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Personal Assistance Services for Individuals with Psychiatric Disabilities: Provider Training Curriculum

This issue

PERSONAL ASSISTANCE SERVICES

"PAS is fundamentally different from other services because in PAS, the consumer is the one who hires, trains, pays, and (if necessary) fires the person providing the support. The services provided are those that the consumer decides he or she needs help with, rather than the services being decided by an "assessment" done by professionals. While the cost of paying PAS workers is provided by a social service agency, the consumer is the employer of record. By changing the power dynamics between helper and "helpee," PAS provides a powerful example of empowerment and recovery."

—Judi Chamberlin, Senior Consultant, Center for Psychiatric Rehabilitation

People with lived experience frequently desire support to accomplish their goals. What steps should they take? Support for consumers over the long term can unfortunately put a strain on relationships with family, employers, and others, while also not always providing the actual support desired. Personal Assistance Services (PAS) and the Center for Psychiatric Rehabilitation's Personal Assistance Services Curriculum may be part of the solution—and key to independent, self-determined lives.

What Are the Values and Principles of PAS?

Individuals have the right to determine their own lives and goals. The purpose of a personal assistant is to support an individual as he or she seeks to achieve his or her preferred goals in a way that affords them the opportunity to live with dignity, independent of others and better able to participate fully in the community. Collaboration between persons with lived experience and personal assistants (PAs) can be extremely rewarding as well as challenging. This interaction can also be a powerful force for change in the lives of both consumer and provider.

The PAS model of services is very different from traditional mental health services; it is based on a set of values and principles that differ from those that guide the medical model. In sharp contrast to the traditional medical model of mental health services, the PAS model focuses on the individual's self-defined goals and the needs of the person receiving the services. In a medical model of mental health services, individuals—even in community-based services—are identified as patients. "Patients" are considered incapable of making their own decisions, setting their own goals, living independently, and/or participating in their communities of choice. Individuals are frequently told the only way to get better is to follow the doctor's orders with an emphasis on taking medication as prescribed. Often, feelings and actions such as anger, frustration, sadness, grief, or questioning the system are considered part of the individual's illness or pathology.

On the other hand, in the PAS model the role of the "person with lived experience" or "consumer" is that of an empowered individual who directs the process of his or her own recovery. Individuals are not seen as "sick" or "broken." Instead, having a disability such as a mental illness is seen as something with which the individual can learn to live. Various services and supports are integral to this process, helping the individual to achieve their desired goals and lifestyle. The individual determines which services (e.g., skills training, peer support, and others) are necessary to

achieving independence. The purpose of PAS is to help the individual achieve a more fulfilling life than was possible under the discredited practices of the past which led to "warehousing" people in day programs and halfway houses.

Self-determination is a key concept. A consumer with the opportunity for self-determination will choose a doctor *he* or *she* feels comfortable with; someone who will listen and work in partnership with that person. The role of the personal assistant may be to help the consumer who wants more information about medication to do research, so that the person can make informed decisions. The personal assistant might also help the consumer prepare for doctors' appointments by assisting him or her to make a list of questions to ask the doctor. PAS focuses on helping in a way that fosters empowerment.

Background and Development of Personal Assistance Services

The mental health consumer movement developed along parallel lines to movements by people with physical disabilities—such as wheelchair users and people with visual and/or hearing impairments—and people with developmental disabilities formerly called "mental retardation." In all cases, these individuals seek to define their own needs and reject the idea that other people can speak "for" them. All seek to live independent lives, make their own decisions, and be valued despite their differences. This is often referred to as "empowerment" (Wilkinson, 1996–1997; Chamberlin, 1984).

One valuable resource that emerged from the disability rights movement was the Independent Living Center (ILC). There are now nearly 500 ILCs across the nation, creating a service model in an empowering environment run by and for people with disabilities. Independent Living Centers are nonprofit, consumer-controlled, community-based, nonresidential agencies that provide services and advocacy by and for people with all types of disabilities.

Independent living means having control over one's life and being able to make important decisions toward that end. ILC philosophy includes concepts such as the right to fail and the dignity of risk, the right to self-determination, and maximizing self-reliance.

One of the last groups to be served through ILCs was persons with psychiatric disabilities. The goals and challenges of this group were unfamiliar to ILC staff, many of whom did not understand the group-specific problems and initially had difficulty seeing similarities between the experiences of people with physical and psychiatric disabilities. Providing PAS to mental health consumers was a radical idea for many of the ILCs, which primarily served people with mobility disabilities (i.e., people in wheelchairs). ILCs did not understand this different set of disabilities and lacked staff with the skills to provide services to them. Even though many of the issues and needs for consumers were the same (such as access to housing, employment, etc.), additional education and awareness was necessary. Some ILCs overcame these problems to serve individuals with serious psychiatric disabilities (Deegan, 1996–1997). However, even today, many ILCs have yet to fully understand and appreciate the needs and issues of this community. The PAS provider training curriculum developed at Boston University's Center for Psychiatric Rehabilitation is designed to remedy this situation.

PAS developed when it became apparent that a new type of home-based personal assistance was needed to perform the services that many believed could only be done by nurses. One critical element in the process was derived from conversations people with disabilities were having with each other, sharing their experiences and ideas for a more consumer-driven system for necessary personal services. Together, they came to realize that a lay person, hired and trained by the consumer, could perform many of the functions that were previously seen as nursing services. Eventually, personal assistance became a Medicaid-funded service, because it

cost substantially more to keep a person in a nursing home than it did to have a person live independently with support through personal assistance. This change in funding came about because of advocacy by people with disabilities and their organizations (National Council on Independent Living, 1988). Personal Assistance Services are conducted according to the following guiding principles, beliefs, and key values:

Guiding Principles and Beliefs

- Belief that MH consumers (PAS-employers) can recover from mental illness with proper skills and community supports.
- Belief that MH consumers (PAS-employers) belong in the community and not in segregated settings.
- Belief in non-medicalized service models that offer ways to increase community independence.
- Belief that MH consumers (PAS-employers) know themselves and their needs best, and are able to set and attain personal goals.
- Belief in a recovery/resilience-oriented approach, where MH consumers (PAS-employers) are seen as more than the sum of their disabilities.
- A true commitment to these rehabilitation and recovery concepts at all organizational levels, particularly from top leadership, is necessary to implement programs and services using the new PAS model (Bradley, V., 1996).

Key Values

- *Valuing Others*
  Affirms a common humanity with the people they support, recognizing that they share similar aspirations, dreams, hopes, and goals; we are more similar than different.
- *Valuing Self*
  Affirms a common humanity with the people they support, recognizing that they share similar aspirations, dreams, hopes, and goals; we are more similar than different.
- *Valuing Helping*
  Belief in the importance of compassion, empathy, caring, commitment, and cooperation. Recognizes that the administrative priorities of human service organizations sometimes conflict with providing support and finds ways to emphasize the support priorities whenever possible.

What Is the Personal Assistance Services for Individuals with Psychiatric Disabilities Provider Training Curriculum?

The Personal Assistance Services Provider Training Curriculum was developed through a partnership between the Louisiana Department of Health and Hospitals and the Boston University Center for Psychiatric Rehabilitation with partial support by the National Institute on Disability and Rehabilitation Research (NIDRR), the Center for Mental Health Services, and the Substance Abuse and Mental Health Services Administration.

The Personal Assistance Services Provider Training Curriculum prepares those interested in becoming PAS providers for individuals with psychiatric disabilities. The curriculum is designed to be used by other individuals with lived experience—mental health workers as well as those with no expertise in mental health. The PAS Curriculum is free and available through the Center for Psychiatric Rehabilitation's website (www.bu.edu/cpr).

The curriculum consists of two components: knowledge and skills.

- The first component focuses on the knowledge base and is intended for self-study with tests at the end of each chapter. Sections cover materials such as what PAS is; understanding the job of PAS; how people recover and the idea of resilience; and important issues in delivering services.
- The second component focuses on four critical skill sets: Connecting, Coaching, Collaborating, and Managing Crises. This component contains the information a

trainer needs to teach those who wish to provide PAS in each skill area; examples and practice exercises; and workbooks on how to deliver PAS.

Overview of the Trainer Guide to the PAS Curriculum

The Trainer Guide is a resource for trainers who are teaching skills to those who are (or who will be) providing Personal Assistance Services to persons with psychiatric disabilities. The Trainer Guide is a lesson plan for a specific skill set. The four skill sets that comprise the Personal Assistance Services Curriculum are:

- Connecting
- Coaching
- Collaborating
- Managing Crises

Each lesson plan is divided into five sections using teaching technology developed under previous NIDRR/CMHS funding (Cohen, 1985):

- Review—Skill set is introduced.
- Overview—Key information about the skill set is presented.
- Presentation—Specific skills are taught.
- Exercise—Trainees' learning is consolidated.
- Summary—Learning experience is reviewed.

In a classroom setting, trainees learn how to perform new skills from:

- The information that the trainer imparts to them about the skill.
- Observing examples of the skills being performed.
- Having opportunities to practice the skill.

The lesson plan is written as a script with "Tell-Show-Do" instructions for trainers. The knowledge is presented as "Tell," the examples as "Show," and the practice opportunities as "Do." Preparation is key in training; trainers are encouraged to read relevant literature about PAS as well as recovery and rehabilitation prior to the training. Trainers are encouraged to learn of the backgrounds, experiences, and environments of the people they will be training. While each lesson plan includes a sample schedule, this is intended as a guide only, and the trainer must consider the parameters of the particular training experience as they plan the schedule and prepare for the training session. Training is a process, and a trainer's ability to engage and respond to the trainees in the moment and to modify the lesson plan as needed is key to a successful training experience.

Conclusion

Individuals seek to guide their own lives to the fulfillment of their self-determined goals. Comprehensive training in values and skills for personal assistants is the difference between the former practice of provider-driven support and more recent, consumer-driven assistance for the individual.

The PAS Curriculum may be downloaded from the Center for Psychiatric Rehabilitation website at www.bu.edu/cpr/resources/pas-curriculum/index.html.

References

Bradley, V., Taylor, M., Warren, Jr., R. (1996). *Community Support Skills Standards: Tools for Managing Change and Achieving Outcomes.* Cambridge, MA: Human Services Research Institute.

Chamberlin, J. (1984). Speaking for ourselves: An overview of the ex-psychiatric inmates movement. *Psychosocial Rehabilitation Journal* 8(2), 56–64.

Cohen, M. R., Danley, K. S., & Nemec, P. B., (1985), *Psychiatric rehabilitation training technology: Direct skills teaching* (Trainer package). Boston: Boston University, Center for Psychiatric Rehabilitation.

Deegan, P. E. (1996–1997, Fall/Winter). *Personal Care Attendant (PCA) services available to people with psychiatric disabilities.* Lawrence, MA: National Empowerment Center.

The National Council on Independent Living (1988). *Consumer control in independent living.* South Hampton, NH: The Center for Resource Management.

Wilkinson, A. P. (1996–1997, Fall/Winter). *We are more than our disorder.* Lawrence, MA: National Empowerment Center.

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