

## **Exploring Personal Assistance Services for People with Psychiatric Disabilities: Need, Policy, and Practice**

By Dianne Doyle Pita, Marsha Langer Ellison, and Marianne Farkas, Sargent College of Health and Rehabilitation Sciences Center for Psychiatric Rehabilitation, Boston University, and Thomas Bleecker, World Institute on Disability

**JOURNAL OF DISABILITY POLICY STUDIES**

VOLUME 12, NUMBER 1, 2001

Copyright © **PRO-ED, Inc.**

Reprinted with permission

This article explores the concept of personal assistant services (PAS) applied to people with psychiatric disabilities through a study of state policy, a secondary analysis of existing data on PAS for all disability populations, and a needs assessment conducted with consumers of mental health services. Findings indicate that some state programs include this population among the other disability groups or eligibility criteria used. Further, administrators tended to confuse PAS with rehabilitation and case management. A majority of consumers surveyed considered PAS to be potentially very helpful in their daily lives. They also valued having direct control over the assistant. The services they most frequently reported as needing included transportation, emotional support, help with negotiating social service agencies, and hands-on assistance with household needs. A unique agenda for psychiatric PAS calls for a combination of the delivery of the above services within a context of consumer control.

Personal assistance services (PAS) for people with physical disabilities is well defined, and policy and implementation of PAS has gained a secure footing over the past 30 years (Batavia, DeJong, & Bouscaren-McKnew, 1991; Litvak, Zukas, & Heumann, 1987; Flanagan, 1994; Kimmick & Godfrey, 1991). The PAS model has also been applied to people with psychiatric disabilities (Stewart, 1991; Litvak, 1998; World Institute on Disability, 1999; Nosek, 1990b). This article attempts to illuminate the state policy, implementation, and need for PAS services for people with psychiatric disability, a modality referred to here as psychiatric PAS.

Understanding PAS as constructed for those with physical disabilities provides groundwork for conceptualizing psychiatric PAS. According to Doty, Kasper, and Litvak (1996), the term personal assistance services refers to a range of human and mechanical assistance provided to persons with disabilities of any age who require help with routine activities of daily living (ADLs) and health maintenance activities. PAS may be broadly defined as including assistive technologies, home modifications, psychosocial rehabilitation, and other specialized products and services (Doty et al., 1996). Commonly, PAS is conceived as the provision of assistance by one person (an attendant) to another, so that major life activities are accomplished. PAS is meant to enable individuals with disabilities to live successfully in the community and to function as full citizens. Research supports the perspective that PAS facilitates increases in work and community engagement (Richmond, Beatty, Tepper, & DeJong, 1997; Nosek, Fuhrer, & Potter, 1995; Dautel & Frieden, 1999). In-home supports like PAS have also been shown to be cost-effective relative to institutional costs (Ellison & Ashbaugh, 1990).

Adoption of the PAS model is apparent by its availability for some populations in every state. In 1987,

145 state-operated PAS programs were identified by the World Institute on Disability (Litvak et al., 1987). PAS has been available in the federal Medicaid program through the personal care services option since 1965, and as of 1994, 32 states included this option in their state plan (Egley, 1994). Other sources of funding for PAS have included the Social Services Block Grant, Medicaid waivers, Older American's Act funding, Veteran's Aid and Attendant Allowance, and state and local funds (Litvak et al. 1987).

## **Consumer-Directed Personal Assistant Services**

An important evolution of the PAS model has been the advent of consumer-directed PAS (CD-PAS). Many of the original formulations of PAS adopted a medical model wherein physicians authorized services in accordance with a treatment plan, nurses supervised the attendant, and services were administered and delivered through a home health care agency. However, arising from the independent living movement, many proponents of PAS have stressed the need for a model in which consumers of services have ultimate control and direction over their PAS. Areas of control included the definition of services rendered, service frequency and duration, and the selection, training, and retention of the personal attendant (Defong & Wenker, 1983; Shapiro, 1993; Flanagan, 1994; Doty et al., 1996). Research on CD-PAS has shown that many consumers prefer PAS arrangements that allow them to be in control and that such programs are legally and economically feasible (Litvak, 1998). A resolution to this effect was passed at the International Personal Assistance Service Symposium (IPASS) sponsored by the World Institute on Disability (WID) in 1991.

The resolution stated that the provision of PAS should assist individuals with disabilities to participate in every aspect of socio-cultural life including, but not limited to home, school, work, cultural and spiritual, leisure, travel, and political life. The resolution highlighted the importance of PAS not becoming simply another name for agency-provided and agency-controlled home care (Nosek & Howland, 1993). The limitation of CD-PAS is that with choice and control come responsibility and risk for the consumer; the attendant may be considered the consumer's employee rather than an independent contractor. As an employee, consumers assume the burden of paying attendants, Social Security, unemployment taxes, associated liabilities of employers, and insurance for attendants. In addition, persons with disabilities vary greatly in their ability and desire to manage their attendant (Flanagan, 1994). In response to these issues, states have begun to develop a variety of intermediary service organization (ISO) models to facilitate the use of CD-PAS by consumers. An ISO is an entity that acts as an interagent between a CD-PAS program and participating consumers for the purpose of disbursing public funds and assisting consumers in performing tasks associated with the employment of PAS attendants (Flanagan & Green, 1997).

## **Psychiatric PAS**

A growing population base for PAS services is among people with developmental disabilities (Kimmick & Godfrey, 1991; Litvak, 1998). Similarly there is an evolving recognition that PAS has the potential for becoming a meaningful, efficient, and effective means for serving people with long-term mental illness (Dautel & Freiden, 1999; Nosek, 1990b; Stewart, 1991). Expanding this service to people with psychiatric disability is highlighted in an executive summary of a conference of experts in the field of personal assistant services (World Institute on Disability, 1999). As it is conceived for people with physical disabilities, an individual may provide assistance to people with psychiatric

disabilities so that they can achieve greater independence from more intensive or medically oriented services and function more fully as citizens. The actual services provided by the attendant, however, are likely to differ from those provided to people with physical disabilities. Help with activities of daily living will less likely require hands-on assistance to transfer from one place to another, but will more likely mean providing the cues, reminders, and encouragement necessary for those with psychiatric disabilities to focus on needed tasks, sequence necessary steps, and initiate effective and concerted actions. Like people with physical disabilities, those with psychiatric problems may also require assistance with budgeting, meal preparation, hygiene, and transportation, but again the form of the assistance would likely change from a provider who contributes the physical assistance to one who provides cognitive and emotional assistance.

The application of PAS to the psychiatric population is attractive for several reasons. PAS has an established funding base through the Medicaid personal care option, which can be a considerable source of federal revenue for states that wish to serve their Medicaid recipients with psychiatric disabilities in this way. By linking with PAS, the psychiatric disability community strengthens its inclusion in cross-disability groups and advocacy efforts (Deegan, 1992). Further, the consumer directed models of PAS are consistent with consumer calls for greater empowerment in the services they receive (McLean, 1995; Ellison, 1996; Rappaport, Swift, & Hess, 1984). Nonetheless, there are difficulties in a simple expansion of the original concept to those with psychiatric disabilities. Chief among these is the confusion of PAS with other services already well defined for the psychiatric population, especially case management and psychiatric rehabilitation services (Ellison, Rogers, Sciarappa, Cohen, & Forbess, 1995; Anthony, Cohen, & Farkas, 1990). For example, there may be direct overlap between a psychiatric PAS provider and a mental health case manager, when the typical functions of both providers may include setting up appointments with social service agencies, arranging transportation, and accompanying the client during an agency visit.

Similarly, how are we to construe the help that is provided by a supported housing counselor who will help a resident with a psychiatric disability get up, remember to take medication, and plan and prepare a meal? Is this PAS or rehabilitation? Is the vocational rehabilitation counselor a personal assistant when they accompany the individual to a job interview or when they provide support on the job? Key criteria for distinguishing these models may be the aspects of consumer control and citizenship. It becomes less a question of the nature of the tasks performed and more of the context and purpose of the service. Does the service model embody consumer independent living, empowerment, and citizenship? Conversely, does the service rely on professional and medical decision making and methods of social control? To help differentiate an agenda for psychiatric PAS and to determine the presence, strength, and direction of psychiatric PAS in the United States, a three-fold research effort was undertaken: (a) a national policy assessment, (b) an analysis of existing data on PAS programs, and (c) a needs assessment of this service derived from people who have a psychiatric disability. Methods and findings for each of these efforts follow.

## **NATIONAL POLICY ASSESSMENT**

### **Method**

To conduct the policy assessment, a telephone interview strategy with state administrators knowledgeable about PAS was developed. After discussions with key informants in this area, an

interview guide was constructed to obtain comparable information across states. The interview guide consisted of open-ended items that queried state administrators on topics including the purpose of their program, eligibility requirements, numbers of people served, services offered, funding mechanisms used, consumer satisfaction with services, overall perspectives on implementing these services in this state, and related questions. The survey instrument was sent to directors of state mental health agencies listed on a roster of the membership of the National Association of State Mental Health Program Directors (NASMHPD). It was also sent to each state Medicaid director listed by the National Association of State Medicaid Directors. This mailing resulted in a response rate of 10% by mail and telephone. Potential respondents were then also contacted through email addresses provided on the two directories. In all, information was received from 41 states through email, mail survey, and telephone interview sources. Nine states made no replies to any inquiries.

## Results

For the nine states that did not reply, we can make no assumptions about the presence of psychiatric PAS. Among the 41 states that did respond, 32 (78%) indicated that they provided psychiatric PAS and did so through a variety of programs funded by the Medicaid option for psychosocial rehabilitation services. When queried further about the nature of the services offered, it became clear that nearly all respondents were referring to services in their state as being PAS, although these services were conceived, implemented, and funded within the framework of psychosocial rehabilitation services. Commonly, case management services were described as being PAS. Further, the majority of states viewed psychiatric personal assistance as an element of psycho-social rehabilitation rather than seeing it belonging as to an independent living framework. In addition, the majority of states that have chosen the Medicaid rehabilitation option as a PAS funding mechanism reported doing so for a variety of philosophical, financial, political, and organizational reasons, including a lack of knowledge as to how to otherwise obtain federal funding for PAS. They also explained making this funding choice because the rehabilitation modality is more empowering than PAS. Respondents explained that in rehabilitation, the person is viewed as being in the process of learning the skill for him? or herself, whereas in the latter case, the person is receiving a support service and having a task done for them.

Four states indicated that they provided PAS services to people with psychiatric disabilities through the Medicaid waiver. One of these waivers was designed exclusively for people with psychiatric disabilities and was created in response to a class action lawsuit. As this was the only PAS program identified that exclusively served people with psychiatric disabilities, more detail on it follows. To qualify for this program, one must be Medicaid eligible, 18 years or older, have severe mental illness, and qualify for long-term care. Since 1994, approximately 785 people with mental illness have been served. To receive this service, application is made at a local mental health system. A case manager does an assessment, and the consumer and case manager develop a plan of care. Service begins 1 to 2 months later. This program is not consumer directed, although recipients have input in the treatment plan. The respondent indicated that most recipients have a diagnosis of schizophrenia. Little other data were available.

None of the other waivers reported on were written exclusively for adults with psychiatric disabilities; however, state administrators reported that people with psychiatric disabilities are eligible and are being provided PAS through these waivers. For example, one state uses a waiver to redirect people

inappropriately placed in skilled nursing facilities to community-based living arrangement by providing PAS. On the whole, administrators were not able to report the number of people with psychiatric disabilities served, although the total numbers of people or percentage with psychiatric disabilities served is reportedly small. Administrators were also unable to describe how PAS differed for this population in comparison with the other populations included. Data on consumer satisfaction with services were also not available.

Several managers expressed frustration with the way in which the waivers and options were determined. They felt their states were smaller, poorer, and had less power over federal waiver administrators than other states that were able to implement PAS for persons with psychiatric disabilities. Other program managers did not know how to go about implementing psychiatric PAS. Some state administrators expressed fear that lawsuits demanding comparable coverage for psychiatric disabilities vis-a-vis other disability groups could be financially unmanageable. Others characterized the ongoing shift toward managed behavioral health care structures as having potential for increased psychiatric PAS. The majority of all program managers expressed satisfaction with current services, were not considering changing their services in the future, and were mainly concerned with keeping current services funded.

Four states indicated that they provide PAS solely to children with psychiatric disabilities, and two additional states referred to initiating this service. These services were primarily offered through Departments of Mental Health using Medicaid waivers to prevent institutional care. Children are evaluated for functional limitations, and the attendant assists the parent in managing the needs of the child. For instance, a personal assistant comes to the home to help the parent get the child off to school. As one informant put it, "These waivers are offered so that caretakers can access attendant care and get a break." The total numbers of children served were unavailable.

Regarding consumer-directed PAS, only one state reported experience with this. This state described the past existence of a failed consumer-directed PAS demonstration project. In another state, administrators were interested in the consumer-directed model, but were unable to find qualified providers. They attempted to implement ISO PAS, but found that service providers qualified to offer PAS to persons with a physical disability did not have the necessary knowledge and awareness to offer PAS to those with a psychiatric disability.

## **SECONDARY DATA ANALYSIS FROM THE WORLD INSTITUTE ON DISABILITY**

### **Method**

A secondary analysis of the WID database on PAS programs in the United States was also conducted to augment the findings of the policy assessment. The 1995 WID sample comprised 144 state-level PAS programs across all disabilities including the aged. Any one state could sponsor several PAS programs through different state departments, for different populations, and for varying purposes. Data on the identified programs were derived from a variety of state and federal sources and were refined over three successive survey waves of program directors. The WID sample is likely to be the most comprehensive listing of state-sponsored PAS programs in the United States and a fourth survey is presently under way.

## Results

Analysis of 1995 data showed that 41 (28%) of the 144 WID identified programs indicated that a psychiatric disability qualifies an individual for receiving PAS in their program. When PAS programs that exclusively served the aged were eliminated from this list, there were 30 programs (21% of 144) that included adults with psychiatric disabilities among their eligible populations. These 30 programs also included other disability groups among their eligible populations (e.g., mental retardation, brain injury, and physical impairments), and other eligibility criteria aside from disability status were often used, (e.g., HIV status or at risk for institutional care). There were no programs identified that reported serving exclusively those with psychiatric disabilities in this data set.

## NEEDS ASSESSMENT OF PSYCHIATRIC PAS

### Method

An additional perspective on psychiatric PAS was acquired through a needs assessment of consumers of mental health services. Consumer-participants in psychosocial rehabilitation facilities across the United States completed a brief paper and pencil survey that inquired about the types and amounts of such services they perceive as needed. To acquire the sample, a roster of program members of the International Association of Psychosocial Rehabilitation Services that serve at least 50 consumers of mental health services was used as a sampling frame. Programs were stratified by region of the country, then randomly selected. Each program was solicited for participation, and random replacements were made to select another program in that region if the first refused. All participating programs agreed to distribute 30 surveys to their members with psychiatric disabilities, collect completed surveys, respond to any questions respondents had in filling them out, then return surveys by mail to the Center for Psychiatric Rehabilitation. Each participating program received \$100 for their assistance. Identities of individual respondents were kept anonymous. The survey consisted of 11 closed-ended items, including a checklist of services needed, and an additional section of demographic questions.

### Results

A total of 462 consumers replied in 19 programs across 15 states. Demographic characteristics of this sample were as follows: 50% (n = 230) of the sample were women; the mean age was 42 years (range 19-78); 36% (n = 166) completed high school, 21% (n = 96) did not have a high school degree, and 40% (n = 183) had more than a high school education (4%, n = 17, were missing); 57% of the sample (n = 263) were single, 11% (n = 49) were married or cohabitating, 32% (n = 137) were divorced, widowed, or separated, 3% (n = 13) were missing; 58% (n = 256) received SSI benefits and 48% (n = 208) received Medicaid benefits; and 72% (n = 334) were White, 22% (n = 101) were Black non-Hispanic, and the remaining had other minority statuses. Working status suggests that 63% (n = 291) were unemployed and the remaining had a variety of independent and supported work statuses. Forty-three percent (n = 199) indicated that they live alone, 22.9% (n = 106)

lived with a spouse or significant other, and the remainder lived with family or roommates or in a group home. Table 1 displays the frequency of importance assigned by respondents to a list of services traditionally offered through personal assistants and those that may be included in psychiatric PAS. We found that the most frequently mentioned services rated as very important were transportation (67%, n = 298), supplying emotional support with problems and feelings (63%, n = 278), and help with negotiating social service systems and agencies (63%, n = 272). Nearly half of the sample indicated that more traditional PAS services (e.g., help with household routines [43%, n = 1801 and help with physical bodily needs [40%, n = 1741) were very important. Among "other" replies to services needed, 7 people referred to needing help with employment, 6 people referred to help with socializing, and 3 referred to legal advocacy. Respondents indicated that they would need these services often: 25% (n = 114) indicated daily need, 35% (n = 157) indicated such need for a few times a week. Eleven percent of the sample replied that they would need no hours of PAS. Two

thirds of the sample (66%, n = 296) felt these services would help them "a lot" in their daily life. The majority of respondents indicated that they were already receiving some help with these PAS tasks, primarily from family members, friends, or roommates (56%, n = 258), their case manager (55%, n = 252), their clubhouse or self-help organization (39%, n = 182), or their residential counselor, job coach, or rehabilitation counselor (27%, n = 123). Notably, 62% (n = 207) of the consumers considered it very important or important to have direct control over the personal assistant (e.g., that they select, train, and supervise the assistant), but 58% (n = 268) responded that "a great concern" would be responsibility for paying salary, withholding taxes, and filing government forms. The majority (62%, n = 285) indicated they would most likely prefer to have an agency handle these tasks. Among a list of other possible worries about using a personal assistant, having funding to pay for a personal assistant concerned 66% (n = 304) of respondents. Fears about safety with a personal assistant were reported by 43% (n = 198) of respondents, knowing how to select a good personal assistant was a concern for 42% (n = 193), knowing how to supervise a personal assistant concerned 37% (n = 170), and 36% (n = 168) worried about an invasion of their privacy.

TABLE 1  
Perceived Importance of Potential Psychiatric Personal Assistance Services Among Consumers of Mental Health Services

| Services (total number excluding missing answers)  | Very important |       | Somewhat important |       | Not important |       |
|--|----------------|-------|--------------------|-------|---------------|-------|
|  | %              | (n)   | %                  | (n)   | %             | (n)   |
| Help me to get to the places I want to go (transportation). (N = 444)  | 67             | (298) | 19                 | (85)  | 14            | (61)  |
| Having someone who I can discuss my problems or feelings with. (N = 442)   | 63             | (278) | 24                 | (107) | 13            | (57)  |
| Help me deal with social service agencies or medical facilities (for example, social security, welfare, hospitals, vocational programs). (N = 434)   | 63             | (272) | 21                 | (93)  | 16            | (69)  |
| Help me cope with or get through my symptoms (for example, panic attacks, depression, disorientation, hearing voices, inability to concentrate or focus). (N = 438)                          | 57             | (248) | 23                 | (103) | 20            | (87)  |
| Help me manage my money (for example, budgeting, writing checks, using the bank). (N = 421)  | 48             | (200) | 24                 | (100) | 28.5          | (120) |
| Help me with my household needs or routines (for example, cooking, cleaning, shopping). (N = 422)  | 43             | (180) | 30                 | (128) | 27            | (114) |
| Help me cope with stressful situations on the job. (N = 399)   | 49             | (194) | 25                 | (100) | 26            | (105) |
| Help me remember to take my medication. <sup>a</sup> (N = 358)   | 45             | (162) | 22                 | (78)  | 33            | (118) |
| Help me organize or remember my daily tasks and activities. (N = 429)  | 41             | (177) | 31                 | (132) | 28            | (119) |
| Help me deal with my physical/bodily needs (for example, personal hygiene, eating properly, getting proper sleep, dealing with illness or physical problems, improving my health). (N = 422) | 40             | (174) | 26                 | (111) | 33            | (142) |
| Help me deal with my landlord or other problems associated with my living situation. (N = 427)   | 40             | (169) | 29                 | (125) | 31            | (133) |
| Help me with parenting my children. <sup>b</sup> (N = 185)   | 33             | (61)  | 21                 | (37)  | 47            | (87)  |
| Help me start the day (for example, calling or assisting me to get up). (N = 429)  | 29             | (125) | 26                 | (112) | 45            | (192) |

<sup>a</sup>Not applicable n = 64 (14% of 462). <sup>b</sup>Not applicable n = 245 (53% of 462).

## Discussion

Findings showed that psychiatric PAS is still in a nascent state in terms of policy and practice whereas there is ample consumer interest in these services. The analysis of the WID data confirmed the findings of the policy review, that is, there is virtually no implementation of programs of psychiatric PAS per se. WID data demonstrates that to the extent that people with psychiatric disabilities are receiving PAS, it is primarily because they either qualify under criteria created for those with other disabilities or because psychiatric disability has been included in a roster of qualifying conditions along with other disabling conditions. It is unknown how many people with psychiatric conditions may be receiving PAS in such a manner, although it would appear to be small. Likewise, it is unknown how and to what extent traditional PAS services are being reconfigured to support people with psychiatric disabilities. In addition, one must ask whether an agency that is delivering services primarily to people with physical disabilities or with mental retardation can be expected to competently and appropriately address the needs of psychiatric consumers. Therefore, competency guidelines and program evaluations need to be considered for agencies serving persons with a psychiatric disability.

Reviewing the findings of the policy analysis, there is evident confusion surrounding how PAS is

interpreted for people with psychiatric disabilities. Given the broad definition of PAS provided in our survey materials, it is easy to understand how state administrators, especially when they are not already familiar with PAS through another context, may perceive psychosocial services as fitting under a PAS definition. The policy assessment demonstrated that state administrators generally substitute rehabilitation services and case management for psychiatric PAS. The overlap between these services and that of PAS is clear, and teasing apart these two models of service delivery may be difficult. Further, unlike psychiatric PAS, rehabilitation and case management each have considerable history and a well-developed ideology and practice base, as well as widespread implementation.

Taking the findings of the WID data and of the policy analysis together, it becomes apparent that when PAS is implemented for people with psychiatric disabilities, it is done under existing conceptualizations and mechanisms of PAS for other groups; further attempts to distinguish psychiatric PAS leads to interpreting it within preexisting mental health service modalities. Consequently, establishing an agenda that is particular to psychiatric PAS becomes necessary. This may require either repackaging existing service strategies or distinguishing a set of principles and practices that are unique to psychiatric PAS.

The creation of a uniquely conceptualized service can draw in part from the consumer-controlled aspect of PAS. While self-determination is a goal in both rehabilitation and case management, neither of these service modalities is likely to support the extent of consumer control found in some PAS and in its ideology. Promoting psychiatric PAS may have more to do with advancing a civil rights perspective for people with psychiatric disabilities and empowering them to direct their own assistance. Nonetheless, addressing the aspect of consumer-directed PAS is complex. A majority of consumers in the needs? assessment survey preferred to have direct control over their PAS. However, they also expressed a preference for having an agency handle legal and bureaucratic requirements. Intermediary service organizations appear to be a viable solution for this dilemma.

Reviewing findings of the consumer-needs survey reported on here can also contribute to conceptualizing a unique psychiatric PAS modality. Consumers in the survey did report that a PAS modality can help them "a lot" with daily life. Of significance is the constellation of practices that they have defined as most important. In descending importance, transportation was key to most consumers and this service is often missing from rehabilitation and case management programs. Help with social service agencies, having someone with whom to discuss problems, and help with symptom management are roles well defined by case management and traditional mental health services. However, given the spotty access to case management across the country, these would seem to be necessary components of psychiatric PAS. Help with money management, household routines, and organizing daily tasks were important to nearly half of consumers. These services would typically be provided by residential counselors, but then, such counselors are often found in fairly restrictive housing settings. Promoting an agenda of supported housing for people with psychiatric disabilities in the least restrictive settings is clearly linked to consumers having access to such help, and this help can be provided in such settings by using a PAS model. The survey findings also demonstrated that the expressed need for PAS is moderate. System planners can take some assurance in initiating a fairly inexpensive service model that is not likely to yield unmanageable demands for services.

Further, the agenda of PAS indicates that assistance should be made available so that people with psychiatric disabilities can participate in all areas of life. Presently, rehabilitation programs and case management tend to carve out areas of assistance, such as housing, work, and social networks. PAS offers the possibility of highly flexible support that is not encumbered by predefined areas of intervention. In brief, we can construct a psychiatric PAS agenda that is based on the following: high levels of consumer control, but with support for employer practices, provision of transportation, emotional support, social system advocacy, and help with daily routines.

## **Future Directions**

Additional research is needed to explore the existing practices of psychiatric PAS so that they can provide directions for future program planning. Direct comparisons of psychiatric PAS with similar programs, such as case management, supported housing, or rehabilitation, will inform us as to the cost effectiveness of one model versus another, as well as to the relative differences in empowerment or other outcomes in major life domains.

The data so far provide little instruction on the political path to take to establish psychiatric PAS. WID and other disability groups have advocated for a national entitlement to PAS, particularly by expanding the Medicaid Personal Care Option. This is certainly the route that, if successful, can reach the greatest number of people. An entitlement would also root itself in a civil rights perspective, which is likely to be more empowering for psychiatric consumers than would be formulations rooted in the medical model. Certainly, joining psychiatric consumers with other disability groups to form cross ? disability coalitions can only strengthen the political potential for realizing psychiatric PAS. However, national action is difficult to achieve, and when it is out of reach, states will act independently. Of equal importance, then, would be concerted efforts to include psychiatric PAS among all other state PAS efforts. However, the policy analysis showed that states were frustrated or uncertain how to proceed with obtaining PAS. Hence, it appears that providing technical assistance and sharing with more experienced states are indicated. A thorough needs assessment within a particular state will also help to clarify the dimensions of any pilot psychiatric PAS programs. Increased state implementation of psychiatric PAS would result in greater experience with and clarification of such services. Widened experience, particularly with consumer-controlled PAS, will contribute to understanding best practices and to conceptualizing the psychiatric PAS agenda.

## **ABOUT THE AUTHORS**

Dianne Doyle Pita, PhD, is an instructor at the University of Massachusetts-Boston and an adjunct professor in the Department of Rehabilitation Counseling at Boston University. She is a dual disorder program consultant with Volunteers of America. She completed her post-doctoral training in psychiatric rehabilitation research at the Boston University Center for Psychiatric Rehabilitation. Marsha Langer Ellison, PhD, MSW, is a research assistant professor at the Sargent College of Health and Rehabilitation Sciences and a senior research associate at the Center for Psychiatric Rehabilitation at Boston University. Marianne Farkas, ScD, is a research associate professor at the Center for Psychiatric Rehabilitation, Sargent College, Boston University. She is also the director of the World Health Organization Collaborating Center in Psychiatric Rehabilitation. Her research interests include psychiatric rehabilitation effectiveness, consumer influence, and recovery-oriented systems. Thomas Bleecker, PhD, is a licensed clinical psychologist and works as the director of

research for the Rehabilitation Research and Training Center on Personal Assistance Services (RRTC-PAS) at the World Institute on Disability in Oakland, California. In addition to disability studies, his research interests include survey methodology, HIV, and domestic violence. Address: Marsha Langer Ellison, Center for Psychiatric Rehabilitation, 940 Commonwealth Ave. West, Boston, MA 02215 (email: ellison2@bu.edu).

## NOTE

This study was supported by a grant from the National Institute on Disability and Rehabilitation Research (Grant No. H133B40024) and the Center for Mental Health Services, Substance Abuse and Mental Health Administration. The views contained herein, however, are the sole responsibility of the authors and do not necessarily reflect the views of the sponsoring agency.

## REFERENCES

- Anthony, W. A., Cohen, M. R., & Farkas, M. D. (1990). *Psychiatric rehabilitation*. Boston, MA: Boston University, Center for Psychiatric Rehabilitation.
- Batavia, A. L., Dejong, G., & Bouscaren-McKnew, L. (1991, Fall). Toward a national personal assistance program: The independent living model of long-term care for persons with disabilities. *Journal of Health Politics, Policy and Law*, 16(3), 523-545.
- Dautel, P., & Frieden, L. (1999). *Consumer choice and control: Personal attendant services and supports in America* (Report of the National Blue Ribbon Panel on Personal Assistance Services). Houston, TX: Independent Living and Research Utilization Program.
- Deegan, P. (1992). The independent living movement and people with psychiatric disabilities: Taking back control of our lives. *Psychosocial Rehabilitation Journal*, 15(3), 3-19.
- Dejong, G., & Wenker, T. (1983, November). Attendant care as a prototype independent living service. *Caring*, pp. 26-30.
- Doty, P., Kasperj, & Litvak, S. (1996). Consumer-directed models of personal care: Lessons from Medicaid. *The Milbank Quarterly*, 74(3), 377-409.
- Egley, L. (1994). *New federal PC option PAS funding rules: Summary*. Berkeley, CA: World Institute on Disability.
- Ellison, M. L. (1996). *Empowerment and demedicalization in mental health case management. Meaning and measurement*. Unpublished doctoral dissertation, Boston University.
- Ellison, M. L., & Ashbaugh, J. (1990). *The dollars and sense of promoting self-sufficiency of persons with disabilities through programs of independent living, in-home and family supports*. Cambridge, MA: Human Services Research Institute.
- Ellison, M., Rogers, E. S., Sciarappa, K., Cohen, M., & Forbess, R. (1995). Characteristics of mental health case management: Results of a national survey. *The Journal of Mental Health Administration*, 22(2), 101-112.
- Flanagan, S. (1994). *Consumer-directed attendant services: How states address tax, legal and quality assurance issues*. Cambridge, MA: Systemetrics, The MEDSTAT Group.
- Flanagan, S., & Green, P. (1997). *Consumer-directed personal assistance services: Key operational issues for state CD-PAS programs using intermediary service organizations*. Cambridge, MA: Systemetrics, The MEDSTAT Group.

Kimmick, M., & Godfrey, T. (1991). *New models for the provision of personal assistance services: Final report*. Bethesda, MD: Human Services Research Institute.

Litvak, S. (1998). Personal assistance services policy: Where we have been and where we are going. *American Rehabilitation*, Winter, 9-14.

Litvak, S., Zukas, H., & Heumann, J. E. (1987). *Attending to America: Personal assistance for independent living. A survey of attendant service programs in the United States for people of all ages with disabilities*. Berkeley, CA: World Institute on Disability.

McLean, A. (1995). Empowerment and the psychiatric consumer/ex-patient movement in the United States: Contradictions, crisis, and change. *Social Science and Medicine*, 40(8), 1053-1071.

Nosek, M. (1990a). *Personal assistance: Key to employability of persons with physical disabilities in the United States*. Report. San Francisco, CA: Disabilities Rights Advocates.

Nosek, M. (1990b). Personal assistance services for people with mental disabilities. Houston, TX: Baylor College of Medicine.

Nosek, M., Fuhrer, M., & Potter, C. (1995). Life satisfaction of people with physical disabilities: Relationship to personal assistance, disability status, and handicap. *Rehabilitation Psychology*, 40(3), 191-202.

Nosek, M., & Howland, C. A. (1993). Personal assistance services: The hub of the policy wheel for community integration of people with physical disabilities. *Policy Studies Journal*, 21, 789-800.

Rappaport, J., Swift, C., & Hess, R. (Eds.). (1984). *Studies in empowerment: Steps toward understanding and action*. New York: Haworth.

Richmond, G. W., Beatty, P., Tepper, S., & Dejong, G. (1997). The effect of consumer-directed personal assistance services on the productivity outcomes of people with disabilities. *Journal of Rehabilitation Measurement*, 1(4), 48-51.

Shapiro, J. (1993). *No pity: People with disabilities forging a new civil rights movement*. New York: Times Books/Random House.

Stewart, L. (1991). Personal assistance services for individuals with psychiatric disabilities. In World Institute on Disability, *Personal assistance services: Political and personal insights in developing a national system* (Report). Oakland, CA: World Institute on Disability.

World Institute on Disability. (1999). *PAS: A new millennium conference executive summary*. Berkeley, CA: Author.