

Personal Assistance Services: A Vital Workplace Support

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Abstract

This manuscript reports findings from focus groups and survey research related to 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 movements 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 customer-directed PAS model systems being developed in a number of states. These model systems are enabling countless of 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 workplace. 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 handwritten 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 in being able to successfully direct a person's personal assistant.

The Rehabilitation Research and Training Center (RRTC) has long recognized PAS as a valuable support in enabling people with significant disabilities to live in the community. RRTC shares the belief PAS services are

most effective when they are directed by people who use them. This is simply because when people with disabilities are able to control PAS, they can utilize these services when needed without being dependent on a home health care provider. RRTC made this discovery by inter-acting 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 RRTC, expresses 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 project mentor to develop self-advocacy skills to resolve their problems. A research study conducted by RRTC to determine factors which impact self-determination, respondents said being able to manage their personal assistant was important to their independence (West, Barcus, Brooke, & Rayfield, 1995). This experience lead to RRTC conducting investigations aimed at determining if any substantive research had been done about how 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 mobility 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 with disabilities, many of whom lived in a residential care facility or in the community but with little or no experience at managing their own care. 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 a list of tasks that are required to be done by personal assistants in the workplace (see Table 1).

Table 1
Duties of Personal Assistants

Personal Duties	Job Function Duties
Assist with grooming tasks	Making telephone calls (if necessary)
Assist with getting beverages	Assist with filing
Assist with food	Taking dictation
Assisting with toileting (if necessary)	Voice interpretaton (if necessary)
Assisting with transportation	Assist with making copies
Traveling on business trips	Data entry

Assist with dressing & grooming tasks on trips

Taking notes in meetings, reading documents, assisting with mail, & keeping work-space organized

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 was primarily constituted of customers and one primarily constituted 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

Sample

The sample for the survey consisted of 80 representatives of independent living centers in the United States and Canada. The survey was mailed to 400 CILs, with a letter requesting that the most appropriate staff member complete and return. The 80 returned surveys represented 20% of the total population of CILs.

Procedure

The survey instrument was developed following the focus groups, and addressed the issues brought out by the participants. An initial draft of the survey was piloted, and modifications subsequently made to the items. The final version of the survey contained six items related to experiences with obtaining PAS on the worksite for the agency's customers, use of public and private rehabilitation agencies to obtain PAS on the worksite, and issues related to PAS on the job such as training of providers, customer supervision, etc. Each survey item included a menu of choices and space to provide additional information or comments.

The total sample for the survey consisted of lists of CILs from two sources: The Independent Living Center Research and Training Center in Houston, TX; and the National Council on Independent Living (NCIL). The survey distributed by mail to all 400 CILs on the two lists after cross matching to eliminate duplicates. A follow-up reminder letter was mailed after one month to encourage return of the survey. A total of 80 complete and usable surveys were returned.

Results

Focus Groups The focus group comprised solely of individuals with significant disabilities were in agreement that 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. The focus group also revealed an intense interest and need by employees with significant disabilities for such training on how to manage their personal assistant 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 (see Table 2).

Methods for Locating Personal Assistance Services

Advertise in local newspapers.

Call a local Center for Independent Living and see if they maintain a Registry of personal assistants.

Advertise by "word-of-mouth".

Tell your co-workers that you are seeking a personal assistant.

Tell friends you are looking.

Check with local churches or service clubs.

Advertise in the local high schools, colleges, and universities.

Check out the "want-ads" in local newspapers.

Look in the Yellowpages of your local phonebook for home care services.

Check with schools that are training students for the health care profession about their students who are seeking practical experience.

Check with local college about a business intern who may be interested in serving as a personal assistant and learn about the business at the same time.

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 to obtain 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 to obtain PAS, is that the need has 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, 16.0%)

Of the 80 respondents, 20 (25.4%) indicated that they or their customers had worked with vocational service providers (i.e., VR, employment support organizations, private rehabilitation agencies, etc.) in an attempt to incorporate PAS on the job. The majority of comments given to this item related to limited resources to fund PAS and difficulty in working with the agencies. As examples: "No funding for PAS in Tennessee beyond \$160,000 that is currently in use by 15 people statewide." "It was fairly cumbersome...it appeared to use that other organizations did doubt 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 ceased." "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 to this item 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 in 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 listed in the survey. Respondents were requested to indicate whether any of four issues were substantially different or more problematic when applied to the work setting as opposed to home-based PAS. No issues were indicated as substantially different by more than a quarter of participants. The responses to this item are presented in Table 3.

Table 3 Respondents Indicating PAS Issues are Substantially Different at Work

Issue	Number	Percent
PAS Training Programs	20	25.0%
Recruitment Strategies	24	30.0%
Training/supervision provided by customers	26	32.5%
Other areas	15	18.8%

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 were these: "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 folks 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."

Discussion

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

From prior experiences, staff at the RRTC are convinced a employee with a disability who has 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. 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 him/her 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 not only increase productivity but can 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, dispute resolution techniques and learning to use self-advocacy as a management tool.

The personal assistants should understand how to provide essential support to the person that hired him/her in a job setting. Training protocols for personal assistants should stress the differences between providing support in a business environment from a home environment. 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. One of the outcomes of that conference was to establish a set of values that would drive 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, persons who are severely disabled whose income exceeds that established for eligibility should be allowed to buy into an insurance policy which 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 has gone unfulfilled. Finally, after considerable pressure from disability organizations like ADAPT, the Speaker of the U.S. House of Representatives 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 re-unite and fight harder to have the bill re-introduced.

As customer-directed Personal Assistance Services 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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