



Personal Assistance Services: A Vital Workplace Support

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ABSTRACT

This article reports findings from focus groups and survey research on experiences and issues related to the use of personal assistance for persons with disabilities in work settings. These findings underscore the need for consumer control and self-advocacy in planning and arranging workplace personal assistance.

Great disability rights leaders and self advocates like Ed Roberts and Judy Huemann have proven the value of customer-directed personal assistant services (PAS) through their work in the independent living movement and at the World Institute on Disability (WID). These two pioneers demonstrated the value and cost effectiveness of customer-directed PAS in enabling people with significant disabilities to live in the community. Their work was documented in the research monograph *Attending to America* (Litvak, Zukas, & Huemann 1987). This document has become a blue print for establishing the customer-directed PAS model systems being developed in a number of states. These model systems are enabling thousands of individuals with significant disabilities to live and work in the community.

PAS is broadly defined by Nosek (1991) as "assistance from another person with activities of daily living to compensate for a functional limitation" (p. 2). Activities of daily living (ADLs) include such activities as personal hygiene, meal preparation, housekeeping and household chores, and community mobility. In the words of Litvak et al (1987), these are "tasks that individuals would normally do for themselves if they did not have a disability" (p. 1). PAS allows people with severe physical or health impairments to participate more fully in community settings and activities, including employment (West, Mast, Cosel, & Cosel, 1996).

Shortly after the passage of the Americans with Disabilities Act (ADA), the President's Committee on Employment of People with Disabilities (PCEPD, 1998) wrote:

In the workplace, PAS is provided as a reasonable accommodation to enable an employee to perform the functions of a job. The employer's responsibility for providing reasonable accommodations begins when the employee reaches the job site and concludes when the work day ends. PAS in the workplace does not include skilled medical care.

The Job Accommodation Network (JAN) developed a list of possible tasks that could be done by personal assistants in the work-

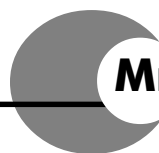
place. Work-related PAS might include filing, retrieving work materials that are out of reach, or providing travel assistance for an employee with a mobility impairment; helping an employee with a cognitive disability with planning or decision making; reading hand-written mail to an employee with a visual impairment; or ensuring that a sign language interpreter is present during staff meetings to accommodate an employee with a hearing impairment. Each person with a disability has different needs and may require a unique combination of PAS.

Many customers with disabilities have gained the skills necessary to manage their own personal assistant by attending PAS training programs offered by Centers for Independent Living (CILs). CILs have done an excellent job of training their participants about how to recruit, hire, and manage a personal assistant in the home environment. CILs consider self-advocacy a very important part of their PAS management training because it is essential to successfully directing a person's personal assistant.

The Rehabilitation Research and Training Center at Virginia Commonwealth University (VCU-RRTC) has long recognized PAS as a valuable support in enabling people with significant disabilities to live in the community. The VCU-RRTC shares the belief that PAS services are most effective when they are directed by people who use them. When people with disabilities are able to self-direct PAS, they can utilize these services when needed without being dependent on a home health care provider.

These beliefs have been reinforced by years of interaction with people with disabilities through demonstration projects, self-determination research studies, and by employing people with significant disabilities. In one of its recent projects, a participant who is now employed at the VCU-RRTC expressed her concerns regularly at not being dressed on time to meet her ride to work. This individual lives in a residential care

facility where the staff seem to not understand her desire to be on time for work. Another individual in the same project had great difficulty in finding a personal assistant to assist him with meals while at work. Both individuals worked with a mentor to develop self-advocacy skills to resolve their problems. In a research study conducted by the VCU-RRTC to determine factors which impact self-determination, respondents said that being able to manage their personal assistant was important to their independence (West, Barcus, Brooke, & Rayfield, 1995). These experiences led to the VCU-RRTC conducting investigations aimed at determining how best to use PAS in the workplace.



METHODOLOGY

There were two distinct phases of this research: two focus groups to define the issues related to PAS in the workplace, and a survey of CIL personnel related to access to PAS in the workplace for their customers. These two phases will be discussed separately.

FOCUS GROUP RESEARCH

Sample: The two focus groups consisted of a total of nine individuals with significant physical disabilities who were employed, four CIL employees, and one personal assistant. The groups also utilized a recorder who has significant disabilities, two facilitators, and two assistants.

The first group included individuals who had little or no experience at managing their own care. Many lived in a residential care facility. The remainder of the group resided in the community.

The other group was conducted at the 1998 National Council on Independent Living (NCIL) Conference held in Washington, D.C.

This group included employees from CILs who utilized PAS in the workplace themselves or CIL managers who provided such services to their employees as a reasonable accommodation. The input obtained from the second focus group lead to the development of a list of tasks that are required to be done by personal assistants in the workplace. See Table 1 below.

Procedure: One focus group was conducted in the Richmond, VA area, and one at the annual meeting of the National Council on Independent Living (NCIL). Congruent with standard focus group procedures (Krueger, 1994), the two groups were homogenous, including one which primarily consisted of customers and one primarily consisted of service providers. The questions posed to the groups were related to the need for personal assistance on the job and difficulties in obtaining PAS for workplace support.

SURVEY RESEARCH PHASE

Survey Development: The survey instrument was developed following the focus groups and addressed the issues by the participants. An initial draft of the survey was piloted, and modifications were subsequently made to the items.

The final version of the survey contained six items related to experiences with obtaining PAS in the workplace for the agency's customers, use of public and private rehabilitation agencies to obtain PAS in the workplace, and issues related to PAS on the job such as training or providers, and customer supervision. Each survey item included a menu of choices and space to provide additional information or comments.

Sample and Procedure: The sample for the survey was drawn from two lists maintained by The Independent Living Center Research and Training Center in Houston, TX and the National Council on Independent Living (NICIL). The survey was mailed to all 400 CILs on the two lists after cross matching to eliminate duplicates. Included in the mailing was a letter requesting that the most appropriate staff member complete and return the survey. A follow-up reminder letter was mailed after 1 month to encourage return of the instrument. A total of eighty completed and usable surveys were returned for a 20% return rate. These representatives were from independent living centers in the United States and Canada.

TABLE 1 -- DUTIES OF PERSONAL ASSISTANTS

PERSONAL DUTIES	JOB FUNCTION DUTIES
<ul style="list-style-type: none"> ● Assist with grooming tasks ● Assist with getting beverages ● Assist with food ● Assist with toileting ● Assist with transportation ● Travel on business trips ● Assist with dressing and grooming tasks while on business trips 	<ul style="list-style-type: none"> ● Make telephone calls ● Assist with filing ● Take dictation ● Voice interpretation ● Assist with making copies ● Enter data ● Take notes in meetings ● Read documents ● Get and open mail ● Keep work-space organized ● Travel on business trips



RESULTS

FOCUS GROUPS

The focus group held in Richmond agreed they were more concerned about obtaining PAS at home than in the workplace. They believed that PAS could be obtained through coworkers, health care providers, and the VR system. Also identified was the need for employees with significant disabilities to receive training on how to manage their personal assistants in the workplace.

One of the most important outcomes from the NCIL group was the wide variety of needs expressed by its members. These ranged from assistance in getting a cup of coffee to having sophisticated computer skills in order to support a researcher at WID. Other information obtained from the NCIL focus group led to a laundry list

of methods used to recruit potential personal assistants who could perform support in the workplace (as seen below in Table 2). Another outcome of the focus groups and of the survey was to come up with a definition of PAS in the workplace that can be understood by employees with disabilities, personal assistants, and employers. This definition is:

“Personal assistance services in the workplace are services provided to an employee with a disability by a personal assistant to enable the employee to perform the essential duties of a job more efficiently.”

This definition can be clearly understood by employees with disabilities, personal assistants in the workplace, and potential employers or their human resource managers.



TABLE 2 -- METHODS FOR LOCATING PERSONAL ASSISTANCE SERVICES

- Advertise in local newspapers.
- Advertise by “word-of-mouth.”
- Tell friends you are looking.
- Advertise in the local high schools, colleges, and universities.
- Look in the Yellowpages of your local phonebook for home care services.
- Check with local colleges about a business intern who may be interested in serving as a personal assistant and learn about the business at the same time.
- Call a local Center for Independent Living and see if they maintain a registry of personal assistants.
- Tell your co-workers that you are seeking a personal assistant.
- Check with local churches or community service clubs.
- Check out the “want-ads” in the local newspaper.
- Check with schools that are training students for the health care profession who might be interested in obtaining practical experience.
- Advertise in a business newsletter.

SURVEYS

Of the 80 CIL representatives responding to the survey, 25 (31.6%) indicated that they had assisted a consumer in obtaining personal assistance services (PAS) for the workplace. Of those who had not, the overwhelming majority (39, 78.0%) indicated that the primary reason they had not assisted a consumer in obtaining PAS was that the need had not yet arisen. The only other primary reason given by more than two respondents was that the CIL was unable to locate a funding source (8 respondents, 16%).

Of the 80 respondents, 20 (25%) indicated that they or their customers had worked with vocational service providers (i.e., VR, employment support programs, private rehabilitation, etc.) to incorporate PAS on the job. The majority of comments given to this item were related to limited resources to fund PAS and difficulty in working with the agencies. For example:

- “No funding for PAs in tennessee beyond \$16,000 that is currently in use by 15 people statewide.”
- “It was fairly cumbersome...it appeared to us that other organizations doubted the consumer’s ability to perform job duties.”
- “It was a positive experience in that we were finally able to secure the services. However, it was a challenge to work with Social Services, Home Health Services, and Social Security.”
- “[VR] will only provide PAS while the consumer is in vocational training, but once the consumer is employed, their PAS funded through [VR] is stopped.”
- “The Personal Assistance Program has a lengthy waiting list due to funding...”
- “The individual services contract program provides financial assistance to consumers for PAS on the job; however, the consumer must meet the MR/DD eligibility to receive the [service].”

Sixteen of the respondents (20.0%) indicated that their CIL had attempted to locate work-related PAS through home health care agencies. Overwhelmingly, the comments provided centered on restrictions on funding to home-based services.

- “We have found that home health care agencies can’t provide PAS via Medicare or Medicaid if the consumer is working and not home-bound”
- “We have been specifically told that home services are limited to the confines of the home; PAS at work is the employer’s responsibility.”
- “Only available dollars are to fund home support. No money for job supports.”
- “Agencies that provide home health care in our area do not provide services outside of the home because Medicare/Medicaid do not pay for such services.”
- “Agencies insist that they are not allowed to provide personal assistance services at the job site.”

A number of PAS-related issues were in the survey. Respondents were requested to indicate if any of the four issues were substantially different or more problematic when applied to work settings as opposed to home-based PAS. The responses to this item are shown in Table 3 on the following page. It is notable that less than one-third of the respondents viewed any of these PAS-related activities as substantially different when applied to the workplace.

Respondents were given the opportunity to make additional comments related to PAS services. Most of the comments reiterated the difficulty in locating PAS funds or providers. Some of the more salient comments are listed on the following page:

- "Most individuals with disabilities and many Rehabilitation Counselors are not aware of PAS funded services through Title I. Our local office (VR) has not funded this service."
- "Living in a rural area, sometimes it is hard to find individuals to work for you."
- "Sometimes the consumer has problems being the employer. They become friends with their PA and then struggle on how to direct them."
- "I think the primary reason we have not been requested to provide assistance [at work] is because PAS services in general are so limited. They are only available now to provide the bare minimum daily assistance for consumers."
- "PAS is a critical need in our state. Many people live in nursing homes due to NO choice. It would be crucial for the employer to assume responsibility for PAS on the job, independent of income. This is not required by the ADA and will be a difficult sell to employers."
- "Most individuals with severe disabilities are in such low-paying jobs, they will never be able to hire a personal assistant if they needed one."

TABLE 3 - RESPONDENTS INDICATING PAS ISSUES ARE SUBSTANTIALLY DIFFERENT AT WORK

ISSUES	NO.	%
PAS Training Programs	20	5.0%
Recruitment Strategies	24	30.0%
Training/supervision provided by customers	26	32.5%
Other areas	15	18.8%



DISCUSSION

The findings of this study underscore the barriers to employment faced by individuals with significant personal assistance needs. Less than one-third of the CIL representatives who responded to the survey indicated that they had experience in locating PAS for work-related needs. The comments provided by the focus groups and the survey respondents indicate that PAS is a critical support for workplace functioning. Yet, to a large extent, PAS needs are not being addressed by public and private sources.

The VCU-RRTC has long recognized PAS as a valuable support in enabling people with significant disabilities to live in the community. From prior experiences, staff at the VCU-RRTC are convinced that employees with a disability who have the ability to recruit, hire, and manage their own personal assistant in their workplace will be more successful in their chosen careers. Having this knowledge and ability can mean the difference between maintaining or losing employment opportunities.

The need for individuals with disabilities to be very knowledgeable and resourceful in acquiring and managing PAS in the workplace is reinforced by the current tendency of PAS funding sources to emphasize home as compared to work-based assistance. For example, the Massachusetts Health Care Plan incorporates PAS for people with disabilities who are employed (Ghiloni, 1999). Coverage is provided through two programs. The first is the MassHealth Standard Plan for people who are disabled according to Social Security Administration (SSA) standards and whose family income is no more than 133% of the Federal poverty level. The Alternative Coverage Plan is offered through the CommonHealth program, which is available to adults with disabilities and children who are not eligible for the

MassHealth Standard Plan, usually because their family income exceeds income limits. There are eligibility guidelines for the Standard Plan for working adults (age 18-64) involving the requirement of 40 hours or more a month of employment (with the option to pay a one-time deductible for individuals working less than 40 hours a month or not working at all). The CommonHealth program bases monthly premiums and deductibles on family income, although there is not a set cap on income or asset limit (Ghiloni, 1999).

Eligibility for PAS through MassHealth requires that the person with a disability be evaluated by a designated agency, which at times is an independent living center. An individual's PAS needs are evaluated by a registered nurse, who then forwards the assessment report to the state Department of Medical Assistance. Once approved, all personal assistance funded through MassHealth must be home-based. There is no coverage through MassHealth for worksite-based PAS, because it is viewed as a reasonable accommodation to be provided by the employer. There are examples in Massachusetts of persons in supported employment utilizing PAS through the MassHealth program, but these services are limited to assisting individuals in getting ready for work and preparing items that might be needed during the day.

The PAS coverage in MassHealth is of substantial value. One example is an individual who pays a monthly premium of \$204 but receives \$1,400 in PAS a month (Ghiloni, 1999). However, because it restricts PAS to home-based services, the Massachusetts program does show the importance of PAS recipients being knowledgeable and capable of self-direction in obtaining needed services. The individual with a disability must have the skills, knowledge, and confidence needed to potentially negotiate with an employer to first gain agreement that PAS is a reasonable accommodation, and then make the arrangements and conduct the training that will

result in PAS services being delivered as unobtrusively and efficiently as possible within the individual's work schedule and overall job environment. Readily available training resources and mentoring support are needed to support development of self-direction and self-advocacy skills among PAS recipients to address both home-based and work-based PAS issues and problems.

It is important for rehabilitation personnel and potential employers to have a better understanding of PAS as a workplace support. In order for PAS in the workplace to be beneficial, its potential positive impact must be understood. Employees with disabilities must have the skills to find the most appropriate personal assistant who can best support them on the job. Personal assistants must be trained on how to provide the necessary support in the most unobtrusive manner. Employers must recognize that an employee with a disability, with the support of a personal assistant, can both increase productivity and add diversity to the workforce.

Self-advocacy is a key component of the PAS in the workplace. Knowing how to use self-advocacy skills is essential for employees in managing their personal assistant and in relating to employers and immediate supervisors. Employees with disabilities should develop skills needed to recruit, hire, and manage personal assistants to perform the duties in the workplace. Some of the activities will include writing recruitment ads, writing contracts, learning dispute resolution techniques, and also learning to use self-advocacy as a management tool.

Personal assistants should understand how to provide essential support to the person who hired them to work in a job setting. Training protocols for personal assistants should stress the differences between providing support in a business environment from a home enviro-

onment. The training should include methods on ways to remain unobtrusive while providing the level of support needed by the employee.

In the early 90's, WID held a conference of PAS Stakeholders to come up with a plan to develop a national PAS program. Conference participants established a set of values that would drive PAS services provided through a national program. These values are:

1. No medical supervision is required.
2. The services provided include personal maintenance and hygiene including catheterization, mobility, and household assistance.
3. The maximum service limit should exceed 20 hours per week.
4. Service is available 24 hours a day, seven days a week.
5. The income limit for eligibility is greater than 150% of the poverty level. Further, individuals who are severely disabled whose income exceeds that established for eligibility should be allowed to buy into an insurance policy that would provide attendant care. Marital status and consequent financial circumstances should not govern access to personal care assistance.
6. Individual providers can be utilized by the consumer.
7. The consumer hires and fires the assistant.
8. The consumer pays the assistant.
9. The consumer trains the assistant.
10. The consumer participates in deciding on the number of hours and type of service he/she requires.

For years, the plan to establish a national program went unfulfilled. Finally, after considerable pressure from disability organizations like ADAPT, the Speaker of the U.S. House of Repre-

sentatives introduced a bill, that if passed, would establish the long awaited program. Unfortunately, the last session of Congress ended without passage of that bill. Therefore, advocates must reunite and fight harder to have the bill reintroduced.

Additionally, the time is ripe for Congress to rectify the discrepancies in the Social Security Disability system in its treatment of individuals based on disability group identification. For the vast majority of individuals with disabilities, the income level for determining engagement in Substantial Gainful Activity (SGA), and therefore ineligible for benefits, is \$700, effective July 1, 1999. Seven hundred dollars is insufficient income to live independently, especially if one must pay for personal assistance. In contrast, the level of SGA for wage earners who are blind is currently \$1,110 and has automatic annual cost of living adjustments.

As a matter of equity and common sense in public policy, the differences in SGA for blind recipients and all other recipients should be removed. At present, few individuals who receive disability benefits attempt work, and almost none earn enough to become financially independent (U.S. Government Accounting Office, July 1995; February, 1996). If an SGA of \$1,110 is sufficient to encourage blind recipients to attempt work, then it would be sufficient for recipients with other disabilities as well, especially for those who must hire personal assistants in order to work. Applying the SGA level for blind recipients to all others would enable those with large work-related expenses, such as the need for personal assistants or assistive technology, to access those services independently.

Until that time, more individuals with personal assistance needs who are Social Security Disability recipients should be made aware of available work incentives, most notably the Plan for Achieving Self-Support (PASS). A PASS can be written to shelter income for the purpose

of hiring a personal assistant. Using a PASS for this purpose would allow the worker with a disability to increase his or her earnings enough to be able to hire a personal assistant, while still retaining eligibility for health care assistance under Medicare or Medicaid (West, Wehman, & Revell, 1996).

As customer-directed PAS moves into the employment arena, there is little doubt that it will have a positive impact on all concerned. For employees with significant disabilities, it will

mean being able to recruit, hire and supervise a personal assistant who will provide the level of support needed to maximize their efficiency. For personal assistants, it will expand employment opportunities in more exciting work environments. For employers and human resource personnel, it will provide opportunities to diversify their workforce and increase the productivity of employees with disabilities. Utilizing PAS in the workplace can be a win-win situation for everyone.

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