

PART III: STATISTICAL INFORMATION FOR INDIVIDUALS SERVED

A. AGE OF INDIVIDUALS SERVED

Age	
0 to 12	72
13 to 18	143
19 to 25	179
26 to 64	1104
65 and over	31

B. GENDER OF INDIVIDUALS SERVED

Male	968
Female	568

C. RACE/ETHNICITY OF INDIVIDUALS SERVED

Race/Ethnicity	
1. American Indian/Alaskan Native	29
2. Arab American	3
3. Asian	20
4. Black/African American	147
5. Hispanic/ Latino	72
6. Native Hawaiian/Other Pacific Islander	7
7. White/Caucasian	1210
8. Multiracial/Multiethnic	13
9. Race/Ethnicity Unknown	34
10. Other Than Above	2

D. LIVING ARRANGEMENTS OF INDIVIDUALS SERVED

Arrangement	
1. Community Residential Home	79
2. Foster Care	16
3. Homeless/Shelter	26
4. Legal Detention/Jail/Prison	74
5. Nursing Facility	140
6. Parental/Guardian or Other Family Home	430
7. Independent	616
8. Private Institutional Setting	45
9. Public (State Operated) Institutional Setting	71
10. Public Housing	14
11. VA Hospital	1
12. Other*	28
13. Unknown/Not Provided	13

E. GEOGRAPHIC LOCATION

Geographic Location	
1. Urban/Suburban	980
2. Rural	543

PART IV: SYSTEMIC ACTIVITIES AND LITIGATION**A. SYSTEMIC ACTIVITIES**

1. Number of Policies/Practices Changed as a Result of Non-Litigation Systemic Activities	114
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B. LITIGATION/CLASS ACTIONS

1. Total Number of Non-Class Action Lawsuits Filed	17
a. Number of Non-Class Action Lawsuits Filed During Fiscal Year (new for fiscal year)	8
b. Number of Non-Class Action Lawsuits Filed at Start of Fiscal Year (carryover from prior fiscal year)	9

2. Total Number of Class Action Lawsuits Filed	5
a. Number of Class Action Lawsuits Filed During Fiscal Year (new for fiscal year)	2
b. Number of Class Action Lawsuits Filed at Start of Fiscal Year (carryover from prior fiscal year)	3

C. DEATH INVESTIGATIONS

1. Number of Formal Death Reports Received	0
2. Number of Informal/External Death Reports Received	2
3. Number of Death Investigations	2

PART V: AGENCY ADMINISTRATION**A. GRIEVANCES FILED**

PATBI grievances filed against the agency during the fiscal year	13
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FY 2006 PATBI Program Allotments

STATE	ALLOTMENT	STATE	ALLOTMENT
ALABAMA	\$50,000	NEW HAMPSHIRE	\$50,000
ALASKA	\$50,000	NEW JERSEY	\$58,529
ARIZONA	\$50,772	NEW MEXICO	\$50,000
ARKANSAS	\$50,000	NEW YORK	\$83,478
CALIFORNIA	\$118,664	NORTH CAROLINA	\$57,666
COLORADO	\$50,000	NORTH DAKOTA	\$50,000
CONNECTICUT	\$50,000	OHIO	\$65,471
DELAWARE	\$50,000	OKLAHOMA	\$50,000
DISTRICT OF COLUMBIA	\$50,000	OREGON	\$50,000
FLORIDA	\$76,406	PENNSYLVANIA	\$67,663
GEORGIA	\$57,990	PUERTO RICO	\$50,000
HAWAII	\$50,000	RHODE ISLAND	\$50,000
IDAHO	\$50,000	SOUTH CAROLINA	\$50,000
ILLINOIS	\$67,989	SOUTH DAKOTA	\$50,000
INDIANA	\$53,016	TENNESSEE	\$52,092
IOWA	\$50,000	TEXAS	\$87,908
KANSAS	\$50,000	UTAH	\$50,000
KENTUCKY	\$50,000	VERMONT	\$50,000
LOUISIANA	\$50,000	VIRGINIA	\$55,373
MAINE	\$50,000	WASHINGTON	\$52,575
MARYLAND	\$51,164	WEST VIRGINIA	\$50,000
MASSACHUSETTS	\$53,650	WISCONSIN	\$51,322
MICHIGAN	\$62,129	WYOMING	\$50,000
MINNESOTA	\$50,273	NATIVE AMERICAN	\$20,000
MISSISSIPPI	\$50,000	AMERICAN SAMOA	\$20,000
MISSOURI	\$51,869	GUAM	\$20,000
MONTANA	\$50,000	NORTHERN MARIANAS	\$20,000
NEBRASKA	\$50,000	VIRGIN ISLAND	\$20,000
NEVADA	\$50,000	TOTAL	\$2,975,999

STATE LIST OF P&As/CAPs

ALABAMA

Alabama Disabilities Advocacy
Program (P&A)
www.adap.net

Division of Rehabilitation Services
and Children's Rehabilitation
Services (CAP)
www.sacap.org

ALASKA

Disability Law Center of Alaska (P&A)
www.dlcak.org

ASIST, Inc. (CAP)
akcap@alaska.com

AMERICA SAMOA

Client Assistance Program and
Protection and Advocacy

ARIZONA

Arizona Center for Disability Law
www.acdl.com

ARKANSAS

Disability Rights Center, Inc
www.arkdisabilityrights.org

CALIFORNIA

Protection & Advocacy, Inc. (P&A)
www.pai-ca.org

Department of Rehabilitation (CAP)
www.rehab.cahwnet.gov

COLORADO

The Legal Center
www.thelegalcenter.org

CONNECTICUT

Office of Protection & Advocacy for
Persons with Disabilities
www.state.ct.us/opapd

DELAWARE

Community Legal Aid Society, Inc.
(P&A)
www.declasi.org

United Cerebral Palsy, Inc. (CAP)

DISTRICT OF COLUMBIA

University Legal Services
www.uls-dc.org

FLORIDA

Advocacy Ctr. for Persons
w/Disabilities
www.advocacycenter.org

GEORGIA

Georgia Advocacy Office, Inc. (P&A)
www.thegao.org

Georgia Client Assistance Program
(CAP)
www.theOmbudsman.com

GUAM

Guam Legal Services (P&A)
Parent-Agencies Network (CAP)

HAWAII

Hawaii Disability Rights Center
www.hawaiidisabilityrights.org

IDAHO

Co-Ad, Inc.
<http://users.moscow.com/co-ad>

ILLINOIS

Equip for Equality, Inc. (P&A)
www.equipforequality.org

Illinois Client Assistance Program
(CAP)
www.dhs.state.il.us/ors/cap

INDIANA

Indiana Protection and Advocacy
Services
www.IN.gov/ipas

IOWA

Iowa P&A Services, Inc. (P&A)
www.ipna.org

Division on Persons w/Disabilities
(CAP)

KANSAS

Disability Rights Center of Kansas
www.drckansas.org

KENTUCKY

Kentucky Protection and Advocacy
(P&A)
www.kypa.net

Client Assistant Program (CAP)
kycap.ky.gov

LOUISIANA

Advocacy Center
www.advocacyla.org

MAINE

Disability Rights Center (P&A)
www.drcme.org

CARES, Inc. (CAP)
www.caresinc.org

MARYLAND

Maryland Disability Law Center
(P&A)
www.mdicbalto.org

Maryland State Department of Education
Division of Rehabilitation Services/MD
Rehabilitation Center (CAP)
www.dorsstate.md.us

MASSACHUSETTS

Disability Law Center, Inc. (P&A)
www.dlc-ma.org

Massachusetts Office on Disability
(CAP)
www.state.ma.us/mod/MSCAPBRO.html

MICHIGAN

Michigan Protection & Advocacy
Services
www.mpas.org

MINNESOTA

Minnesota Disability Law Center
www.mndlc.org

MISSISSIPPI

Mississippi Protection & Advocacy
System (P&A)
www.mspas.com

Easter Seal Society (CAP)
www.mississippicap.com

MISSOURI

Missouri Protection & Advocacy
Services
www.moadvocacy.org

MONTANA

Montana Advocacy Program
www.mtadv.org

NATIVE AMERICAN

Native American Protection &
Advocacy Project (P&A)
www.nativelegalnet.org

NEBRASKA

Nebraska Advocacy Services, Inc (P&A)
www.nebraskaadvocacyservices.org

Client Assistance Program (CAP)
www.cap.state.ne.us

NEVADA

Nevada Advocacy & Law Center, Inc
(P&A)
www.ndalc.org

Client Assistance Program (CAP)
http://detr.state.nv.us/rehab/reh_cap.htm

NEW HAMPSHIRE

Disabilities Rights Center (P&A)
www.drcnh.org

Governor's Commission on Disability
(CAP)
www.state.nh.us/disability/caphomepage.html

NEW JERSEY

New Jersey Protection & Advocacy,
Inc.
www.njpanda.org

NEW MEXICO

Protection & Advocacy, Inc
www.nmpanda.org

NEW YORK

NYS Commission on Quality of Care
& Advocacy for Persons with
Disabilities
www.cqcapd.state.ny.us

NORTH CAROLINA

Governor's Advocacy Council for
Persons with Disabilities (P&A)
www.Gacpd.com

North Carolina Department of Health
& Human Services (CAP)
<http://cap.state.nc.us>

NORTH DAKOTA

North Dakota Protection & Advocacy
Project (P&A)
www.ndpanda.org

North Dakota Client Assistance
Program (CAP)
www.state.nd.us/cap

N. MARIANAS ISLANDS

Northern Marianas Protection and
Advocacy System, Inc.
www.NMPASI.com

OHIO

Ohio Legal Rights Service
www.state.oh.us/olrs

OKLAHOMA

Oklahoma Disability Law Center, Inc
(P&A)
www.oklahomadisabilitylaw.org

Oklahoma Office of Handicapped
Concerns (CAP)
www.state.ok.us/~ohc/cap.htm

OREGON

Oregon Advocacy Center
www.oradvocacy.org

PENNSYLVANIA

Pennsylvania P&A, Inc (P&A)
www.ppainc.org

Center for Disability Law & Policy
(CAP)
www.equalemployment.org

PUERTO RICO

Office of the Governor Ombudsman
for the Disabled
www.oppi.gobierno.pr

RHODE ISLAND

Rhode Island Disability Law Center
Inc.

www.ridlc.org

SOUTH CAROLINA

Protection & Advocacy for People
with Disabilities, Inc. (P&A)

www.protectionandadvocacy-sc.org

Division of Ombudsman & Citizen
Services (CAP)

www.govoepp.state.sc.us/cap

SOUTH DAKOTA

South Dakota Advocacy Services

www.sdadvocacy.com

TENNESSEE

Disability Law and Advocacy Center
of Tennessee

www.dlactn.org

TEXAS

Advocacy, Inc.

www.advocacyinc.org

UTAH

Disability Law Center

www.disabilitylawcenter.org

VERMONT

Vermont Protection & Advocacy, Inc.
(P&A)

www.vtpa.org

Vermont Disability Law Project
(CAP)

www.vtlegalaid.org

VIRGIN ISLANDS

Disability Rights Center of the Virgin
Islands

www.viadvocacy.org

VIRGINIA

Virginia Office for Protection &
Advocacy

www.vopa.state.va.us

WASHINGTON

Washington P&A System (P&A)

www.wpas-rights.org

Client Assistance Program (CAP)

www.capseattle.org

WEST VIRGINIA

West Virginia Advocates, Inc.

www.wvadvocates.org

WISCONSIN

Disability Rights Wisconsin (P&A)

www.w-c-a.org

Department of Agriculture Trade &
Consumer Protection (CAP)

WYOMING

Wyoming Protection & Advocacy
System

www.wypanda.vcn.com



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