

Evaluation of the Protection and Advocacy for Individuals With Mental Illness (PAIMI) Program

Phase III: Evaluation Report



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U.S. Department of Health and Human Services
Substance Abuse and Mental Health Services Administration
Center for Mental Health Services

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EVALUATION OF THE PROTECTION AND ADVOCACY FOR INDIVIDUALS WITH MENTAL ILLNESS (PAIMI) PROGRAM, PHASE III: EVALUATION REPORT

Executive Summary

This report summarizes findings from the first external evaluation in the 22-year history of the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program. The evaluation was funded through a contract to the Human Services Research Institute (HSRI) from the Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Mental Health Services (CMHS), Department of Health and Human Services.

The PAIMI Program

The PAIMI Program was initiated in 1986 in response to congressional findings of widespread abuse, neglect, and exploitation of individuals in state psychiatric institutions. Twenty-two years later, the program is still addressing those issues, along with new problems arising from delivery of mental health services in community-based settings.

Recognition that persons with disabilities are citizens entitled to respect and protection from abuse and neglect emerged in the late 1960s. Individuals with psychiatric disabilities were an early focus of these activities. Initially, reformers focused on conditions in state institutions, mounting challenges to civil commitment laws that allowed for indefinite involuntary institutionalization and advocating establishment of the “right to treatment” (*Lessard v. Schmidt*, *Donaldson v. O’Connor*, 422 U.S. 563 (1975); *Wyatt v. Stickney*, 344 F. Supp. 373, M.D. Ala. 1972). These landmark cases opened the way for an expanded focus—both in courtrooms and legislatures—on the protection of the rights of individuals with mental illness (hereafter referred to as psychiatric disability) and other disabilities, both in hospitals and in community services.

The PAIMI Act of 1986 established the PAIMI Program. Modeled after the Developmental Disabilities (DD) Act and crafted at a time when numerous reports of abuse and neglect in state psychiatric hospitals were substantiated, the PAIMI Program was established to extend similar protections to persons with significant psychiatric disability. PAIMI agencies were mandated to investigate reports of abuse and neglect in facilities, and in 2000, the Act was amended to include individuals in need of advocacy receiving community-based care. Although program eligibility was expanded to include those residing in the community, Protection and Advocacy (P&A) agencies must still prioritize services to persons in institutional settings. Currently, there are 57, with 1 in each state, the District of Columbia, 5 territories, and 1 for several Native

American tribes. The two primary types of PAIMI designation are those housed within state agencies (referred to as state-operated) and those within private, nonprofit organizations.

Responsibilities of the PAIMI Program

Congress intended that PAIMI-eligible clients and families guide the work of each PAIMI and be at the center of the PAIMI's determination of priorities. Specific responsibilities of the program include:

- Investigating abuse including physical maltreatment, verbal harassment, and institutional practices that can be considered abusive
- Investigating neglect including neglect of basic needs as well as failure to provide adequate treatment planning, discharge services, or community care
- Investigating the denial of constitutional and statutory rights including the adequacy of physical conditions in facilities, freedom from undue restraint of liberty, provision of due process in involuntary treatment, and the right to informed consent

Evaluation Design

The PAIMI evaluation involved a three-stage process. The first stage was an evaluability assessment that sought to understand the degree to which the program could be evaluated. This included a thorough document review and stakeholder interviews. The evaluability assessment concluded that a national evaluation of the PAIMI Program was feasible within the funding constraints and presented an important opportunity to the Federal Government to guide subsequent policy direction at the national level. For states and other stakeholders, the evaluation could provide information to bolster system change in mental health services.

The second stage included the development of a logic model that identified the major contextual variables, goals, and functions of the PAIMI Program. This logic model laid out the concept of PAIMI's "shared responsibility" for achieving outcomes. Given the broad goals of the program and its limited resources relative to other programs, it is difficult to establish a direct causal connection between PAIMI actions and intended distal program outcomes, such as increased choice of mental health services and decreased abuse experienced in treatment settings. System change at the state and Federal levels is a function of multiple factors, and the PAIMI Program is but one of these factors. The notion of "shared responsibility" provided a context for framing the evaluation questions that formed the organizational core of the evaluation.

The third stage used both extant data and newly collected information to address each of the evaluation questions.

Extant Data

Documents reviewed included the PAIMI Program’s Annual Program Performance Reports (PPR, 2002–2004); PPR peer review findings (2003–2004); site monitoring tool and site visit reports (2002–2007); PAIMI Annual Reports to Congress; and technical assistance (TA) and conference evaluations from the National Disability Rights Network (NDRN; 2003–2005), the CMHS TA contractor for the PAIMI Program.

New Data Collection

A purposive sample of 20 PAIMI grantees (see Attachment C) was drawn for new data collection. Inclusion criteria for the sample included:

- Geographic distribution (Northeast, South, Midwest, West)
- Size of PAIMI allocation (including minimum through maximum allocation states)
- Organization type (nonprofit, state-operated)

For each PAIMI grantee in the sample, information was solicited from six types of respondents:

- Executive directors of P&A programs
- PAIMI Advisory Council (PAC) chairs
- State Mental Health Authority (SMHA) directors
- Legal counsel to the SMHA directors
- Directors of state chapters of the National Alliance for the Mentally Ill (NAMI)
- Two directors of statewide mental health advocacy organizations nominated by the P&A executive director, with the requirement that one should be a consumer-run organization if available.

In addition, feedback from current and recent PAIMI clients was collected from four of the sampled grantees. Key informant interviews were also conducted with CMHS Government Project Officers (GPOs), the SAMHSA Grants Management Officer, key staff from the National Disability Rights Network (NDRN), PAIMI site monitors, and PAIMI Program Performance Report (PPR) peer reviewers.

Findings and Recommendations

Federal Oversight and Support

This section of the report reviews organizational changes in the administration and management of the PAIMI Program at the Federal level between its inception in 1986 and the current time. Issues reviewed include: CMHS staff organization and resources for program management, oversight of individual PAIMI grantees, and TA activities.

- Federal program and contract officials report that Federal program staff are not sufficiently trained or prepared to provide consultation regarding PAIMI programmatic

issues. The dual responsibilities for the PAIMI and Block Grant programs lead to problems related to time allocation and create the potential for conflict of interest when the interests of the SMHA conflict with those of the PAIMI. The report points out that Federal program staff require additional time and training to effectively manage the PAIMI Program. Further, it recommends that CMHS GPOs reposition themselves from neutral parties to active problem-solvers in situations where there is contention between PAIMI grantees and SMHAs. This entails resolving recurring conflicts with clear guidance on issues such as reporting deaths and PAIMI Programs' access to death reports, putative clients, locations where state-funded mental health services are rendered, and records.

- The Federal application and reporting requirements differ substantially across the multiple P&A programs. This creates a burden on P&A staff in general and PAIMI staff specifically. Electronic application and reporting mechanisms are not yet fully operational. PAIMI staff report that the peer review reports are insufficiently detailed to provide guidance related to program improvement and are not delivered in a timely fashion to facilitate incorporation into the annual planning process. This evaluation recommends that CMHS require and fully support the electronic delivery of PAIMI applications and PPRs and implement a simplified, uniform PPR across all P&A programs.
- Respondents noted that the TA provided by the NDRN is generally available when needed and that the various TA mechanisms—conferences, Web assets, legal backup centers, and publications—are helpful.

PAIMI Program Operations

This section reviews findings related to the P&As, PACs, and PAIMI programmatic functions.

Governance

- P&A Governing Boards: Each P&A system is required to establish a governing authority to provide effective, independent, and ethical leadership. Federal law requires that the PAC chair must be a member of the governing board, although any council member may serve. All grantees surveyed meet this requirement, though in most governing boards, the PAC chair is the only PAIMI representative. A large majority of board members (82 percent) receive an orientation about PAIMI responsibilities, but orientation is not standard across PAIMI Programs (also referred to as PAIMIs). More than two thirds receive orientation about PAIMI operations, abuse and neglect and civil rights violations, legal responsibilities to PAIMI clients, and current casework and litigation. The large majority of PAC chairs (84 percent) reported they believe the PAC's input is respected by their governing boards.
- PACs: PAIMI regulations assign councils several duties: Provide independent advice and recommendations, work jointly with the PAIMI governing authority to develop policies and procedures, and submit a section of the annual report. The federally required standard is that 60 percent of PAC members be individuals who have received mental health services or are family members of individuals who received services. In 2004 (the

most recent data available), 37 of the 57 grantees met this requirement. The role of PACs is less robust than intended. Councils participate in priority-setting but do not guide or critique the work of PAIMIs to the extent envisioned when the program was enacted. Council leaders are relatively unaware of the extent of their role and potential resources available to them. More can be done to enhance the contributions of these stakeholders. For example, along with council chairs, additional members could sit on the P&A governing boards.

Staffing

- PAIMI Staffing: Currently, few P&As retain staff dedicated solely to PAIMI activities. Although several grantees in the sample reported that their P&As have three or more dedicated PAIMI staff, 62 percent reported no dedicated PAIMI staff. This supports the identified trend toward reorganization of P&A work along issues (housing, education, abuse) and away from discrete staff serving people with a specific disability. Comparing the sample's full-time equivalent (FTE) staff, it was found these PAIMIs typically employ 2.9 attorneys, .6 paralegals, and 4.2 advocates. Staffing and level of casework effort within the individual PAIMI Programs should be monitored to ensure that sufficient capacity to advocate and manage litigation on behalf of PAIMI clients is maintained regardless of organizational structure. Most of the PAIMI executive directors surveyed (80 percent) had backgrounds in protection and advocacy prior to assuming their positions.

Funding

- In most PAIMIs that participated in the evaluation, a lack of outside funding negatively impacted the breadth and depth of advocacy effort. According to the P&A executive directors, understaffing and inadequate resources have depleted PAIMI work in vital areas such as jail advocacy, outreach, hospital monitoring, and housing. Other stakeholders surveyed concurred that too few Federal resources are allocated to fulfill programmatic responsibilities at an optimal level. Thus, PAIMI level of effort to actively seek outside funding through structured relationships with other advocates and advocacy organizations warrants more attention and effort.

Organizational Relationships

- P&A executive directors reported that significant efforts are directed toward promoting PAIMI services and making them accessible to individuals with psychiatric disabilities. Stakeholders were mixed in their assessments of how effective these efforts have been.
- Relationships with SMHAs: It appears that despite the inherent tension between the PAIMI and the SMHA, there is substantial communication on important issues concerning consumers' rights and interests. Collaborations between PAIMI and the SMHAs have resulted in such changes as: a new task force to improve acute care; system reconfiguration; increased community services; restructure of how abuse/neglect grievances are handled; and efforts to reduce the use of restraint and seclusion. Areas of conflict remain that have been present since the program's inception, conflicts such as PAIMI access to records and putative clients that diminish

the capacity of the programs. CMHS should insist states acknowledge the program's rights regarding access.

- PAIMIs' record of supporting other organizations and building advocacy coalitions is mixed. It is clear that relationships have been built and there is much productive, ongoing collaboration. With the continued growth in the number and size of organizations led by people with disabilities, there are opportunities to work much more closely with such groups, but it would have to be a priority to which time and resources are directed.

Services

- PAIMI Goals: Federal legislation requires PAIMIs to attend to clients in both institutional and community-based settings. When establishing goals and objectives, PAIMIs have an impressive diversity of targeted settings. According to PPR data, grantees universally target psychiatric hospitals. PAIMIs also seek to attend to the advocacy needs of those with serious psychiatric disabilities in 24-hour community-based residences serving adults (95 percent), prisons and jails (85 percent), psychiatric wards or emergency rooms in general hospitals (75 percent), nursing homes (70 percent), and children in residential facilities (70 percent).
- Data drawn from the PPRs from 1997 to 2004 indicate that the number of individuals served by PAIMI Programs grew substantially over that time (from 15,658 in 1997 to 21,371 in 2004). However, there appears to be a change in the level of service intensity provided to each client. Although the proportion of cases involving litigation, administrative remedies, abuse/neglect investigation, and negotiation/mediation remained relatively constant between 1997 and 2004, the proportion of cases involving short-term interventions and TA increased from approximately 50 percent to 70 percent during that same period. It appears that two of every three PAIMI clients assisted in individual (not systemic reform) matters are White, and that very few people of Asian and Native American backgrounds are provided PAIMI assistance. While the Hispanic segment of the U.S. population has substantially grown during the PAIMI Program's tenure, the percent of Hispanics represented has declined. This suggests grantees may have only modest visibility in some minority communities and should continuously review the efficacy of their efforts in the areas of outreach and cultural competence.
- Types of Cases Handled by PAIMIs: The 1997 to 2004 PPR data reveal a slow, but steady decline in cases related to abuse and neglect and a significant increase in civil rights matters (e.g., discrimination, public benefits, guardianship, informed consent). The decrease in abuse and neglect cases may indicate a positive systemic impact of external scrutiny by PAIMIs, although many other influences may also reflect the decrease, such as the decreased role of institutions, the setting in which most abuse and neglect complaints arise, and a rising culture of respectful treatment. Between 1997 and 2004, the proportion of PAIMI clients residing in institutions at intake fell from over 70 percent to 58 percent. Correspondingly, the percent of PAIMI clients residing in community settings at intake grew from 20 percent to 41 percent. This trend reflects both the public mental health system's ongoing transition from hospital to community-based services and the 1990 amendments to the PAIMI statute along the same lines.

- PAIMI Programs have a reputation as agencies that focus on litigation. According to a Government Accountability Office (GAO) examination of P&A advocacy practices, most P&A work prioritizes nonlitigious activities, and litigation is used only as a last resort, as per Federal regulations. PAIMI activities and the public’s knowledge of these activities vary from state to state owing to limited resources and state-specific populations and issues. According to interview data from executive directors, recent accomplishments include:
 - Statewide advocacy and collaboration
 - Reduction of use of restraint and seclusion in schools and hospitals
 - Development of state Olmstead (community integration) plans
 - Prevention of unnecessary guardianship
 - Increased collaboration with consumers
 - Reduction of reported abuse owing to increased presence in state hospitals and prisons

Process and Distal Client and System Outcomes

Goal Achievement: PAIMI executive directors report a high degree of goal achievement. Twenty percent of grantees sampled reported they met or partially met all projected goals and objectives. Overall, grantees reported having met 93 percent of targeted goals and objectives. However, only 4 of 20 P&A executive directors reported no cutbacks in goals as a result of insufficient resources. PACs also reported very high PAIMI goal achievement. From 1997 to 2004, PACs reported that their PAIMI had fully or partially achieved well over 80 percent of individual goals and objectives, with a low of 80 percent in 1998, a high of 95 percent in 2000, and a steady rise from 90 percent to nearly 95 percent from 2001 to 2004.

- To receive Federal PAIMI funds, states must ensure the PAIMIs’ independence from any agency providing treatment, and just as importantly, states must ensure PAIMIs have access to people with psychiatric disabilities, mental health facilities, individuals’ records, and certain types of reports (e.g., notices of death). Nevertheless, stakeholder interviews make clear that from the program’s initiation to today, PAIMIs frequently encounter access difficulties. Access problems were most often reported with respect to death reports from mental health institutional settings and reports of abuse/neglect from institutional settings. It remains clear that PAIMIs continue to face access problems not unlike those they faced in the program’s first years. Congress and CMHS have legislative, regulatory, and budgetary options to ensure states comply with the access rules, preventing these problems from arising and repeatedly ending up in court. This is a matter that warrants serious attention.
- Each PAIMI’s annual PPR indicates the percentage of cases resolved in favor of its clients. These reports indicate that between 1999 and 2004, the majority of cases were resolved in favor of the PAIMI clients. In 1999, 75 percent of cases were resolved in favor of the client; the comparable figure in 2004 was 64 percent. Unfortunately, the reason for this decline cannot be discerned.

- Data indicate that PAIMI clients are very satisfied with the advocate or attorney who provided them services. Of the 37 clients interviewed in four states:
 - Eighty-two percent reported the belief that the advocate/attorney listened to their story and truly understood their circumstance.
 - Ninety-two percent reported the belief that their advocate/attorney did everything he/she could do to obtain the outcome desired.
 - Seventy percent reported that the quality of their representation was “excellent,” and 24 percent felt it was “good.”

Conclusion

Evaluation activities should offer guidance for improving the program studied as well as accountability information on the use of public funds. This external evaluation found that individual PAIMI Programs provide those with psychiatric disabilities a voice in the exercise of their rights, and they are highly successful in achieving client and system goals and objectives. The PAIMI Program contributes to the transformation of this Nation’s mental health system into a more open, adaptive system that promotes recovery. The principal constraint facing this program is its large mandate and very limited funding. However, there are aspects of the program that need improvement at both Federal and local levels. The evaluation team and Evaluation Advisory Workgroup (EAW) suggest that the recommendations contained in this report are widely distributed and discussed; changes could result in further program effectiveness.

CHAPTER 1

BRIEF HISTORY AND OVERVIEW OF THE PAIMI PROGRAM

The PAIMI Program was initiated in 1986 in response to widespread abuse, neglect, and exploitation of individuals in state psychiatric institutions. Twenty-two years later, the program is still addressing those issues, along with new problems arising from delivery of mental health services in community-based settings. Below are recent examples of the legal advocacy that PAIMI representation offers vulnerable individuals.

A. Case Examples of PAIMI Advocacy

PAIMI representation assists individuals to have their voices heard. An older adult who currently lives in his own apartment said this about PAIMI representation, “I was in the old unit (state institution). I folded the towels. I was there 10 years. PAIMI helped me get out. I spoke to the judge. The judge said, ‘You don't need to be in that hospital. Give him a chance.’” (Source: PAIMI client interview conducted by an evaluation team member.)

PAIMI representation helps parents find supportive and humane residential treatment for children with behavioral health issues. A parent whose teenager had been placed in a residential program in the community said, “The individuals that need the PAIMI services are not aware of the program. There were several kids at the place that were being abused. While our son had parents to advocate for him, no other kid had parents to advocate. They are mostly foster kids and wards of the state and foster kids are powerless. They feel like nothing better should be expected. Nobody's going to listen to them; they'll just lock them up. They are punished for speaking up. While the facility's director had the right message, and staff toe the line while he's present, once he is not around the abuse and neglect and mistreatment occurs.” (Source: PAIMI client interview conducted by an evaluation team member.)

PAIMI representation helps individuals get the medical care they need. A middle-aged man living in a state psychiatric institution said, “Good thing we have this helping entity. I went from being an independent self-employed businessman to being told what time to eat. And then when diagnosed with kidney cancer and the hospital wasn't getting me to followup treatments, I called for help. And the advocate made the hospital start getting me to treatments. We need more of these advocacy systems. My advocate had deep concern for the patient.” (Source: PAIMI client interview conducted by an evaluation team member.)

PAIMIs investigate deaths and make recommendations for systemic reform with the goal of reducing future deaths. One PAIMI Program investigated the death of a man who choked to death on a hot dog in a seclusion room of a state hospital. The man had been diagnosed with schizophrenia and mild mental retardation, and resided in the hospital for nearly 14 months. He had four teeth and was heavily medicated with Haldol (a psychotropic medication with a known side-effect of suppressing the cough reflex and thus increasing the risk of death by choking). He

was given a double portion of hot dogs for supper and then left alone in a seclusion room. The PAIMI's death investigation found numerous hospital policy violations. As a result, changes were made in several policies: use of time-out rooms, serving meals to psychiatric patients, and required dental assessment and dietary modifications for patients with poor teeth. (Source: *The Protection and Advocacy for Individuals with Mental Illness Program, Report of 2005 Activities*, National Disability Rights Network.)

PAIMI representation can impact how a state treats groups of people. Another state had a practice of discharging middle-aged individuals (36–57 years) from public psychiatric hospitals to nursing homes, some out of state, even though they did not need or meet nursing home levels of medical care. These individuals should have received community-based supports in their home communities. In the nursing homes, they lived as if in prison. One man was required to wear a device on his wrist that triggered an alarm if he attempted to leave the floor or the facility without permission. These individuals did not receive rehabilitative services or mental health treatment that would have allowed them to transfer to community-based services. Thus, the nursing homes had become de facto psychiatric hospitals, but without the psychiatric services that hospitals provide. A PAIMI-funded advocacy program attempted to negotiate with the SMHA to stop this discharge practice, but negotiations were not effective. Subsequently, this state's PAIMI Program, with other parties, filed a lawsuit challenging the improper discharges. The complaint asserted that discharging people with mental illness to nursing homes while equally affordable and more humane residential settings existed or could be made available was illegal under the Federal Americans with Disabilities Act, the Rehabilitation Act, and the Nursing Home Reform Act. The Nursing Home Reform Act was passed specifically to end the practice of inappropriately institutionalizing individuals with mental illness or mental retardation in nursing homes.

This case is not atypical of class actions pursued by PAIMI Programs. Although a constitutional right to least restrictive treatment has been on the books for decades, and has been reaffirmed in subsequent lawsuits, states do not always provide services in accordance with the law. PAIMIs serve to promote needed change by protecting individuals' rights and assisting state mental health officials to move their systems in desired directions, such as development of community based service systems. It is uncertain how this lawsuit will resolve, but in the opinion of the evaluation team, the attention that litigation brings to such practices often results in the implementation of reforms. (Source: <http://www.disability-advocates.org/advocacy.html>, *Edwin T. et al. v. Carpinello et al.*)

It is estimated that one in five adults in the United States will receive treatment for a mental health condition at some point in their lives. For those adults and children receiving care from the public mental health system, the PAIMI Program is typically their only resource for rights protection and advocacy.

B. Initiating the Federally Funded Protection and Advocacy System and Early Compromises That Impact Program Operations

Recognition that persons with disabilities are citizens entitled to respect and protection from abuse and neglect emerged in the late 1960s. Individuals with psychiatric disabilities were an early focus of these activities. Initially, reformers focused on conditions in state institutions, mounting challenges to civil commitment laws that allowed for indefinite involuntary institutionalization and advocating establishment of the “right to treatment” (*Lessard v. Schmidt*, *Donaldson v. O’Connor*, 422 U.S. 563 (1975); *Wyatt v. Stickney*, 344 F. Supp. 373, M.D. Ala. 1972). These landmark cases led to an expanded focus—both in courtrooms and legislatures—on the protection of the rights of individuals with mental illness (hereafter, referred to as psychiatric disability) and other disabilities, both in hospitals and in community services. Not-for-profit organizations were founded to provide legal representation and other advocacy services. Federal attention led to the incorporation of advocacy programs into legislation designed to help vulnerable populations, such as people with developmental disabilities (Developmental Disabilities Assistance and Bill of Rights Act, 1975) and elderly individuals (Older Americans Act, 1975).

Over the past 30 years, Congress has created eight distinct statutory programs, administered by five separate Federal agencies, to address the advocacy needs of persons with disabilities. The P&A system and Client Assistance Program (CAP) make up the nationwide network of congressionally mandated, legally based disability rights agencies. The P&A and CAP programs are also the largest providers of legally based advocacy services to persons with disabilities in the United States (Gross, 2001¹). P&A agencies have the authority to provide legal representation and other advocacy services, to protect rights guaranteed by the U.S. Constitution and all Federal and state laws, to people with disabilities, based on a system of priorities for services. A brief overview of the eight P&A programs follows in order of year enacted.

PADD: The Protection and Advocacy for Persons with Developmental Disabilities Program

Following a series of exposés (e.g., the Willowbrook institution in New York) and high-profile lawsuits (e.g., *Wyatt v. Stickney*) that spotlighted abuse and neglect of individuals with mental retardation and developmental disabilities in state institutions, Congress passed the Developmental Disabilities Assistance and Bill of Rights Act of 1975. Also known as the DD Act, this legislation recognized that a federally directed system of legal advocacy was necessary to ensure the humane care, treatment, habilitation, and protection of persons with mental retardation, autism, cerebral palsy, and other developmental disabilities. Under the DD Act, the PADD Program was created to pursue legal, administrative, and other appropriate remedies to protect and advocate for the rights of individuals with developmental disabilities. To receive DD

¹ Gross, G. (2001). *The protection and advocacy system and collaboration with legal services programs: Management information exchange*. Retrieved from <http://www.nationaldisabilityrightsnetwork.org/aboutus/MIEarticleFinal301.htm>.

Act funds, the governor of each state was to designate a P&A agency to implement the advocacy program.

CAP: Client Assistance Program

The CAP was established by the 1984 Amendments to the Rehabilitation Act (also known as the Rehab Act). As a condition for receiving allotments under Section 110 of the Rehab Act, every state and territory must have a CAP. Many CAP agencies are housed within P&A agencies. CAP services include assistance in pursuing administrative, legal, and other appropriate remedies to ensure the protection of persons receiving or seeking services under the Rehab Act. This includes state vocational rehabilitation agencies such as Rehabilitation Commissions, Commissions for the Blind, and Independent Living Centers.

PAIMI: Protection and Advocacy for Individuals with Mental Illness

The PAIMI Act of 1986 (also referred to as the Act) established the PAIMI Program. Modeled after the DD Act and crafted at a time when numerous reports of abuse and neglect in state psychiatric hospitals were substantiated, the PAIMI Program was established to extend similar protections to persons with significant psychiatric disability. PAIMI agencies were mandated to investigate reports of abuse and neglect in facilities and violations of constitutional and legal rights. In 2000, the Act was amended to incorporate those in need of advocacy receiving community-based care. Although program eligibility was expanded to include those residing in the community, P&As must still prioritize services to persons in institutional settings.² To be eligible for PAIMI funds, PAIMIs are required to demonstrate specific authority for access to facilities and records (P.L. 99–319 Sec. 10805). The system designated to serve as the PADD program in each state and territory also is responsible for operating the PAIMI Program. Currently, there are 57 PAIMI Programs (or PAIMIs), one in each state and territory and one for several Native American tribes.

² The original statutory language describes facilities as follows: (3) The term "facilities" may include, but need not be limited to, hospitals, nursing homes, community facilities for individuals with mental illness, board and care homes, homeless shelters, and jails and prisons.(P.L.99–319, 42 USC Ann., Sec. 10802). This section of the law was amended in 2000 (P.L. 106–310, Sec. 3206(b)) to enable PAIMIs to assist clients living in the community once the overall appropriation level of \$30 million was reached. However, the new law also provided that **“an eligible system must give priority to representing persons with mental illness as defined in subparagraphs (A) and (B)(i) of section 10802(4) of this title [emphasis added].”** Those subparagraphs refer to all of the individuals previously eligible for PAIMI services, but not those living in community settings: (4) The term "individual with mental illness" means, except as provided in section 10804(d) of this title, an individual:

- (A) who has a significant mental illness or emotional impairment, as determined by a mental health professional qualified under the laws and regulations of the State; and
- (B)(i)(I) who is an inpatient or resident in a facility rendering care or treatment, even if the whereabouts of such inpatient or resident are unknown;
- (II) who is in the process of being admitted to a facility rendering care or treatment, including persons being transported to such a facility; or
- (III) who is involuntarily confined in a municipal detention facility for reasons other than serving a sentence resulting from conviction for a criminal offense.

PAIR: Protection and Advocacy for Individual Rights

The PAIR Program was established by Congress as a national program under the Rehabilitation Act in 1993. PAIR programs were designed to protect and advocate for the legal and human rights of persons with disabilities not eligible under the other P&A programs. The system designated to serve as the PADD program in each state and territory also is responsible for operating the PAIR program. Prior to the expansion of PAIMI to communities, the PAIR program provided a resource for people with psychiatric disability who were not eligible under the restrictive PAIMI eligibility criteria. Persons eligible for services under this program represent, by far, the largest segment of the population of persons with disabilities in the United States.

PAAT: Protection and Advocacy for Assistive Technology

The PAAT Program was established in 1994 when Congress expanded the Technology-Related Assistance for Individuals with Disabilities Act (Tech Act) to include funding for P&As. PAATs assist individuals with disabilities, and others involved in their lives, in accessing technological devices and assistive technology services.

PABSS: Protection and Advocacy for Beneficiaries of Social Security

The PABSS Program was established in 1999 when the bipartisan Ticket to Work and Work Incentive Improvement Act (TWWIIA) was enacted into law. Congress recognized that many people with disabilities face major barriers in their efforts to leave the benefit rolls for full employment. The intent of this act was the provision of health care, employment preparation, and placement services to individuals with disabilities.

PATBI: Protection and Advocacy for Individuals with Traumatic Brain Injury

The PATBI Program was established in 2002 to strengthen P&A services for individuals with traumatic brain injury (TBI) and their families.

PAVA: Protection and Advocacy for Voting Accessibility

Established in 2003 as part of the 2002 Help America Vote Act, the PAVA Program was enacted to ensure the full participation of people with disabilities in the electoral process, including registering to vote, casting a vote, and accessing polling places.

While the need for advocacy services³ for people with psychiatric disability was recognized at roughly the same time as similar needs of people with developmental disabilities, it took many years for relevant programs to evolve. A few pioneering projects, based on very different models, began during the early to mid-1970s in several states, including Massachusetts, California, and New Jersey. In 1978, the President's Commission on Mental Health recommended improvements in patients' rights and urged that a national advocacy system for persons receiving mental health services be established. The following year, the Department of Health and Human Services sponsored a number of demonstration programs, heralding the emergence of a Federal mental health advocacy program. The Mental Health Systems Act

³ "Advocacy" is generally defined as "active support," and an "advocate" is one "who supports or defends a cause" or "who pleads in another's behalf" (Webster, 1994).

(MHSA) of 1980 was intended to implement the recommendations of the President's Commission and included the first model mental health Patient's Bill of Rights (still in the PAIMI law), as well as the first federally supported mental health advocacy program. The MHSA provided an important foundation for the later development of the PAIMI Program. Also in 1980, the Civil Rights of Institutionalized Persons Act (CRIPA) (42 U.S.C. § 1997 et seq.) was enacted, giving the Department of Justice a role in investigating and litigating on behalf of residents of mental hospitals, prisons, and other institutions that were shown to demonstrate a "pattern or practice" of violating their rights.

Although the MHSA was largely repealed in 1981 before the advocacy program or other provisions could be implemented (a by-product of the Reagan New Federalism initiative), the model Bill of Rights was retained. Importantly, the process of developing sections on rights and advocacy had enabled stakeholders to begin to negotiate differences of view in the structure of the new PAIMI Program (e.g., whether it should be separate or integrated with the existing PADD programs). Participants in the legislative process included all the mental health organizations active at that time, including professional associations, legal advocacy groups, citizen advocates, provider associations, and state agencies. Family and consumer/survivor groups were in their earliest stages of organization; individuals expressed their views, but there was no strong organizational presence. During this debate, for example, directors of SMHAs were concerned about the impact of lawsuits on their ability to operate state mental health systems, while groups advocating patients' rights saw the right to bring lawsuits as the only credible pressure to address abusive practices. Compromise was struck, as reflected in the PAIMI Act, to ensure lawsuits could be brought only after other avenues had failed.

Legislation incorporated the experiences of existing mental health advocacy programs. For example, a Congressman introduced a bill to create a Federal program based on the New Jersey Department of the Public Advocate. While that model was not adopted in full, many characteristics of that program found their way into the eventual legislation. Characteristics from other advocacy models were also instrumental in the deliberations, such as the investigative and oversight functions of the New York State Commission on Quality of Care. The existence of these models shaped the decision to make the MHSA advocacy program a competitive grant program that would enable each state to choose a model suited to its needs. This marked a rejection of the P&A model of formula grants to a designated agency in each state. Determining the host agency within which a PAIMI Program operates is called "designation," and the two primary types of PAIMI designation are those housed within state agencies (referred to as state-operated) and those within private, nonprofit organizations.

In the early 1980s, funding for the existing Federal disability advocacy programs was expanded modestly, and the 1984 reauthorization of the Rehabilitation Act mandated a new CAP for individuals with severe disabilities. In that context, the continuing lack of rights protection for persons with mental illness represented a glaring gap. In 1984, Senator Lowell P. Weicker, Jr., (R-CT), who chaired both the authorizing and appropriations subcommittees responsible for mental health, commissioned a staff investigation into the institutionalization of persons with mental disabilities, resulting in hearings held in 1985. The investigation's report documented "a

climate of fear and intimidation,” and noted that “(c)onditions in many of these facilities, especially psychiatric hospitals, where some of society’s most severely disabled patients live in a volatile daily mix with some of the healthcare profession’s most under trained staff, would be considered intolerable if [public] airing was full and frequent.” The report drew attention to the fact that patients in the mental health system did not have access to the same type of advocacy services available to individuals with developmental disabilities (Policy Resources Incorporated, 1988; Mental Health Policy Resource Center, 1990⁴).

In response, Senator Weicker introduced the PAIMI Act. The general consensus formed 6 years earlier during consideration of the MHSA had resolved many disagreements among consumers, advocates, and providers. Remaining issues were overcome through compromises in the final version of the bill. However, by this time, the relative strength of the constituency groups had shifted, with family and state groups gaining influence, and consumers and rights advocates losing ground. Some of the related issues raised at the time the bill was passed are reflected in the specific design of the state PAIMIs and constitute ongoing themes in the program, as described below.

Assigning PAIMIs to the DD P&A system was not the initial choice of the mental health community owing to the low level of funding provided through formula grants, lack of trust that DD programs would understand and give appropriate attention to clients with mental illness, and fears that state-designated P&As could not be independent advocates. The MHSA would have allowed existing independent advocacy programs, legal services offices and DD P&As (PADD programs) to apply for funding, gradually adding programs incrementally across the country. However, the political practicalities of 1985 made it easier to pass a bill expanding an existing program than to create a new program. The PADD programs were also seen as stronger than they had been in 1979–1980 as their 10-year history provided some insulation against the potential threat of “redesignation” if they displeased the state. Some P&As were already experienced in working with clients with mental illness, and proponents believed the current and future impact of P&A efforts for several populations, each with a limited budget, would be strengthened by combining forces.

The mental health community ultimately came together to accept the decision to incorporate PAIMI within the PADD system but insisted on provisions designed to ensure the PADD program would pay appropriate attention to mental health concerns, and that those with expertise in mental health would run the mental health program. These concerns prompted several requirements, including:

⁴ Policy Resources Incorporated. (1988). *Protection and advocacy for mentally ill individuals: Legislative analysis and report*. Scallet, L., Marvelle, K., & Davidson, L. Washington, DC.

Mental Health Policy Resource Center. (1990). *Protection and advocacy for mentally ill individuals: Legislative history and analysis of P.L. 99–319*. Scallet, L., Marvelle, K., & Davidson, L. Washington, DC.

- A mandate for a PAC, a provision that encouraged the P&A to contract with existing groups in the state already providing advocacy services to the target population
- A 2 percent set-aside for TA
- The P&A governing board would be “broadly representative”
- The chair of the PAC would serve on the P&A governing board

The presence of a robust PAIMI Program, when housed within the developmental disabilities advocacy system umbrella, remains a salient concern to this day as indicated in key informant interviews and data collected for this study. The evolution of P&As has been toward an integrated staff structure and away from distinct PAIMI programmatic identity with separate staff specializing in mental health issues.

PAIMIs originally were mandated to protect and advocate for the rights of people with psychiatric disability and to investigate reports of abuse and neglect in facilities that care for or treat individuals with psychiatric disability. Agencies could provide advocacy services or conduct investigations to address issues that arose during transportation or admission to, the time of residency in, or within 90 days after discharge from such facilities. Unlike the PADD program, however, state service funds for the target population were not made contingent on establishment of a PAIMI Program in the state.⁵ The limitation to persons residing in care and treatment facilities had two primary origins. First, the original Weicker staff investigation and subsequent hearings focused solely on institutions. During legislative consideration, however, advocates pointed out that most persons receiving mental health care no longer lived in large state hospitals, but rather in a range of residential settings, including nursing homes, board and care homes, and specialized residential programs. Many rights issues involved access to services and benefits in the community, and a failure to address these issues could be a major factor in inappropriate institutionalization. Advocates were also concerned that if eligibility were limited to persons in institutions, it could be tempting for “unscrupulous” providers to “dump” patients into the community to avoid liability for violating their rights.

A second factor contributing to adopting the facility-based criteria was that, unlike for persons with developmental disabilities, there was no objective test to identify and define the eligible population of persons with psychiatric disability when they were not living in institutions. This could create problems, not only for providers in knowing when they might be violating someone’s rights, but also for advocates operating with inevitably limited funding. To resolve these problems, the PAIMI legislation formulated a definition of eligibility that retained the emphasis on serious mental health needs, defined these with sufficient clarity that facilities and staff had fair notice of their responsibilities, and established objective criteria that would cover the population most in need of advocacy services (i.e., individuals who are or have been in a

⁵ P.L. 102–321, which created SAMHSA, provided that states must have a state plan to receive block grant funds but made no reference to PAIMI. The DD Act [42 USC 15043] requires a PADD system to be in place for Federal assistance to be given to the states for state plans and implementation: SEC. 143. SYSTEM REQUIRED (a). In order for a State to receive an allotment under subtitle B [state allotments of Federal assistance to state DD Councils for state plans and their implementation] or this subtitle, the State shall have in effect a system to protect and advocate the rights of individuals with developmental disabilities.

residential service). In addition, the types of violations intended to be targets of advocacy (abuse, neglect) were carefully defined.

The PAIMI Program has evolved as the mental health system has become more community-based. Effective October 2000, PAIMIs were authorized to serve individuals with mental illness living in community settings, including in homes of their own. However, PAIMIs still must give priority to individuals living in institutional settings.⁶ A major focus for PAIMIs since 1999 has been enforcement of the Supreme Court's landmark decision in the case of *Olmstead v. L.C.* (527 U.S. 581, 1999). That case found that the Americans with Disabilities Act requires states to provide community-based services to persons with disabilities who would otherwise be entitled to institutional services, so long as the state's professionals determine such placement is appropriate, the person does not oppose it, and it can be accomplished without placing an undue burden on state resources. Other subsequent developments include the creation of a separate P&A program to serve certain large Native American tribes living on reservations in the Southwest.

Concerns expressed today around eligibility and priority-setting may be traced back to compromises reached to secure passage of the PAIMI legislation (Scallet et al., 1988, 1990). These issues continue to be raised today in interviews with key informants that refer to PAIMI's ongoing need for outreach to potential clients located in various settings, problems with the role and strength of PACs, and the actual or potential impact on PAIMI priorities of being located within the PADD, such as a disproportionate emphasis on special education issues.

C. PAIMI Program Goals

As described above, Congress's basic objective in passing the PAIMI legislation was to create a state-based system to protect the rights of people with significant psychiatric disability or emotional impairment who reside in institutions, including the problems these individuals experienced within 90 days of discharge. Congress expanded the program's mission in 2000, enlarging the service population to include mental health service recipients residing at home, and in homeless shelters, board and care homes, Federal facilities, pretrial facilities (county jails), and state prisons. A PAIMI Program was also created for four Native American tribes. Although PAIMI Program responsibilities have been enlarged, the needs of individuals in institutions are still a primary focus. The enlarged mandate requires that state PAIMI Programs be highly visible organizations, with comprehensive outreach programs, and familiar with a broad range of human service systems (e.g., public welfare, special education, substance use, Department of Veterans Affairs). PAIMIs are to cultivate relationships across their communities to gather information about issues impacting individuals with serious psychiatric disability.

⁶ As articulated in the 2000 amendment to the PAIMI legislation (P.L. 106-310).

PAIMI Responsibility for Investigating Abuse

Although state hospital populations have been declining, thousands of people still reside in such facilities, often for extended periods of time. PAIMIs are responsible for quickly investigating claims of physical mistreatment, verbal harassment, or other misconduct by hospital employees, and for taking appropriate action. Abuse, however, is not limited to isolated actions of individual staff members. Established practices also can be abusive; restraint and seclusion are prime examples. These practices were once viewed as necessary for patient and staff safety and were considered appropriate clinical interventions. It is now known that the use of mechanical and chemical restraint and seclusion is largely arbitrary, can cause serious harm, and that low-cost intervention strategies can dramatically reduce or eliminate their use. Nevertheless, the continued widespread use of these interventions has been targeted as a problem by the National Association of State Mental Health Program Directors⁷ and a host of other national organizations. Congress has shown specific interest in the ability of state PAIMI Programs to investigate these practices. For example, in 2000, Congress provided a direct appropriation of \$1 million to Equip for Equality, the PAIMI in Illinois, for a 5-year demonstration project to determine the benefits of an independent Abuse Investigative Unit focused on restraint and seclusion practices.

PAIMI Responsibility for Investigating Neglect

Congress viewed neglect as a less visible but no less serious problem than abuse. Neglect can be purposive (e.g., the result of the indifference of a single staff person) or indirect (e.g., inadequate staff training or supervision), even unintentional. Harm resulting from neglect can result from inadequate treatment for psychiatric illness; or inadequate protection from self-harm including suicide, poor nutrition, or insufficient health and dental care, and other basic necessities. Congress recognized that neglect can manifest indirectly, noting, for example, that neglect includes abuse by mental health service recipients of other recipients when insufficient staff coverage leads to harm.⁸ Neglect can also be programmatic, such as the failure to provide adequate treatment planning, discharge services, or community care.

Neglect is not always explicitly identified in a complaint to a PAIMI Program. Practices may be so embedded in institutional culture that they are seen, if at all, as “natural.” As mental health services mature and evidence-based practices are identified, neglect may occur when organizations fail to provide services that reflect readily available knowledge.

PAIMI Responsibility for Investigating Denial of Constitutional and Statutory Rights

People with psychiatric disability possess rights that go far beyond freedom from abuse and neglect. A broad range of rights can be found in the provisions of the U.S. Constitution and in numerous Federal and state statutes (see, for example, the multivolume treatise by Michael L. Perlin, *Mental Disability Law: Civil and Criminal*, Lexis Law Publishing, 1998–2003). While these

⁷ http://www.nasmhpd.org/general_files/policy/StatementbyAndrewHyman.pdf

⁸ Protection and Advocacy for Mentally Ill Individuals Amendment Act of 1991, House Report (Energy and Commerce Committee), No. 102–319, November 15, 1999, p. 7, Congressional Record Volume 137, 1991.

extensive rights are not enumerated in the PAIMI legislation, their protection is within the jurisdiction of the PAIMI Program.

Court decisions and settlement agreements based on constitutional guarantees have articulated a progression of specific rights. Facilities must provide adequate privacy; lighting, sanitation, and other physical conditions; access to phones and mail; and adequate space for visitors and for religious observance. Individuals must be free from undue restraint of liberty and provided with due process in involuntary treatment. They must also be offered treatment that reduces the likelihood of restraint of liberty and preserves daily living skills. Ultimately, treatment environments must be safe. Like all citizens, mental health service recipients have a fundamental right to informed consent to treatment. If individuals object to medication or any other interventions, specified procedures must be used to review the objection. In short, the U.S. Constitution provides mental health service recipients in institutional settings with a host of fundamental rights.

Federal and state statutes also provide substantial rights. In a ruling that has the potential to significantly increase opportunities for meaningful choice, the U.S. Supreme Court ruled that the Americans with Disabilities Act of 1990 prohibits the hospitalization of individuals who could live independently in the community with appropriate support (*Olmstead v. L.C.*, 527 U.S. 581 (1999)). In the community, important additional rights are available to those receiving mental health services. Federal and state laws address mental health services, health care, income benefits, freedom from discrimination in housing and employment, and other rights.

When honored, these rights can empower mental health service recipients and support individual choice, recovery, and dignity. For such rights to be meaningful, however, they must be enforced. Individuals must have awareness that the rights exist, have the opportunity to advocate for themselves, and have the assistance of others if they so choose. In addition to creating the PAIMI Program, Congress assigned an enforcement role to the U.S. Department of Justice (DOJ) through CRIPA. Under CRIPA, DOJ addresses "patterns or practices" that result in deprivations of Federal rights in state institutions, particularly, but not exclusively, in mental hospitals. CRIPA is designed to be a "last resort" tool to address a particular category of large-scale problems that cannot be resolved by local or state advocates.⁹ DOJ's important but limited responsibility to protect consumers' rights highlights Congress's expectation that PAIMIs address both individual abuse and neglect cases and systemic deficiencies.

PAIMIs as Consumer- and Family-Directed Programs

Congress intended that PAIMI-eligible clients and families guide the work of each PAIMI, and as a result, they must be at the center of the PAIMI's determination of priorities. This intent is quite evident, well beyond the requirements that mental health service recipients and family members be chairs of and make up at least 60 percent of PACs. For example, Federal funds can be used to pay for travel, lodging, and child care expenses to enable mental health service recipients and family representatives to attend PAC activities. This evaluation assesses the

⁹ 42 U. S.C. 1997(b)

concrete efforts that PAIMIs undertake to support the involvement of mental health service recipients and families, including the promotion of self-advocacy and leadership skill development.

Because PAIMIs cannot address all the problems faced by recipients of mental health services, and needs vary among the states and territories, the leadership of each PAIMI Program must make choices. Congress encouraged the PAIMI Program to advance PAIMI-eligible clients' interests at state-wide policy levels. This may include participation in states' legislative and budget processes, state agencies' regulation and policy formulation processes, and community action toward improvement of mental health services. Such a role is open-ended and could span such matters as diversion and reentry from the criminal justice system, changes in health care services, child welfare practices, special education rules, public benefit levels, housing eligibility, and zoning practices.

PAIMI legislative history also includes a congressional directive to the program that it address the special problems and cultural barriers faced by minorities. Congress instructed Federal agencies to carefully monitor the efforts of PAIMI's efforts in this area (PAIMI Amendments of 1991, P.L.102–173, House Energy and Commerce Committee Report No. 102–319, November 15, 1991). Therefore, this national evaluation assessed PAIMIs' efforts to conduct outreach to minority communities and provide staff training on providing culturally competent representation.

The inherent flexibility of the PAIMI Program permits it to keep step with emergent policy concerns. Thus, while the goals of the PAIMI Program have remained consistent, amendments have reflected contemporary values and policy imperatives, most notably a community-based focus for advocacy and protection. There is a significant degree of consensus among stakeholders about the direction needed to bolster the Nation's mental health systems. Various documents, including the recent President's New Freedom Commission Report, detail this consensus. The clearest alignment may be seen in the emphases on safety, equitable access and treatment, and the involvement of consumers and family members in the PAIMI Program. The program also ensures equitable access to and use of mental health treatment since PAIMI services are designed to be available without regard to ability to pay.

The problems facing individuals receiving mental health services are substantial, but PAIMI funding is quite limited. As a result, the PAIMI Program is not responsible by itself for achieving these goals. (Other sections of this report discuss this shared responsibility more fully.) PAIMI Programs are useful tools for improving the Nation's mental health system within an evolving Federal and state policy context. The Federal Government's review of PAIMI in 2005 gave the program an overall rating of moderately effective because it has ambitious goals and is well managed.¹⁰ The program was found to serve a clear need to protect the estimated 17 million individuals with psychiatric disability from abuse, serious injury, neglect, and violations of their

¹⁰ Office of Management and Budget's (OMB) Program Assessment Rating Tool, known as the PART review. PAIMI findings are found at <http://www.whitehouse.gov/omb/expectmore/summary/10003528.2005.html>.

civil rights. This evaluation has not assumed there is a single or optimal strategy for PAIMIs to achieve the goals articulated in its enabling legislation.

CHAPTER 2

PAIMI EVALUATION DESIGN

A. Overview of Evaluation Stages

This is the first external evaluation in the 22-year history of the PAIMI Program and the first external evaluation of any of the Federal disability Protection and Advocacy programs.¹¹ The evaluation team, together with the EAW, used a three-stage approach to conduct an evaluation consistent with Federal efforts to address issues of accountability, capacity, and effectiveness.

First, the extent to which this program could be evaluated was studied. These findings are reported in the PAIMI Evaluability Assessment Report.¹² When large and/or complex programs with multiple stakeholders (such as the PAIMI Program) are assessed, formal evaluability studies are an important precursor to an evaluation to probe whether a program may be evaluated in a meaningful way.¹³ The evaluability report concluded that a national evaluation of the PAIMI Program presents an important opportunity for the Federal Government to guide subsequent policy direction at the national level. For states and other stakeholders, this evaluation could provide information to bolster system change in mental health.

Second, once there was understanding of the extent to which the PAIMI Program could usefully be evaluated, feedback from stakeholder interviews was incorporated to craft a PAIMI Logic Model (see Attachment A). This logic model schematically depicts how the PAIMI Program operates and focuses on four aspects of the program:

- The context in which PAIMI operates
- The processes established to implement the PAIMI Program (at the state and Federal levels)
- Actual activities and tasks undertaken
- Outcomes achieved (both process and distal)

The logic model was used to select among numerous research questions. The final evaluation questions were those considered by the evaluation team and the EAW to be most essential to examine at this juncture. These questions guided the inquiries and analysis. (See Attachment B for the final set of PAIMI evaluation questions.)

¹¹ The Administration on Developmental Disabilities initiated that system's external evaluation in 2007.

¹² *Evaluation of the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program Phase I: Evaluability Assessment Report*, prepared by the Human Services Research Institute and Expert Consultants for the Center for Mental Health Services, June 2005.

¹³ *Office of Management and Budget's Program Assessment Rating Tool, known as the PART review. PAIMI findings are found at <http://www.whitehouse.gov/omb/expectmore/summary/10003528.2005.html>.*

Third, the comprehensive evaluation report was prepared. The report highlights PAIMI Program strengths, challenges, and policy-specific lessons learned and recommendations that reflect both the praise and concerns of a wide variety of stakeholders.

Challenges to Evaluating PAIMI Program Outcomes

The PAIMI Program does not operate in a vacuum, and the relatively small amount of funding constrains the impact of PAIMI activities on outcomes. Given the broad goals of the program, it is difficult to establish a direct causal connection between PAIMI action and intended distal program outcomes, such as increased choice of mental health services and decreased abuse experienced in treatment settings. System change at the state and Federal levels is a function of multiple factors, and the PAIMI Program is but one of these factors. The consensus of the PAIMI EAW was that measuring PAIMI Program performance based on the degree to which distal outcomes change in the desired direction is not a fair test of PAIMI performance since other factors may play a significant role in the outcome of a PAIMI Program's efforts. A few examples include:

- Judicial rejection of new legal arguments
- Better reporting systems giving the appearance of increased incidents of harm
- Insufficient housing for people with low incomes

The EAW suggested it is more appropriate to determine PAIMI Program performance based on the degree to which grantees take on significant issues facing people with serious psychiatric disability, and to examine the effort invested in securing change given available resources, as opposed to achievement of particular outcomes. The ability of the PAIMI Program to influence system change has to be understood in light of its circumscribed scope and its limited ability to determine state action. *This notion of shared responsibility for outcomes was a central feature in designing the PAIMI evaluation and interpreting evaluation results.*

B. Evaluation Data Collection Methods

Given the relatively higher costs of new data collection, one important goal was to determine the extent to which available (extant) data could be employed to address the selected evaluation questions. Efforts were made to fully utilize extant data, and where gaps existed in areas considered to be critical, to collect new data. Both quantitative and qualitative data were used and linked in ways consistent with producing policy-relevant analyses.

Notice of this evaluation was published in the *Federal Register* in January 2006, and comments from stakeholders were actively solicited for 90 days by evaluation team members and the EAW. Based on comments received, changes were made to the evaluation, most significant of which was to include surveying the legal counsel to states' mental health program directors. A revised evaluation plan was submitted to CMHS in April 2006 for delivery to the Office of Management and Budget (OMB) for review as the proposed evaluation called for new data-

gathering (interviews and surveys) from more than nine individuals using the same instrument. Data sources are briefly described below.

Extant Data

Existing data used for the evaluation include:

- Sections of the PAIMI Programs' Annual PPRs across 3 years, 2002–2004 (Goals and Objectives, Data Tables, PAIMI Advisory Council Reports, and Budget Information)
- PPR peer review findings (2003, 2004)
- CMHS PAIMI Program site monitoring tool (2002) and site visit reports (2002–2007)
- PAIMI Annual Reports to Congress
- NDRN TA and conference evaluations (2003, 2004, 2005)

New Data

A purposive sample of 20 PAIMI grantees (see Attachment C) was drawn for new data collection. Inclusion criteria for the sample included:

- Geographic distribution (Northeast, South, Midwest, West)
- Size of PAIMI allocation (including minimum through maximum allocation states)
- Organization type (nonprofit, state-operated)

For each PAIMI grantee in the sample, information was solicited from six types of respondents:

- Executive directors of P&A Programs
- PAC chairs
- SMHA directors
- Legal counsel to the SMHA directors
- Directors of state chapters of NAMI
- Two directors of statewide mental health advocacy organizations nominated by the P&A executive director, with the requirement that one should be a consumer-run organization, if available

Feedback from current and recent PAIMI clients was collected from four of the sampled grantees.

Participating in this evaluation was presented as voluntary, as was responding to any particular question. Respondents were assured their responses were confidential and advised of their option to skip any questions, and many did so. (See Attachment D for interview and survey instruments.)

Executive Director Interviews

Prior to this national evaluation, no information existed regarding how P&A executive directors assess Federal oversight activities, engage with their governing boards and PACs, or conduct

quality management functions. Evaluation questions included governing board activities, priority-setting processes, the relationship between the governing board and the PAC, the efficacy of Federal support and oversight, and PAIMI Program operations. Twenty-one of the 57 P&A executive directors participated in the evaluation: 20 in the sample, and 1 who field-tested PAIMI. Interviews were conducted in person or by telephone.

PAIMI Client Interviews and Focus Group Meetings

Prior to this national evaluation, there were no national data to indicate how clients of the PAIMI Program perceive the quality and outcomes of program services. As quality management techniques have evolved in the disabilities field, client feedback has become an increasingly important tool for assessing program impact and identifying areas for service improvement. Evaluation team members visited 4 states and collected feedback from 38 clients and recent former clients in face-to-face interviews (both institutionalized and community-based clients). Although 38 satisfaction interviews obviously constitutes only a small portion of the more than 20,000 clients that receive individual representation each year, the interviews nevertheless provide a source of national information on how the program is viewed by persons who use its services—especially since responses are highly consistent among the individuals interviewed.

Stakeholder Surveys

Stakeholders' opinions were solicited via online surveys. All individuals contacted for participation via online surveys were given the option of telephone interviews, and many of the PAC chair and advocacy organization director interviews were conducted by phone. Online surveys were specifically designed for each type of stakeholder feedback. The evaluation team selected Survey Monkey,¹⁴ an online survey application with Section 508 Certification. This Federal certification ensures survey design that is accessible and in compliance with standards for users with disabilities.

PAC Chairs

Because of the importance Congress envisioned for councils in guiding the PAIMI Programs' annual priorities and representing consumers and family members, information was collected on how well these entities are fulfilling their significant mandate. Prior to the national evaluation, there was a lack of information about the satisfaction of PAC members regarding the conduct of their responsibilities, the level and type of support received from the state PAIMI organization, and the extent to which they believe the PAIMIs pursue goals and objectives that are aligned with the priorities recommended by recipients of mental health services and their families.

All PAC chairs in the sample participated, most either in person during site visits or by phone. In over half of these interviews, PAC chairs advised evaluation team members that the experience gave them a much better idea of their roles and responsibilities and the opportunities available to them in this role.

¹⁴ Survey Monkey Web address: www.surveymonkey.com

SMHA Director Online Survey and Legal Counsel

PAIMI Programs are responsible for protecting persons with mental illness against actual or potential abuse, neglect, and violations of civil rights. At the inception of the program, those problems were generally perceived to occur within public mental health institutions. While the mandate of the PAIMI Program has broadened, SMHAs remain both a major potential ally and a potential challenge to the PAIMI grantees. The purpose of these surveys was to determine how the PAIMI Programs are perceived by directors of SMHAs and their legal counsel. Fourteen SMHA directors and 19 legal staff participated in the evaluation.

Other State Mental Health Advocacy Organization Directors

To meet their goals, PAIMI Programs interface with other mental health organizations in their state or territory. For example, they may collaborate with a family advocacy organization to push for additional funding for mental health treatment in jails or with a consumer advocacy organization to block passage of a proposed expansion of an outpatient commitment law. At other times, the PAIMI may take a position that is in opposition to those same organizations. To determine the character of these types of collaborations, a survey was developed for directors of other statewide mental health advocacy organizations to ascertain the extent to which these players understand the role of PAIMI and their perception of PAIMI Program effectiveness.

NAMI State Chapter Executive Directors/Presidents

Leaders of 18 of the sample of 20 state chapters of NAMI, either state presidents or executive directors, participated in the evaluation. Given that NAMI represents the interests of family members of those with psychiatric disabilities, these advocacy organizations are sometimes aligned with PAIMI goals and sometimes not. This evaluation sought to determine the extent of interface and efforts to educate and collaborate among PAIMI grantees and state NAMI chapters.

Directors of Consumer-Run Mental Health Advocacy Organizations

P&A executive directors were asked to identify a statewide consumer-run advocacy organization. Identifying and securing the participation of directors of consumer-run organizations was the most challenging aspect of data collection. While such organizations exist in 19 of the 20 sampled grantees, most have only limited office hours or inaccurate email addresses and/or telephone numbers on record. In many instances, contacts or organizations identified by other stakeholders were no longer accurate or functioning. Seven directors of consumer-run organizations participated in the evaluation, most by telephone interviews rather than the online survey.

Directors of Statewide Mental Health Advocacy Organizations

P&A executive directors were also asked to identify a statewide mental health advocacy organization. Twelve statewide mental health advocacy organization directors participated in the evaluation. Respondents included state chapter directors of mental health associations and the National Federation of Families for Children's Mental Health.

Additional Interview Data Sources

Key informant interviews were intended to ascertain whether Federal oversight has been effective in assuring compliance with statute and regulations. Such oversight included design and review of annual applications, annual program performance reports, site monitoring visits, and fiscal plans and reports. Another purpose of these interviews was to identify the extent to which CMHS-funded TA has been effective in supporting the needs of grantees. The interviews were used to assess the strengths and weaknesses of each of the key Federal monitoring activities (oversight by the GPO, site monitoring visits, PPR peer reviews) and the provision of TA. Each interview was tailored to the respondent type.

CMHS GPOs and SAMHSA Grants Management Officer

GPOs are expected to play a key role as the interface between CMHS and the PAIMI programs. Six GPOs and one SAMHSA Grants Management officer were interviewed. These Federal officers were queried about their knowledge of the PAIMI Program, oversight responsibilities, site monitoring visits, and TA delivered to the grantees.

NDRN Interviews

Seven key NDRN staff involved in the administration of PAIMI TA were interviewed to determine (a) how information is collected from grantees and CMHS regarding needs for TA, and (b) how requests for TA are fulfilled. Feedback was gathered from P&A executive directors regarding the usefulness of rendered TA. The evaluation further examined how PAIMI TA resource allocation decisions are made and oversight is provided by Federal agencies.

PAIMI Site Monitor Interviews

Site monitors are enlisted by CMHS as consultants to conduct onsite PAIMI Program monitoring visits to grantees. Monitors critique PAIMIs on the extent to which they are operating according to Federal statute and regulations. Site monitors are selected by CMHS for their knowledge about PAIMI operations from different perspectives; for example, perspectives of the client, PAIMI staff, and former state commissioners of mental health. Five PAIMI site monitors were interviewed about the strengths and weaknesses of this oversight process.

PAIMI PPR Peer Reviewer Interviews

PPR peer reviewers are enlisted by CMHS as consultants to review the annual PAIMI PPR required of all grantees. Peer reviewers have direct experience with PAIMI operations and include P&A staff, PAC members, and former members. Peer review reports present a brief synopsis of each grantee's strengths and areas for improvement. The peer review process is a relatively recent quality improvement tool, but it constitutes the only feedback grantees receive on the program annually. Five peer reviewers were interviewed for this evaluation.

Planning Phase Interviews

Prior to initiating the PAIMI evaluability assessment, evaluation team members interviewed 23 individuals with long-standing knowledge of and experience with PAIMI. EAW members participated in these interviews, as did Federal partners and others. (A list of those interviewed

appears in Attachment E.) These interviews served to gather ideas about research questions and determine what stakeholders regarded as most important to be examined in the evaluation. Interviews were conducted in person and by telephone.

C. Analysis and Report Structure

Frequency distributions were the primary tool for data categorization and analysis: both qualitative and quantitative. This type of analysis shows what is normative among grantees and where there are outliers at either end of the range of performance.

The following chapters describe findings, each concluding with a summary of key findings and recommendations for enhanced program effectiveness. The evaluation team and EAW anticipate that these findings and recommendations will prove useful to Federal Government partners involved with oversight of and support to P&A programs, P&A senior staff and governing boards, PAC chairs, and other stakeholders within the mental health services community.

CHAPTER 3

FEDERAL OVERSIGHT AND SUPPORT FINDINGS

A. Federal Administrative Structure

The PAIMI Program was originally established within the National Institute of Mental Health (NIMH). In 1992, when CMHS was created, the PAIMI Program was moved to the Planning Branch of the CMHS Division of State and Community Systems Development. CMHS is part of SAMHSA, Department of Health and Human Services.

B. CMHS Staff Organization and Resources for Program Management

Initially, under the auspices of NIMH and then CMHS, the PAIMI Program had one primary GPO whose responsibilities included serving as the contact for all individual PAIMI grantees, as well as developing policy and managing the program. Currently there are 57 grantees. Recognizing the burden of assigning this much responsibility to a single individual, CMHS undertook a major reorganization of the PAIMI Program in 2003. Now, PAIMI oversight is coupled with oversight of the Mental Health Block Grant (MHBG) program so that the same GPO oversees both programs in a state or territory. Systemic PAIMI activities are distributed among the GPOs of the State Planning and Systems Development Branch (SPSDB), Division of State and Community Systems Development. One GPO presently has specific responsibility for the annual peer reviews of the PAIMI grantee PPRs, one for the site monitoring visits, one for the TA contract, and one for policy concerns.

Six GPOs were interviewed for this evaluation. GPOs reported they are not sufficiently trained or equipped to provide consultation on PAIMI issues. An understanding of PAIMI regulations and requirements requires a great deal of time, and GPOs noted they received little to no training and instruction on PAIMI. These Government officials typically have not attended to PAIMI matters except when supervising site monitoring reviews (these reviews are discussed in the following section). They are, however, very clear about their PAIMI responsibilities: to review applications, arrange and lead site monitoring visits, and maintain contact with PAIMI Programs.

GPOs concur that having the dual roles of supervising the PAIMI and MHBG programs is not ideal because (a) the Block Grant takes up much more than its allotted 10 percent of time, leaving little time for PAIMI matters; and (b) conflict of interests can arise between the operations of both programs, and there is insufficient guidance around this dual role. The total MHBG allocation was nearly \$407 million in Federal Fiscal Years (FYs) 2007 and 2008, while the PAIMI total allocation was \$34 million. Viewed at the state level, the State of Massachusetts received 16 times as much under the MHBG as it received for PAIMI. The collective opinion of the GPOs interviewed was that the MHBG program significantly overshadows the PAIMI

Program and that PAIMI grantees should have a separately designated GPO. Recently, the new SPADB chief reinstated the consolidation of PAIMI expertise in one GPO who manages questions from the field regarding PAIMI.

Most of the P&A executive directors interviewed reported agreement regarding the role of a GPO. They view GPOs as available to provide oversight and support, such as clarification on a regulation or budget problems. However, few contacts were found between PAIMI Programs and GPOs, and when contact did occur, it was most likely the result of the initiative of the PAIMI Program. In the past 2 years, 35 percent of P&A executive directors reported they had no contact with their GPO. One director stated that she/he knows who the assigned GPO is only because of having served as a PAIMI PPR peer reviewer.

Although contact with PAIMI grantees is infrequent, the collective opinion of these GPOs is that the PAIMI Program plays an important role in helping to protect consumers' rights, and that substantially more resources are needed to ease the struggle of competing priorities and increased public demand. They report examples of the impact grantees have had, including reforming discharge planning and fighting for the rights of homeless people. Although the work of the PAIMIs is seen as valuable by GPOs, these officials note that conflicts between the SMHAs and PAIMI Programs do arise because of lack of clarity in regulations or different standards for different populations. On occasion, conflict arises because there is not a clear expectation that States report deaths to the P&As, or that PAIMIs have access to putative clients and their records. The Federal Government's PART (Program Assessment Rating Tool) review of the PAIMI Program noted this:

The program's effectiveness is limited by uneven cooperation from the States. The program could more effectively use its resources if States had greater understanding of and acknowledged the program's rights to access facilities, consumers, and information involved incidents they investigate.¹⁵

GPOs do not typically have a role in working out such conflicts. They report to view themselves as neutral, though the influence wielded by SMHAs as the predominant recipient of CMHS funding does not provide much assurance that PAIMI concerns can compete equitably.

C. Oversight of Individual PAIMI Grantees

Federal oversight activities consist of reviewing grantees' annual program applications, annual PPR, fiscal status reports, and conducting onsite monitoring visits. The effectiveness of each of these oversight activities was examined and is reported below.

¹⁵U.S. Office of Management and Budget, PAIMI PART Review findings:
<http://www.whitehouse.gov/omb/expectmore/summary/10003528.2005.html>

Applications

By the start of every FY (October 1), each eligible applicant must submit a new application for the PAIMI grant. The PAIMI application package describes the purposes of the act and provides instruction on completing the form and related assurances and on setting goals and objectives. Within its application, each PAIMI grantee lays out goals and objectives for the coming year. Each goal is accompanied by measures of achievement (i.e., details about the specific population to be served, a projected numerical target or measure for each objective listed under the goal, and an indicator of success for each objective).

CMHS allows PAIMIs to select their own goals and objectives. This is unusual as the Federal Government directs the structure of other grant program goals and objectives. CMHS views grantees' performance in setting goals and objectives as in need of improvement. One area for improvement is to reduce the number of goals P&A systems set. PPRs from 2003 show a range of goals from 0 to 132 with an average of 21 goals.

P&A executive directors in the sample were asked if they had experienced any difficulty with their PAIMI applications in the past 2 years. The majority (76 percent) reported they had not, while 24 percent did experience difficulty. When asked what help those who had difficulty sought, directors showed a clear preference for guidance within the application's instructions (100 percent reported as either "very" or "somewhat useful"). Next, assistance from the current TA contractor was perceived as most useful (76% percent reported "very" or "somewhat useful").

Each of the Federal P&A programs requires different forms, and this creates confusion in agencies operating multiple disability advocacy programs. The different format required by each of the Federal grants for the annual statement of priorities is considered by directors to be cumbersome and difficult to manage. A workgroup of Federal partners has been meeting to develop a unified set of forms; however, the workgroup does not have a targeted completion date, and the initiative is perceived to be stalling out.

Electronic delivery of the annual application was initiated by CMHS a few years ago; however, directors noted the online application does not yet include all required forms or the capacity for electronic signature. These features should be put in place.

PPRs

At the end of each FY, PAIMI grantees must submit an annual PPR describing their activities and accomplishments.¹⁶ Goals and objectives from the prior year are rated as either "met," "not

¹⁶ PPR qualitative data reports on the most important accomplishments and any requests for TA. Quantitative data report information about the governing board, the PAIMI Advisory Council, client demographics, and the number and types of representation and advocacy undertaken and the outcome, as well as training and educational activities provided. Qualitative data in the PPR include the grantee's presentation of its most important accomplishments and recommendations for TA.

met,” or “exceeded.” CMHS uses this information in aggregate for a biannual report to the President and Congress. As of July 2008, quantitative PPR data by grantee have been posted to the SAMHSA website for years 2003, 2004, and 2005.¹⁷ Public posting of this information is an important step in accountability. However, there appears to be either a significant delay in posting information or this initiative has been dropped. As of the date of this evaluation report, PPR data for 2006 and 2007 had not been posted.

P&A executive directors were asked whether they had experienced any difficulty in the past 2 years with completing PPRs. It appears the PPR presents a greater challenge than the application as 56 percent of directors responded they did have difficulty with this reporting requirement. When asked to rate the usefulness of available assistance for completing the PPR, directors most frequently ranked the CMHS GPO assistance as “very useful” (43 percent), closely followed by PPR instructions (42 percent). When asked what other guidance is useful for completing annual PPRs, nearly half stated they did not seek other forms of assistance. However, those who did look for help noted reaching out to their peers, visiting the director’s electronic listserv (NDRN, the TA contractor), reviewing past PPRs, and the PPR Report (discussed next) from the prior year.

While PPR information is assumed to be useful to the Federal Government for oversight and management of the program, executive directors were asked if these reports influenced their own program administration. Directors reported the PPR as only somewhat useful or minimally useful (both 35 percent) for program administration. The PPR narratives on goals and priorities were reported as most useful since drafting the narratives requires the grantees to take a close look at what they do programmatically and ensure everything is addressed in the narrative.

P&A executive directors offered numerous recommendations to improve the utility of the PPR for evaluating grantee performance. Most frequent was a plea for simplification and nonduplication. As with the application, PAIMI PPR information requirements are different in content and format from PPRs for other Federal P&A programs. This makes planning, collecting data, and reporting cumbersome, difficult to coordinate, and time-consuming. Here too, a unified reporting document across the eight P&A programs is desired. More realistic performance indicators were also suggested, particularly when estimating the impact of systemic advocacy and policy work. Directors noted the PPR is not well designed for presenting group advocacy activity (as it emphasizes individual representation), and that no information is collected on the racial/ethnic composition of the groups to which P&As provide advocacy. Last September, SAMHSA submitted a public notice to make changes to the PPR (*Federal Register* Vol. 72, No. 174, Agency Information Collection). Changes that would address inconsistencies among the P&A organizations were not included because SAMHSA is waiting for the Administration on Developmental Disabilities (DD) to promulgate rule changes for the DD Act of 2000 amendments.

¹⁷ <http://mentalhealth.samhsa.gov/cmhs/PAIMI/>

PACs also have responsibility for authoring a section of the PPR, the Annual Report of the Advisory Council. The PAC report was conceived to be an independent assessment of the effectiveness of the services provided on behalf of PAIMI-eligible individuals and their family members. The survey of 20 PAC chairs found that 22 percent were unfamiliar with this report. However, 72 percent reported they considered the PPR very useful (44 percent) or somewhat useful (28 percent) as a vehicle to report on PAIMI activity. PAC chairs were asked how the Council fulfills its duty to determine if the PAIMI Program met its goals and objectives for the prior year. Most frequently, P&A staff advise Council members on the extent to which goals and objectives are met (67 percent). Less frequently (44 percent), the Council receives data and makes an independent determination. (Several PAC chairs reported using both strategies; thus, percentages added up to more than 100.) In one case, the PAC chair was not sure how such determinations were made.

As with the annual applications, here too fully operational electronic reporting would save time and facilitate more efficient analysis. All the GPOs interviewed reported to be in favor of electronic delivery of PPRs.

PPR Peer Review

In FY 2004, CMHS implemented an annual quality review process of PAIMI Program performance that institutionalizes the review of applications and PPRs.¹⁸ The reports produced by this process represent the only feedback that all grantees receive annually on their work. Each PAIMI Program's application and its PPR are evaluated by a team of "peer reviewers" that includes individuals with direct experience as members of the P&A staff, PAC members, or others who have considerable contact with the PAIMI Program. Team members are chosen by CMHS and receive training to foster reliability across review teams.

Process and Findings. For the first few years, peer review teams consisted of the same reviewers assigned to the same PAIMI grantees, with the expectation that this familiarity would yield more insight and deeper scrutiny. However, with subsequent reviewer turnover, a rotation assignment to teams and grantees was adopted. Five PPR peer reviewers were interviewed for this evaluation. Their opinion favors the rotation approach because it facilitates exposure to a wider variation of goals, objectives, strategies, and performance, which can enhance reviewers' skills.

All peer reviewers interviewed recommend that conference calls with P&A executive directors be held to discuss impressions and findings prior to drafting the grantee's report. From their perspective, conversation with the grantee allows for clarification by both reviewer and grantee in advance of a written report. This approach was piloted with a few states one year, but it has not been adopted as part of the review process.

¹⁸ For a more detailed description of the peer review Process, see Evaluation of the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program Phase I: Evaluability Assessment Report, prepared by the Human Services Research Institute and Expert Consultants for the Center for Mental Health Services, June 2005

Peer Review Reports. Peer reviewers interviewed viewed PAIMI performance as widely divergent. Some programs were described as excellent and others as substantially underperforming. HSRI reviewed individual program reports¹⁹ from the first and second year reviews and did not discern this wide diversity of performance, in part because these reports are extremely brief, generally less than two pages. Reports provide no overt comparison of a program’s standing in relation to other grantees.

Peer review reports identify the strengths and weaknesses in individual programs, and where appropriate, recommend changes. In the upcoming reviews, CMHS anticipates examining whether grantees made the changes recommended in peer review reports. Among the strengths identified by peer reviewers were well-written priorities (e.g., those that use clear language, are concise, use measurable indicators, and relate priorities and objectives to issues addressed in the SAMHSA Matrix²⁰). In some cases, praised work was vaguely reported, and while likely understandable to the particular grantee, would not be a valuable learning tool for all grantees. For example, “outreach to special populations” was noted for displaying innovative strategies, but the report did not provide specifics. Peer reviewers also identify challenges common across the system. Many grantees struggle to secure sufficient diversity of representation on governing boards and PACs—both for types of members and for minority representation reflective of the population. These findings are consistent with findings from the CMHS Site Monitoring Review Reports.

Is this quality improvement strategy influencing PAIMI performance? Most of the P&A executive directors sampled (65 percent) reported they have made changes based on peer report recommendations; 35 percent have not. Examples of changes initiated in response to peer review reports include increased diversity on the PAC, expanded outreach to minority communities, and improved description of collaboration with other organizations. Directors advised that the vagueness of reports impedes their utility as a vehicle for change. For example, “minority outreach” as a recommendation does not adequately specify what is needed in that domain, and there is no reference to a program that is performing well in the area suggested for consultation.

Timeliness and Distribution. Written peer review reports are delivered to grantees approximately 8 months after the review meeting is held. When asked what would most improve the utility of the reports, executive directors most often mentioned timely delivery (63 percent). One director noted that the report is so delayed that the programs operate in the following fiscal year for more than 6 months before receiving the review of the prior year’s report. Such delayed report delivery means directors do not have benefit of this quality improvement feedback in time for use in preparing the subsequent annual PPR.

¹⁹ Reports reviewed were those states selected in the evaluation sample.

²⁰ SAMHSA created a tool depicting the collaboration needed to promote holistic, integrated approaches that advance the health and well-being of individuals, families, and communities. The graphic representation is referred to as the SAMHSA Matrix.

Peer review reports are required to be distributed to P&A executive directors, governing board chairs, and the PAC chair. More PAC chairs reported they have not seen a PPR peer review report (42 percent) than those who have seen a report (32 percent). Grantees see only their own reports and not those of others. P&A executive directors report that the brevity of the reports and their belated delivery results in limited usefulness for program operations. Directors were asked what value was gained from these reports, and many indicated learning from their peers and comparing their program to similar grantees was helpful. Further, sending a staff person to serve as a peer reviewer was seen as highly useful. However, 25 percent of directors perceive this quality improvement approach to have no utility.

Fiscal Oversight and Support

PAIMI is a formula grant program in which funds are allocated based on population and per capita income. Funding levels are public information and can be accessed on the SAMHSA webpage.²¹ Grantees are monitored for compliance with fiscal rules and regulations. The purpose of fiscal oversight is twofold: to assure appropriate expenditure and to provide consultation to keep grantees on track with changes in fiscal procedures and standards.

For this evaluation, the Federal official within SAMHSA Grants Management Office with oversight of the PAIMI Program was interviewed. Evaluation team members learned there are numerous areas in which the fiscal oversight mechanisms of the various P&A programs differ, and this can cause confusion for grantees. To prevent problems, the Grants Management Office offers TA for completing required reports and understanding rules that govern spending and accounting. Although Grants Management staff are available for consultation, grantees only occasionally call or email with questions. Ninety percent of executive directors interviewed report no contact with SAMHSA Grants Management staff in the past 2 years.

Multiple mechanisms of Federal fiscal oversight are in place: application review, PPR review, financial status reports, CMHS site monitoring visits, and review of grantees' annual independent audits. Applications and PPRs include detailed budget information and are reviewed by the assigned GPO and the Grants Management Office for nonallowable costs²² or items that need further explanation. While Grants Management staff have the final review and decision authority, PAIMI GPOs are also charged with reviewing grantee budgets and expenditures. GPOs specifically examine staffing to ensure the P&A is using PAIMI funds to support staff conducting PAIMI work. Another level of fiscal review is a required financial report (SF269-Financial Status), not considered very useful by the Grants Management officer interviewed. This report is used primarily to close out grants in the payment management system.

The most useful financial critique, according to Grants Management staff, is the site monitoring visit. Onsite reviews examine actual grantee operations. Thus, where a grantee may write a policy that meet standards, a site visit will confirm compliance in operation. However, because

²¹ <http://www.samhsa.gov/statesummaries/StateSummaries.aspx?state=ma&year=2007>

²² Nonallowable budget items are found in the OMB circular on this subject.

onsite monitoring occurs infrequently, it is not a robust tool for determining ongoing fiscal compliance.

The final level of fiscal oversight is to ensure grantees are complying with the requirement for an annual independent audit (known as the A133 audit). This audit is mandatory for organizations receiving Federal funds and must be conducted by an independent auditing firm hired by the organization. PAIMI audits, according to the Grants Management official interviewed, always meet compliance.

According to the SAMHSA fiscal officer, few fiscal problems have been seen in recent years. Examples of problems identified through reviews are: (a) failing to demonstrate there was competitive solicitation for qualified contractors, and (b) a conflict of interest with a board or staff member who receives a contract with the P&A. The program's PART review determined that funds are obligated in a timely manner and spent according to intended purpose.²³ For the 4 years of fiscal data PART reviewers examined, no grantees were found to be out of compliance in appropriately obligating and expending PAIMI funds. P&A executive directors (95 percent) confirm that SAMHSA fiscal reviews have not identified any issues related to PAIMI expenditures in the past 2 years.

Should a fiscal issue be identified, the procedure is for SAMHSA to send a letter to the P&A outlining the problem and requiring a response. Corrected fiscal reports may have to be filed. If fraud is identified, the grantee is placed on "high risk" status, which results in restricted spending, and CMHS must approve expenditures. To remove the high risk designation, the grantee must submit and comply with a Corrective Action Plan. The Department of Health and Human Services, Office of the Inspector General, may also be involved to review grantee fiscal problems should prosecution be necessary, but in the history of the program, this has never happened. A more serious sanction available within SAMHSA's authority is to ask the governor of the state in which the grantee is located to redesignate the program. Redesignation that was not initiated by the P&A has occurred only twice over the history of the program. In one case, the redesignation was made to resolve conflicts between Federal P&A statutes and regulations and the restrictions of the Legal Services Corporation, not because of financial impropriety.

The Grants Management official interviewed concurred with statements from CMHS GPOs that responsibility for both the MHBG and PAIMI constitutes a conflict. The perception is that PAIMI is overshadowed by MHBG duties and responsibilities. This is exacerbated by CMHS division leadership's focus on the state mental health program directors as the MHBG client. The PAIMI Program's clients are individuals with psychiatric disabilities, and the interests of state mental health program directors and people with psychiatric disabilities are not always in alignment. The Grants Management official also concurred with the PAIMI GPOs interviewed that the reorganization of GPO responsibilities is not functionally optimal. CMHS GPOs are perceived as insufficiently trained in PAIMI or fiscal issues and do not always know what to look for on a site visit. Communication between the SAMHSA fiscal oversight office and the CMHS branch that

²³ <http://www.whitehouse.gov/omb/expectmore/detail/10003528.2005.html>

oversees PAIMI is neither routine nor standardized, which is seen as a problem. According to the Grants Management official interviewed, there is also a need for additional Grants Management staff to become knowledgeable about PAIMI. Grants Management staff work collaboratively with their counterparts at the Administration on Developmental Disabilities (ADD) and the Rehabilitation Services Administration (RSA) responsible for monitoring the fiscal performance of the same P&A grantees.

Onsite Monitoring Reviews

Review Instrument and Process. CMHS conducts periodic, onsite monitoring visits to individual PAIMI Programs to review fiscal and management practices and verify compliance with the PAIMI statute and regulations.²⁴ Site visits have been part of the program administration for many years, although there also have been periods during which, lacking resources, site visits did not occur. After a 5-year hiatus, monitoring visits were resumed in FY 2001. In that year, three of the five programs visited were placed on “high risk” status by SAMHSA’s Division of Grants Management for purported non-compliance. The resulting grantee advocacy and pressure led to a revised monitoring tool developed with input from various stakeholders that covers four areas of statutory compliance: governance, fiscal operations, administration, and services. This tool has been in use since 2003.

The current monitoring tool is based on the PAIMI Program statute and regulations. Because the statute historically focused on services to persons in institutions, the protocol is strong in this area but less robust in evaluating community-based advocacy. No attention is paid to outcomes for clients, the impact of grantee activity, or level of grantee effort to move a system toward Federal goals. Systemic work is not as thoroughly reviewed as individual representation. Strengthening the review tool in these areas may require establishing supporting regulations or a consensus among stakeholders that the tool should be revised to address community-based and systemic advocacy activities. Given the objective and transparent character of the current review tool, it can be used for self-evaluation and to prepare for monitoring visits.

Site visit teams are generally composed of the grantee’s GPO and three other monitors. The monitors receive 1½ days of training prior to the visit. The GPO’s role is to facilitate the review process and conduct the entrance and exit interviews, not to participate directly. Monitors include PAIMI staff from other states and consumers and family members involved in other states’ PAIMI Programs. Site visit teams may make specific recommendations for program improvements, both at the exit conference and in a written report. Programs have an opportunity to respond to the written report before a site visit report becomes final. If a problem is corrected within 90 days of the site visit, that is formally noted in the final monitoring report. If that is not possible, grantees are expected to respond with a Corrective Action Plan. TA may be provided in support of this plan.

²⁴ CMHS, SAMHSA. (2002, October). *Protection and Advocacy for Individuals with Mental Illness (PAIMI) monitoring manual.*

The Federal ADD also conducts site monitoring visits. ADD site visits review the overall P&A Program, exclusive of the PAIMI Program, as well as all other federally funded disability advocacy programs in a state, such as the University Centers for Excellence and the State Councils on Developmental Disabilities. In the past, site monitoring visits conducted by ADD and CMHS were scheduled for the same week, and staff shared monitoring findings. However, monitoring visits are now conducted separately, and findings are not formally shared between Federal partners.

Frequency of Review. When HSRI initiated this evaluation in 2004, CMHS was conducting six to seven monitoring visits per year, a schedule that would result in an onsite review less than once every 10 years. By the end of 2007, not every grantee had received a site monitoring visit. As of 2008, CMHS increased its schedule to nine site visits per year and included several grantees that had not previously received an onsite monitoring review.

Report Findings. Where exemplary performance is found, site monitoring reports appear to note such. Where a grantee’s performance does not meet one of the standards of practice, a finding of “not in compliance” on that standard is reported. When a grantee’s performance is not out of compliance, but reviewers have a suggestion for improvement, a “best practice” recommendation is made. Completed monitoring visit reports available from 2002 to present indicate that the majority of PAIMI Programs (56 percent) were found to be operating in compliance with program standards at the time of a monitoring visit, while 15 percent were operating out of overall compliance. For a number of reports, the evaluation team had difficulty determining whether CMHS found a grantee to be operating in or out of “overall compliance.” A statement on overall compliance was missing in 28 percent of reports reviewed. Table 1 below shows this lack of clarity regarding overall compliance status.

Table 1. Overall Compliance Findings in PAIMI Site Monitoring Reports Reviewed 2003–2007

Review Year	Monitoring Reports Reviewed	In Compliance Overall	Not in Compliance Overall	Unable to Determine Overall Compliance Standing
2003	6	5	1	0
2004	6	6	0	0
2005	6	1	0	5
2006	8	4	3	1
2007	7*	2	2	3
Total Reviewed	32	18	6	9

*One additional PAIMI received a site monitoring review in 2007, but as of August 2008, the report was not final and was not included in the evaluation.

Reports show a grantee can be found to operate “in compliance overall,” even when there are areas of noncompliance. In the evaluation team’s opinion, a program out of compliance on even a single criterion is still out of compliance in that performance area. The evaluation team recommends that if CMHS continues to use the concept of operating in compliance overall, it

should refine the line between in and out of compliance overall and publicize the rating criteria in the monitoring instrument.

Compliance issues (areas of performance that do not meet the standard and must be corrected) per grantee ranged from none to 17. The range of best practice recommendations (suggested areas of improvement) was 2 to 19. Attachment F illustrates CMHS' findings from site monitoring reports of best practice recommendations and areas of noncompliance. The evaluation team determined that programs found to be out of compliance overall tended to be noncompliant in several key areas, including financial practices and written policies and procedures. Common problem areas were those related to grievance procedures, conflict of interest statements, and consultant agreements, as well as insufficient PAC representation. While it is not surprising that a site visit might find a grantee's PAC temporarily lacking a key representative, the fact that grantees continue to lack a grievance policy 22 years after expectations for such policies were established is a cause for concern.

All six programs found not in compliance between 2003 and 2007 were required to submit a Corrective Action Plan. However, the evaluation team found only two direct recommendations that a grantee secure TA. Although offering best practice recommendations is a form of TA, the reluctance to recommend training or TA stands out. Table 2 below shows the number of best practice recommendations and out-of-compliance issues found in site monitoring reports by year.

Table 2. Compliance and Best Practice Findings Within Site Monitoring Reports 2003–2007

Review Year	Number of Site Monitoring Visits	Compliance Issues	Best Practice Recommendations
2003	6	17	36
2004	6	15	75
2005	6	21	73
2006	8	16	72
2007	7*	65	63

*Not all reports from 2007 reviews were final and are not included in analysis.

Since the new site visit protocol was introduced in 2002, half of P&A executive directors interviewed have experienced a site visit. Nine stated that monitoring findings was valuable and the experience validating. In one case, the monitoring visit was reported as not helpful, with ill-prepared monitors and erroneous findings. Directors were asked whether information conveyed during the exit interviews and the written reports was helpful, and what would improve these aspects of the process. Exit interview information was predominately viewed as helpful; directors were provided positive feedback and also received some best practice recommendations to pursue. Their ratings of written reports were more mixed; the principal complaint was that reports were not delivered in a timely manner. (This is discussed in more depth below.) Directors have used information conveyed by site monitors to make significant

changes in their practices, such as improvements to their grievance policy, PAC operations, case closure procedures, and establishing sound subcontracts.

Report Delivery. CMHS's monitoring protocol calls for a draft report to be delivered to the P&A executive director no later than 8 weeks after the review. The director then has 2 weeks to review and comment, and a final report is issued no more than 12 weeks after the site review. Fifty percent of directors who had site monitoring visits since 2002 reported CMHS did not provide site review reports according to the established time lines. CMHS site monitors also stressed that the time lines for delivery of reports are not followed. GPOs concur with directors that the delay in delivering reports is problematic and that it can take up to 16 months before grantees receive written reports.

Report Dissemination. CMHS intends that site monitoring reports be distributed to each PAIMI's governing board president, the PAC chair, and the P&A executive director. These reports are so carefully guarded they are not shared with other PAIMI GPOs or other grantees, a practice that impedes systemic learning and improvement. Since the PAIMI programs are public programs funded with Federal monies, monitoring reports should be publicly available. Reports do not name clients and therefore do not violate confidentiality laws. When this evaluation was initiated, the evaluation team's initial impression was that the findings from all site monitoring reports should be combined, identifying information removed, and the combined reports disseminated to all grantees to provide clarity as to what constitutes compliance and what does not. Last year, NDRN created such a compilation for peer learning. NDRN's *A Summary of Recommendations FY 2007* describes the areas of review and compliance and best practice issues identified in that year's monitoring reports. These reports could be a valuable source for improving systemic program effectiveness.

Government Performance and Results Act

The first Federal initiative to explicitly mandate performance-based accountability was the Government Performance and Results Act (GPRA) of 1993. Under GPRA, Federal agencies are required to identify goals and measures for each program, and then report annually on progress toward each goal. CMHS initiated PAIMI system GPRA measures in the early 1990s with two performance measures: (1) Increase the number of persons served, and (2) increase the percentage of substantiated incidents reported to state P&A systems that are favorably resolved. The PAIMI Program has shown progress along both performance measures. More recently, four additional performance measures were added. Although the program may not have met its targets for each year, progress has been made on all measures according to the PART review findings discussed in the next section. Table 3 below presents the current GPRA performance measures for the PAIMI Program.

Table 3. Current PAIMI Program and GPRA Measures of Performance

Term	Measure Type	Measure
Long Term/ Annual	Outcome	Percentage of interventions on behalf of groups of PAIMI-eligible individuals that were concluded successfully
Annual	Output	Increase in the number of persons served
Long Term/ Annual	Outcome	Increase percentage of complaints of alleged abuse and neglect, substantiated and not withdrawn by the client, that resulted in positive change for the client in his/her environment, community, or facility, as a result of PAIMI involvement
Annual	Efficiency	Cost per 1,000 individuals served/impacted
Annual	Efficiency	Ratio of persons served/impacted per activity/intervention
Long Term/ Annual	Outcome	Increased percentage of complaints of alleged rights violations, substantiated and not withdrawn by client, that resulted in positive change through the restoration of client rights, expansion or maintenance of personal decisionmaking, or elimination of other barriers to personal decisionmaking, as a result of PAIMI involvement.

The evaluation team considers the current set of GPRA indicators insufficient to measure program effectiveness in useful ways. Concerns identified include:

- An efficiency measure of cost per person served encourages programs to conduct less intensive work; for example, more information and referral than actual representation. It is also a disincentive for investing in more expensive staff where needed such as an in-house attorney knowledgeable about mental health. An alternative efficiency measure is to consider a program's overhead costs.
- Output measures that, year after year, call for more persons to be served emphasize quantity over quality. At what ceiling would a PAIMI be considered to be operating at maximum capacity? It is expected this would be challenging to determine. A more realistic measure of output may be the number of individual cases that turn over in a 6-month period.
- Outcomes that only target the percentage of group interventions that are successful do not account for advocacy activity that initiates a systemic change that will later be adopted as standard procedure.

The OMB PART review evaluated the PAIMI Program on goal-setting and attainment measures and awarded the program a passing grade.²⁵

²⁵ <http://www.whitehouse.gov/omb/expectmore/summary/10003528.2005.html>

Structure and Oversight of TA

TA to support activities of P&A agencies began with the creation of the PAIMI Program in 1986. TA was included in the PAIMI legislation to ensure that the existing P&As, which had been created to serve people with developmental disabilities, would have sufficient information about specific issues affecting people with psychiatric disabilities to serve them effectively. The statute required that up to 2 percent of funds off the top of the PAIMI Federal allocation be set aside for TA relevant to those with psychiatric disabilities.

Initially, NIMH dispersed the TA funds through a series of small grants to individual attorneys and organizations, such as the Bazelon Center for Mental Health Law, specializing in disability rights. In the early years, PAIMIs repeatedly reported insufficient funds to support adequate staffing, leading to unqualified staff, burnout, and unfamiliarity with mental health issues. In response, almost all PAIMIs took advantage of the provision in the law allowing them to spend up to 10 percent of their appropriation for staff training and TA. By 1991, NIMH was persuaded that consolidating TA into one grant for the PAIMIs was a more effective and efficient approach. The consolidated grant went directly to the National Association of Protection and Advocacy Services (now the NDRN). Similar arrangements involving NDRN were made with the RSA for the PAIR Program, and the ADD for the PADDs. Eventually, given the administrative complexities of managing several grants, the Federal agencies with oversight for disability advocacy programs (CMHS, RSA, and ADD) agreed to consolidate their funding through an interagency agreement into one competitive contract. ADD was designated as the lead agency. The current budget for the combined TA, called the Technical Assistance Skills Contract (TASC), amounts to nearly \$2 million. NDRN holds the contract.

CMHS requires that a portion of the funds it contributes to the consolidated Federal contract be directed to topics it specifies. CMHS has designated \$200,000 to present specific behavioral health issues at NDRN's annual conferences. With the exception of those earmarked funds, TA funded through the PAIMI Program is devoted to building organizational capacity and expertise in a range of areas that cross disability populations, such as housing and special education. One potential outcome mentioned by some key informants was the possibility that the Federal partners may disaggregate the TA funding and go back to separate and targeted procurements. If the TA is split up into categorical units and becomes more particular, it may run counter to the current trend among P&As to organize their activities in a functional rather than a disability-specific fashion. It also will result in more administrative complexities.

Using TA is voluntary, but there have been suggestions over the years that TA should be mandatory, particularly in cases where a grantee is found to be operating out of compliance. However, NDRN and the P&As have resisted this approach on the assumption that if the TA is relevant to their needs, grantees will take advantage of training opportunities. TA is rarely recommended by CMHS; grantees are much more likely to initiate requests for TA than to have it recommended to them.

TA Needs Assessment

NDRN's TASC. NDRN focuses on meeting the legislative mandate that training and TA be driven by P&As' needs and requests. P&As make numerous individual requests for information, advice, training and TA by telephone, and email and listservs; NDRN staff generally respond through the same format. The specific components of TA are dictated by the TASC solicitation, a formal needs assessment, issues that come up through the listservs, prominent court decisions, and changes in Federal laws and Federal priorities. As specified in the TASC contract, NDRN undertakes a formal needs assessment of the P&As every 3 years. The next formal needs assessment is planned for 2008.

CMHS Staff. The primary role of the PAIMI GPOs regarding TA is to forward requests to NDRN. NDRN follows up with the individual P&As where there has been a recommendation for TA. While oversight officials may be troubled when a P&A refuses recommended training or TA, officials do not feel it is within their authority to mandate these activities. GPOs receive no report back on the outcome of these referrals. Four of 20 executive directors reported that no TA needs were identified by their own agencies within the past 2 years, although 16 directors self-identified issues and requested TA. Examples of requested TA included:

- PAC development
- Encouraging clients to follow through on complaints
- Addressing juvenile justice problems
- Development of outreach publications
- Investigation training
- Review of death reports

Nearly all executive directors (90 percent) reported CMHS had not made any recommendations for TA as a result of an oversight activity.

TA Delivery Methods and Usefulness to PAIMI Grantees

TA provided to PAIMI Programs is diverse and wide-ranging and considered effective by grantees participating in this evaluation. Nearly all P&A executive directors interviewed (95 percent) reported that TA sufficiently addresses PAIMI issues. All grantees that requested TA received the specific assistance requested.

NDRN delivers most of its TA on advocacy, organizational, and fiscal matters through its conferences, website, general trainings, listservs, and publications. NDRN also contracts with several legal backup centers to provide legal support. Training or TA that grantees purchased beyond that available through NDRN was not evaluated. A report on how P&A executive directors use the primary methods of TA available and their opinions regarding the efficacy of these resources is provided below.

NDRN Consultation. Consultation with NDRN staff is rated as the most useful TA delivery mechanism by P&A executive directors; 94 percent rated it “very useful.”

Conferences and Meetings. As specified in the Federal contract, NDRN now sponsors three conferences each year. These conferences address a broad range of substantive, skill-building, and organizational development topics. The Skill-Building and Fiscal Managers’ conferences are considered “very useful” by 74 percent of P&A executive directors interviewed. Most PAC chairs (or another member of the PAC) have attended one of the national conferences within the past 2 years (83 percent), and almost all (92 percent) found the experience helpful in their work as council members.

NDRN Website. NDRN has a multifaceted website with a public area and an area accessible only to P&A-affiliated individuals through a password. It is clearly appropriate for some of the online information to be password-protected (e.g., litigation strategy), and in other areas privacy is understandable, such as topic-specific listservs (electronic mailing lists where members can ask and answer one another’s questions). However, it is not clear to the evaluation team why information on such topics as cultural competency and external training opportunities is kept private on a website supported by public funds.

NDRN uses listservs to identify the needs for TA in real time and to respond rapidly to emerging issues. Currently, there are 18 listservs addressing legal and policy areas, such as abuse and neglect and community integration, and others targeted to individuals with specific responsibilities, such as legal directors and fiscal managers. All are archived and available online. A review of two listservs indicates active, substantive dialogues on new developments and long-standing issues, with NDRN staff taking a leadership, though not controlling role of the discussions. P&A executive directors rated nearly all the listservs as either “very” or “somewhat” useful. Rated as the most useful listservs were the *Issues for Boards of Directors and CEOs* and the one dedicated to *Voting* (67 percent). The listserv receiving the least “very useful” ratings, *Secure Confinement*, was reported as helpful by 44 percent of directors.

Legal Backup Centers. NDRN executes annual contracts with several recognized disability law centers to provide expertise and assistance on complex legal issues. P&A staff may call these centers directly with questions, up to a certain number of billable hours, after which the P&A must pay for additional consultation hours. NDRN staff may become involved as co-counsel in more complex litigation. The backup centers NDRN contracts with change over time in accordance with the needs of the P&As and the expertise of organization’s staff. While the work of legal backup centers is overseen by the NDRN legal committee, there is no systematic evaluation protocol. Nearly all the executive directors (86 percent) rated the legal backup centers as “very useful.”

Publications. With TASC resources, NDRN publishes a variety of reports and publications ranging from a monthly newsletter to topical fact sheets to manuals that cover topics in depth. Nearly all P&A executive directors (95 percent) consider publications and educational materials either “very helpful” or “somewhat helpful.”

In summary, TA appears to be available when needed and is considered to be of high quality. The need for TA is most often identified by grantees. PAIMI-related training and TA are delivered through a variety of methods that appear to meet the grantee expectations and are valued by those who utilize them. It is not clear whether underperforming grantees self-initiate requests for TA in their weak areas of performance, but it is clear CMHS could perform a more direct role in recommending TA and ensuring grantees utilize the available expertise.

D. Federal Oversight and Support: Lessons Learned and Recommendations

CMHS Staff Organization and Resources for Program Management

- GPOs assigned to cover both the SMHB Grant and PAIMI Programs are not adequately supported for this role. CMHS staff and contractors involved with PAIMI need a thorough understanding of the program. GPOs with oversight and support responsibilities for PAIMI grantees should be experts in PAIMI regulations and issues.
- GPOs should reposition themselves from neutral parties to active problem-solving agents in situations where there is contention between PAIMI grantees and SMHAs. This entails resolving the recurring conflicts with clear guidance on issues, including reporting deaths to PAIMI Programs and PAIMI access to death reports, putative clients, and locations where state-funded mental health services are delivered, and records.
- There should be a focus on sharing knowledge among CMHS divisions and among other Federal agencies with oversight of disability advocacy programs.
- CMHS should include information on unmet needs in internal annual budget recommendations.

Applications and PPRs

- Require and fully support the electronic delivery of PAIMI applications and PPRs.
- Implement a uniform PPR across all Federal P&A Programs. Limit the number of goals and objectives on which PAIMI grantees report.
- The PPR and application each year should include a section addressing unmet needs. PACs could provide information on unmet needs in their annual report.
- Provide equivalent attention to PAIMI advocacy for systems change as for individual representation including tracking minority representation.
- PACs are not preparing their annual critique of PAIMI activities independently. It is recommended that the structure of these reports be altered to allow independent critique from the knowledge and experience of PAC members. For example, PACs could report on PAIMI effectiveness in conducting outreach to minority populations or working in concert with other advocacy organizations. Last year, CMHS altered the PAC report format in this manner. It remains to be determined if changes facilitate an independent critique of PAIMI activity. This is discussed further in chapter 6.

PPR Peer Review

CMHS' peer review of PAIMI applications and PPRs is an important mechanism for monitoring grantee performance. This quality improvement process is based on the shared opinion of individuals highly knowledgeable about PAIMI operations. Presently, P&A executive directors are not required to make changes recommended in peer review

reports. To maximize the impact of this quality management tool, CMHS should:

- Make recommendations for improved performance clear and explicit and include suggested TA resources. Direct underperforming grantees to secure TA from grantees that have excelled in that area and reward the mentoring PAIMI.
- Track each PAIMI's areas for improvement and efforts to address. Programs that do not appear to work assertively to address significant problem areas should be targeted for site monitoring reviews.
- Provide reviewers an understanding of where a grantee stands in comparison to other grantees. For example, quantitative data from PPRs could be compiled (as was done for this evaluation) to illustrate a grantee's performance: (a) in the context of other similarly sized programs, (b) compared to all grantees, and (c) over time for trend analysis. The evaluation team provided similar data analysis to peer reviewers for their 2006 meeting and it enhanced the critique. This type of analysis could readily be provided by NDRN, which already assembles PPR data for the national PAIMI Program reports to Congress.
- Institute debriefing conference calls with grantees as part of the peer review process.
- Prepare reports electronically.
- Deliver peer review reports within 6 weeks. Distribute reports with signature acknowledgement to P&A executive directors, chairs of governing boards/authorities, and PAC chairs. GPOs could facilitate teleconferences with each grantee to discuss report findings.

Fiscal Oversight and Support

- The SAMHSA Grants Management Office and reviewers should have more substantive contact with PAIMI GPOs.

Onsite Monitoring Reviews

Site monitoring visits are the Federal government's most potent vehicle for determining whether PAIMI Programs' reported activities are being carried out. However, the lack of frequency of grantee monitoring does not engender confidence that a previously well-performing program has remained so. Over the 22-year history of the program, not all grantees have received the scrutiny of a site visit. CMHS rarely recommends TA, even when grantees are found "out of compliance" with Federal regulations. Given that the monitoring tool has remained unchanged since 2002 and contains little, if any, subjective review, and Federal regulations too remain largely unchanged since the program's inception, all programs should pass.

- Every program should be visited every 4–5 years, and programs that have had significant problems should be revisited for followup or placed on a more frequent review cycle; 2008 marks CMHS's start along a 5-year onsite monitoring cycle.
- Written reports should be delivered in a timely fashion, within 2 months of the site visit.

- Grantees should be required to conduct self-assessments on a regular basis. In years when a grantee does not receive a formal site review, a program could conduct a self-assessment using one domain of the monitoring tool (e.g., governance).
- A monitoring report template should be instituted to improve consistency and save money on editing. (Each time a report is reedited, it costs \$500 per page.) Reports should clearly state dates of all site monitoring visits and activities. The logistics contractor that coordinates the site visit process and report drafting should be selected based on knowledge and experience with the PAIMI Program.
- If CMHS is going to use the standard of “in compliance overall,” criteria for determining the line between overall compliance and noncompliance should be explicit and included in the review instrument. A finding as to the grantee’s standing overall should be included in every report; otherwise, such generalization should be omitted from all reports.
- Specific TA opportunities should be recommended for programs with “out of compliance” findings.
- Site monitoring visits should include examination of a grantee’s level of effort to identify salient issues to those using public mental health services as well as the grantee’s efforts to secure meaningful client feedback on quality of service and outcomes.
- A compilation of findings from monitoring visits, including compliance, best practice, and exemplary practices should be produced annually and distributed among grantees for program improvement. Over time, data should be evaluated for trends.
- All GPOs with PAIMI oversight responsibility should receive copies of draft and final PAIMI site monitoring reports.
- Site monitoring reports should be publicly available. At minimum, Federal partners engaged in oversight of disability advocacy programs should receive copies. PAIMI grantees should have access to one another’s reports. At minimum, report executive summaries could be posted to websites: SAMHSA, P&A agencies, and the TA contractor.

GPRA

- CMHS should establish GPRA indicators suited to evaluate performance of the PAIMI Program over time that address outcomes.

TA

- While appropriate to share TA resources for issues common across the disability advocacy programs, there continues to be a need for TA specific to the PAIMI population. A proportion of TA funding should continue to be separately allocated to cover these issues.
- CMHS GPOs should receive feedback about the outcomes of TA referrals passed on to NDRN, particularly for underperforming grantees.

CHAPTER 4

PAIMI PROGRAM OPERATIONS FINDINGS

A. PAIMI Program Structure at the State Level

As described in Chapter 1, P&A systems are classified as either state-operated or private nonprofit agencies.²⁶ Most states and territories have designated private nonprofit agencies to provide PAIMI services through P&A systems. Of the 57 PAIMI Programs, 10 are currently state-operated.²⁷ There are pros and cons of both models. Critics of the state-operated model point to the relative power granted to the governor as potentially threatening: for example, a governor might try to impede a PAIMI intervention. Proponents of the state-operated model note that PAIMI staff in these situations have much more access to government officials and can use their access for more informal advocacy in ways that are not readily available to nonprofit programs operating outside of government.

Congress did foresee some of the challenges that a state-operated program model could pose and provided for certain protections. Grantees must provide assurances to CMHS in the annual application that PAIMI Programs will operate without undue influence of the governor. The legislation also requires that state-operated P&A systems must be exempt from state hiring freezes, reductions in force, prohibitions on staff travel, or other policies imposed by the state, to the extent that such policies would impact program staff or activities funded with Federal dollars and prevent the P&A system from carrying out its mandates under the Act (Federal Code 42, Sec. 51.31). At inception, more PAIMI Programs were state-operated than the current 10 grantees (19 percent). To date, every PAIMI Program that has changed its designation has moved from state-operated to a nonprofit organization.

B. Conducting Business as an Effective Legal Advocacy Organization

Whether they are state-operated or nonprofit, PAIMIs, like all effective organizations, must:

- Establish a governance structure
- Determine what work to do
- Gather resources and plan for use of resources to conduct the work
- Carry out the work, problem-solve, and interact with the environment
- Evaluate how well the organization did what it intended to do

²⁶ There is also at least one hybrid model where the state agency operating the P&A contracts with nonprofit organizations for legal and other services.

²⁷ When this evaluation was initiated, there were 11 state-operated PAIMIs. In 2007, North Carolina's P&A system, with ADD approval, was redesignated by the governor from state-operated to a private, nonprofit entity.

In this chapter, evidence gathered pertinent to PAIMI operations as effective organizations is presented. Throughout the discussion, key evaluation questions are selected for emphasis.

Governance: P&A Governing Boards and PACs

Each P&A system is required to establish a governing authority to provide effective, independent, and ethical leadership. The type of governing authority of the P&A system depends on the type of organization. State-operated PAIMIs use governing authorities within a public agency, while PAIMIs embedded in nonprofit organizations utilize the P&A board of directors. Both types of governing bodies are broadly responsible for the P&A system's planning, operations, program design, and implementation, including selection of board members and evaluation of the P&A executive director.

P&A Governing Boards

Just as the size of a PAIMI grant varies by state population, so too the size of governing boards varies. Across sampled P&As, the number of board members ranged from 7 to 17 with an average of 12 members. Membership tends to fall into one of three sizes, composed of either 7, 11, or 15 members. P&A boards are required by Federal law²⁸ to include significant representation of individuals that are, or have been, eligible for or used mental health services, and the family members, guardians, advocates, or representatives of such individuals. Executive directors interviewed report their board members are knowledgeable about mental health issues (42 percent). Federal law also requires that the PAC chair be a member of the board, although any additional council members may serve. While chairs do serve on the P&A boards, they also tend to be the sole council representative (61 percent). Almost all chairs have a vote on the board (85 percent), although the evaluation team is concerned that 10 percent did not know if they had a vote, and 5 percent reported they did not have a vote. Governing board members typically receive an orientation about PAIMI responsibilities (82 percent). Commonly covered topics are PAIMI operations, understanding abuse and neglect and civil rights violations, legal responsibilities to PAIMI clients, and current advocacy casework and litigation.

Fewer than half of the boards in the sample prepared strategic plans for P&A operations within the past 5 years. Of those that did draft a plan (42 percent), PAIMI issues were represented through determination of priorities and facilitating consumer-run organizational development and growth. A large majority of PAC chairs (84 percent) reported that PAC input is respected by boards. Fifty-six percent of PAC chairs portrayed interactions with their board as "very collaborative and respectful;" none described them as "not collaborative." When differences arise, they are resolved through discussion and reaching consensus. The most frequent joint activity for the two bodies are special invitations to attend key meetings (70 percent), although 65 percent have an open invitation to attend other meetings as well. Other regular joint activities include public education (30 percent) and fundraising (25 percent).

²⁸<http://mentalhealth.samhsa.gov/publications/allpubs/CMH97-5016/default.asp#51.22>, SAMHSA online publication of PAIMI regulations, Sec. 51.22 governing authority.

PACs

PAIMI regulations endow councils with several duties:²⁹

- Provide independent advice and recommendations
- Work jointly with the PAIMI governing authority to develop policies and procedures
- Submit a section of the annual report

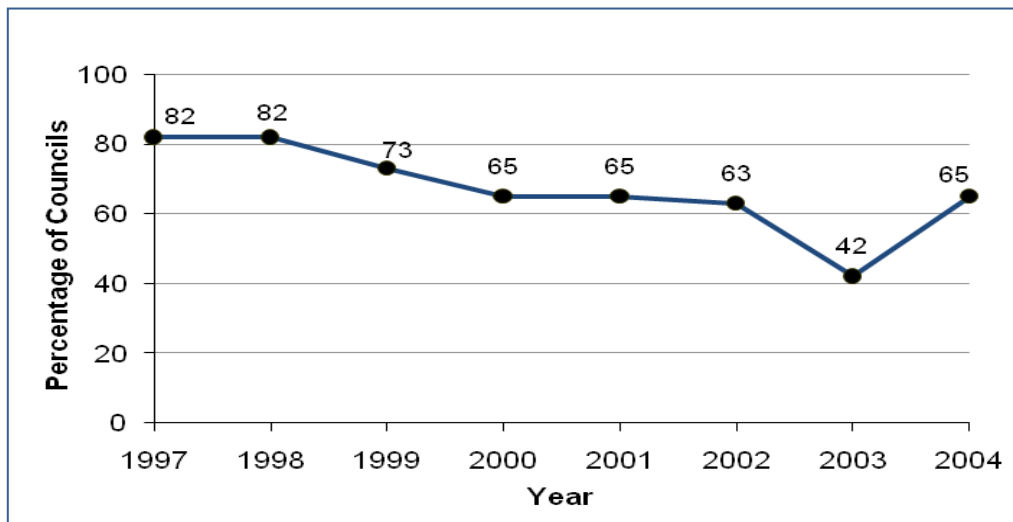
To effectively prioritize potential activities, PAIMIs are required to seek significant and meaningful input from PAIMI-eligible individuals, clients, and family members. Council representatives serve as a vital mechanism for this input. However, the role of the PAC is advisory, and thus the scope of its decisionmaking limited. Yet even within their designated role, the full extent of council potential contribution is not utilized by grantees. For example, only 35 percent of chairs report that the PAC reviews draft policies and procedures related to PAIMI work.

In the early stages of the PAIMI Program, grantees were typically successful in recruiting enough recipient and family members to serve on the PACs. They met the federally required standard of 60 percent representation by individuals who had either received mental health services or were family members of those who received mental health services. A decline began in the late 1990s and reached a low in 2003. After 2003, compliance with this standard began to improve. In 2004, 37 of the 57 grantees met the requirement of 60 percent recipient or family membership, although individual grantees varied widely in the extent to which they met this requirement (14 percent to 89 percent).

P&A executive directors report there is considerable confusion as to how to count mental health service recipients that serve as council members. Recent instruction from CMHS was to count a representative only once. Thus, if an individual is an attorney and also uses mental health services, the PAIMI could count the individual as one or the other representative, but not both. While this may have been imposed to ensure sufficient representation by service recipients and family members, in the view of evaluation team members and the EAW, such categorization promotes stigmatization and is not recovery-oriented. Figure 1 below tracks compliance of all councils on the requirement for 60 percent consumer and family representation from PAIMI initiation through 2004.

²⁹ <http://mentalhealth.samhsa.gov/publications/allpubs/CMH97-5016/default.asp#51.23>, SAMHSA online publication of PAIMI regulations, Sec. 51.23 Advisory Councils.

Figure 1. Percentage of PACs Meeting the Required 60 Percent Membership Standard, FY 1997–2004



Providing culturally competent services has increasingly been recognized as an important quality consideration in human services. PAIMIs are required to seek PAC members that reflect the representation of racial and ethnic minorities among the populations they serve. The range in PAC member diversity per grantee is vast—from less than 10 percent minority membership to 100 percent. A large majority of PAC chairs (80 percent) report that their council membership reflects the state population with respect to race and income as well as members who are recipients of mental health services, family members, and professionals. Yet four PAC chairs (20 percent) reported a need for additional representation, specifically additional minority or underserved community representatives (three PACs), and members generally knowledgeable about the mental health system (one PAC).

More than half (55 percent) of PAC chairs surveyed reported unfilled positions. Member turnover for half of these PACs averages less than one position per year, but for the other councils, turnover is higher, with two or three members moving away per year. Most vacancies result from retirement or rotation off the council because of term limits. It appears more challenging to recruit representatives who meet the required characteristics now than in the early years of the program. When the methods used to recruit council members now serving as chairs were examined, selection of current P&A staff was the most frequent successful recruitment strategy (40 percent), followed closely by knowing someone else on the council (35 percent).

All PAC members have term limits, ranging from 2 to 4 years, generally with a two-term limit. A large majority (81 percent) have staggered terms. Many PACs are not in compliance with the requirement for a single 4-year term, and several chairs reported dissatisfaction with this requirement. Their general preference would be to allow two consecutive 3-year terms because of the time it takes to become an effective member. According to PAC chairs, becoming an

engaged and contributing member entails participation in several meetings. Just over half (52 percent) think it takes between 1 and 2 years to become a fully contributing member. The evaluation team concurs as it takes a full year to experience the management cycle of outreach to assess needs, learn the priority-setting process, understand the ongoing review of PAIMI activities, and participate in the annual review of goal achievement.

More than one-third of chairs have been members of the PAC for 1–2 years, and another third have 2–3 years of experience. Sixty percent have served as chair for less than 1 year, which indicates most chairs have relatively little experience on the PAC before assuming the leadership role. However, nearly three-quarters of chairs reported experience on another advisory or governing board before joining the PAC. When combined with term limits, all these factors suggest possible problems in ensuring that a PAC is well positioned to advise the PAIMI and the governing board.

Are P&As Sufficiently Supporting PAC Development and Effectiveness?

Many new PAC members receive considerable orientation, usually from P&A staff. Orientations stress the history of the PAIMI Program and priority-setting. There is significant agreement among respondents (71 percent) on what is covered in the orientation, although there does not appear to be a standard national training.³⁰ However, some PAC chairs do not receive enough orientation and training to be as effective as possible. One particular concern of the evaluation team was that the orientations reportedly gave the lowest level of attention to P&A legal and ethical responsibilities to clients. Moreover, just 60 percent of P&As advise their PACs about current casework and litigation and Federal reporting requirements; and fewer (53 percent) present information on understanding abuse, neglect, and civil rights violations. Information about grievances or intake and referrals is even less frequently shared (40 percent).

The majority of PAC chairs (84 percent) report that policies and procedures are in place to guide members in their responsibilities, but few have received guidance on matters such as keeping information confidential, remaining free of conflicts of interest, and the role of the governing board. Twenty-five percent of PAC chairs advised that members do not receive a written copy of P&A policies and procedures.

Council members rely on staff support to a significant degree. Along with orientation, PAC members need ongoing training and development support. The majority of P&A executive directors (72 percent) report that PACs receive training in areas such as leadership skills and self-advocacy, but only 41 percent of PAC chairs report training in these areas. PACs generally set agendas (70 percent) and produce the minutes (42 percent) with P&A staff input. The number of P&A staff that attend PAC meetings ranged from one to seven, and most PAC chairs (95 percent) consider the presence of staff at meetings to be helpful. Almost all PAIMIs have designated staff to provide ongoing support to the PAC, and these staff provide significant information about PAIMI and P&A program operations. Nearly all PAC chairs (90 percent) feel well supported by the P&A, and many remarked that staff are available to meet and discuss

³⁰ PAC training materials reviewed at Ohio Protection and Advocacy appear to thoroughly cover PAIMI and P&A.

issues of concern at any time. Many PAC chairs have the personal cell phone numbers of executive directors and report using this line of communication without hesitation.

Practical supports for participation as a PAC member are in place. Nearly all grantees (90 percent) provide reimbursement to PAC members for transportation and meals, and 79 percent pay for hotel stays to attend PAC meetings. Many PAIMI chairs reported that a PAC member attended a national P&A conference within the past 2 years (83 percent), and those attending reported they found the experience helpful to them in their role on the PAC.

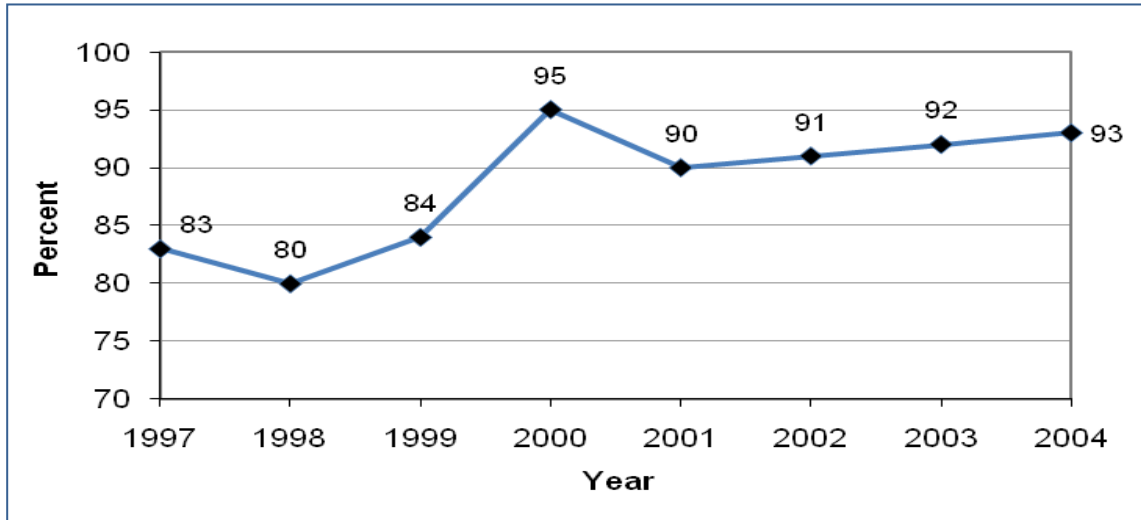
Overall, this suggests that P&A staff recruit, orient, and assist PAC members in their work as advisors, but they could engage PAC members more broadly in P&A operations. There was no suggestion, however, that PAC members have difficulty getting any information they may desire. Many PAC chairs stated they have full access to any information they request, but they do not always know what to request. The evaluation team was surprised by the number of PAC chairs who commented that participation in this evaluation led to a deeper understanding of their role and resources available to provide support.

How Useful Is the PAC Report?

PACs are charged with critiquing their PAIMI's performance annually by completing a section of the PPR regarding PAIMI goal achievement. Although conceived as an independent check on PAIMIs, in practice, councils typically do not generate these council reports independently. The general arrangement is for P&A staff to draft the report and the PAC to review the staff's draft and sign off. Seventy-five percent of both PAC chairs and executive directors concur that this describes the process. Only 44 percent of PACs report that they procure any information independently for this report, although 11 percent of PACs draft their report without input from staff.

Council reports consistently find that PAIMIs are very successful in achieving planned goals and objectives. Figure 2 shows the high rate of success reported over the course of the program. In recent years, the ratings are above 90 percent and continue to rise annually.

**Figure 2. Percentage of PAC Priorities/Goals Achieved
Across All PAIMI Programs, FY 1997–2004**



Because of the turnover in PAC members and leaders and the time it takes to become a fully contributing member (with member reliance almost exclusively on the P&A staff to provide data and help draft the report), this particular role seems to lack the vigor envisioned by PAIMI founders. Rather than the PAC guiding the direction of the PAIMI in the preparation of these reports, it appears the P&A guides the PAC. In chapter 6, alternative mechanisms for strengthening the role of this advisory body are suggested.

Setting Goals and Establishing Service Priorities

The establishment of priorities was intended to be a collaborative process emphasizing the direct experience of PAC members with their state’s mental health system. PAIMI priorities are to be developed with the input of the PAC, data collection (e.g., number of individuals with psychiatric disability housed in a state’s jails), and opinions solicited through public outreach activities. Recommendations from the PAC for PAIMI priorities are forwarded to the governing board for final acceptance. Both PAC chairs and P&A directors report that three-quarters of PACs send recommendations to the governing board and almost all recommendations (90 percent or more) are adopted.

As noted earlier, less than half of P&A governing boards (42 percent) in the sample had prepared a written strategic plan to guide the organization within the last 5 years. Of those with strategic plans, the PAIMI is generally included, and the PAC has major input. Regardless of whether the P&A has a written strategic plan, PACs play a significant role in setting priorities and goals. PAC chairs report the following strategies as most frequently used to collect data for developing priorities:

- Review the prior year’s PPR goals and objectives
- Review priorities recommended by P&A staff

- Conduct outreach to PAIMI-eligible individuals and family members to gather their opinions on greatest needs

P&As are expected to offer the public opportunity to comment on the priorities and activities of the P&A every year. Notice of these opportunities is to be rendered in a format accessible to individuals with psychiatric disability, including those residing in facilities. Family members also are to receive notice. As to how aware these stakeholders are of the annual opportunities to comment, it was found that just half of SMHA directors surveyed knew whether mental health service recipients and their advocacy organizations participated in the PAIMI priority planning process. Fewer knew whether families and their advocacy organizations were involved. Similarly, more than two-thirds of legal counsels to SMHA directors were unaware of comment opportunities.

Directors of consumer-run mental health advocacy organizations were much better informed about recipient participation, although this awareness was not universal. More than half knew about public meetings and that consumer advocacy organizations were encouraged to participate. However, most of these respondents did not know about opportunities for families to participate.

Directors of mental health advocacy organizations are better informed, both about the opportunities to provide public comment and about the participation of both consumers and family members in priority-setting. Ninety percent reported that consumers and consumer-run organizations participate in priority-setting, and slightly fewer (from 70 percent to 80 percent) reported knowledge of family participation. Yet data from NAMI respondents demonstrate that less than half knew anything about families' involvement in P&A planning for PAIMI priorities, and even fewer knew about consumer involvement.

Once information is collected, decisions must be made on what to prioritize. Three-quarters of PAC chairs reported they are effective in moving the PAIMI Program in desired directions. More than one-third of NAMI respondents indicated that when PAIMIs identify priorities for systems change, they have correctly targeted the important issues "always," "most of the time," or "often."

Gathering and Utilizing Resources to Address Priorities

When the PAIMI legislation was enacted, P&A agencies typically were organized by program funding stream, creating disability- or population-specific staff expertise. Under this type of organizational structure, there is a discrete PAIMI unit or program, a PADD unit, and a CAP. Over time, the disability field has become more aware that people with disabilities, regardless of the type of disability, face similar problems, such as lack of housing, access to treatment, and support with finding work. This has led to P&A systems organizing along what is referred to as "functional" dimensions, rather than by disability population or by "program funding." Under a functional model of service delivery, staff assist clients based on their presenting issue, such as an allegation of discrimination, and they use intermingled funding streams to pursue client and

agency goals. Federal oversight of this systemic change has been in the form of observer, not director.

This evaluation did not collect sufficient information to assess the extent to which these organizational issues impact program effectiveness. Given consistent concerns about the potential vulnerability of PAIMI priorities, resources, and understanding of mental health issues within a developmental disabilities agency, it is recommended that, if CMHS has concerns in this area, the next national evaluation should examine this issue.

Are PAIMIs Staffed Sufficiently to Address Priorities?

Regardless of whether the PAIMI is organized by disability/funding or functional models, staff must be trained to conduct the work set out in PAIMI priorities. PAIMIs typically are staffed with a mix of attorneys (who provide legal advice and representation) and advocates (who provide legally based problem-solving and other representation services). However, some programs consist solely of attorneys and others solely of advocates. Furthermore, as with most public interest legal organizations (and private law firms), many actions taken on behalf of clients do not require an attorney's level of training, and the use of nonattorneys reduces costs significantly.

Whatever the setting, when nonattorneys assist clients with legal matters, it is vital to ensure that the advocates are competent and that rules prohibiting the unauthorized practice of law are honored. Appropriately, the CMHS PAIMI Site Monitoring Manual requires programs to have written policies that specify the qualifications, duties, and responsibilities of each position.

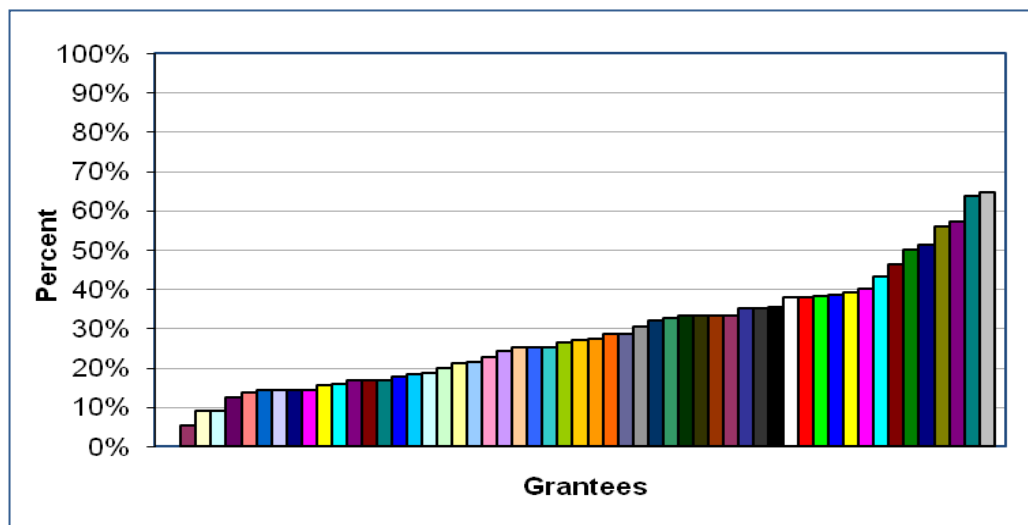
Currently, few P&As retain staff dedicated solely to PAIMI activities. Although several grantees in the sample reported their P&As have three or more dedicated PAIMI staff, 62 percent reported no dedicated PAIMI staff. This bears out the trend toward reorganization of P&A work along issues (housing, education, abuse) and away from discrete staff that serve people with a specific disability. Comparing the sample's full time equivalent (FTE) staff, it was discovered that these PAIMIs typically employ 2.9 attorneys, .6 paralegals, and 4.2 advocates. One in five programs contracts with a private attorney to represent a client on occasion. The vast majority of programs do not use volunteers to provide direct services to clients, although a few engage law school or graduate school students who work under the supervision of staff.

Anecdotally, the general public and advocacy organizations often believe that PAIMI Programs are heavily staffed by attorneys and therefore are primarily focused on suing states. The misperception has existed since the program's inception. In 1992, Michael Perlin wrote an article pointing out the gap between the myth that attorneys were available and skilled to pursue legal cases on behalf of individuals with psychiatric disability and the reality.³¹ Recent PAIMI staffing data affirms that most clients (62 percent) are served by nonattorney advocates;

³¹Perlin, M. (1992). Fatal assumption: A critical evaluation of the role of counsel in mental disability cases. *Law and Human Behavior*, 39.

16 percent are represented by attorneys. Some clients are represented by both an attorney and an advocate (19 percent). In 2004, the percentage of PAIMI staff who were attorneys ranged from less than 10 percent to more than 60 across the 57 programs. Figure 3 shows that PAIMI work is conducted predominately by nonattorney staff.

Figure 3. Percentage of PAIMI Staff Who Were Attorneys in FY 2004



P&A executive directors play an important role in a PAIMI’s effectiveness by providing leadership and direction. This evaluation asked directors for information on their backgrounds and disability expertise. While not a representative sample, this group constitutes 35 percent of executive directors, and the depth of their experience is a sign that expertise is being built and retained in the PAIMI Program. These directors came to their leadership position very experienced in protection and advocacy work. Most were employed either at their current P&A agency or another P&A prior to assuming the director position (74 percent). A large majority (80 percent) have 10 or more years’ experience in PAIMI or other P&A programs. Forty percent are attorneys and a substantial majority (72 percent) have professional experience representing people with serious psychiatric disabilities. Further, most have the experience of being a family member to an individual with psychiatric disability (67 percent). Few directors, however, are identified as having any type of disability (83 percent report no disability).

An important aspect of staffing is being able to recruit qualified staff to fill new and vacant positions. Many industries report difficulty in finding qualified candidates, but the PAIMI Program appears not to be so challenged. Grantees generally fill positions within 2 months (60 percent), although many directors noted 3 to 6 months as the norm.

Are PAIMIs Utilizing Skills of Recipients of Mental Health Services to Conduct PAIMI Business?

PAIMI Programs were designed to involve consumers in significant ways. Most P&As in the sample (84 percent) hire service recipients but differ in the way individuals' skills are utilized. For example, the Utah P&A has a strong commitment to hiring as staff those who self-identify as recipients or former recipients of mental health services. Other P&As use recipients, former recipients, and family members in peer support programs or to conduct trainings and outreach. The California P&A operates a peer advocacy program funded with PAIMI dollars. Advocates conduct weekly training on facility monitoring and outreach. This P&A also holds a contract with the State Department of Mental Health and provides patient advocates at each of the State's psychiatric hospitals. Other grantees report using service recipient expertise to conduct training and outreach activities, and to monitor the activities of coalitions.

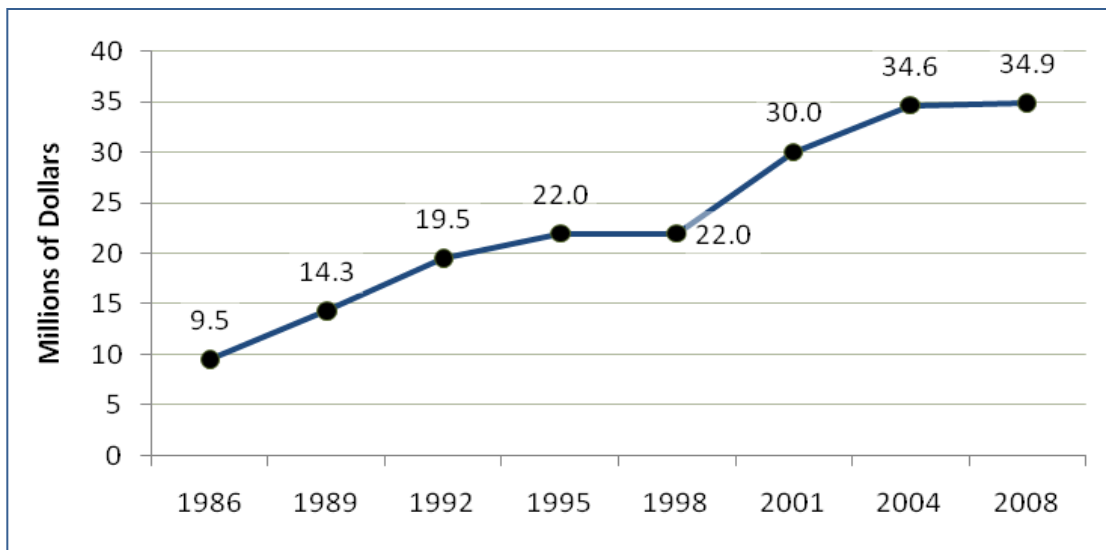
Are P&As Making Efforts to Secure Funding Beyond the PAIMI Allocation?

PAIMI Programs are not restricted to operating solely within their Federal appropriations, but they are encouraged to seek funding from additional sources. It is clear that Congress intended to maximize the resources going to service delivery over administrative activities; it encouraged the use of subcontracts with existing advocacy organizations and placed limits on expenditures for administration and TA. During the evaluation planning process, several interviewees reported that the success of governing boards and PACs in securing additional monies for the P&A is one criterion against which to evaluate PAIMI Programs. This evaluation asked about grantees' efforts to obtain additional funding sources.

Although the majority of P&A executive directors interviewed (80 percent) reported their agencies have no written plan for obtaining additional sources of funding, many are actively searching and applying for supplemental funding. Five grantees reported receiving grants and supplementary fiscal support of \$200,000 or more from one or more of the following sources: local and state Interest on Lawyers Trust Account (IOLTA) programs, registration fees for conferences and trainings, the Christopher Reeve Foundation, PAC funds, SMHA grants, and individual donors and businesses. Nearly half of PAC chairs surveyed (47 percent) reported active participation in fundraising activities.

There is considerable variation in the size of PAIMI Programs, both with regard to grant dollars and numbers of staff. PAIMI grants are based on a formula that takes into consideration the state population weighted by its relative per capita income, with a minimum allotment to those states with smaller populations. Regardless of the amount of the grant, each PAIMI Program must adequately cover its geographic domain, minority and underserved populations, and community- and facility-based eligible clients. Each grant award is contingent upon congressional reauthorization of the PAIMI Act and the availability of appropriated funds. Never adequate for its intended goals, PAIMI funding has matched neither its expanded mandate nor normal increases in program expenses. Therefore, it has not been possible for the program to realize its full capacity. Figure 4 depicts PAIMI appropriations over time.

Figure 4. National PAIMI Appropriations (in Millions), FY 1986–2008



In most PAIMIs that participated in the evaluation, a lack of outside funding negatively impacts the breadth and depth of advocacy effort. According to the P&A executive directors, understaffing and inadequate resources have depleted PAIMI work in vital areas such as jail advocacy, outreach, hospital monitoring, and housing. Other stakeholders surveyed concur that too few Federal resources are allocated to fulfill programmatic responsibilities at an optimal level.³² Thus, these programs need to actively seek outside funding to pursue their priorities. Therefore, PAIMIs should be structuring relationships with other advocates and advocacy organizations to extend their advocacy reach. The level of effort in which grantees reach out to partner and seek external funding is worth examining in a formal manner.

Are PAIMIs Utilizing Technology?

PAIMI grantees appear to be doing an adequate job of adopting and facilitating technologies to support program operations. Nearly all executive directors interviewed indicated their programs use a wide variety of technologies, including websites, email contact with clients, databases for client information, information and referral tracking, tracking PAIMI funds, and electronic information such as legal analysis services provided by Lexis/Nexus. Just over half of the directors (52 percent) commented that no additional technological support is needed for program operations. Those who indicated additional technology was needed specifically mentioned greater access to online databases, updated document/case management software, and more training for staff on new technologies.

³² Almost 40 percent of NAMI respondents, more than 50 percent of directors of consumer-run advocacy organizations, and more than 83 percent of mental health advocacy organization directors replied that too few Federal resources are allocated to PAIMI to address program mandates.

Collaborating With Other Organizations and Relating to Local Environments

Are Potential Clients Aware of PAIMI Services?

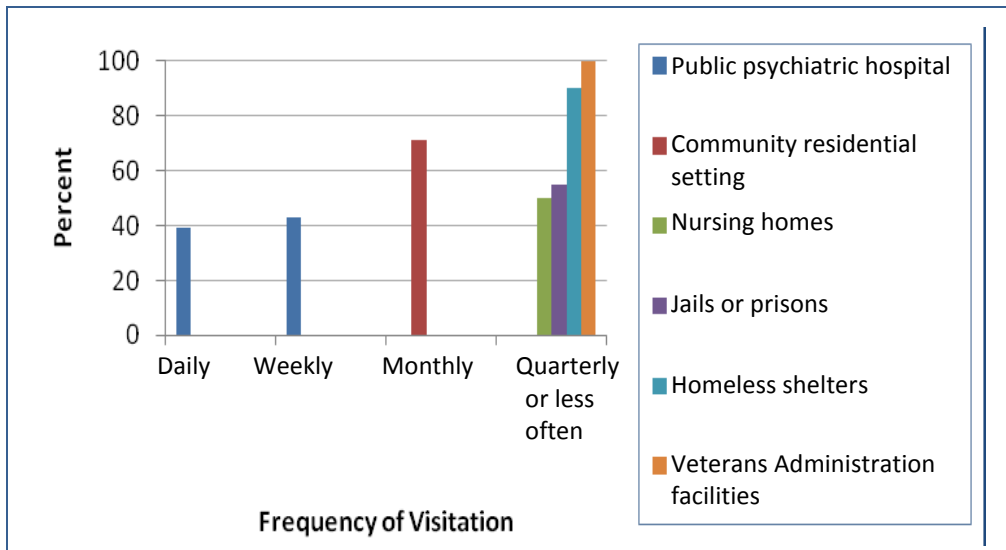
People with psychiatric disabilities become aware of PAIMI through many avenues, from hearing PAIMI mentioned at a meeting to looking for legal assistance in the Yellow Pages. The primary ways people learn about their state PAIMI Program are from:

- Flyers or pamphlets
- PAIMI staff visiting facilities
- Referrals from service providers
- Recommendations from family members or friends; almost one in five clients has previously received PAIMI services

P&A executive directors reported that significant efforts are directed toward promoting PAIMI services and making them accessible to individuals with psychiatric disabilities. These outreach efforts include opening satellite offices in remote areas, frequent use of posters and flyers, hiring bilingual staff and interpreters, and developing relationships with minority community organizations. However, despite these efforts, stakeholders hold conflicting opinions about how well-known PAIMIs are. For example, 35 percent of state NAMI directors surveyed said that PAIMI efforts to make themselves known to individuals with psychiatric disabilities were “mostly ineffective.” Six of 16 NAMI directors stated they knew little about their state P&A or PAIMI Program. At the same time, 65 percent of directors of other statewide mental health advocacy organizations reported that PAIMIs’ efforts to make themselves known to individuals with psychiatric disability were “always effective” or “mostly effective.” The responses of directors of consumer-run advocacy organizations to the same question were mixed: 28 percent reported these efforts were “always effective,” and 28 percent said they were “mostly ineffective.”

One aspect of this issue was reviewed by asking the sample of P&A executive directors how often their staff visit different types of facility settings. It was reported that PAIMI staff members visit public psychiatric hospitals most frequently and other settings far less regularly, if at all. Figure 5 depicts the frequency of PAIMI staff visits to public mental health service settings.

Figure 5. Frequency of PAIMI Staff Visits to Service Settings, FY 2006–2008



Obviously, the capacity to visit and conduct outreach to different types of settings reflects grantee decisions on prioritization of limited resources. As public psychiatric institutions close, more individuals with psychiatric disability are found in nursing homes and jails. In the evaluation team’s opinion, such settings constitute the new institutions. Given that the Federal regulations still emphasize institution-based over community advocacy, more PAIMI attention should be directed to work in these facilities. When asked, many P&A executive directors interviewed commented to evaluation team members that their organization would review its facility visitation approach and use of other outreach and communication strategies (e.g., posters, leaflets), particularly with regard to remote facilities and isolated communities.

Are PAIMIs Collaborating With Consumer-Run and Other Advocacy Organizations?

On occasion, PAIMIs serve as co-counsel with other groups on major litigation. More frequently, however, PAIMIs work extensively with many types of advocacy groups, both in ongoing relationships or on an issue-specific basis. These groups include consumer-run and family-led organizations; service providers; NAMI; mental health associations; Federation of Families for Children’s Mental Health chapters; and the International Association of Psychosocial Rehabilitation Services, as well as Legal Services Corporation-funded programs and public defender agencies. PAIMIs reported joining other advocates in activities such as:

- Ad hoc partnerships focused on specific issues (e.g., opposing outpatient commitment, “Not In My Backyard” controversies)
- Campaigns addressing a single objective (e.g., reducing restraint and seclusion, enacting health insurance parity legislation)
- Established coalitions that hold regular meetings and address broad goals (e.g., increasing state funding for mental health and other services, seeking reorganization of service delivery systems)

PAIMIs are viewed as aligned with the positions of consumer-run advocacy organizations. A significant majority (85 percent) of the directors of statewide consumer-run advocacy organizations stated that their group's positions and PAIMI's positions on advocating for changes in mental health law and policy were "always" or "often" in alignment.

More mixed is the perception of PAIMI staff as leaders in mental health coalitions. About one-third of NAMI respondents reported that P&A programs provide leadership in coalitions "always or most of the time" or "often," but nearly one-quarter reported they "rarely or never" provide such leadership. Mental health advocacy organizations reported that P&As provided leadership "always," "most of the time," or "often" a total of 90 percent of the time, and that they chose compelling issues 90 percent of the time. Directors of consumer-run advocacy organizations reported that P&As "always" (29 percent) or "sometimes" (57 percent) provide leadership in coalitions. More than three-quarters reported that the P&A chooses the most compelling issues.

How Do PAIMIs Engage With the SMHAs?

P&As recognize that they operate within a political environment, and PAIMI grantees and SMHAs almost invariably engage in public conflicts—sometimes in lengthy, acrimonious litigation. Nonetheless, most executive directors reported they try to maintain both informal and formal lines of communication with their SMHA's leadership. These dialogues generally focus on policy change and dispute resolution. Most SMHA directors surveyed (71 percent) report they are "somewhat informed" about the work of the P&A in their state. Fifteen percent of the P&A executive directors reported personal contact with the SMHA agency head or other top level manager on a weekly basis, and 47 percent reported such contact two to three times per month. Almost two thirds (63 percent) of the directors characterized these contacts as mostly "cooperative," while 50 percent of the SMHA directors characterized them as "mostly cooperative." However, about 10 percent rarely or never met with these state leaders, and about the same percentage characterized their contacts as mostly adversarial. While a few executive directors indicated they have experienced some pressure from the state to reduce advocacy efforts, on the whole, these appear to be rare occurrences.

As to formal mechanisms, 53 percent of executive directors stated their P&A has a representative on their State Mental Health Planning Council. Those who did not have representation gave varied reasons for their absence; for example:

- "We haven't been excluded; it's more a combination of happenstance and our being so busy."
- "We don't think it's where the action is—we're involved in other state groups that are more important."
- "The state is afraid of revealing information that we may 'use against' them, so they exclude us."

When the SMHA has set up advisory committees on changes to the service system, 55 percent of the P&A executive directors stated their P&A was "always" or "often" invited to participate,

compared to the majority of SMHA directors (79 percent) who perceive P&As as “always” or “often” invited to SMHA advisory committees on changes to the service system. A few P&A executive directors reported they are “never” invited to such dialogues.

Most SMHA directors reported being involved in the annual PAIMI planning and priority-setting processes (67 percent) and contracting with the P&A to provide particular advocacy services to clients (77 percent). Many, but not all, SMHA directors confirmed that the mental health authority is involved in filing reports of abuse and neglect for individuals (71 percent) and aggregated reports (36 percent) to the P&A. More than half of SMHA directors polled reported the interests of the P&A and the SMHA regarding mental health statutes were aligned “always” or “most of the time” (57 percent). With respect to alignment on state mental health appropriations, SMHA directors and P&A executive directors consider their organizations aligned only 40 percent of the time.

SMHA legal counsel and SMHA directors affirmed that P&As are engaged in state-level advocacy by serving on various types of workgroups (e.g., committees, taskforces), pursuing legislative change, voting reform, and seclusion and restraint standards. When PAIMIs initiated efforts to address systemic problems that could lead to litigation, the P&A executive directors reported they attempted to resolve the matter through informal negotiations with the SMHA 100 percent of the time. This perception is shared by SMHA directors, who noted that informal negotiation efforts occurred 93 percent of the time. Such practice is in keeping with PAIMI requirements.

It appears that despite the inherent tension between the PAIMI and the SMHA, there is substantial communication on important issues concerning consumers’ rights and interests. Collaborations between PAIMI and the SMHAs have resulted in such changes as:

- A new task force to improve acute care
- System reconfiguration
- Increased community services
- Restructure of how abuse/neglect grievances are handled
- Efforts to reduce the use of restraint and seclusion

Specific research on this communication might identify practices that bring about positive change most efficiently.

Providing Legal Advocacy Services

Do PAIMIs Target the Primary Intended Types of Cases—Abuse, Neglect, Civil Rights?

In 2004, nearly all sampled grantees targeted neglect issues pertaining to inappropriate commitment, failure to discharge, failure to place individuals in the least restrictive environment, and failure to provide a safe environment and humane conditions (95 percent). The most common goals related to abuse issues were restraint and seclusion (85 percent) followed by inappropriate and/or involuntary treatment (75 percent). Issues related to patient-on-patient violence (20 percent) were the least targeted for advocacy within the abuse and neglect domain, which may be explained at least in part by the lesser frequency of these complaints compared to other types of neglect complaints.

While two grantees (10 percent) had goals across each area of civil rights violations, the majority (30 percent) planned to address six areas under civil rights violations. Among the areas of civil rights violations, the most prevalent issue targeted was public benefits (80 percent). Least targeted was access to legal counsel. This may indicate that PAIMIs need to address this issue only periodically as when states challenge the PAIMI authority to represent clients or to access settings where putative clients are located.

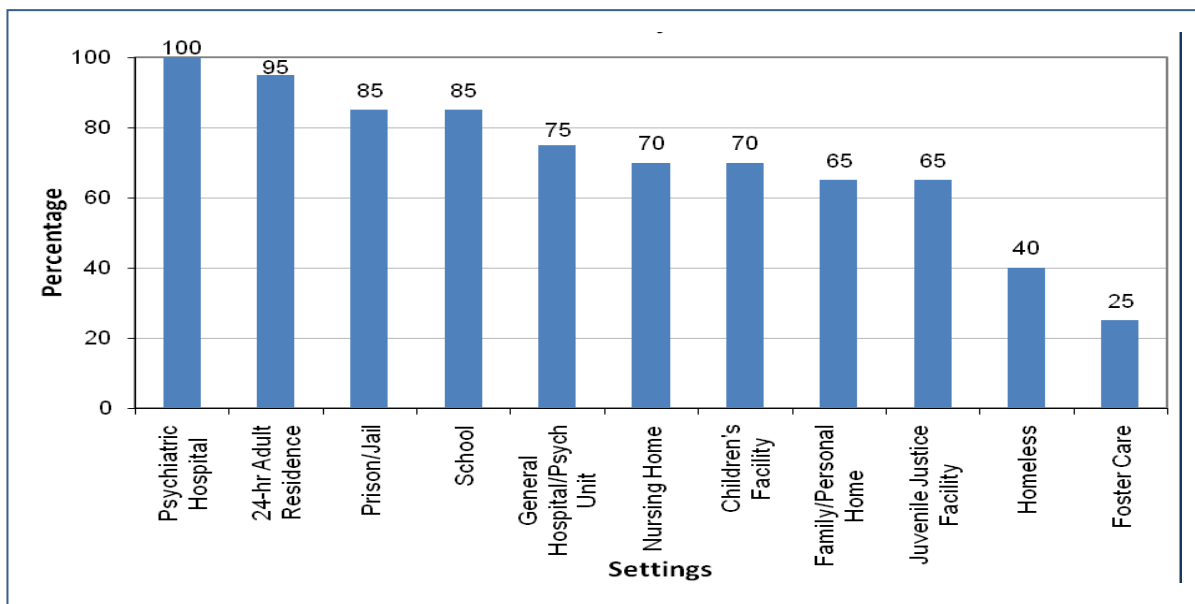
Do PAIMI's Conduct Advocacy Across Residential Settings—Institutions and Community?

Settings Targeted in PAIMI Goals. Federal legislation requires PAIMIs to attend to clients in both institutional and community-based settings. There is no expectation that each grantee covers every mental health service setting. This evaluation describes the extent to which PAIMIs strategically plan to provide client representation in both institution and community-based service settings.

When establishing goals and objectives, PAIMIs have an impressive diversity of targeted settings. According to PPR data, grantees universally target psychiatric hospitals. PAIMIs also seek to attend to the advocacy needs for those with serious psychiatric disabilities in prisons and jails (85 percent), psychiatric wards or emergency rooms in general hospitals (75 percent), nursing homes (70 percent), and children in residential facilities (70 percent).

While representing clients in psychiatric institutions is the most prevalent setting for case-finding, the second most frequently targeted setting is 24-hour, community-based residences serving adults (95 percent). A variety of other community-based settings are also targeted: schools (85 percent), followed by family homes (65 percent), and foster care (25 percent). Forty percent of PAIMIs also reported goals to provide advocacy to persons who are homeless. Figure 6 displays the frequency with which various institutional and community-based settings are targeted for advocacy interventions.

Figure 6. Sample of Grantees: Percentage of Settings Targeted for PAIMI Intervention in FY 2004



Little qualitative data exist on PAIMI activities on behalf of groups or classes of individuals with serious psychiatric disability.³³ However, some information can be extracted from the narrative section of PPRs where grantees note examples of advocacy activities directed at groups. The evaluation team examined a sample of PPRs from 2004 and found examples of systemic advocacy strikingly similar to conditions that led to the passage of the program 22 years ago. Examples of systemic advocacy based in facilities included:

- Protecting children from abusive restraint practices in juvenile detention facilities
- Protecting those institutionalized in psychiatric facilities from patient-on-patient abuse
- Ensuring due process when involuntary medication treatment is recommended
- Providing for individuals to be treated with dignity (such as not being subjected to illegal leg shackling in irons and chains when transported to civil commitment hearings)
- Protection from abusive invasion of privacy (such as illegal room searches)

What Other Advocacy Issues Are Found in PAIMI Goals?

PAIMIs also target issues that promote individuals' capacity to self-advocate, such as learning about individual rights and self-advocacy resources. Among sampled grantees, all had goals to promote knowledge of individual rights, consumer self-advocacy, and access to appropriate education and transition from child to adult mental health services. Less prevalent, though still representing significant resource allocations, were securing access to facilities (45 percent) and reducing stigma (30 percent). See Attachment G for examples of the scope of advocacy

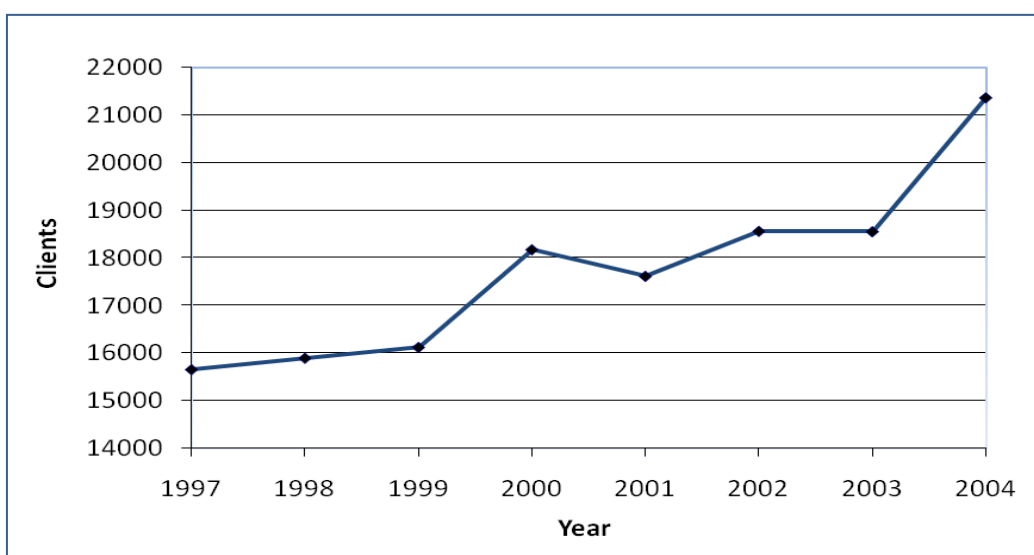
³³ Data regarding the number of cases successfully concluded affecting groups and the number of individuals impacted by group advocacy, along with examples, can also be found in the annual PAIMI Program reports prepared by the National Disability Rights Network, www.ndrn.org.

activities undertaken each year by grantees. While continuing to advocate for the protection of established rights, PAIMIs also pursue initiatives into new advocacy areas, such as the provision of culturally competent services.

Who Has Used PAIMI Representation?

Data drawn from the PPRs from 1997 to 2004 indicate that the number of individuals served by PAIMI Programs grew substantially over that time. This suggests either increased efficiency or reduction in the level of service intensity provided to each client to cover more clients. Figure 7 shows a 136 percent growth in numbers of individuals assisted annually from the program’s initiation through FY 2004.

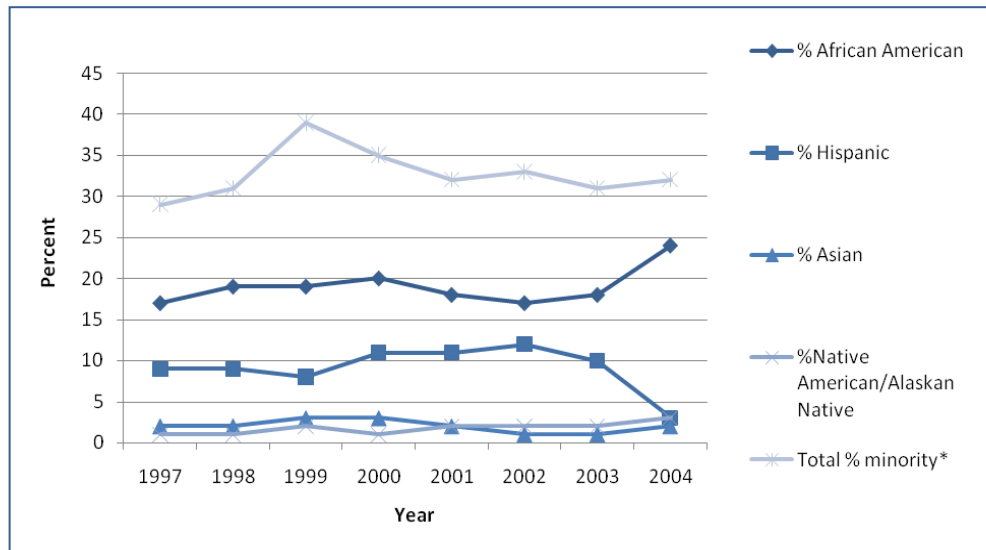
Figure 7. Clients Served by PAIMI Program Nationally, FY 1997–2004 (Using GPRA Indicators)



With regard to individual representation, it appears two of every three clients receiving individual representation are White, and very few people of Asian and Native American backgrounds are provided PAIMI assistance. While the Hispanic segment of the U.S. population has substantially grown during the past 2 decades, representation of Hispanic clients has actually declined. This suggests grantees may have only modest visibility in some minority communities and should continuously review the efficacy of their efforts in the areas of outreach and cultural competence. Figure 8 below illustrates the ethnicity and race of PAIMI clients over time, from 1997 through 2004.³⁴

³⁴ The available data on PAIMI client characteristics are generally limited to those served as individuals and do not include those assisted through systemic reform strategies. Therefore, the race and/or ethnicity of plaintiffs in PAIMI class action litigation is (are) generally not identified or reported.

Figure 8. PAIMI Clients Served Nationally, by Ethnicity/Race, FY 1997–2004



According to the PPR data, men consistently outnumber women as PAIMI clients by a 10 to 20 percent margin (see Figure 9 below). Whether this has an epidemiological basis (e.g., psychiatric disabilities are slightly more common in men than women) or is the result of other factors, such as more males being institutionalized than females, is an issue that may warrant study.

Figure 9. Percentage of PAIMI Clients Served Nationally, by Gender, FY 1997–2004

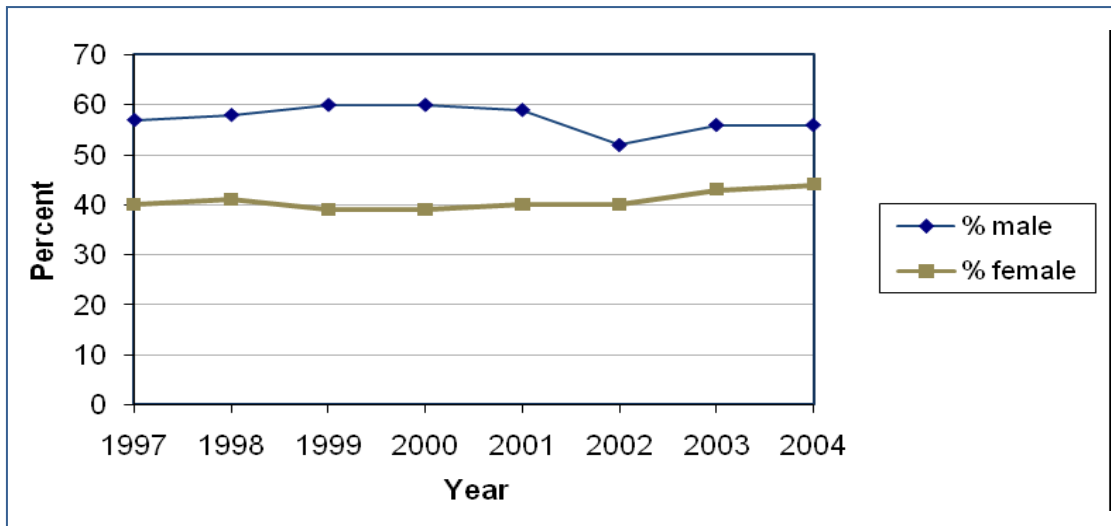
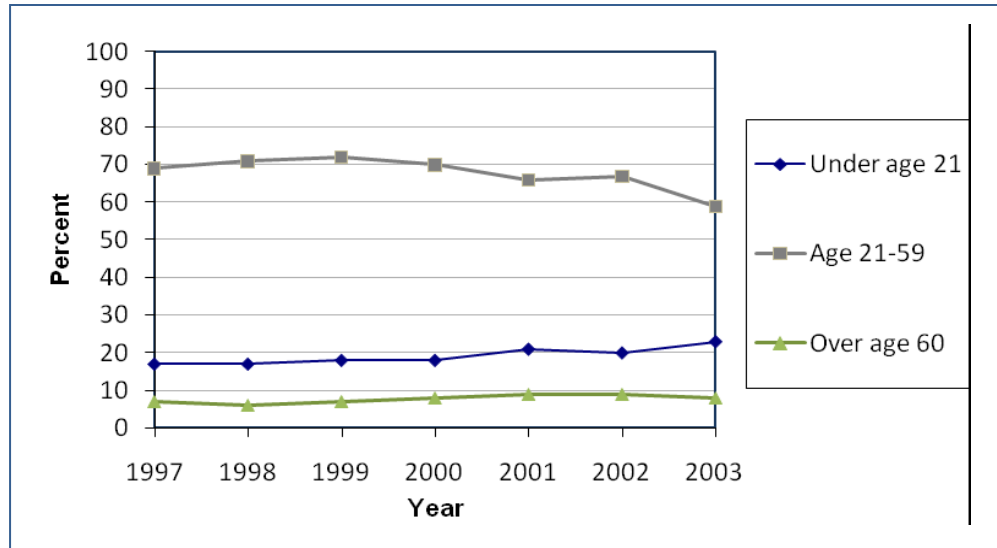


Figure 10 below indicates the age of PAIMI clients over time. Fewer than 10 percent of PAIMI clients are over the age of 60. As the elderly population in the United States continues to grow, new outreach approaches will be necessary, including but not limited to increased visits to nursing homes.

Figure 10. Percentage of PAIMI Clients Served Nationally, by Age, FY 1997–2003

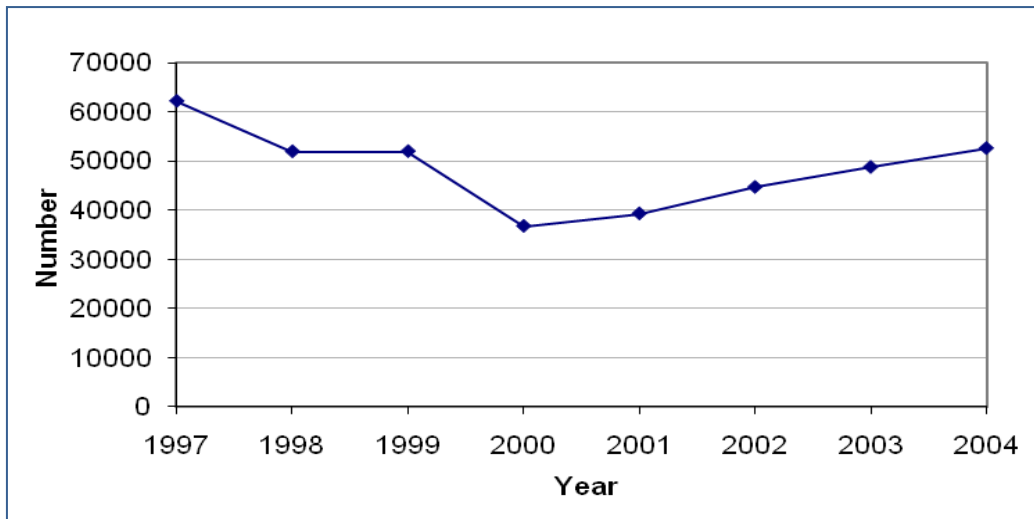


What Happens When an Individual Contacts a PAIMI Program?

Cases are typically screened in for further assessment and/or accepted for representation, screened out, or provided information and referral to another program for assistance with the presenting problem. A potential client’s first contact with a PAIMI program is generally a telephone or face-to-face conversation with a staff member specifically responsible for intake and screening. (This evaluation did not examine the level of effort individuals experience to reach an intake worker. Several EAW members suggest this be examined in any subsequent program evaluation.) Most grantees report they cannot serve all who seek their services. Advising callers of the service priorities is a Federal requirement, 42 CFR 51.31(b), and four of five clients reported they were advised of program priorities.

In FY 2004, 23 percent of grantees reported no one was denied service, although one program reported denying services to more than 10,000 people. Any such outlier warrants an examination. Excluding that program, grantees on average denied services to about 350 individuals that year. When a person is denied services, almost 90 percent of the time it is because the problem is not within the PAIMI case priorities, or because the grantee lacks sufficient staff to accept every case within their priorities. Although most grantees post notices of their Grievance Procedures and are required to provide a written copy to each client (generally at the opening and closing of the case), it is not clear that individuals denied services are informed of the procedures. About half the programs track service denials to identify trends that may warrant attention. Very frequently, PAIMI staff can assist individuals by providing basic information about legal rights and procedures (often available in writing and in multiple languages) and/or by referring the person to a local human service agency that may be able to help with their particular problem. This occurs approximately 40,000 to 60,000 times per year, with some data fluctuations reflecting ambiguities in the CMHS definition of and/or requirements for reporting client “contacts.” See Figure 11 below.

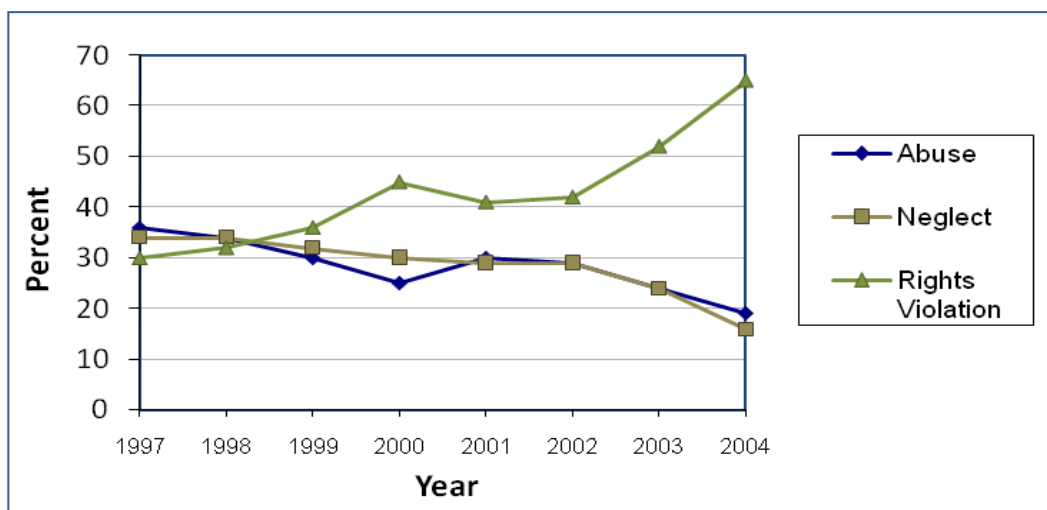
Figure 11. Information and Referral Contacts, by Year, FY 1997–2004



What Types of Representation Are PAIMIs Undertaking?

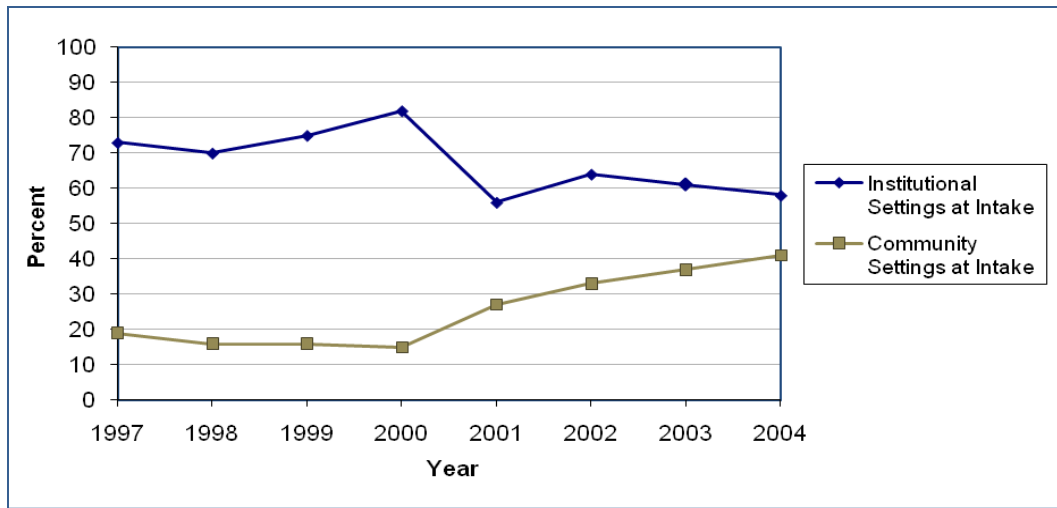
Traditionally, abuse and neglect matters made up the largest number of PAIMI cases as those problems provided the impetus for the PAIMI statute’s enactment. Clients participating in this study reported that abuse and neglect in a facility remain the leading reasons (51 percent) for contacting a PAIMI organization. The 1997 to 2004 PPR data, however, reveal a slow but steady decline in abuse and neglect cases and a significant increase in civil rights matters (e.g., discrimination, public benefits, guardianship, informed consent). See Figure 12 below. The decrease in abuse and neglect cases may indicate a systemic impact of external scrutiny by PAIMIs, although it may also reflect the decreased role of institutions, the setting in which most abuse and neglect complaints arise.

Figure 12. PAIMI Complaint Categories Nationally, by Year, FY 1997–2004



Although most PAIMI clients live in institutional settings, the 1997 to 2004 data show a significant shift towards serving clients in the community. By 2004, the gap had closed from 58 to 41 percent. See Figure 13 below. This trend reflects both the public mental health system’s ongoing transition from hospital to community-based services and the 1990 amendments to the PAIMI statute along the same lines.

Figure 13. Percentage* of PAIMI Clients Served Nationally, by Setting, FY 1997–2004



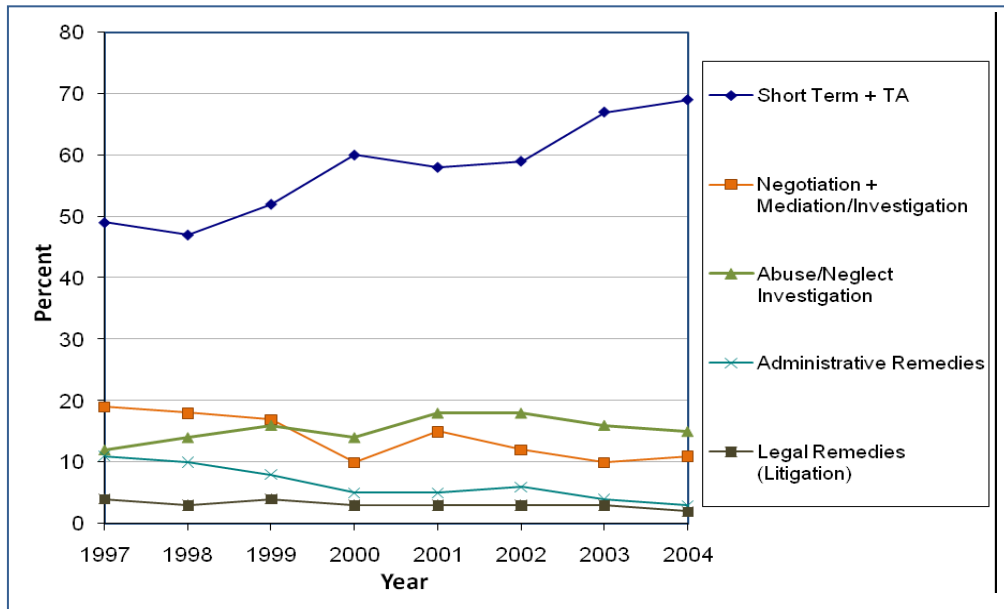
*Percentages do not total 100 because of missing data and calculations made using actual numbers of persons served, not GPRA reported numbers.

What Happens When PAIMI Accepts a Case?

It is clear that PAIMI clients are much more likely to receive informal and expeditious advocacy (e.g., short-term casework, TA) over more formal actions (e.g., negotiation, investigation, mediation, litigation). As Figure 14 below shows, short-term casework and TA have increased over the program’s history from half of all representation to 70 percent. This trend toward short-term casework and TA advocacy as other types of representation stay flat or even decline, even as the number of clients rises, may be worth examining more closely in the next evaluation.

Given PAIMIs’ limited resources, the speed and cost of achieving a client’s objective are obviously important considerations. Depending on the priorities set by the individual program and the specific state circumstances, decisions may be made to initiate more long-term (and expensive) systemic reform efforts (discussed below), a choice that often results in fewer cases of individual representation. This approach reflects the provisions of the PAIMI statute, which generally mandate that PAIMIs exhaust administrative remedies before initiating litigation (42 USC 10821).

Figure 14. Types of Interventions, FY 1997–2004



PAIMI Training on Legal Rights and Self-Advocacy

PAIMIs devote resources to empowering mental health service recipients by providing information about individual rights and legal procedures and teaching self-advocacy skills. More than 90 percent of the clients surveyed said they were given information about their rights, and a large majority (74 percent) considered it the right amount of information.

PAIMI clients reported being provided with self-advocacy skills or resources, and over half considered this assistance to be provided in the right amount at the right time (57 percent). Other clients were split as to whether too little self-advocacy instruction or too much was provided (29 percent each).

Surveyed stakeholders’ assessments of whether clients are encouraged to connect with consumer-run programs and supports was mixed. Fewer than half of the stakeholders surveyed reported consumers were encouraged to connect with such programs and supports “always or most of the time.” Many respondents did not know whether this happened.

Similarly variable and less definitive results were found in the assessment of the amount of training clients receive about their rights from other stakeholder groups. NAMI representatives reported the training was too little (50 percent) or they did not know about it (44 percent). About half of the statewide mental health advocacy organization directors reported training is at about the right level (45 percent), while almost half did not know. Directors of statewide consumer-run advocacy organizations reported the amount of training provided is too little (43 percent).

PAIMIs also provide education about the rights of mental health service recipients and the problems of abuse and neglect to the general public as well as to the staff of mental health service providers. Fifty-five percent of the directors of state mental health advocacy organizations think PAIMIs provide “about the right level” of public education, but only 27 percent consider training sufficient to the staff of mental health service providers.

Are PAIMIs Capable of and Undertaking Individual Litigation?

Stakeholders reported that an important measure of PAIMI performance is the demonstrated capability to follow through with litigation. It is interesting that, while some PAIMIs frequently engage in litigation, others never use this tactic. The reasons for this are not clear and may require further investigation. Do some PAIMIs litigate without exhausting less restrictive interventions? Do some lack the capacity to litigate?

The overwhelming majority of P&A executive directors participating in this evaluation stated they handle litigation cases. Three stated they try to refer appropriate cases to private attorneys or seek their involvement as co-counsel. Three others noted their P&A’s ability to litigate cases is affected by the money available at that point in the year, their ability to shift budgeted funding, or their ability to realign staff roles. One director said that owing to resource limitations, “We handle only a few individual cases, generally those which involve the most egregious circumstances.” Another director stated the PAIMI handled individual cases in the past but no longer does: “Due to lack of funding, we have shifted from doing some individual cases to doing all systemic cases.”

It is important to note that a PAIMI’s effectiveness in coalition-building to advance systems change can be as important as its ability to litigate. However, capacity in both areas seems important to maintain credibility among stakeholders, pursue effective systemic change, and provide substantive individual representation.

Are PAIMIs Capable of and Undertaking Complex Law-Reform Litigation?

Almost all P&A executive directors said they pursue law reform litigation cases, although they made it clear the expense of handling class actions, appellate litigation, and other complex cases aimed at systemic change limits their ability to do so—particularly given the high demand for individual representation. Several executive directors stated that because of inadequate funding, they frequently seek the pro bono involvement of private attorneys and local or national advocacy groups to handle these cases. Along with a lack of resources, barriers to undertaking systems change litigation include avoiding a negative Federal court precedent on an issue should the litigation fail, or the program’s location within the jurisdiction of a Federal Court of Appeals Circuit known to be hostile to certain legal theories. One P&A director observed that “it’s helpful when the P&A has a history of successful litigation, as then the state negotiates; it brings them to the table.” Many directors acknowledged the helpfulness of the TA in handling complex litigation provided to their staff by the TA contractor, NDRN, and the legal backup centers they contract with.

The PAIMI Program has developed a reputation as a change agent that focuses on litigation. According to a Government Accounting Office (GAO) examination of P&A advocacy practices, most P&A work prioritizes nonlitigious activities and permits litigation only as a last resort, as per Federal regulations.³⁵ Other stakeholders surveyed, including NAMI directors (38 percent), state mental health advocacy organization directors (64 percent), consumer-run advocacy organization directors (29 percent), legal counsel to state mental health directors (31percent), and state mental health directors (44 percent), identified litigation-based activities as PAIMIs' central accomplishments during the past 2 years—if they reported knowledge about PAIMI. Clearly, litigation and specifically class action litigation receives more attention from the media and therefore is more likely to resonate with the public and stakeholders than other PAIMI advocacy activity.

Are PAIMIs Influencing State Legislatures?

Legislative advocacy among PAIMIs appears to vary widely as the result of confusion about what is permissible under the Federal regulations that govern the program—confusion that is troubling to the evaluation team. It is recognized that this issue may have other components, such as Internal Revenue Service rules concerning the activities of nonprofit organization; however, almost 25 percent of the P&A executive directors stated they did little or no legislative advocacy because of lobbying regulations. Directors perceive there to be more prohibitions around legislative advocacy, or have received conflicting instructions from CMHS. The Federal regulations (42 CFR 51.6) state:

- (b) Allotments may not be used to support lobbying activities to influence proposed or pending Federal legislation or appropriations. This restriction does not affect the right of any P&A system, organization or individual to petition Congress or any other government body or official using other resources.*
- (c) Allotments may not be used to produce or distribute written, audio or visual materials or publicity intended or designed to support or defeat any candidate for public office.*

Given this language, it is clear that a PAIMI Program is not prohibited from advocating on behalf of its clients before the state's legislature. Indeed, such advocacy is an important component of many PAIMI efforts. This was made clear by the P&A executive directors, as well as by many other advocacy organizations and by state officials. One state counsel simply stated, "Sometimes we work jointly on legislation." PAIMIs solicit input from consumers, local programs, and stakeholders on legislative issues and sometimes assist individuals preparing to testify before legislative committees and organizations to draft written comments. It is apparent that CMHS needs to clearly communicate the plain language of the regulation to the PAIMI grantees.

³⁵ Government Accountability Office (GAO) report, Involvement in Deinstitutionalization Lawsuits on Behalf of Individuals with Developmental Disabilities, September 2003, <http://www.gao.gov/new.items/d031044.pdf>

The following examples of PAIMI involvement in systemic advocacy on state budget issues were found in 2004 PPRs:

- One P&A's executive director was appointed to a committee on implementation of a "State Coverage Initiative," using unspent funds for children's health care coverage to subsidize employer-based health insurance program for uninsured individuals.
- PAIMI participated in a Coalition for Insurance Parity, which has funded an actuarial study that indicates the cost to the state during first 5 years of implementation is zero and net impact on premiums is <0.5 percent.

Are PAIMIs Undertaking Other Systems Change Efforts?

PAIMIs address a wide range of systemic issues involving local, state, and Federal policy concerns. With regard to local concerns, PAIMIs have addressed such issues as "Not in My Backyard" resistance to community services, consumers' requests for training on the Americans with Disabilities Act, and the problem of increasing homelessness. At the state level, PAIMIs have been involved in systemic issues including outpatient civil commitment, the lack of mental health services in the criminal justice system, and advocating for service system reconfiguration. Many P&A executive directors said their agency's focus included Federal initiatives such as reducing the use of restraint and seclusion and implementing the recommendations of the New Freedom Commission.

Stakeholders were surveyed about their state PAIMI's advocacy for systems change in mental health issues beyond the public mental health system. State directors of mental health advocacy organizations view PAIMIs as advocating most often on systems issues regarding juvenile justice (67 percent), followed by social services for children and special education (both 58 percent). Consumer-run mental health advocacy organization directors view their PAIMIs as most often engaged in systems change that target social services for adults and criminal justice issues (both 57 percent). NAMI respondents view PAIMIs as most active in systems advocacy directed at criminal justice work (44 percent). The directors of the SMHAs consider PAIMIs active in system advocacy beyond the public mental health system as most likely to take on issues related to social services for adults (43 percent). This opinion was shared by their legal counsel.

PAIMI Quality Management

Are PAIMIs Meeting Their Established Goals (Service Priorities)?

The PAIMI Act³⁶ allows each PAIMI Program to establish its own priorities and activities as long as those activities further the cause of ensuring the rights of individuals with psychiatric disabilities under the U.S. Constitution and Federal and State statutes. Grantees report a high degree of goal achievement. Twenty percent of grantees sampled reported they met or partially met all projected goals and objectives. Overall, grantees reported having met 93 percent of targeted goals and objectives. However, only 4 of 20 P&A executive directors reported no cutbacks in goals as a result of insufficient resources.

³⁶ The Protection and Advocacy Act for Individuals with Mental Illness (PAIMI) Act of 1986, Public Law 99-319.

PACs also reported very high PAIMI goal achievement. From 1997 to 2004, PACs reported their PAIMI had fully or partially achieved well over 80 percent of individual goals and objectives, with a low of 80 percent in 1998, and high of 95 percent in 2000, and a steady rise from 90 percent to nearly 95 percent from 2001 to 2004.³⁷ This evaluation also examined the reasons provided by PAIMI Programs when targeted goals and/or objectives were either partially met or not met, to determine the nature of any constraints. In the 2004 PPRs examined, 60 specific goals for that year were not fully achieved. Interviews with P&A directors confirmed that most PAIMIs (80 percent) altered their planned goals. These included outreach activities, advocacy in jails and other criminal justice settings, and presence in nonstate hospitals. Grantees' explanations for not achieving goals most frequently cited an insufficient number of cases (28 percent), either because the PAIMI did not receive referrals in the targeted issue area or because not enough referrals evolved into cases during the year. The second most frequently cited reason was that the PAIMI decided to defer pursuing the goal (23 percent). Insufficient staff time (12 percent) and challenges to interagency cooperation (10 percent) were also cited.

Do PAIMIs Adequately Supervise and Train Staff?

P&A executive directors reported that a range of supervision strategies are in place to monitor the representation of PAIMI clients. These include team meetings (in a number of cases, weekly), case presentations and reviews, one-on-one supervision, and direct observation of performance. In one PAIMI, the legal director meets regularly with each attorney and advocate and also reviews all legal papers before they are filed. In other offices, managing attorneys periodically conduct quality assurance reviews, such as a random sampling of Information and Referral (I&R) calls. In one program, an attorney reviews every request for service and each open case monthly.

Closing cases is another point of quality review. In one office, performance reviews include a review of randomly selected case files. One grantee uses a review of client satisfaction surveys and appeals for evaluating the quality of representation and staff performance.

To keep apprised of changes in the substantive law, developments in legal strategy, and organizational improvements, legal advocacy organizations provide for staff development and trainings. Nearly all P&A directors interviewed consider their staff in need of additional training (95 percent). Directors noted training would be useful in advanced investigation, professional development, time management, stress management, assistive technology, using technology, and case management. These topics appear to be those common to all types of organizations and not (with the exception of investigations) specific to PAIMI work. Directors stated that insufficient funds and lack of staff time are impediments to meeting these training needs. Nevertheless, as presented in Chapter 2, P&A directors generally believe the currently available training and TA sufficiently address PAIMI issues.

³⁷ It is not clear what to make of this indicator. PPR peer reviewers were concerned that some grantees appear to change their goals between the application and the PPR to make the final goals fit with what they actually did.

If it is challenging for most P&As to meet the training needs of paid staff, how are directors ensuring that volunteers assigned to work on PAIMI issues (who may perform the same functions) are provided equivalent training and supervision? It was discovered that grantees that use volunteers to do PAIMI-related work provide those volunteers with extensive training, very specific work activities, and supervision on a frequent basis.

Are PAIMIs Gathering Information About Client Satisfaction With Services and Creating an Open Dialogue for Complaints and Grievances?

A critical aspect of quality management is gathering data on the experience of using PAIMI services. P&A executive directors reported that client satisfaction is monitored on an ongoing basis through paper or online satisfaction surveys at case closure (80 percent). However, the low response rate of these surveys emerged as key area for improvement. With respect to notice about the right to make a complaint or grievance, a significant number of clients (22 percent) reported they were not informed or advised about this right. Given that all P&A executive directors interviewed reported that all clients are advised of the grievance procedure, this report by clients seems high. Despite whether formally notified of this right, all clients interviewed said they would have been comfortable making a complaint, and three clients did so. All three stated their complaint was heard fairly. One complaint was about the poor attitude displayed by the P&A receptionist. The client advised the attorney and the problem was fixed. By this example, it seems that clients are not necessarily using the formal complaint and grievance system but may be using less formal methods, which may not be tracked.

PAIMI law requires that programs report to their governing body and the PAC, at least once a year, on grievances received and resolutions (42 CFR 55.25 (b)(2)). The vast majority of executive directors interviewed (85 percent) share information on client grievances with their PACs on a “frequent” basis. However, 15 percent indicated the PAIMI Program “rarely” provides the council with this information. Nevertheless, all directors reported client grievances are tracked and reviewed by P&A governing boards to determine if there are systematic and/or individual employee issues. Despite this reported high rate of tracking, 50 percent of directors surveyed do not track numbers of those denied PAIMI services, a group that may be interested in filing grievances. This raises the question of whether PAIMIs are providing equal opportunity to make a grievance to all relevant parties including clients and prospective clients intended.³⁸ This regulation is in place so that the system is assured individuals with psychiatric disability have full access to PAIMI services (42 CFR 55.25(a)(2)).

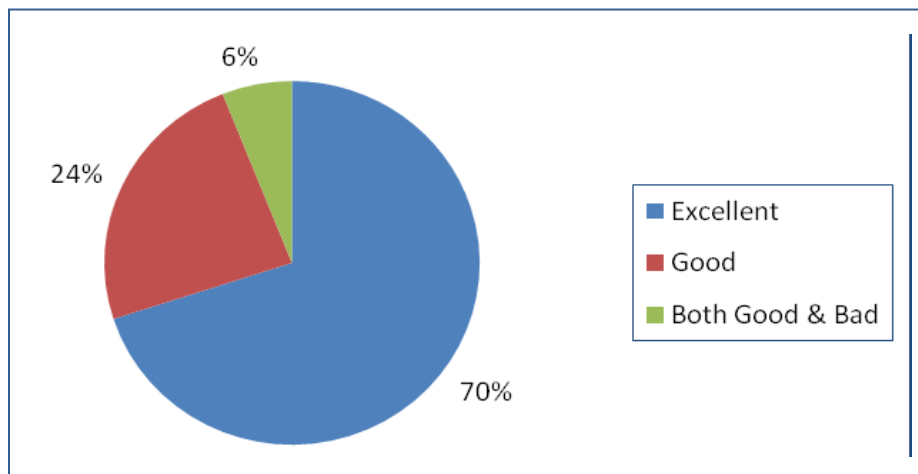
How Is the Quality of PAIMI Representation Perceived by Clients and Other Stakeholders?

Most PAIMI clients (84 percent) believe their representation was as good as if they had paid for it (13 percent preferred not to speculate). When asked to rate the representation they received overall, more than 70 percent rated the service “excellent,” 24 percent rated it “good,” and 6 percent as both “good and bad.” None found representation in need of improvement. All individuals said they would use the PAIMI services again. Figure 15 below shows how clients

³⁸ Individuals who have received or are receiving mental health services in the state, family members of such individuals, or representatives of such individuals or family members.

interviewed perceived the quality of their representation along a continuum of bad to excellent.

Figure 15. Client Impression of Representation Quality



This sense of the high quality of representation provided to clients is shared by PAC chairs; 50 percent rated it “excellent,” and 39 percent rated it “good.” In all cases, clients believe PAIMI representation made a difference.

Evaluation participants, including EAW members interviewed for the evaluation, suggested PAIMIs could increase stakeholders’ knowledge about their activities and successes by developing more specific plans with narrowly defined goals achievable in shorter time frames. Others suggested a focus on Olmstead issues and greater collaboration with and quality assessment by mental health service recipients. PAIMI Programs considered most successful were reported to have very skilled and committed leadership, along with those in states with a history of organized disability advocacy. These key stakeholders see PAIMI strengths represented in the quality of the staff and the advocacy and legal representation services they provide. PAIMI weaknesses were most often reported to be a lack of funding and staff, especially relative to the amount of work that needs to be done. A less reported, but important concern focused on the perceived adversarial nature of PAIMI staff. This was reported by one-third of State mental health program directors and one-quarter of legal counsel. It is important to note, however, that the PAIMI was created in part to provide individuals receiving treatment with the ability to contest decisions of the SMHA.

C. PAIMI Program Operations Lessons Learned and Recommendations

PAIMI Programs are addressing the broad range of areas for intervention as directed by Federal legislation. Priorities reflect what recipients of mental health services and family members consider important, tempered by what is reasonable given very limited Federal resources, and environmental circumstances such as a judge with a viewpoint in opposition to a PAIMI argument. Grantees provide advocacy services across the full range of institutional and community settings, including nursing homes, adult and juvenile criminal justice facilities, group homes, psychiatric and general hospitals, and to those who are homeless, although not with equal levels of effort. More emphasis could be placed on providing advocacy to individuals with psychiatric disability residing in nursing homes and criminal justice settings where these individuals are particularly vulnerable and isolated. PAIMIs tend to establish a large number of goals and objectives and predominantly report meeting their established benchmarks. Closer examination is needed over the substantial rise in short-term and TA types of representation over more substantive and protracted engagement in systems change advocacy.

- PAIMIs have always operated with limited funding that is not sufficient to fulfill the broad goals of its legislative mandate; funding should be increased in relation to increased mandate.
- PAIMIs should set fewer goals and objectives, clearly based on local needs assessment data and a transparent prioritization rationale. Goal statements should specify areas of need that would be addressed if additional resources were available.
- Although PACs and PAIMIs report significant outreach efforts to solicit stakeholder opinion on service priorities, surveys of directors of stakeholder organizations suggest that more effort is needed to publicize opportunities to participate.
- No evidence of dissatisfaction among the PAC chairs in their role as advisors was found. Yet, these advisory bodies are not contributing to overall P&A functioning as envisioned by enacting legislation. Councils need additional support and opportunities to weigh in on P&A policies and procedures and other organizational operations. PAIMIs should add more council members to their governing boards. Councils could also produce more independent reports such as collecting client satisfaction feedback for quality improvement. (This is presented in the independent report suggestion in Chapter 6.)
- CMHS should clearly communicate to PAIMI grantees what types of legislative advocacy are and are not permitted.
- CMHS should clearly define and communicate to PAIMI grantees how it defines “client contact” and the related reporting requirements.
- CMHS should examine the wide disparities in data reported by PAIMI grantees (e.g., 23 percent of grantees reported that no one was denied service, and 1 program reported denying services to more than 10,000 people).
- PAIMI grantees should continuously review the efficacy of their outreach and cultural competence efforts. CMHS could request more specific reporting.
- Communication to clients and potential clients of complaint and grievance policies and procedures should be presented in a format to ensure client comprehension and

exercise of this right. Such communication should be documented. Inquiring whether the right to complain and how to complain is communicated clearly to potential clients could be a function of a PAC quality improvement initiative.

CHAPTER 5

PROCESS AND DISTAL CLIENT AND SYSTEM OUTCOMES FINDINGS

A. Process Outcomes

Do PAIMIs Have Access to Facilities, to Individuals With Psychiatric Disabilities, and to Information Regarding These Individuals?

Enactment of the PAIMI legislation was based on a congressional finding that individuals with psychiatric disabilities suffered significant mistreatment in state mental hospitals, many of which housed large numbers of people, were remotely located, and operated without any outside scrutiny. The evidence showed that state hospital residents suffered recurrent abuse, neglect, and denial of legal rights, often with no recourse, and frequently without any knowledge of their rights. Congress found that state mechanisms to protect patients' rights were often nonexistent or inadequate. Through the PAIMI Program, the Federal Government provides states and territories with funding to support organizations that advocate for the rights of mental health service recipients and pursue openness and accountability in mental health services.

To receive Federal PAIMI funds, states must ensure the PAIMI's independence from any agency providing treatment and just as importantly must ensure PAIMIs have access to people with psychiatric disabilities, mental health facilities, individuals' records, and certain types of reports (e.g., notices of death). Congress imposed some limits on PAIMIs' access to records, deciding not to permit access to quality assurance records afforded confidentiality under State law. Beyond this, Congress's mandate that PAIMIs be provided full access was clear. Within these parameters, many PAIMI Programs have negotiated workable access arrangements, some de facto and others in writing, with SMHAs, nonstate service providers, correctional institutions, school systems, and other service providers (e.g., nursing homes).

Nevertheless, stakeholder interviews make clear that from the program's initiation to today, PAIMIs frequently encounter access difficulties. This occurs even in the face of Federal regulations that state access shall be afforded "when the P&A system determines there is probable cause to believe an incident (of abuse or neglect) has or may have occurred" 42 CFR 51.42(b)(2). Multiple court rulings have held that PAIMIs are the "final arbiters" of probable cause as to whether abuse or neglect has or may have occurred. The enactment of the Health Insurance Portability and Accountability Act (HIPAA) of 1996 has, in some states, rekindled access disputes that seemed to have been resolved. This is unfortunate since HIPAA clearly authorizes disclosures that are "required by law" 45 CFR 164.512(a)(1), which include the PAIMI statute and regulations, and the Department of Health and Human Services has issued interpretive guidance to that effect (65 FR 82594).

Despite their clear legal rights to access, PAIMIs continue to face obstacles. Problems may arise from a genuine legal issue, such as when a guardian or other individual with legal authority opposes PAIMI having access to a person’s records. However, it appears most access problems reflect obstacles created by the state or other service provider. Table 4 below summarizes the responses of P&A executive directors to questions about access issues. It shows that failure to provide PAIMIs with timely notification of deaths and abuse and neglect complaints are the most acute component of the access problem.

Table 4. P&A Directors’ Report of Timely Access to Individuals and Records

	Timely Access	Not Timely Access	Mixed: Timely and Not Timely
Death reports from mental health institutional settings	45% (9)	40% (8)	20% (4)
Reports of abuse/neglect from institutional settings	58% (11)	32% (6)	16% (3)
Unannounced visits in 24-hour facilities	80% (16)	5% (1)	20% (4)
Announced walking around in 24-hour facilities	85% (17)	5% (1)	15% (3)
Privacy to meet with clients and prospective clients	90% (18)	0% (0)	15% (3)
Access to client records with client’s consent	84% (16)	5% (1)	16% (3)

Most SMHAs do not dispute the existence of these problems. Among legal counsels to state mental health program directors, only 58 percent indicated their agency provided PAIMI with timely reports of deaths in mental health facilities. Beyond the notification problem, there are problems in PAIMIs’ access to state reports following investigations of deaths. One P&A executive director stated, “The most challenging area of access has been accessing the mortality review reports prepared by the SMHA in the suicide deaths of eight state hospital residents. They have declined to release the records and claim they are peer review records protected by state law. Litigation to resolve this issue is likely.”

Other P&A executive directors reported great difficulties obtaining information on deaths related to restraint and seclusion in private provider residences for individuals with psychiatric disabilities. Problems getting notice of deaths occurring in jails were among the numerous access issues regarding individuals with psychiatric disabilities detained by the police and those in local jails and state prisons.

P&A executive directors also identified access problems related to minors in private mental health facilities, juvenile justice custody, and educational programs. Of particular concern are problems gaining access to information about the use of restraint and seclusion on children and adolescents, given the awareness of the heightened risks these practices present to these age groups. Access to nursing homes was also identified as a problem.

Some access problems are the result of progress in service delivery rather than resistance. For example, the growth of programs that enable people with psychiatric disabilities to live in

community settings rather than a state institution results in PAIMI staff spending more time locating and traveling to visit clients.

PAIMIs continue to face access problems not unlike those they faced in the program's first years. Congress and the CMHS have legislative, regulatory, and budgetary options to ensure states comply with the access rules, preventing these problems from arising and repeatedly ending up in court. This is a matter that warrants serious attention. When PAIMIs do not receive prompt notification of abuse or neglect complaints, they are impeded in performing their primary function. When forced to litigate access issues, significant portions of their limited resources are consumed—resources that would be better used moving the nation's mental health system forward.

Are PAIMI Services Provided in a Culturally Competent Manner?

The skills and knowledge required to practice law are many, but they do not necessarily include the knowledge and sensitivity needed to assist people with disabilities or those from minority backgrounds. PAIMI staff need an understanding of psychiatric disabilities, the experience of undergoing invasive treatments, discrimination that often is experienced by those with psychiatric disability, and the tenets of recovery. To provide culturally competent services, PAIMI staff also need to have respect for, and an understanding of, ethnic and racial groups—including their histories, traditions, beliefs, and value systems. This knowledge would then be transformed into representation aligned to working with the people with psychiatric disabilities.

The evaluation found that PAIMIs use a variety of approaches to try to ensure services are provided in a culturally competent manner. PAIMIs often collaborate with language- and ethnicity-based organizations to maximize the accessibility of services to individuals from minority backgrounds. They also try to include people with psychiatric disabilities, their family members, and individuals from minority communities on the PAC and as staff members. PAIMIs may also provide ongoing staff training, targeted outreach efforts, and American Sign Language speakers and interpreters with written materials translated. This evaluation found that fewer than 60 percent of chairs surveyed consider PAIMI staff respectful of clients' cultural heritage either "always" or "most of the time."

One measure of a PAIMI's cultural competence is the extent to which the agency's staff represent the cultural makeup of the state or territory. This evaluation inquired about the racial and ethnic identification of P&A executive directors and PAC chairs (response to these questions was voluntary). Executive directors are predominantly White (84 percent), while 16 percent are Black/African American. PAC chairs are also predominately White (77 percent), followed by American Indian/Alaska Native (18 percent), and Black/African American (12 percent). The sample of 20 P&As may not be representative of the population of executive directors or PAC chairs, but it shows there is room for increased minority representation. This finding was not news to directors or PAC chairs.

Another measure of cultural competency is to examine the degree of minority representation on PAIMI caseloads. For most PAIMIs, individuals from minority groups account for less than 50 percent of active caseloads. Overall, 32 percent of the total clients served in 2004 were minorities, a consistent pattern of the past few years. PAIMI clients interviewed for this evaluation (who tended not to be of minority status) were almost unanimous (97 percent) that staff were respectful of their religious, racial, and language backgrounds.

Although definitions of cultural competency exist,³⁹ putting the definition into practice is an evolving area of service delivery. According to several key informants, training on diversity in ethnic, racial, and disability issues, and whether staff understand how to work with other cultures, are the most important aspects of cultural competence. Another measure is whether law reform litigation is brought that addresses the problems that minorities face, such as overrepresentation of African Americans in state hospitals. The establishment of a separate Native American PAIMI for four tribes is, in the view of evaluation team, a demonstration of practicing culturally competent service delivery. The executive director of a P&A that is innovative and highly committed to addressing diversity in a state with a numerous minority communities stated, “We require that every employee have individual objectives regarding cultural competency, and their progress towards these objectives is reviewed in the annual performance appraisals.” Cultural competence is an area that needs continuous attention, and it appears PAIMIs are aware of the need and seeking to address it, though not with equal vigor.

Are PAIMIs Influencing the Policies of SMHAs?

As noted in earlier chapters, there can be acrimonious litigation brought by PAIMIs against SMHAs. It was also found that there can be substantial dialogue between them, and the evaluation team attempted to gain understanding of the impact such dialogues have on policy. One state mental health program director stated that his/her agency had “good relationships with the PAIMI staff, and we are able to discuss openly our different perspective.” A state mental health legal counsel in another state said, “PAIMI leadership has worked hard at creating trusting relationships. We are very receptive to PAIMI’s concerns, suggestions...which results in improvements of which all are proud.” One-half of the P&A executive directors surveyed stated that SMHAs were receptive to PAIMI proposals for changes in policies and practices in the public mental health system either “always or most of the time” or “often,” and 45 percent of the executive directors said the SMHA were receptive to PAIMIs’ proposals for changes in the agencies’ regulations. The SMHA directors said that in advocating for changes in state mental health statutes, the P&A directors and his/her agency were either “always or most of the time” or “often” in alignment 57 percent of the time.

³⁹ “The term “culturally competent” is defined in the DD Act as services, supports or other assistance that are conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language and behaviors of individuals who are receiving services, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program” (DD Act, Section 102 (7)).

The SMHA directors cited the significant influence of PAIMI advocacy on their agencies' activities, including the following examples:

- Implementing and monitoring the state's Federal SAMHSA grant to reduce seclusion and restraint use at state hospitals
- Developing, implementing, and providing training on the state's new psychiatric advance directives law
- Promoting a "rights and recovery" model of services
- Training staff on "patients' rights" (23 percent of the state mental health program directors reported contracting with the PAIMI for such training)
- Planning for closure of state hospitals and large personal care homes

Other SMHAs are not receptive to PAIMI policy input. The reasons for this sometimes appear to reflect fundamental differences in substantive positions, and other times appear to involve interpersonal conflict.

Are PAIMIs Subject to Political Influence?

Congress made clear in the enabling legislation that states receiving PAIMI dollars must fund programs that can advocate for their clients with independence. In response to the question as to whether they have experienced political pressure that interfered with pursuing mental health advocacy, experiences were mixed, but half the P&A executive directors stated they felt no political pressure to constrain their organization's activities. In fact, one director stated that staff of a state agency had encouraged the P&A to address problems faced by people with psychiatric disabilities in that state's prisons. However, two directors stated they generally felt pressure, though not to a great extent. A director of a PAIMI that is part of a state agency said his/her program "had to be careful" but had not as yet experienced interference.

More troubling are the reports of two executive directors who each cited a recent situation in which they were pressured to rethink their organizations' positions on a specific substantive issue, although neither characterized it as overt interference. One P&A executive director stated the P&A governing board had stopped accepting state funding because they felt the receipt of those funds had resulted in political pressure to curb their advocacy aggressiveness. It may be unrealistic to expect agencies charged with monitoring a state system will be completely free from political pressure, particularly when some funds may come through a state agency.

Are PAIMIs Supporting Other Organizations and Building Advocacy Coalitions?

PAIMIs collaborate with many advocacy organizations and increasingly work with consumer groups on activities like providing training on legal rights and self-advocacy, jointly developing legislative testimony and public comments, sponsoring state and local conferences, and paying for individuals with psychiatric disabilities to attend national meetings such as the annual Alternatives Conference funded by the CMHS.

One PAIMI played a major role in the development of the first consumer-operated statewide organization. Another PAIMI is working with people with psychiatric disabilities and others to enact legislation creating a statewide independent ombudsman program for mental health service recipients and families. Another PAIMI works with a survivor group on a project to “honor the thousands of people who died in state institutions, many of them buried on state hospital grounds.” Another PAIMI is the cofounder and leader of a statewide cross-disability coalition. Some PAC members seek membership on other organizations’ boards or advisory committees to ensure information-sharing. In general, however, it does not appear PAIMIs are very involved in directly linking their efforts with those of other disability rights advocates. One P&A executive director acknowledged that his/her PAIMI “needed to build coalitions with the elderly and their advocates, and with activists concerned about personal care services.”

In general, the leadership of statewide mental health advocacy organizations is positive about PAIMIs as collaborators, as indicated by the comments of four directors:

- “Our advocacy organization can assist the majority of folks who call, but ‘extra’ power is at times needed.”
- “We work together on a weekly, sometimes daily basis.”
- “In everything they do, P&A collaborates with the advocacy community.”
- “The executive director is available for consultation whenever needed and has served as a valuable advisor in several programs we have developed.”

The directors of statewide mental health advocacy organizations said their P&As provided substantial leadership to statewide coalitions seeking system change (“always or most of the time” 50 percent, “often” 40 percent). Consumer-run advocacy organization directors were less enthusiastic about their collaborations with PAIMIs. Although 67 percent said they talk with the P&A executive directors either weekly or two to three times per month, but only 29 percent agreed with their PAIMI’s priorities for systems-level change “always or most of the time.” Fifty-seven percent said the PAIMI “sometimes” took a leadership role on statewide coalitions seeking system change. “The P&A is somewhat slow to take leadership in wider community discussions,” said one director of a consumer-run advocacy organization.

In summary, PAIMIs’ record of supporting other organizations and building advocacy coalitions is mixed. It is clear that relationships have been built and that there is much productive, ongoing collaboration. With the continued growth in the number and size of organizations led by people with disabilities, there are opportunities to work much more closely with such groups, but it would have to be a priority where time and resources are directed.

B. Distal Client and System Outcomes

Are PAIMI Clients Satisfied With the Services They Receive?

Data indicate that PAIMI clients are very satisfied with the advocate or attorney who provided them services. Of the 37 clients surveyed in 4 states:

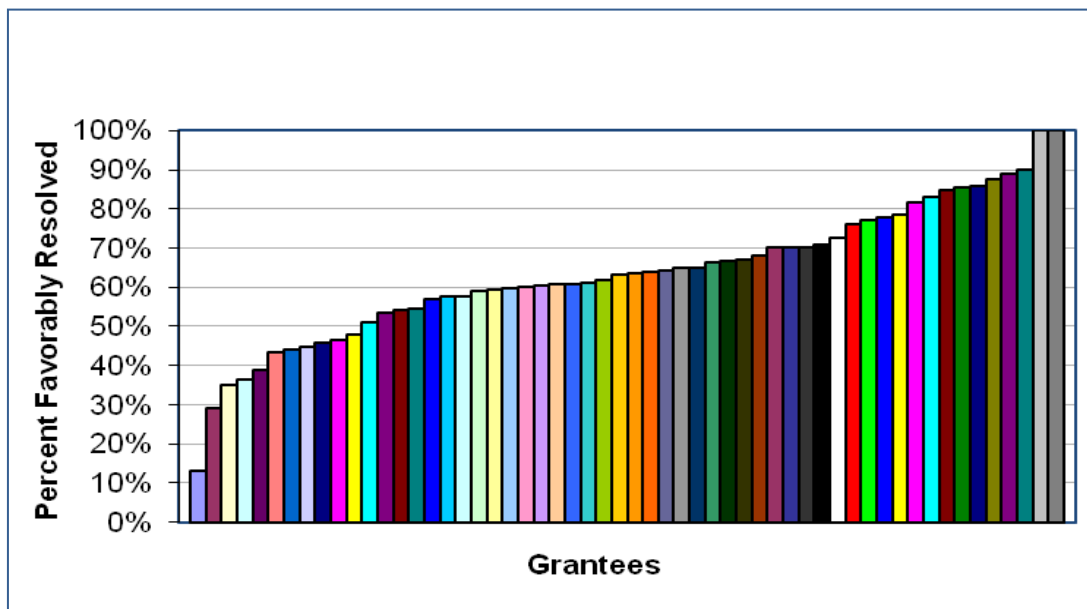
- Eighty-two percent believed the advocate/attorney listened to their story and truly understood their circumstance.
- Ninety-two percent felt they were able to meet or talk with their attorney/advocate often enough to know the status of the case and when decisions had to be made.
- Eighty-one percent believed decisions in their case were made jointly with their advocate/attorney.
- Ninety-two percent believed their advocate/attorney did everything possible to obtain the outcome desired.
- Seventy percent felt the quality of their representation was “excellent,” and 24 percent felt it was “good.”

Although there are no benchmarks for meaningfully comparing these responses, it seems clear PAIMI staff are assisting individuals with psychiatric disabilities in an appropriate manner and their clients are generally satisfied with the services they receive.

Do PAIMIs Produce Favorable Results for Individual Clients?

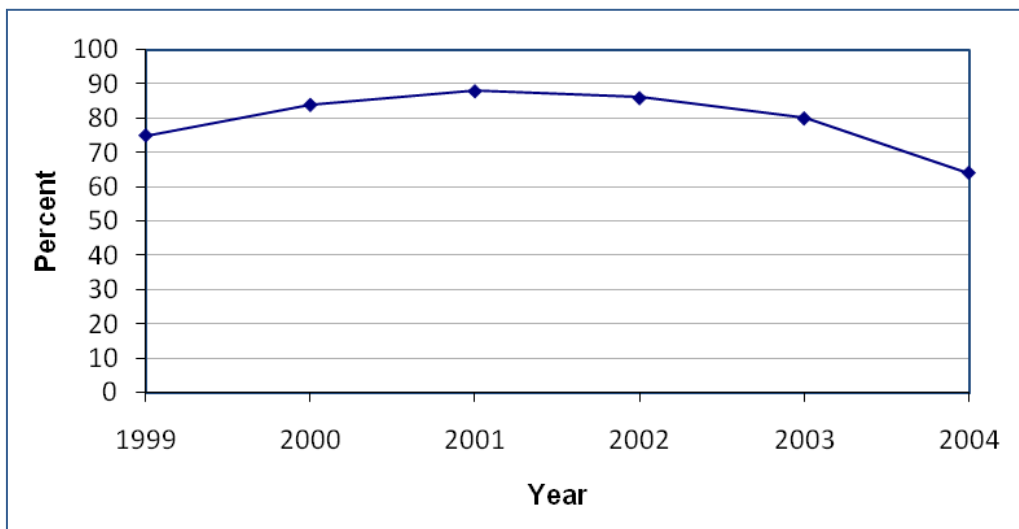
Each PAIMI’s annual PPR indicates the percentage of cases resolved in favor of its clients. These success rates vary widely. For example, in FY 2004, two programs reported success in every case they handled, but one PAIMI reported success in only 13 percent of cases that year. Figure 16 notes the range among all grantees in 2004 of complaints resolved in the clients’ favor.

Figure 16. Percentage of Complaints Resolved in Clients’ Favor, Nationally, FY 2004



The overall percentage of clients' complaints favorably resolved has fluctuated slightly year to year, but it generally approaches two-thirds or higher. It is unknown why the percentage declined between 2001 and 2004. Figure 17 shows the percentage of cases resolved in clients' favor nationally over the PAIMI Program's history.

Figure 17. Percentage of Complaints Resolved in Clients' Favor, Nationally, FY 1999–2004



It is a positive finding that the majority of cases are reported as resolved in favor of PAIMI clients. People with psychiatric disabilities having a voice, when they traditionally had little input into decisions affecting them, is itself of significant value. At the same time, it is difficult to draw inferences from these data because of the many variables involved, including: the nature of the clients' presenting problems, the varying levels of difficulty of the cases undertaken, the number of clients with more than one problem, and differences in how PAIMIs define "favorable" resolution. Moreover, case resolution represents data collected from PAIMI staff, not the direct report of clients. Yet, the independent query of PAIMI clients found rates of satisfaction and impact consistent with staff reports of case outcomes.

Unlike the kind of legal practice where inputs and outcomes can be calculated in dollars, specific measurement of the impact of PAIMI services would require an evaluation methodology that does not exist in the area of public interest law. The idea of evaluating such programs is in its infancy. The advocacy programs most similar to PAIMI are those funded by the Federal Legal Service Corporation, which has been providing assistance to indigent clients in civil law matters for 40 years. Efforts to establish program standards and evaluation systems have been initiated in recent years by the Legal Services Corporation and the American Bar Association, and those endeavors continue. However, the authority and responsibility of the PAIMI Program are more far expansive than that of the legal services program. For example, Federal regulations prohibit legal services staff from addressing specified legal issues and from filing class action lawsuits. In essence, legal service programs are not permitted to seek systemic change, which is one of the basic missions of PAIMI Programs. There is, in short, no assessment tool for public interest law programs on the horizon.

In the absence of a formal evaluation methodology, PAIMI clients were asked two bottom-line questions. First, what difference has P&A representation made in your life? Most clients advised that owing to PAIMI representation, their situation was much improved. See Table 5 for additional information on impact from the client perspective.

Table 5. Clients’ Report on the Impact of P&A Representation

Response	Response Count	Response Percent
No change, nothing is different	2	4%
Some change was made, but not everything I wanted	5	13%
I understand what I can do to improve my situation	6	16%
My situation is much improved	25	67%
Total	37	100%

We also asked clients whether PAIMI staff helped with the problem that brought them to the organization. Every client surveyed responded “yes.” These clients’ own words provide a meaningful window on the individual impacts that PAIMI representation has made:

- “I feel safer knowing that PAIMI staff are there to help.”
- “PAIMI has the best lawyers. They are doing everything they can. If it wasn't for them I'd never be getting discharged.”
- “PAIMI is the best thing that ever happened to me. It helped me get back on disability services.”
- “I believe that PAIMI is recovery-oriented and works diligently on behalf of their clients. I have always been treated with the utmost respect and all of my concerns listened to and addressed. PAIMI is visible to us in the community, holding meetings around the state about advocacy. The materials they have developed on recovery and rights have been extremely valuable to consumers learning how to be self advocates.”
- “I contacted PAIMI for a discrimination issue. The staff person and I discussed what options I had. We decided on one course of action. He gave me time to think about the options presented. I changed my mind and he still supported me. The decision I subsequently made was a serious moral victory for me. Further, everyone else I interfaced with was very professional, personable and full of information! It made me feel good that PAIMI helps us receive the rights we deserve. We usually fight alone.”
- “PAIMI has been instrumental in having my independence and promoting and sustaining the recovery process. PAIMI has given me the hope that I have needed, when I needed hope the most.”

Do PAIMIs Produce Relevant Systemic Change?

As noted by the clients quoted above, many serious problems still exist. P&A executive directors, as well as all the other stakeholders surveyed, were asked for their views on recent

systemic accomplishments in their states. A selection of their responses below note impact across all the major program goals:

Abuse and Neglect

- The number of reported abuse and neglect complaints is decreasing, and PAIMI investigations and scrutiny may well be a contributor.
- It is clear that, along with the CMHS, many PAIMIs have focused on restraint and seclusion, resulting in decreased use of these interventions.
- A PAIMI successfully litigated individuals with psychiatric disabilities a “right to fresh air,” which significantly increased their opportunities to get off the ward and go outside.
- One legal counsel for a state mental health program director, commenting on lawsuits brought by a PAIMI challenging hospital conditions and practices, said, “State hospital programs have met the high standards set forth in class action settlement agreements. Hospital staff have embraced the changes and are proud of working in these programs.”
- In one state, a PAIMI worked with stakeholders to ensure what advocates described as the “responsible closings of state hospitals.” In another state, PAIMI efforts were a major factor in “the closure of a state hospital with the majority of consumers going back into their home communities.”

Civil Rights

- At a hospital for elderly individuals with psychiatric disabilities, a PAIMI successfully sued to stop the practice of conducting strip searches of every person on a ward when staff became concerned about matters like missing or misplaced door keys or the possibility of matches on the ward.
- Another PAIMI went to court to prevent the use of a nasogastric tube to administer psychotropic medication over the person’s objection, and won the case.
- A number of PAIMIs worked to prevent the enactment of state laws creating outpatient commitment systems and advocated instead for increased availability and quality of voluntary community services.
- PAIMIs were instrumental in getting psychiatric advance directive laws enacted in a number of states, often drafting the legislation.
- Many PAIMIs played a role, sometimes a very significant one, in legislative examination of health insurance parity for mental health services.
- PAIMIs worked with states to change voting and absentee ballot procedures to facilitate the participation of people with psychiatric disabilities.

Criminal Justice

- Stakeholders lauded PAIMIs for being “great advocate[s] for change in the criminal justice system” through “networking with law enforcement agencies.”
- In one major city, the PAIMI was able to negotiate a settlement in a class action suit that lasted 10 years. The settlement ensures that local jail inmates with psychiatric disabilities are discharged with appropriate aftercare plans and services scheduled, ending the practice of “taking them in a van to a remote subway station at 3:00 a.m. and giving them a few dollars.”

- Many PAIMIs have worked with other advocates to develop training based on Memphis, Tennessee’s Crisis Intervention Team and other models for local and state police, as well as for fire and rescue personnel.
- Improvements in mental health services in local jails and state prisons have resulted from several PAIMIs’ efforts.
- A PAIMI joined in a lawsuit filed by a private individual regarding delays in transferring people with psychiatric disabilities from jail to forensic mental health facilities. The case resulted in legislative funding for more forensic services, which reduced delays significantly.
- Another PAIMI “persuaded the SMHA to convene a workgroup to expedite competency evaluations for defendants awaiting trial in jail.”
- A PAIMI was “instrumental in getting diversion legislation,” enabling people with psychiatric disabilities “to receive treatment instead of being incarcerated in the county jail.”

Self-Advocacy

- “PAIMI was the lead organization in the development and implementation of the state’s first (and only) exclusively consumer-operated and administrated organization. They provided in-kind support (office space and use of office equipment, toll-free number, website and web master, staff support, mailing costs, etc.) for the first 15 months. They also assisted members [to] participate in a workgroup with the State Certification Board aimed at establishing a Peer Specialist Certification.”
- Another PAIMI was a key player in the development and implementation of a State Office of Consumer and Family Affairs.

Knowledge of Legal Rights

- PAIMIs have published readability-reviewed information about legal rights and procedures in multiple formats (e.g., pamphlet, poster, online) and languages.
- “In our state, the PAIMI is producing and promoting excellent materials on Rights and Recovery.”

Individual Choice

- An advocate stated, “PAIMI staff are strong advocates of the principles of self-determination and choice. They are very respectful of the perspectives and experiences of persons with disabilities. They also have excellent cross-disabilities awareness.”
- Another advocate said, “The PAIMI was key to the passage of the Psychiatric Advanced Directives Law, which will help individuals plan ahead in case of psychiatric hospitalizations, whether voluntary or involuntary, and have their preferences respected and needs met.”
- Two SMHA directors cited PAIMI’s active involvement in the development and implementation of their Olmstead Plan as likely to produce greater individual choice.
- One state mental health program director stated that the PAIMI “has been an active advocate and facilitated the agency’s receipt of new resources for Supported Housing and Children’s Services.”

Children's Mental Health and Educational Services

- An advocate said the PAIMI had “brought attention to exclusionary practices in schools.”
- Another advocate stated that PAIMI had “obtained access to serious incident reports to assist students. They monitor “on-restriction” practices and the use of seclusion, and aid in appropriate classroom programs when needed.”
- A third said that PAIMI “monitored out-of-state placements and assisted with returning residents if desired.”

Other Activities

- One state mental health program director stated, “PAIMI helped us prioritize issues that are essential to wellness and recovery focus.”
- An advocate said that PAIMI “has developed wonderful relationships with our state senators.”
- One PAIMI has initiated a program that “formally and publicly recognizes individuals who serve as effective change agents in professional, volunteer or self-advocate roles.”
- A legal counsel for a state mental health program director commented that the PAIMI is “keeping the adversary system in the proper tension for it to work effectively.”

What Are PAIMIs Not Doing and Why?

The stakeholders surveyed overwhelmingly agreed that PAIMIs have only a fraction of the staffing and resources they need to adequately serve the legal and advocacy needs of people with psychiatric disabilities. Opinions were more varied when stakeholders were asked what activities PAIMI should be initiating or undertaking more frequently, and what types of rights infringements should be given priority.

Views on Activities PAIMIs Should Be Initiating or Undertaking More Frequently

- Many stakeholders surveyed think that, as one stated, “Rights education among persons with psychiatric disabilities needs a major 'ramping up.'” Another stated, “It would be nice if they held seminars to teach adults strategies on how to advocate for themselves since we get many calls from frustrated adults who felt the PAIMI Program didn't help them and it really was due to their expectations and abilities to handle the situations they find themselves in.”
- Some stakeholders reported belief that PAIMIs are not sufficiently aggressive: “They need to take a stronger stand on systems change initiatives. Our mental health system is in a shambles. Mental health services are less and less available to the uninsured, many of whom end up in the criminal justice system. Individuals languish in state psychiatric hospitals for lack of resources in the community. Children have died in restraints in adolescent care facilities. PAIMI needs to step forward and file some class action lawsuits.”
- Another respondent commented that the PAIMIs are “not as forceful as they should be; they sue late, and don't do enough.”
- Other stakeholders report that PAIMIs should more often use approaches other than going to court. One said, “They do too much litigation and not enough investigation.”

Another observed, “They appear to have become a public legal firm recently rather than a Federal oversight organization.”

- Some stakeholders urged PAIMIs to focus more on joint efforts with people with other disabilities and their advocates: “Cross-disability communities should come together to do legislative education.”

Views on Particular Rights Denials That Should Be Higher Priorities

- A number of stakeholders echoed the view of the director of a consumer-run advocacy organization who said, “The focus of PAIMIs needs to expand to incorporate rights regarding employment (work with Equal Employment Opportunities Commission) and housing (Fair Housing Act).” Survey data showed that 6 of 10 directors of consumer-run advocacy organizations viewed employment as PAIMIs’ weakest area of advocacy.
- “Staffing for children and their families is not as strong as I’d like to see. In recent years, special education issues have not been a PAIMI priority, yet it remains a huge area of need.”
- “From what I know from my work at the intersection of mental health and the criminal justice systems, P&As appear to have very little presence within correctional settings, specifically as it relates to persons with psychiatric disabilities.”

Views on What Holds PAIMI Back

- The overwhelming consensus among all groups surveyed was that insufficient funding is the most crucial factor limiting the PAIMI Program’s effectiveness.
- There is much confusion about what P&A staff refer to as “the lobbying rules,” and this has a significant impact on PAIMIs’ activities. One state legal counsel said, “PAIMIs do not do enough legislative advocacy. Our interests may be aligned, but the Department is often...almost the only voice on subjects affecting mentally ill consumers that the legislature hears.”
- One stakeholder noted a problem that had worried advocates when the PAIMI law was enacted: PAIMI Programs were placed within existing P&As that had previously focused only on people with developmental disabilities. “From talking with many family members who are in need of advocacy for both adolescents and adults in hospitals or residential programs, the attitude is that the P&A deals mainly with developmental disabilities and doesn’t help individuals with mental illness.”
- One stakeholder commented on bureaucratic constraints: “I think that the PAIMI Program occasionally gets bogged down within the strict limits of what the overall guidelines allow them to do.”

Clearly, even with the most transparent and participatory priority-setting process, PAIMIs will be unable to do everything that stakeholders and staff would like to see accomplished. This would probably be true even if the programs received much greater funding since advocacy has limited power to change public systems, particularly one as entrenched and complicated as the public mental health system. However, it is important to recognize how much of the law’s capacity is underutilized.

Rights Are Not Self-Executing and Must Be Vigorously Promoted and Protected

People with psychiatric disabilities have a broad range of rights that go well beyond the right to be free from abuse and neglect. Numerous court decisions and settlement agreements based on the constitutional right to substantive due process have articulated a progression of specific rights for those living in institutions: Facilities must provide adequate privacy, lighting, sanitation, and other physical conditions; access to phones and mail; and adequate space for visitors and religious observance. Individuals have the right to be free from undue restraint of liberty, to treatment to reduce the need for restraint, and the right to a safe environment. Like all citizens, people with psychiatric disabilities have a fundamental right to give informed consent to treatment. This right must be vigorously protected, and objections to medication and other interventions must be addressed through procedures that assure due process. In short, the U.S. Constitution provides individuals with psychiatric disabilities in hospital settings a broad range of fundamental rights.

Federal statutes also guarantee significant rights. In a ruling with enormous implications for individuals with psychiatric disabilities to have meaningful choice in their lives, the U.S. Supreme Court ruled that the Americans with Disabilities Act prohibits the hospitalization of individuals who could live independently in the community with appropriate support (*Olmstead v. L.C.*, 527 U.S. 581 (1999)). In the community, individuals with psychiatric disabilities have rights under Federal and state laws to individualized mental health services, health care, and income benefits, and to be free from discrimination in housing and employment. Children and young adults have the right to a free, appropriate public education.

Rights are not self-executing but must be vigorously promoted and protected. The enforcement of the right to be free from “unnecessary institutionalization,” and the other rights enumerated above, has the capacity to transform the mental health system and to give each person the opportunity for “a life in the community.” This most fundamental of rights will be achieved only with skilled, dynamic, and sustained advocacy. PAIMIs have sought to enforce many of their clients’ rights and have employed a variety of tactics to protect and extend these rights. These programs have created new entitlements, such as the right of individuals in locked facilities to have daily access to the outdoors. Approaches vary across PAIMIs because no specific mix of available protection and advocacy strategies (e.g., informal assistance, individual representation, law reform litigation, legislative lobbying, policy advocacy, education) has proven most effective in every situation in advancing the interests of people with psychiatric disabilities. States also differ with respect to the existence and role of other advocacy organizations. For example, in some states, there may be a need for the PAIMI to address housing-related discrimination, but in others a separate advocacy organization may handle those cases and the PAIMI can make referrals and prioritize another area of need. PAIMIs need to work with their client communities in each state and territory to continuously revise the program’s priorities, review its effectiveness, and adjust its strategies.

PAIMIs have done much, yet the reality remains that public mental health services are woefully inadequate across the country, and more rights protection efforts still are needed. The much-

viewed recent video of a woman left without services for more than 24 hours in an urban psychiatric emergency room, who lay ignored on the floor until her death, shows the unfathomable degree of abuse that continues in some parts of the mental health system.⁴⁰

C. Outcomes: Lessons Learned and Recommendations

Process Outcomes

- CMHS should use its regulatory authority to enforce the law regarding PAIMI access to individuals, records, and facilities.
- CMHS should periodically remind the SMHAs that receipt of PAIMI funding requires PAIMI Programs be ensured independence in discharging their responsibilities.
- PAIMI grantees should work as closely as possible with organizations led by people with disabilities.

Distal Client and Systemic Outcomes

- Insufficient funding is the most crucial factor limiting the PAIMI Program's effectiveness.
- PAIMIs should work with their advocacy and minority communities in each state and territory to revise program priorities and review effectiveness of advocacy interventions.

⁴⁰ <http://www.youtube.com/watch?v=Cblb5QKPUXQ>

CHAPTER 6

SUMMARY OF LESSONS LEARNED AND RECOMMENDATIONS

A. Tensions Remain Inherent in Program Structure

When the PAIMI Program was enacted, several key issues were resolved through compromise.⁴¹ As this evaluation demonstrates, many of these issues continue to play an influential role in how, and how well, individual PAIMIs fulfill their responsibilities. Placement of the PAIMI Program, an advocacy program created for individuals with persistent psychiatric disability at risk of abuse and neglect, within the developmental disabilities P&A system has played out most of the strengths and challenges perceived at the outset of that compromise.

On one hand, the evolution of a multifaceted advocacy program with varied funding streams has provided a stronger and more stable base for the program than would a separate mental health advocacy program. The fears of retaliatory redesignation if a program antagonized a governor have not been realized, although lesser efforts to control PAIMI advocacy have been experienced on occasion. The migration of state-agency–based programs over time into nonprofit advocacy organizations has addressed another concern.

On the other hand, continuing challenges remain because of structural tensions. Programs must contend with extensive duplication and record-keeping burdens resulting from separate legislative provisions and administrative oversight. At the same time, the ability of programs and staff advocates to provide specialized services for individuals with psychiatric disabilities is challenged. The lack of separate PAIMI staffing, together with overall resource constraints on staffing and TA, compromise the capacity of staff to maintain specialized mental health expertise and relationships with the myriad of mental health stakeholders.

Significantly, the provisions designed to ensure that those with experience utilizing mental health services would influence the P&A are not as strong as they should be. For example, PACs are not nearly as influential as intended. PACs were established to provide some assurance that the needs of people with mental illness were fully known and understood within the P&A. However, P&A staff guide councils through their paces—not the other way around. Council term limits, which force member turnover, were enacted to move the baton of membership to more individuals in a community—a sound idea. However, the current term limits have also led to inexperienced councils. Turnover requirements should be revised to allow at least two consecutive 3-year terms.

Rather than duplicate or rubber-stamp the assessment of PAIMI goal achievement annually, councils could turn their focus to quality improvement work. Councils are already conducting

⁴¹ Scallet, L. J., Marvelle, K., & Davidson, L. (1990). *Protection and advocacy for mentally ill individuals*. Legislative history and analysis of P.L. 99–319, Mental Health Policy Resource Center, 1988.

focus group meetings and outreach for PAIMI priority-setting, activities related to quality management. Their activities could be directed to gather client-related outcome data for targeted and ongoing quality improvement. National data on client outcomes are scarce in the PAIMI system. CMHS could consider piloting a quality improvement tool with several questions regarding outcomes for clients that received PAIMI advocacy services. The tool could be pilot-tested for a few years with several volunteer councils, critiqued, and perhaps adopted across the system. The survey instrument created for PAC chairs for this evaluation could serve as a starting point for such a tool.

This evaluation also found that P&A governing boards lack much breadth in mental health representation. Nearly all boards in the sample have one representative who is knowledgeable about issues impacting those with psychiatric disabilities and their families—the PAC chair. Further, council chairs are not very experienced with PAIMI, or P&A, matters, when they assume this leadership position. In addition to the PAC chair, other council members should be voting members of their P&A governing boards.

B. The Funding and Administrative Position of the PAIMI Program Do Not Fully Meet Program Objectives

The program was originally enacted with full recognition that funding would not be enough to fully meet the objectives sought, and this has proven true. Funding has not kept up with inflation, much less with the expanding legislative mandate. A specific requirement for the annual report to Congress was to include “a description of needs for such activities and services which have not been met by systems established under this title” [Sec. 114(a)(4)]. Partly as a result of its low funding level, the administrative position of the PAIMI Program is seriously compromised within CMHS. Given the far more extensive CMHS funding for and interaction with SMHAs, placement of the administration of the PAIMI Program together with administration of the SMHB grant is problematic. It is part of the design of the PAIMI that its interests and views on appropriate state policy may conflict with those of its SMHA. However, within CMHS, financial resources and Federal staff expertise and capacity are weighted toward state concerns to the detriment of PAIMI. GPOs are insufficiently supported to provide the oversight and support necessary to manage the program and advance its success.

Each of the eight federally created disability advocacy programs has different rules and reporting requirements. While Federal officials have duly noted such and are working to create means to reduce redundancy and clarify areas of opposite directives, no urgency is noted in these endeavors. This evaluation found little communication among Federal officials within the same branch of an agency and far less between Federal agencies devoted to disability work.

C. PAIMIs Address the Issues and Settings Intended but Continue to Have Problems Obtaining Access to Some Facilities and Records

This evaluation documents the wide range of issues and settings represented in PAIMI activities. Within the limitations of funding, the programs are doing a good job setting priorities while addressing the fundamental concerns for which the PAIMI Program was established. At the same time, the evaluation has also documented the continuing problems with access to facilities and records. The CMHS must assist the program by sending a clear and repeated message to SMHAs that the rights of those with psychiatric disabilities are to be respected, and where infringement of a right is necessary, to provide full due process to the individual including representation that gives the individual a voice in the proceedings.

As presented in Chapter 5, the rights of people with psychiatric disabilities are not self-executing and must be vigorously promoted and protected. PAIMIs have done much, yet the reality remains that public mental health services are woefully inadequate across the country, and more rights protection efforts still are needed.

D. Conclusion

Evaluation activities should offer guidance for improving the program studied as well as accountability information on the use of public funds. This external evaluation found that individual PAIMI Programs provide those with psychiatric disabilities a voice in the exercise of their rights and are highly successful in achieving client and system goals and objectives. The program nationally contributes to the transformation of the mental health system into a more open, adaptive system that promotes recovery. The principal constraint facing this program is its large mandate and very limited funding. However, there are aspects of the program that need improvement at both Federal and local levels.

Abbreviations and Acronyms

ADD	Administration on Developmental Disabilities
CAP	Client Assistance Program
CMHS	Center for Mental Health Services
CRIPA	Civil Rights of Institutionalized Persons Act
DD Act	Developmental Disabilities Act
DOJ	Department of Justice
EAW	Evaluation Advisory Workgroup
FTE	Full-Time Equivalent
FY	Fiscal Year
GAO	Government Accountability Office
GPO	Government Project Officer
GPRA	Government Performance and Results Act
HIPAA	Health Insurance Portability and Accountability Act
HSRI	Human Services Research Institute
MHBG	Mental Health Block Grant
MHSA	Mental Health Systems Act
NAMI	National Alliance for the Mentally Ill
NIMH	National Institute of Mental Health
NDRN	National Disability Rights Network
OMB	Office of Management and Budget
P&A	Protection and Advocacy
PAAT	Protection and Advocacy for Assistive Technology
PABSS	Protection and Advocacy for Beneficiaries of Social Security
PAC	PAIMI Advisory Council
PADD	Protection and Advocacy for Persons with Developmental Disabilities Program
PAIMI	Protection and Advocacy for Individuals with Mental Illness
PAIMIs	Refers to PAIMI Programs
PAIR	Protection and Advocacy for Individual Rights
PART	Program Assessment Rating Tool
PATBI	Protection and Advocacy for Individuals with Traumatic Brain Injury
PAVA	Protection and Advocacy for Voting Accessibility
PPR	Program Performance Report
RSA	Rehabilitation Services Administration
SAMHSA	Substance Abuse and Mental Health Services Administration
SMHA	State Mental Health Authority
SPSDB	State Planning and Systems Development Branch
TA	Technical Assistance
TASC	Technical Assistance Skills Contract
TBI	Traumatic Brain Injury
TWWIIA	Ticket to Work and Work Incentive Improvement Act

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