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P&A Consumer Education Fuels Self Advocacy

By Sakena McWright, Outreach Advocacy Specialist

Throughout the United States and its territories Protection and Advocacy (P&As) and Client Assistance Programs (CAPs) are involved in an array of activities to provide consumer education and promote self advocacy.

P&A consumer education and self-advocacy efforts stem from the knowledge and belief that people with disabilities must participate in determining the direction of their own lives, as well as the direction of the communities in which they live.

Consumer education takes place in many forms; giving a consumer information over the telephone on how to get her Ticket to Work reassigned running an institute that provides consumer rights training; assisting a student in special education to obtain appropriate services; or educating people on the fundamentals of voting.

In order to better know their communities and develop meaningful educational and training strategies, P&As are moving outside of their offices and comfort zones and devising a variety of innovative methods to inform, empower, and support people with disabilities and others in the community who share their interests and vision.

A result of consumer education, self advocacy can be very tangible – a consumer taking action based on the advice and counsel received from a P&A or securing better medical care based on information from the P&A on how to exercise his rights with the treatment team. On the other hand, outcomes of consumer education and self advocacy may not be so easy to capture. For instance, an encounter with P&A staff and services can foster growth and development that allows an individual to move forward in ways that fall outside of the agency's radar. Working with a P&A to educate other consumers and/or working to alter the service delivery system may not have an obvious or immediate effect on an individual's life, but may, over time, influence how she interacts with the world outside the boundaries of the P&A.

In this *P&A News*, we offer insights into the consumer education being done by P&As to fuel self advocacy.

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Consumer Education: Reaching Out to Unserved and Underserved Communities

Making inroads into unserved and underserved communities requires P&As/CAPs to continue to think differently about how and where their services are offered. As part of their outreach efforts, more materials are being translated into other languages, staff is being hired with ties to identified communities, and trainings are taken on the road to targeted communities and in settings such as mental health facilities, state fairs, community picnics, Native American reservations, community centers, and shelters serving people without homes. While these ventures give P&A staff opportunities to inform people about their rights and related services, they also provide opportunities to meet people where they live, socialize, and/or receive treatment. This exposure is helping P&As deliver culturally competent and meaningful services to these communities.

Serving individuals with traumatic brain injury (TBI) is an established goal for P&As. The **New York P&A** staff visits major stakeholders involved in providing service to individuals with TBI. This outreach has included meetings with the Brain Injury Association of New York State (BIANYS), Department of Health TBI Waiver staff, Regional Resource Development Specialists, Office of Mental Retardation/Developmental Disabilities (OMRDD) TBI Waiver staff, consumers, and family members. In **Iowa**, P&A staff traveled to various locations to inform potential consumers about their programs. The Upper Peninsula of Michigan is a traditionally underserved area and home to a large Native American population that, like many communities, probably has a number of individuals with unidentified brain injuries. The **Michigan**

P&A staff provided training for the area's residents in self advocacy on issues related to TBI.

Many other states also recognize their communities of Native Americans are being underserved. The **Arizona P&A** is seeking to enhance its presence in this community through participation in such events as the Native Americans Disability Conference. **Wyoming, Louisiana,** and **California** are also working to increase their knowledge of, and services to, these communities. **California P&A** staff visited reservations and rancherias, acquainting themselves with the Renewal Hoopa-Yurok and Pitmeville Reservation Native American Indian Vocational Rehabilitation (VR) programs in the north, and the Sycuan Intertribal VR program in the southern part of the state. The **Louisiana P&A** sent letters to the Social Service Directors of the Chitimacha, Coushatta, Jena Band of Choctaw, and Tunica Biloxi tribes explaining their services.

Consumers with diagnoses of mental illness are a group that P&As are working with to cultivate and refine appropriate relationships and services. In states such as **Maine, Connecticut, Hawaii, New York,** and **Illinois,** the **P&As** provide rights training and meet individually with consumers residing in a variety of mental health facilities. The **Illinois P&A** had posters printed in both English and Spanish that reinforce consumer rights and P&A services. The posters were placed near telephone booths in all units of a mental health facility.

Protection and Advocacy for Individuals with Mental Illness (PAIMI) Advisory Councils throughout the country give consumers opportunities to develop an understanding of the P&A system, which then

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allows them to reach out to their peers, as well as assist the P&As with developing a greater understanding of the needs of the community. In **South Carolina**, the P&A recognizes that their PAIMI Council does a good job of identifying issues affecting people with mental illness, bringing in experts and conducting research in order to educate Council members on issues impacting those with mental illness. This helps Council members gain a better understanding of the complex and multifaceted nature of barriers impacting people with mental health needs. It is also especially helpful for the agency's priority-setting process, as Council members are better able to connect PAIMI's role and system capabilities with magnitude and severity of need. Consequently, Council members can be better advocates and the P&A can provide education, training, and other services in keeping with the "real" needs of the community.

Children are one group within the community of persons with mental illness that has been given additional attention by some P&As. As part of their plan to expand services into the children's mental health service system, the **Connecticut P&A** did a series of trainings with individuals 16 – 18 years of age on self advocacy and rights. The staff of the **Puerto Rico P&A** is also reaching out to this group, visiting several institutions for children and adolescents with mental health conditions and emotional problems, as well as a hospital facility of the Program of Children and Adolescents of the Substance Abuse and Mental Health Services Administration (ASSMCA) of the Commonwealth of Puerto Rico. Information about PAIMI Act amendments and services to children with emotional problems was also provided to staff at these facilities.

P&As are working to fortify their relationships with a variety of minority and ethnic groups in their states. During the past year, the **Massachusetts P&A** held focus groups throughout the state with the spotlight on attendance by individuals and

family members from minority and underserved ethnic communities. This was not only an effort to get their input in the establishment of program priorities, but also an opportunity for staff to educate participants about the PAIMI program.

The **New Jersey P&A's** Protection & Advocacy for Traumatic Brain Injury (PATBI) coordinator is also a member of the Health Services Advisory Committee for the Montclair Child Development Center. A brief presentation is made at each quarterly meeting to target changing parent participants. Additionally, agency materials are distributed in English and Spanish, as the children, families, and advisory members of the program come from a variety of ethnic and cultural backgrounds.

In many underrepresented communities, picnics, celebrations of cultural heritage, and activities sponsored by various groups offer opportunities for outreach by P&As. In **Arizona**, staff participated in the Black Expo and staff from the **Wyoming P&A** attended a Juneteenth picnic. In **Idaho**, two staff members of the P&A were invited to join the Women of Color Alliance Board, allowing additional insight into some of the issues affecting women and racial minorities in the state.

P&A staffs are also continuing to diversify. The **Massachusetts P&A** secured the services of an African-American attorney, who is also an American Sign Language (ASL) Interpreter, to support their efforts to reach out to, and represent, PAIMI-eligible clients. **Maryland**, **Missouri**, and **Michigan** are just three examples of states that have bilingual staff to facilitate service delivery to consumers who may not be comfortable communicating in English. The **Maryland** program employs a Spanish-speaking attorney while, in **Michigan**, the P&A has an advocate on staff who speaks Arabic to assist with their efforts to gain prominence in the large Arab-American community in the state.

Through contact with the primary Latino organization in the state, **Kansas P&A** staff plans to meet with Latino groups to provide information about return-to-work issues and other agency services. States such as **Texas** are also posting information on websites, translating materials into Spanish, using translators at conferences, and holding community forums to set priorities.

P&As are developing resources to overcome barriers of serving the needs of communities where English is not necessarily the first language. Not only is bilingual and culturally competent staff being recruited and hired, but brochures and educational materials are being translated into other languages, and agencies are using media serving such communities to get their messages out.

The **Missouri P&A** put their brochures into other languages, while the **California P&A** made their "Consumer Information Handbooks" available in Spanish, Tagalog, Chinese, and Korean. Peer/Self Advocacy staff in the state continues to assess the language needs of those they serve and provide language translators as appropriate. Staff from the **Wyoming P&A** appeared on Spanish-language television and radio broadcasts. The **Rhode Island P&A** placed an ad for their program in the Latino Yellow Pages. In **Ohio**, the **P&A** completed research to finalize an American Sign Language (ASL) Self Advocacy Booklet. A contract was awarded to an artist who is deaf to develop illustrations of ASL signs used to show advocacy in action.

Representatives from the **Minnesota P&A** met with immigrants from Africa, Asia, and the Middle East at a community center.

On **Guam**, non-English-speaking people from such countries as Micronesia, Korea, Japan, and China comprise the primary underserved community. This community – along with families of Chamorro and Filipino ancestry – often views having a relative with a mental illness as a stigma. With an understanding of community norms, the **P&A** is reaching out to these groups both by passing on information through word-of-mouth and identifying visible community contacts with whom residents are likely to talk in order to get help.

The **Alaska P&A** provides intake services at a shelter serving individuals who are homeless. The **Iowa**

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P&A also identified this population as an underrepresented community, with an emphasis on children. One of their efforts to engage young people in shelters involved a pizza party at a drop-in center in downtown Des Moines. The P&A supplied food and beverages, and presented information about their program.

People diagnosed with HIV/AIDS are also being recognized as a group that needs attention from P&As. The **Texas**, **Colorado**, and **Alabama P&As** are representative of states that are working to learn more about this community in order to address their needs for consumer education, training, and self advocacy.

To reach the geographically diverse populations of **South Dakota**, the **P&A** distributed program information through a variety of methods, including newspaper articles, television, and radio broadcasts. In addition to reaching people with disabilities, P&A staff also focused on reaching service providers to keep them current on information that may benefit consumers. Staff from the **Northern Marianas Islands P&A** also relied on the media

and their website to provide residents of the islands with information and educational materials.

Collaboration: Working Together to Increase Self Advocacy

Through partnerships with consumers, parents, and representatives from a variety of community groups and organizations, P&As have been able to increase their knowledge and understanding of the needs of various groups and communities, forge new and broader alliances to promote consumer education and self-advocacy training, share resources, and increase opportunities for people with disabilities to exercise choices and participate in their communities. Following are some examples of how P&As collaborate with others to educate consumers and support change.

1. Serving the Needs of Consumers of Mental Health Services

Self advocates have a wealth of knowledge, experience, and understanding of the community of people with mental illness to share. P&As are continuing to find ways to use the talents of this group to assist in their efforts to educate, train, empower, and support people with mental illness, their families, and other stakeholders. Through understanding the concepts of “recovery” and “transformation,” P&As are moving beyond the limits of traditional service agencies to redefine what it means to be a consumer and what it means to deliver consumer-oriented services.

Through the efforts of its PAIMI Advisory Council, the **Ohio P&A** created the Leadership Institute. Council members involved with the project received instruction to become self-advocate trainers, providing trainings at consumer conferences and local mental health (MH) boards during the months that followed. In **Florida**, identified self advocates are hired to work with consumers. Trust, self-acceptance, and acceptance by others are some of the apprehensions experienced by indi-

viduals as they approach the service delivery system. Identified self advocates, who have faced these same hurdles, can help ease the transition for the consumer and the P&A. **California** utilizes consumers in many capacities, including participation in intra-agency work groups.

The **Arkansas P&A** developed a volunteer system and an internet message board in 2004. The volunteer system seeks to develop a cadre of P&A volunteers who can serve as links between the agency and local communities throughout the state. These volunteers will help expand, amplify, and clarify community needs information coming into the PAIMI planning process. The message board uses internet technology to promote peer support and problem solving for parents with children receiving Special Education services, including services for children with mental illness. This model will be expanded into other disability, service and issue areas in coming years.

To benefit consumers with mental illness in **Maine**, the **P&A** did a series of trainings for the state's human rights officers, many of whom had never received any such training. The trainings focused on the rights of individuals with mental illness and how these rights could be enforced. As a result, some of the officers have called the P&A for advice on how to handle various situations they have encountered in their duties.

In **Vermont**, the **P&A** worked toward a collaborative model with staff from local mental health agencies to provide support for clients to speak with their own voices when they feel they have advocates available should they need greater expertise.

Realizing that mental health services in the county were in a state of crisis, the **Wisconsin P&A** formed an alliance with other advocacy and consumer groups to develop the Milwaukee County Men-

tal Health Task Force. A summit was held that included representatives from key stakeholder groups to discuss the problems the area was facing. The Task Force also sponsored a law enforcement training event, with attendees including the County Executive, two state legislators, and representatives from the Sheriff's Department and Milwaukee Police Department. As a result of the Task Force and increased discussion of the county's mental health problems the County Executive and the heads of private hospitals announced a plan to combine resources to triple the capacity of Milwaukee's small crisis-respite system. An additional psychologist with a specialty in working with people with a dual diagnosis of mental illness and developmental disabilities was also included by the County Executive to work at the County's Behavioral Health Division in response to a need identified by the Task Force.

Montana recently began implementing a regional public mental health system, which gives planning and oversight authority to local and regional authorities, a majority of whose members are consumers and family members. **Montana P&A** staff played an active role in the development of these entities to support efforts to achieve access, choice, and rights protection within the arena of public mental health. P&A staff attends all meetings, contributes to public debates, helps organize educational activities, and conducts legal research and advocacy on behalf of regional and local entities. P&A staff also participates in a local council where leaders obtained funding for law enforcement crisis-intervention training and began laying the groundwork for an inpatient psychiatric crisis and detox facility.

The **American Indian Consortium** developed and conducted four trainings that took place in Farmington, New Mexico; the Keams Canyon (Hopi Reservation); and Window Rock, Arizona. Organized using community input to insure that topics

and presentation styles met the needs of the participants, the trainings primarily addressed housing issues and the rights of students with mental illness and other disabilities. The Consortium also collaborated with neighboring state P&As and other relevant advocacy agencies on issues that impact their clients. Additionally, the **Native American Protection & Advocacy Project** (NAPAP) worked closely with tribal and regional agencies on community education and systemic advocacy initiatives. For instance, NAPAP partnered with the two Independent Living Centers serving the region to educate individuals with disabilities in self-advocacy strategies to improve conditions on the reservation. NAPAP also worked with the state Parent Training Information (PTI) centers to plan and publish training for parents of children with disabilities.

In **Kentucky**, the **P&A** collaborated with the Kentucky Consumer Advocate Network (KYCAN) and Recovery, Inc., a consumer group that focuses on enabling the homeless to "re-imagine" the future of the consumer movement in the state.

The **Pennsylvania P&A** continued to collaborate with consumers, attorneys, and consumer groups and advocates across the state. Regular meetings were held to strategize about how to impact state plans for discharge of individuals from state hospitals. Staff participated in consumer advocacy initiatives to increase funding for discharges to the community, as well as in a consumer education initiative to prepare consumers for being prominent vocal participants in the state's regional planning efforts. P&A staff assisted with the promotion and support of consumer-directed planning at nine state hospitals, assuring that consumers are actively involved in planning and recovery.

2. Promoting the Interests of Children

Children are often unable to advocate for their needs; so it is up to parents, professionals, and other consumers to speak on their behalf. P&As have

worked with families and other interested parties to ensure that the best interests of children are served by the society.

In **Maryland**, the **P&A's** outreach and training efforts focused on teaching parents self-advocacy skills so they can resolve problems on their own. Learning how to file a complaint with the Maryland State Department of Education (MSDE) was a critical aspect of the program.

Staff at the **Virginia P&A** worked on advocacy in the area of school-to-work transition. In collaboration with several other entities, P&A staff provided trainings on transition issues for the Virginia Board for People with Disabilities, Partners in Policymaking program, and Parents Education and Advocacy Training Center.

The **Mississippi P&A** provided training to parents on their rights and met with school personnel – including program developers, teachers, and principals – to ensure that children ages 3 to 21 receive appropriate services and placements in the most integrated settings under the Individuals with Disabilities Education Act (IDEA) and Section 504.

In collaboration with the Full Life Ahead Foundation – a parent advocacy group for families of teenagers dealing with transition issues – the **Alabama P&A** developed an intensive, two-day training on school-to-work transition. The training was designed specifically to target families living in the underserved “Black Belt” area of the state, providing information on transition requirements found in IDEA, conflict-resolution procedures available to families at odds with schools, and school/home communication skills. To assist parents and stu-

dents in transition advocacy, the P&A also published a brochure devoted to transition issues and planning and Alabama's graduation options.

In **Indiana**, the **P&A** hosted a one-day training designed to promote advocacy among parents and an array of professionals working with children receiving special education services. Besides dealing with substantive issues surrounding special education, the training offered an introduction to tactics and strategies for effective advocacy.

The **Washington P&A** collaborated with Parents Are Vital in Education (PAVE) to create work-incentives training for parents of transition-age students with disabilities. The P&A also partnered with People First and was awarded a grant to foster outcomes in the areas of work incentives, benefit management, and self advocacy/self determination for transition students in special education.

The **Idaho P&A** is represented on the Youth Leadership Forum Planning Committee created through a grant from the Office of Special Education to develop an annual conference for students with disabilities. This event provides students with information about transition services through VR and has led several students to contact CAP for services.

The **North Dakota P&A** continues to offer “Common Ground” trainings focusing on giving students, parents, and educators information on the rights of students under IDEA and Section 504. The trainings also provide participants with effective problem-solving and conflict-resolution techniques, and have proven to be effective in ensuring students receive an adequate education.

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Michigan P&A (MPAS) personnel collaborated with the Student Advocacy Center, Youth United in Detroit, the Michigan Poverty Law Program, Association for Children's Mental Health, and interested individuals in the "All Kids in School" project. In Michigan, as in other states, the list of children suspended or expelled from school too often includes special education students, particularly children with emotional impairments. Students and other participants in the project made a presentation before the State Board of Education on ways to prevent suspensions and expulsions and keep children in school.

The **Oklahoma P&A** developed "Partners in Education Advocacy," a specialized training program for people who want to be advocates for children in public schools. This fiscal year, the P&A increased the number of participants who advocate for children with serious mental illness. Special attention was devoted to developing behavioral intervention plans and positive behavioral support so children with mental illness are able to stay in school.

3. Voter Education and Accessibility

Like many Americans, people with disabilities are eager to participate in the election of local and national government officials. P&As worked with representatives from the community of people with disabilities and other stakeholders on systemic issues, as well as local concerns. The **Washington P&A** organized a meeting with consumers and the Secretary of State's Office to look at ways to increase accessibility to voting systems and plan for ongoing consultation with representatives from that community.

Providing education on the voting process was central to P&A activity related to removing barriers to allow people with disabilities to vote, as many would be voting for the first time. The **New Hampshire, New Mexico, and Delaware P&As** are representative of programs that developed PowerPoint presentations designed specifically to educate people with disabilities on this topic. The **Minnesota P&A**, like a number of agencies, worked with chapters of People First, the Arc, and the Centers for Independent Living to provide training to consumers throughout the state. In **New Hampshire**, People First agreed to train consumers based on training developed by the P&A.

To increase voter registration and participation in the electoral process, the **District of Columbia P&A** conducted registration drives in nursing homes, assisted-living communities, and subsidized apartments throughout the District. Agency staff successfully advocated for nursing homes to provide transportation to polling places so people with disabilities could vote in person, while applying for absentee ballots for other residents. In

Iowa, the **P&A** distributed voter registration and absentee ballot forms. Staff did trainings throughout the state focusing on voter rights and responsibilities, voter registration, and how Iowans with disabilities could vote. They also met with representatives from the Secretary of State's Office to review the Help America Vote Act (HAVA), give input on plans to educate staff on disability rights, and collaborate on voting priorities. As a result, a record number of people with disabilities voted, and Iowa ranked sixth in the nation for voter turnout for the 2004 presidential election.

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In **Georgia**, the **P&A** took voter education into the state hospital and registered individuals to vote in the 2004 presidential election. **Vermont P&A** advocates provided voter education services as part of their routine monitoring and education visits to clients in community and institutional settings. These sites included Vermont's prisons, the State Psychiatric Hospital, all designated psychiatric units and community mental health centers, as well as many community placements, such as residential care homes. In order to reach as many people as possible, P&A staff worked with service agencies, other advocacy groups, and peer support groups to ensure that accurate voter rights information was widely available to individuals with disabilities. Some of the groups and organizations included community mental health centers, area agencies on aging, community action programs, adult learning centers, prevention and health access offices, and shelters for people without homes.

4. Pursuing Other Relationships to Benefit Consumers

P&As are an integral part of efforts to create a more responsive service-delivery system. Whether it is collaborating with governmental entities, participating in community caucuses, or promoting the welfare of people with disabilities in the criminal justice system, P&As are finding new paths to meet challenges presented by individuals, groups, communities, and society.

Nevada's P&A cosponsored "Between Two Worlds," the first statewide Native American Health Care and Disability Summit. The three-day conference provided a forum for discussion of health care and disability-related issues/needs, as well as promotion of collaboration between providers and Native Americans in creating strategies to meet these needs. The conference was attended by consumers, the majority of whom were tribal members representing various tribes throughout Nevada and the region.

In partnership with the Oregon Council on Developmental Disabilities and the Oregon Health & Science University, the **Oregon P&A** organized a one-day training for tribal leaders on students in special education with traumatic brain injuries. Attendees came from tribes and social service agencies in Oregon and Utah that serve Native Americans.

The **District of Columbia P&A** and the Consumer Action Network – a new peer advocacy group – met monthly with the Director of the Office of Consumer Affairs and the Deputy Director of Policy, as well as others, to discuss resolution of systemic issues at the Department.

To reach individuals with a disability who are incarcerated, the **Utah P&A** developed an "Inmate Guide" to provide information about how to use the medical and mental health systems, and what to do if you have a complaint about these services. This booklet was distributed by the P&A and the Department of Corrections (DOC), who presented this effort as a model of P&A and DOC collaboration at a national meeting of Department of Corrections Executive Directors.

P&A staff from the **Virgin Islands** participated in a "Voices that Count" conference held on St. Thomas and St. Croix that grew out of the Developmental Disabilities (DD) Network's concern for promoting self-advocacy skill development among people with disabilities. The conference featured a "strength coach," who talked about the feelings of satisfaction that come from doing things on your own. Conference participants put together a list of issues that were important to them, including education, employment, health care, and transportation.

The **Michigan P&A** staff participated in a work group that developed a handbook for applicants and customers of Michigan Rehabilitation Services.

es. The handbook laid out the rehabilitation process, what they can expect from the agency, and their responsibilities.

The **West Virginia P&A** successfully collaborated with several entities in the state to form a disability caucus to serve as a vehicle for educating people with disabilities about the legislative process.

In seeking to increase awareness and effective self advocacy among people with disabilities and their families, the **American Samoa P&A** collaborated with the Mental Health Clinic to provide training. Based on requests from the community, this program is expected to continue through the coming year.

Training Strategies

As we have seen, collaboration, networking, conferences, trainings, participation on boards and workgroups, and the use of various media are just some of the many tools used by P&As to educate consumers and support self advocacy. This section features some of the other training/education methods employed by P&As to get out their messages and meet the needs of consumers.

The **North Carolina P&A** operated a booth at the State Fair. Participation in this event provided staff with opportunities to network with other organizations and groups, advertise their services, and provide direct assistance to consumers. Referrals were made directly from the booth, and staff educated consumers on how to get a Ticket to Work and other issues related to Social Security.

In **California**, the **P&A** developed an interactive board game titled "How to Beat the Conservatorship," which enables participants to try a number of different options for getting off conservatorship. Facility residents have successfully used the game to learn more about their rights while conserved.

The **District of Columbia P&A** developed a workbook for consumers of mental health services called "Advance Mental Health Planning." The workbook allows consumers to work independently or with others in completing assignments. Some of the topics include: navigating potential potholes of vocational rehabilitation, job training, and the workplace; the importance of support systems; anticipating types of stress before they occur; recognizing early warning signs of problems; and the value of keeping a journal and developing an action plan when things start to break down. The workbook was designed to assist individuals with anticipating and solving problems they may encounter in job training and work settings.

A toolkit providing information on services, support, and advocacy for people with recent brain injuries was created by the **Washington P&A** in collaboration with the TBI Advisory Board of Aging and Disability Services.

The **Arizona P&A** maintains a website and Employee Advice Line, providing technical assistance and legal advice on the Americans with Disabilities Act (ADA), including reasonable accommodations to people with mental illness.

As part of their plans to promote self advocacy, the **Florida P&A** created fact sheets with important how-to information. The fact sheets were distributed statewide through mail and email, as part of information packets sent to all Protection and Advocacy for Individual Rights (PAIR) callers, and on the P&A website, "PAIR link." The **West Virginia P&A** also developed and distributed information packets. Special education packets contained template letters for requesting school records, Individualized Education Program (IEP) meetings, and filing state complaints with the Office of Special Education (OSE).

In March 2004, the PAIMI Council of the **Ohio P&A** sponsored "The Right to Recovery Campaign Kickoff," focusing on the relationship between rights and recovery, and the role of advocacy in achieving both. Videos and various other materials were also developed.

In **Illinois**, the **P&A** continued to operate its "Training Institute for Disability Rights." The result of a strategic planning process with people with disabilities, the Institute not only offers self-advocacy training to consumers and their families throughout Illinois, but is also listed as an agency that provides EEOC-mandated ADA training for employers. In FY2004, the P&A partnered with the Illinois Technology Center to do webcasts of their self-advocacy trainings on such topics as special education, Ticket to Work, and voting. Viewers have the option of seeing the webcasts live or watching them later via an archive on the Technology Center's website, greatly expanding the reach of the P&A's self-advocacy trainings.

Self Advocacy: Positive Outcomes

Self advocacy is a result of consumer education and training. With information, advice, and support, consumers can take action on their own behalf. Being able to take care of one's own needs promotes a sense of well-being and connection to the larger community. Following are examples of people who used self-advocacy skills to take responsibility for their lives.

The **Washington P&A** was contacted by the mother of a girl with anxiety and severe behav-

ior problems who was not taking her prescribed psychiatric medications and had been bounced back and forth between hospitals and temporary placements. The mother wanted to secure a long-term residential placement where her daughter would be safe and receive services to foster stability. The girl was a client of both the Division of Developmental Disabilities and the Division of Mental Health, but neither wanted to assume responsibility for solving the "problem." A P&A advocate was able to provide the mother with advocacy strategies and information, such as individuals to contact within the service delivery system, services she was entitled to, and how to access them. As

a result of the technical assistance provided by the P&A, the mother was able to advocate for her daughter and a satisfactory placement was secured.

In **Minnesota**, a woman with traumatic brain injury and physical disabilities was able to get her case manager to help her move out of a nursing home into her own apartment. The **P&A** staff discussed options with her and specific requests she could make to the case manager for assistance.

A 46-year-old woman from **Ohio** with traumatic brain injury was in her final quarter of an Associates degree program. The school denied her further financial assistance due to a prior record of poor grades. She was also denied access to the college's "poor grade forgiveness policy." The **P&A** staff attorney offered support and advised her about her legal rights and techniques in self advocacy. As a result, the client was able to successfully negotiate with

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the school to grant her request for grade forgiveness and continued financial aid.

In **Michigan**, a man contacted the **P&A** for assistance in getting his Supplemental Security Income (SSI) payee changed. He had disputes with the payee, who was returning his checks to the Social Security Administration (SSA). Consequently he became homeless and did not have money for food and other necessities. Acting on P&A staff advice, the man was able to identify a new payee, get the previously returned checks from SSA, and secure housing.

Medicaid notified a family in **New Hampshire** that the number of in-home nursing care hours they received for their toddler with numerous developmental disabilities was going to be reduced from 60 to 50 hours a week. With counsel and advice from **P&A** staff on how to present their case at the Medicaid hearing, the family was able to reach a satisfactory settlement.

Unwilling to consider the alternative of in-home nursing care, a hospital in **New York City** told a young woman recovering from a medical emergency related to an orthopedic impairment and diabetes that she would be discharged to a nursing home. With advice and information provided through the **P&A**, she was able to advocate for herself and get community-based services in place so she could be discharged to her home.

After being advised by **Louisiana P&A** staff about legal requirements for paratransit systems, a Lake Charles woman met with the Mayor and other city officials in an attempt to resolve problems with the accessibility of the city's transportation system.

In **Texas**, a 50-year-old diagnosed with schizophrenia was treated at Dallas Metro Care for years and was functioning well with the aid of Seroquel. When she moved, her new doctor wanted to change

her medication to Haldol. The consumer had been on Haldol and remembered that it made her very drowsy and dizzy. Currently in school and working part time, the consumer has to be able to "think clearly." When the woman called the P&A for assistance, she was adamant that she did not want to be on Haldol, but did not believe she had the right to tell the doctor what she wanted to take, thinking the decision was solely up to the physician. Through the P&A handout, "Your Right to Refuse Medication," she learned that it is her choice to take the medication she believes best meets her needs, and that she has the right to participate in the treatment team and have input into her treatment plan. Armed with this knowledge, the consumer informed her doctor that she was aware of her rights related to treatment and medication. When her doctor (again) suggested putting her on Haldol against her wishes, she informed the doctor that she wanted to remain on Seroquel because she functioned very well on it. The doctor then decided to keep her on Seroquel and even began giving her samples. She is now taking Seroquel on a regular basis and states that she is doing well in school and on her job.

The parents of an 18-year-old with a mental illness diagnosis were concerned about the support services she would receive upon discharge from a residential treatment program in **Hawaii**. In an effort to avoid future hospitalizations, they wanted services in place prior to her discharge. They contacted the P&A, where an advocate guided the family through the process of getting appropriate mental health services in the community. As a result of working with the advocate, the young woman returned to her home school and is doing well with a very high level of wraparound services through the Department of Health.

In **Tennessee**, a 15-year-old student with ADHD was suspended from school without a manifestation determination. **P&A** staff provided self-advoc

cacy training for the parent to facilitate effective communication with school personnel. The parent was instrumental in reaching a positive outcome on the student's behalf.

An adult male with schizophrenia in **South Carolina** contacted the **P&A** for assistance with concerns about excessive medication, individualized therapy and appropriate medical treatment. P&A staff met with the client and provided written directions for self advocacy. He was able to use the written instructions to talk to the treatment team about his concerns. Based on this discussion, he saw a neurologist and ophthalmologist for medical treatment. As a result of P&A intervention, he received a copy of his individualized treatment plan and his medication regime was modified to more accurately meet his needs.

California P&A staff provided support to individuals with psychiatric disabilities engaged in a recovery model of mental health. A Creekside Discharge group initially expressed a sense of hopelessness about chances of moving out of the Institutions for Mental Disease (IMD) facility. Many residents had physical barriers to living in the community, as well as psychiatric disabilities. After participating in the group, feelings of empowerment were expressed. Each resident began developing a personal discharge plan and became aware of a number of previously unidentified community resources. Seven residents requested and received a pass to leave the facility, taking public transportation to visit different housing options they were considering. After returning, the residents were more optimistic about their discharge possibilities.

Three clients of the **Ohio P&A** were able to successfully advocate for themselves after receiving information and referral, technical assistance, and advice and counseling from P&A staff. The first case involved how to deal with the question regarding mental health issues on the nursing license appli-

cation. The second case concerned re-admission to a university following a disability-related leave, while the third revolved around a teacher having difficulty returning to employment following disability-related issues with his employer.

During the process of transferring to a different community college, a 24-year-old diagnosed with ADHD and borderline personality disorder was told she would be denied educational accommodations. She contacted the **Nebraska P&A** for assistance, where staff advised her to obtain a letter from her doctor stating her disability, the necessity for accommodations, and what accommodations were appropriate for her. When she received that letter, staff further advised her to submit a written request for accommodations to the college, along with the letter from her physician. The college not only provided the necessary accommodations in time for Fall quarter, but also inquired about a few accommodations the client had not requested.

In **South Carolina**, a woman with bipolar and schizoaffective disorders moved from Bryan Psychiatric Hospital to a "Toward Local Care" (TLC) apartment in the community. P&A worked with the client to promote her individual thoughts and decisions about what supports she felt were needed in order to be successful in the TLC. The client received the necessary supports and chose to remain in the TLC apartment and is doing well.

While not all self-advocacy initiatives produce a successful outcome in terms of individuals getting what they want, they do provide opportunities for individuals to learn more about themselves and the roles P&As can play in their lives. P&As also learn more about how they need to direct their participation to support self advocacy. As the relationship between consumers and P&As continues to evolve, P&A consumer education will grow in its ability to fuel self advocacy.

Protection and Advocacy Agencies in the States and Territories:

ALABAMA

Alabama Disabilities Advocacy Program
www.adap.net

ALASKA

Disability Law Center of Alaska
www.dlcak.org

AMERICAN SAMOA

Client Assistance Program and Protection & Advocacy
No website available at this time
Phone: 011-684-633-2441

ARIZONA

Arizona Center for Disability Law
www.acdl.com

ARKANSAS

Disability Rights Center
www.arkdisabilityrights.org

CALIFORNIA

Protection & Advocacy, Inc.
www.pai-ca.org

COLORADO

The Legal Center
Website www.thelegalcenter.org

CONNECTICUT

Office of P&A for Persons with Disabilities
www.state.ct.us/opapd/

DELAWARE

Community Legal Aid Society, Inc.
www.declasi.org

DISTRICT OF COLUMBIA

University Legal Services
www.dcpanda.org

FLORIDA

Advocacy Center for Persons with Disabilities
www.advocacycenter.org

GEORGIA

Georgia Advocacy Office, Inc.
www.thegao.org

GUAM

Guam Legal Services
No website available at this time
Phone: (671) 477-9811

HAWAII

Hawaii Disability Rights Center
www.hawaiidisabilityrights.org

IDAHO

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

ILLINOIS

Equip for Equality, Inc.
www.equipforequality.org

INDIANA

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

IOWA

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

KANSAS

Kansas Advocacy & Protective Services
www.drckansas.org

KENTUCKY

Kentucky Protection and Advocacy
www.kypa.net

LOUISIANA

Advocacy Center
www.advocacyla.org

MAINE

Disability Rights Center
www.drcme.org

MARYLAND

Maryland Disability Law Center
www.mdclbalto.org

MASSACHUSETTS

Disability Law Center, Inc.
www.dlc-ma.org

MICHIGAN

Michigan P&A Services
www.mpas.org

MINNESOTA

Minnesota Disability Law Center
www.mndlc.org

MISSISSIPPI

Mississippi P&A System, Inc.
www.mspas.com

MISSOURI

Missouri P&A Services
www.moadvocacy.org

MONTANA

Montana Advocacy Program
www.mtadv.org

NATIVE AMERICAN

Native American Protection & Advocacy Project
www.nativelegalnet.org

NEBRASKA

Nebraska Advocacy Services, Inc.
www.nebraskaadvocacyservices.org

NEVADA

Nevada Advocacy & Law Center, Inc.
www.ndalc.org

NEW HAMPSHIRE

Disabilities Rights Center
www.drcnh.org

NEW JERSEY

New Jersey P&A, Inc.
www.njpanda.org

NEW MEXICO

Protection & Advocacy, Inc
www.nmpanda.org

NEW YORK

NYS Commission on Quality of Care for the Mentally Disabled
www.cqc.state.ny.us

NORTH CAROLINA

Governor's Advocacy Council for Persons with Disabilities
www.gacpd.com

NORTH DAKOTA

North Dakota Protection & Advocacy Project
www.ndpanda.org

N. MARIANAS ISLANDS

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

OHIO

Ohio Legal Rights Service
http://olrs.ohio.gov/

OKLAHOMA

Oklahoma Disability Law Center, Inc.
www.oklahomadisabilitylaw.org

OREGON

Oregon Advocacy Center
www.oradvocacy.org

PENNSYLVANIA

Pennsylvania P&A, Inc.
www.ppainc.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
www.protectionandadvocacy-sc.org

SOUTH DAKOTA

South Dakota Advocacy Services
www.sdadvocacy.com

TENNESSEE

Tennessee P&A, Inc.
www.tpainc.org

TEXAS

Advocacy, Inc.
www.advocacyinc.org

UTAH

Disability Law Center
www.disabilitylawcenter.org

VERMONT

Vermont Protection & Advocacy, Inc.
www.vtpa.org

VIRGIN ISLANDS

Virgin Islands Advocacy, Inc.
www.viadvocacy.org

VIRGINIA

Virginia Office for Protection & Advocacy
www.vopa.state.va.us

WASHINGTON

Washington P&A System
www.wpas-rights.org

WEST VIRGINIA

West Virginia Advocates, Inc.
www.wvadvocates.org

WISCONSIN

Wisconsin Coalition for Advocacy
www.w-c-a.org

WYOMING

Wyoming Protection & Advocacy System, Inc.
http://wyopanda.vcn.com

For More Information about local P&As:

Protection and Advocacy offices are located in all 50 states, the District of Columbia, Puerto Rico and the federal territories. Additionally, the Native American Protection & Advocacy Project assists clients who live on or near the Navajo Nation and the Hopi Reservations. The Protection and Advocacy offices provide free advocacy (legal and non-legal) on behalf of people with disabilities to ensure access to the community, education, employment, health care, housing, and other issues.

For more information about the P&A Network, or to find the P&A office nearest you, please visit our website at www.napas.org. You can easily find your state and thereby find the P&A office near you.

We also invite you to take some time and navigate our website and its vast array of substantive content. The topic areas on our website include: Abuse and Neglect; Advance Directives; the Americans with Disabilities Act (ADA); Assistive Technology; Community Integration; Criminal Justice; Education/Individuals with Disabilities Education Act (IDEA); Employment/Return to Work; Help America Vote Act (HAVA); Housing; and Traumatic Brain Injury (TBI).



P & A

News

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