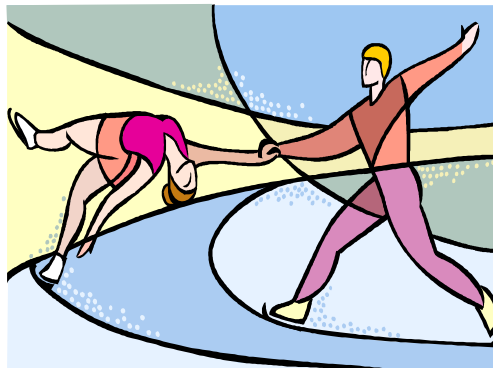


A NATURAL PARTNERING:

**The Role of The
Protection and Advocacy System
To Implement The Recommendations
of The New Freedom Initiative
Commission on Mental Health**



NOVEMBER 2004

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I. BACKGROUND

On April 29, 2002, President Bush announced the creation of the New Freedom Commission on Mental Health, and declared, "Our country must make a commitment. Americans with mental illness deserve our understanding and they deserve excellent care." Toward that end, he created the New Freedom Initiative Mental Health Commission and asked them to make recommendations for enabling individuals with mental illnesses to live, work, learn, and participate fully in their communities. In July 2003, the Commission issued the report and made recommendations for ending the "piecemeal" approach to mental health provision and creating a system that supports recovery and evidence based practices.

The Commission, makes clear that the changes called for in the report must occur not only from the efforts of federal agencies such as the Substance Abuse and Mental Health Services Administration, but also through work at the state and community levels by people involved with the mental health delivery system. The Protection and Advocacy Agencies (P&As) and the Client Assistant Programs (CAPs) will absolutely have a role to play in bringing about this "transformation of the mental health system." In fact, since its inception, the P&A System (comprised of both P&As and CAPs) has been governed by statutes with a similar mission and goal.

In particular, the Commission's report emphasizes the importance of a recovery model for the mental health system. Recovery is defined in the report as "the process in which people are able to live, work, learn, and participate fully in their communities." This is also a fundamental goal of the P&A System. The P&A/CAP network supports people with mental health needs and their families as they struggle to make a better life for themselves in the community. P&As make it possible for persons with disabilities to obtain access to employment, housing, quality education and medical services. When all those services are in place, individuals with disabilities live a stable and secure life as tax-paying members of the community. P&A/CAP advocates do all they can to ensure that individuals have access to needed services, housing and support to ensure success in the community and that individuals will not have to live a life of dependency and poverty.

This paper highlights a few examples of P&As and CAPs work that promote the mental health system transformation sought by the Commission. It also offers recommendations for federal actions that would assist the P&A/CAP network to

increase its ability to advocate for a mental health system that truly facilitates recovery.

II. P&A AND CAP WORK IS ALREADY SUPPORTIVE OF THE CHANGE SOUGHT BY THE COMMISSION

The Commission's recommendations are set forth below, followed by a few examples of current P&A or CAP work reflecting those goals. There are many more examples of this type of work in the P&A/CAP network that demonstrates the P&A System's long standing commitment to the goals of full community participation for persons with mental illness.

Recommendation 1:1 – Advance and implement a national campaign to reduce the stigma of seeking care.

Numerous P&As used the fifth anniversary of the U.S. Supreme Court decision in *Olmstead v L.C. and E.W.* to draw media attention to the continued stigma and unnecessary institutionalization experienced by individuals with mental illness and other disabilities. For example, Equip for Equality, **the Illinois P&A**, brought together a variety of disability groups who held a press conference on the fifth anniversary of the Olmstead decision announcing the release of two Olmstead implementation progress reports: one, drafted by the Center for Independent Living in Chicago, which focused on community integration for individuals with physical disabilities; the other, written by the Illinois P&A, and focusing on community integration and individuals with mental illness.

The **Arkansas P&A** Created the “Can Do Committee” a coalition of consumer, elderly, and youth agencies working together to carry out a state-wide media campaign to increase the positive perspectives of all people with disabilities and of the need for inclusion in all aspects of society. The Campaign has given presentations, prepared public service announcements, been on public television with the message, encouraged advertising, sponsored a poster, prepared written media materials and organized a candlelight vigil.

Recommendation 1:2 – Address mental health with the same urgency as physical health.

The **Washington P&A** formed a coalition with numerous disability organizations in the state to provide information to the public and lawmakers about the need for a state mental health parity statute. The Coalition prepared fact sheets and articles about the impact of insurance company policies that restrict access to needed mental health supports. Most recently, the Coalition developed a pamphlet with the stories of people who have been harmed because their health insurance wouldn't cover their mental health treatments.

This is an excerpt from the **California** P&As position on a proposed state mental health bill:

“The Mental Health Services Act is a proposed citizen initiative, expected to appear on the November 2004 ballot that would expand mental health care programs for adults and children. PAI supports the initiative, given the need for access to comprehensive, voluntary mental health services. However, PAI [the California P&A] has concerns about:

* Segregating Mental Health From Health Generally

To the extent that the initiative encourages the continued separation of mental health care from other types of health care, it does a serious disservice to the people of California. We need a system that will not only treat mental health but will treat the problems that mental illness may mask. We need a system that will in addition to checking the heart and the lungs, check the person's mental health. Rather than a separate system, we need a system that will enable the person with diabetes, cancer, HIV or a heart condition to get the therapy, counseling and medication necessary to ameliorate the condition. We need a system that, along with educating the public about the warning signs for cancer, will also discuss the warning signs for mental illness. We need a system that will treat each person as a whole, as someone with a complex interaction of chemicals and organs, and as someone with a soul. The treatment of all of this must be integrated. The proposed Mental Health Initiative Services Act funding strategy furthers separation, and hence segregation and isolation.

* Shaming of Persons Who Have Psychiatric Disabilities

The Mental Health Services Act campaign materials contain language portraying negative stereotypes about people with psychiatric disabilities. PAI is especially concerned that media materials treat portray people with psychiatric disabilities and their families with the respect that is their human right. PAI would like to work with the campaign to ensure that the dignity of persons with psychiatric disabilities will be given the highest priority throughout the process of gathering support for the initiative among the electorate.

Recommendation 2:1 and 2.2 – Develop an individual plan of care for every adult and child with serious mental illness and involve consumers and families in orienting the mental health system towards recovery.

P&As are working across the country to stop the “dumping” of individuals from state hospitals directly into inappropriate mental health “board and care” homes

with no individualized plan of care and little if any mental health services. For example, Disability Advocates, the **New York P&A**, filed suit against the Governor alleging that the continued placement of individuals with mental illness in board and care centers with inadequate services and paltry mental health supports violates the ADA integration mandate and other federal and state laws. The suit is ongoing, but is expected to result in improved mental health supports in these facilities and a stop to the practice of moving individuals from hospitals into board and care homes without adequate discharge supports.

The **Alabama P&A** worked in coordination with other private attorneys and the Judge David L. Bazelon Center for Mental Health Law to design the *Wyatt* Settlement. This settlement required the state to develop a three-year plan to identify consumers to be out-placed from mental health facilities and to increase community-based placements and community-based services for such consumers with mental illness. The settlement makes clear that alternative placements and services shall be established before an individual is discharged from the facility. The *Wyatt* settlement requires, among other things:

“Use professional assessments to develop a discharge plan for each consumer discharged from a state mental health facility. The discharge plan shall determine the maximally effective, efficient, and safe out-placement in the most integrated setting appropriate for the consumer’s needs. The discharge plan shall identify community services consistent with the consumer’s identified needs. Regarding the discharge plan developed, Defendants shall document in each consumer’s record the opinions of the inter-disciplinary treatment team and the preferences of the consumer and/or his or her guardian, responsible party or next-friend, and as applicable, a representative of the Alabama P&A.”

Recommendation 2:3 Align relevant Federal programs to improve access and accountability for mental health services

The Legal Center, the **Colorado P&A**, represented a parent of an eight-year-old boy who was terminated from community mental health services because the Community Mental Health Center believed he had a primary diagnosis of developmental disability and therefore should be served through the developmental disability service system. The boy been receiving medication services from the mental health program and his medication was abruptly terminated without consideration of side-effects or other consequences. The P&A negotiated a six-month extension of services from the Mental Health Center for the boy; and in the interim educated the Center about its obligation to provide appropriate mental health services to children, even as, the Center pursues reimbursement from other appropriate state agencies.

Recommendation 2:4 – Create a comprehensive state mental health plan

The Hawaii Disability Rights Center, the **Hawaii P&A** brought attention to the population of individuals with mental illness who are incarcerated. The state was failing to plan for the needs of this population in its Olmstead implementation efforts. The P&A, studied a random sample of 67 pretrial detainees who were the subject of court-ordered forensic examinations throughout 2001 and 2002. In February 2004, the P&A prepared a report to inform Hawaii State decision-makers and the public of the problems faced by pretrial detainees who are deprived of their constitutional due process rights while they await court-ordered mental evaluations, provided for by state law. The report documents a system that routinely fails to provide mental health services to individuals during the period in which they await a mental health evaluation. The report also discusses a variety of solutions to the suspension of pretrial detainee due process rights, any one of which would go a long way towards ameliorating the situation.

The **Florida P&A** funded a state-wide study which identified gaps in the state's current mental health system for children with mental health needs. The study included specific recommendations for improving mental health supports for youth. After wide dissemination of the report the P&A organized a statewide summit of consumers, family members, advocacy groups, and state officials who came together to hear the recommendations and agree on action steps.

Every P&A has been involved in the development of its state's plan to implement the Supreme Court's Olmstead decision. One example is the **Maine P&A**, which organized significant grassroots pressure, to protest the fact that the state's Olmstead plan insufficiently addressed the needs of people with mental illness. The P&A also protested that the plan called for community needs assessments to be conducted with "assessment tools" which did not properly assess mental health needs (it was designed solely for individuals with developmental disabilities). As a result of consumer and advocate pressure, the state agreed to re-visit the plan and address these concerns.

Recommendation 2:5 – Protect and enhance the rights of people with mental illness

This is the central role of the P&A System, which is mandated, under the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Act, - to investigate abuse and neglect of persons with mental illness, and to pursue administrative, legal and other appropriate remedies to ensure the protection of rights. The PAIMI program has 57 agencies working in the 50 states, 6 territories and the Native American reservations of the southwest. PAIMI served over 15,000 individual clients as well thousands of information and referrals, systemic advocacy and class litigation. The cases cover the range of issues facing people with mental illness from abuse and neglect, access to community services, transportation, housing and employment.

Protection and Advocacy, Inc, the **California P&A**, conducted several investigations into deaths related to the combined use of multiple psychiatric medications. The P&A arranged for three of the 2004 P&As cases to be reviewed by experts in clinical psychiatry, psychopharmacology and toxicology. In each case, the experts were critical of the polypharmacy regimen prescribed and the adequacy of the clinical response in the face of patient deterioration. In at least one case, PAI's experts concluded that the drug regimen was fatal. In the other two cases, polypharmacy likely contributed to the adverse outcome, based on the combined pharmacological effects of the medications used. In each case, the regimen prescribed was aggressive and unsupported by the patient's clinical presentation and the medical literature. Also, there appeared to be little clinical evaluation in the face of patient deterioration. Days lapsed between physician visits. Medication lists were not reviewed and drug levels were not monitored.

Armed with the expert findings, the P&A released a report to the public highlighting the potentially fatal consequences of polypharmacy; and encouraging health care professionals to implement safeguards when prescribing multiple medications in combination.

Recommendation 3.1 and 3.2 – Improve access to quality care that is culturally competent and improve access to care in rural and geographically remote areas

The Arizona Disability Law Center, the **Arizona P&A**, represented a young boy with emotional disabilities who required specialized educational supports, only available at one school in his district. The boy's parents contacted the P&A when the school made it clear to the parents and the school district that it did not want to provide the mental health supports the child required. First, the school pressured the school district to enroll him in another school several hours from his home. When pressure did not work, the school attempted to use the boy's misconduct, directly related to his disability, as an excuse to expel him from school. The P&A represented the boy at an administrative hearing before a judge and obtained a court order re-enrolling the boy in the school and requiring the school to provide the needed behavioral supports.

Cultural Competency - The **Illinois P&A**, NAPAS, and the Illinois Department of Human Services Division of Mental Health collaborated on a pilot project, to identify systemic barriers within the state system that impede the state's ability to deliver culturally and linguistically competent mental health care services, as well as to identify impediments which have hindered the ability of consumers from diverse communities from accessing and utilizing culturally and linguistically appropriate services.

Geographically Remote Areas - The **Washington P&A** was part of a group of advocates who supported the state's initiation of transportation brokerages. The state Medicaid agency established thirteen medical transportation service

districts and contracted with a network of regional transportation brokers to cover the entire state, even rural areas. Brokers receive an administrative fee to coordinate the program as well as reimbursement for direct costs. When a client needs a ride to a medical provider, she calls the broker, who verifies Medicaid eligibility, determines the necessity of each trip and assigns the appropriate provider.

Recommendation 4:1 – Promote the mental health of young children

The **Virginia P&A** filed suit in October 2004 against the state's Department of Medical Assistance Services alleging that the state was failing to provide appropriate Medicaid supports to children, particularly behavioral health services. The state settled the case only 3 weeks after it was filed, and agreed to: 1) notify all children of the behavioral health and other screening and diagnostic supports available under the state's Medicaid program; 2) develop a new Member Handbook to include specific, detailed and understandable information on children's Medicaid services; 3) train Department of Social Services personnel on the program and to conduct a training session for all Medicaid Case Managers and Service Facilitators on the topic of children's behavioral health supports; and 4) revise its children's health informational brochure and send it to all eligible persons.

The **Maryland P&A** is working to stop the alarming number of children with behavior disorders still in hospitals, even after their doctors have found them ready for discharge to less restrictive environments. Often these hospitals are not equipped to provide treatment to these children and, yet outmoded state policies keep them trapped. What makes the situation worse, is that many of these children's parents (one study says 27%) had to, or were advised to, give up custody in order for their children to become eligible for the mental health treatment services they need. The P&A formed a coalition of families, consumers, advocates and providers, which inform policy makers about ways to eliminate these barriers to appropriate mental health treatment. Some recommendations included providing more individualized supports, and better coordination between the state agencies that provide services to the same children.

Recommendation 4:2 – Improve and expand school mental health programs

Advocacy inc, the **Texas P&A** is working in Coalition to collect information on the use of law enforcement by school districts for students receiving special education in the state. The P&A identified a trend of schools calling law enforcement to deal with behavior of students with emotional disturbances, which in the past would have been managed by school personnel. The P&A will use the information collected to determine if there is a need for state law or policy.

The **Montana** P&A worked with parent groups to obtain a rule change that clarifies that IEPs must include positive behavior supports as the primary method for addressing problem behavior by students with disabilities. The **New Hampshire** P&A led a coalition of 18 partners (including providers, educators, school officials and individuals) who signed a Memorandum of Understanding about preventing school exclusions (e.g. suspension and expulsion) for children with mental illness.

Recommendation 4:4 – Screen for mental disorders in primary health care across the life span, and connect to treatment and supports

The P&A network assists the families of young children who may have mental health needs in obtaining the screening services provided by EPSDT (Medicaid for children). In addition, P&As work to improve the accountability of Early Childhood programs will result in improved compliance with the obligation to locate and serve children with mental health needs (the “child find” obligation) required by the IDEA.

Recommendation 5:2 – Advance evidence-based practices using dissemination and demonstration projects and create a public-private partnership to guide their implementation.

The **Kentucky** P&A runs a program focused on individuals called “Making Our Own decisions.” As part of this program, in 2002 alone, the P&A trained over 500 people at 22 therapeutic rehabilitation programs about state law covering psychiatric advance directives. Following this training, 50 people sought additional assistance from the P&A to create a directive. Once the directive is completed the P&A provides a copy to the individual and keeps a copy in a central advance directive registry maintained at the P&A office. These individuals are also given a wallet sized card that notifies police and hospital staff of the existence of the directive and how to contact the P&A to obtain a copy. The P&A collaborates with other disability rights agencies in Kentucky to provide information about the assistance the P&A will provide.

The P&As also promote is use of mental health courts to divert individuals with mental health from entering the correctional system. P&As do this by educating the legal system about the need for more mental health jail diversion programs and by training law enforcement officials about diversion programs. For example, the **New Jersey P&A** represented an eighteen-year-old with schizophrenia and resistance to medication compliance. During an encounter with the local police, the P&A’s client was jailed instead of being transported to a crisis-intervention screening center. The P&A contacted the jail administrator and the psychologist of the Mental Health Unit, and as a result the individual was transferred to a psychiatric hospital for assessment and appropriate follow-up treatment.

Recommendation 5:3 – Improve and expand the workforce providing evidence based mental health services and supports

The Advocacy Center, **The Louisiana P&A**, determined that the state was failing to inform and provide individuals about the transition services available to individuals with disabilities under the Individuals with Disabilities Education Act. The P&A began an initiative in five New Orleans public high schools to reach out to students with disabilities, including mental illness and behavioral disorders, who are nearing graduation and ensure they receive transition services. The project coordinator provides training on the transition supports and vocational programs available to students and educators. The program also provides training and individual support to students on job seeking skills, self esteem issues and other relevant topics.

The Social Security Administration funds the Protection and Advocacy for Beneficiaries of Social Security which enables the P&As to assist recipients of SSA benefits find employment. The PAIMI and PAIR programs also support assistance to people to obtain and maintain employment. For example, the **Hawaii P&A** negotiated a win-win solution for an employer and an employee with a mental illness. After the employee was discharged from the hospital, he realized that he could not return to his former position. The P&A worked with the employer and the insurance carrier to get a full health benefit package for the employee and his family, workers' compensation, a recommendation from the employer that the employee was an "employee in good standing," and assistance from the state vocational rehabilitation agency for new employment training. The worker is currently employed in a new position.

Recommendation 6:1 & 6.2 Technology

P&As receives money from the National Institute for Disabilities and Rehabilitation Research (NIDRR) to assist people with mental illness with assistive technology. While not directly on point with this recommendation, it is appropriate to note the involvement of the P&A network in expanding technology to all people with disabilities

III. RECOMMENDATIONS FOR FEDERAL AGENCY ACTION TO ASSIST P&As/CAPs FACILITATE COMMISSION GOALS

RECOMMENDATION: Issue Regulations To Implement The Children's Mental Health Act of 2000

As soon as possible, The Centers for Medicare and Medicaid Services (CMS) should issue, consistent with the requirements of the Children's Health Act of 2000, regulations that establish comprehensive standards for health care facilities' use of restraint and seclusion, and designate the P&A System as the recipient of reports concerning restraint-related deaths and injuries for

investigation. (CMS has failed to comply with a 2001 deadline for the issuance of such regulations.)

P&As have broad authority under the PAIMI Act to access state and private facilities and their residents and records to investigate abuse and neglect, but limited investigative authority in the context of federal facilities such as federal prisons and hospitals operated by the Department of Veterans Affairs. HHS should support an amendment to the PAIMI Act that extends P&As' investigative authority to federal facilities, which serve many vulnerable persons with mental illness. The PAIMI Act also should be amended to ensure that P&As' authority to access records to investigate abuse and neglect is as far-reaching as that mandated under the Developmental Disabilities Act of 2000.

Many persons with mental illness continue to suffer deadly abuse and neglect as a result of improper restraint and seclusion, denial of appropriate medical care or assault by caregivers and others, and there continues to be insufficient funding to the P&A System to allow it to address these incidents systemically. HHS should support significantly enhanced funding to the P&A System to promote an improved capacity to investigate and remedy these abuses.

RECOMMENDATION: Establish a P&A Program To Represent Families of Special Education Students with Mental Health Needs

Currently the P&A network receive no funding specifically to provide services to the families of students (birth through age 21) with disabilities. This is problematic as the level of compliance with the IDEA (the federal law that creates the special education program) is very low and families have few legal resources -- public or private to turn to for help. The network does assist a great many special education students with mental health needs every year using other funds, but a funding stream specifically dedicated to special education services would provide much greater access to this information and increased assistance for families to ensure that their children's needs are met.

Every year, the P&A network represents thousands of children with mental health needs who receive services through the public schools. The network also assists many families in obtaining information about service options available to their children. This assistance results in expansion of the services available to these students in both their neighborhood schools and in special programs for children with emotional disabilities. In addition, the network also represents students with mental health needs who are eligible under Section 504 of the Rehabilitation Act, but who may not be eligible under the IDEA, thereby reaching students who are impacted less severely by their mental health needs.

RECOMMENDATION: Support Grants For at least five P&As to advocate for more affordable housing options for people with mental illnesses

People with mental illness face special difficulty obtaining appropriate housing in the community. Some people -- because of prejudice and misunderstanding-- do not want homes for people with disabilities to be built in their neighborhoods. This opposition is known as NIMBY-ism (not in my back yard). Additionally, some individuals are forced to give up their autonomy and agree that in exchange for the ability to rent the public housing, they will adhere to rigid compliance with mental health services. Another important population these P&A grants could focus on is individuals with disabilities, released from prisons, jails or mental health forensic units. These individuals often face even greater barriers to housing than other persons with mental illness.

P&A with a housing demonstration grant could work to ensure that the annual plans issued by housing authorities included the needs of people with mental illness. P&As could also expand anti-stigma education and outreach. In addition, the P&As could provide individual advocacy to prevent people with mental illness from being evicted from their homes or denied housing because of their disabilities.