

USING PERSONAL ASSISTANCE AS A WORKPLACE SUPPORT

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For many people with significant disabilities, the use of Personal Assistance Services (PAS) as a workplace support is as essential to successful employment as these services are for successful community living. During the 1980's, great disability rights leaders and self advocates like Ed Roberts and Judy Heumann proved the value and cost-effectiveness of customer-directed PAS through their work in the independent living movement and at the World Institute On Disability (WID). These two pioneers demonstrated that customer-directed PAS could enable people with significant disabilities to live and actively participate in their community. This historic work was documented in the research monograph "Attending To America" (Litvak, Heumann, & Zukas, 1987)¹.

As a new millennium dawns, people with disabilities who have managed personal assistants in their home environment now realize similar supports are needed on the job. Knowing how to manage a personal assistant at work could mean the difference between maintaining or losing a job. Even with the vast array of assistive technology now available, some tasks require the intellectual skills and abilities of another human being. To be successful in a career, the employee with a significant disability must balance the right assistive technology with the appropriate level of support from a workplace Personal Assistant. Effectively managing a Personal Assistant involves having the skills needed to direct a support person to do those tasks that would be physically impossible or extremely time-consuming for the employee with a disability to do without assistance.

Unlike home and community-based PAS, when PAS is used as a workplace support, it is not based on medical need. As a result, employees with disabilities have great difficulty in using traditional resources to find qualified workplace personal assistants. This difficulty is especially true of home-health care agencies who only recruit personal assistants to do personal care and some minor medical services; these individuals would possibly have limited understanding of how to support an individual on the job.

¹Litvak, 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 of Disability.

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Even individuals with disabilities who have experience recruiting, hiring, and managing a personal assistant for home place duties are having to learn new skills in order to find competent support in the workplace.

Before the employee can successfully use PAS in the workplace, he/she must understand that from a legal and regulatory standpoint, PAS as a job accommodation are not necessarily services of a personal nature. Instead, PAS at the workplace involves services that the employee needs to complete essential job functions in a timely manner. Title I of the Americans with Disabilities Act (ADA) states that services of a personal nature are not the responsibility of the employer. Therefore, PAS at the workplace would not typically include tasks such as feeding, grooming, or toileting. Rather, PAS would involve job related functions that assist in the completion of essential job functions in a timely manner.

Grooming might be a possible exception to PAS as a workplace job accommodation. Certainly in business, academic, and other professional settings, it is essential the employee be well-groomed. However, in most other cases, it is the responsibility of the employee with a disability, not the employer, to find someone to perform services that are deemed personal. To avoid possible undue hardships for employers, writers of Title I of the ADA were very specific in how workplace PAS are defined as a reasonable accommodation. Although the business community may consider the ADA definition a fair concession, it presents many challenges to employees with more significant disabilities.

◆ **DEFINING PAS AS A WORKPLACE SUPPORT**

The following definition of PAS in the workplace was developed by the Job Accommodation Network (JAN) of the President's Committee on Employment of People with Disabilities (PCEPD) shortly after the passage of the ADA. JAN's definition includes examples of tasks that can be performed by personal assistants for employees with different disabilities. The Jan definition of PAS is as follows:

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.

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.

The President's Committee on Employment of
People with Disabilities (PCEPD, 1998)

Another definition of PAS as a workplace support was developed by the Virginia Commonwealth University, Rehabilitation Research & Training Center (VCU-RRTC) on Workplace Supports in 1998. The purpose of this definition is to assist employees with disabilities, workplace personal assistants, and employers (including human resource managers) to better understand PAS as a workplace support. It was generated after conducting two focus group sessions: one group contained experienced users of workplace PAS; the other group had mostly very inexperienced users of PAS. The first session was held during the 1998 National Council of Independent Living (NCIL) Conference in Washington, D.C. This group was comprised of experienced users of PAS in the workplace. The second session was held as an activity in a demonstration Supported Employment project involving individuals with very significant disabilities. Many of the people in this group lived in a residential care facility with very little or no control over how their care was provided. The consumers' definition developed by these two groups is as follows:

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.

In identifying PAS needed at the workplace, it is important that PAS support needs related to personal care be differentiated from those involving the performance of essential duties of the job. The following are examples of Personal Assistance Services at the workplace, that respond to personal needs or to directly performing the essential job duties more efficiently.

***WORKPLACE PAS THAT RESPOND
TO PERSONAL NEEDS:***

- ▶ Assist with grooming tasks;
 - ▶ Assist with getting beverages;
 - ▶ Assist with food;
 - ▶ Assisting with toileting (if necessary);
 - ▶ Assisting with transportation;
 - ▶ Assisting with dressing and grooming tasks on business trips
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***WORKPLACE PAS THAT RESPOND DIRECTLY TO EFFICIENTLY
PERFORMING ESSENTIAL JOB DUTIES:***

- ▶ Assist with making phone calls;
 - ▶ Assist with filing;
 - ▶ Taking dictation;
 - ▶ Voice interpretation;
 - ▶ Assist with making copies;
 - ▶ Data entry;
 - ▶ Taking notes in meetings;
 - ▶ Reading documents;
 - ▶ Getting and opening mail;
 - ▶ Keeping work-space organized; and
 - ▶ Traveling on business trips.
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As noted, the ADA definition of Personal Assistance Services at the workplace clearly differentiates PAS responding to personal needs from PAS necessary to perform essential job functions. Negotiating clear differentiations between these two types of workplace PAS needs can be a challenge for the employee with a disability and a potential employer. The PAS needs self-assessment information contained in Chapter 2 of this consumer guide will help in clearly identifying workplace PAS needs.

Even though personal assistance services such as grooming, assistance with restroom needs, and eating are not normally services that are paid for by employers, they can be essential for many employees with significant disabilities. In many employment settings, particularly more professional settings, it is critically important for the employee's

appearance to reflect a positive image for the business represented. For example, the employee may represent his/her business in arenas where a professional appearance is viewed as essential to effective job performance. Also, the employee must be able to take care of personal needs in a timely manner. Having a personal assistant to help with personal needs will frequently make the employee more efficient. In some cases, the professional employee with a disability has successfully made this case to the employer and gained personal services as part of their workplace PAS package.

Vital to this process will be accurately describing the specific duties that will be required of the PA in the workplace. In one case where a large national bank agreed to provide personal services as part of workplace PAS because grooming requirements were an important part of the work culture, neither the employee nor the employer thought to describe the specific work tasks of the workplace PAS. As a result, the employer got very angry when the professional employee asked his workplace PA to pick up his dry cleaning before returning from lunch. It was extremely natural for the employee to make this request of the PA that assists him at home. However, the supervisor did not see this as part of the duties of a workplace PA and began to view the employee in a negative light. This situation could have been avoided had the new employee and the employer specifically described the duties of the workplace PA. In cases where the employee is paying for his/her own PA, it is still a good idea to compose a list of job duties that will be expected of the PA.

◆ WHY PEOPLE WITH DISABILITIES NEED PAS IN THE WORKPLACE

Like all employees, employees with disabilities have very different and unique needs. Therefore, what works for one employee might not work for another employee who has the same type of disability. Some can use assistive technology or simply have their work station modified to do their job efficiently without the support of a personal assistant while others may need a personal assistant in combination with some type of assistive technology.

The type of support used will depend on the person's level of need. Assistive technology can help some cases, but there are many job related tasks that may need the support of a personal assistant to be accomplished. Thus, it is so important that employers/human resource

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managers not judge an employee's request for PAS as a reasonable accommodation solely by disability types. Employers and/or human resource managers should get to know the individual to better understand what their employee's needs are and how to accommodate those needs. If necessary, the employer should consult with a rehabilitation professional before making a decision about granting PAS as a reasonable accommodation. There are many reasons that may not be obvious to the employer, why the employee might require the services of a personal assistant to be efficient. Both the employee and employer should have all the necessary information before determining the role of the PA.

With many people who have disabilities, maintaining physical stamina on the job is a big issue. If a person spends a lot of time doing labor intensive tasks that are not deemed as essential functions of the job, that person will not be physically or mentally able to do the essential functions. An employee with a disability expending large amounts of energy doing tasks that could more easily be done by a workplace personal assistant is simply not cost-effective for the employer. For example, a person who has a speech impairment or who has poor hand coordination might spend several hours keying in information on a word processor and could become too physically exhausted to think properly about what needs to be written. Voice activated computer software programs can alleviate the data entry problem, but they have not proved effective for someone who has a speech impairment. In this case, it would be more cost-effective to have a qualified workplace personal assistant taking dictation from the employee with the disability. It would also increase the employee's efficiency and productivity on the job by allowing him/her to focus on developing the material.

Another example might be a visually impaired employee utilizing a reader instead of a reading machine (Kurswald Reader) that could possibly break down and leave the person unable to read (hear) critical documents. Also, with a machine, it requires the person to place documents in precisely the right position to be read properly. With a personal assistant, the task could be done more efficiently, giving the employee time to respond to the reading matter. These are but two examples where clearly the use of a personal assistant makes the employee with a disability more effective, and therefore reduces the cost of wasted time for the employer. The decision to utilize PAS as a reasonable job accommodation should be made through a joint agreement between the employer and employee.

BARRIERS TO HAVING ADEQUATE PAS AT THE WORKPLACE

Employees with disabilities who utilize personal assistance services at the workplace face many potential challenges. There is the challenge of recruiting a qualified, reliable, and punctual personal assistant. Additionally, the PA must have the skills and personality needed to provide support effectively within a work environment. Next, the employee must be able to effectively explain the need for PAS to the employer/supervisor and establish an agreement on how the PA will function. To meet these challenges, the employee with a disability must be knowledgeable about his/her PAS support needs and self confident in explaining these needs to both potential personal assistants and to employers.

Some employers still do not understand their responsibility to provide PAS as a reasonable accommodation. They still may perceive it as two people doing the same job. Here, the employee must be very patient in making the case for PAS to be provided as a reasonable accommodation. If the employer suggests some assistive technology that might address the employee's needs, it should be considered courteously. However, if PAS would be a better accommodation, the employee should remain firm in explaining how the personal assistant will help in getting the job done more efficiently. Employees with disabilities should understand the ultimate decision to approve and agree to pay for PAS as a reasonable accommodation is the employer's. When such a request is denied, the employee has to decide whether or not to accept a lesser accommodation or turn down the job and seek other employment that would provide more adequate accommodations.

Even after the employer has agreed to pay for the employee to have a personal assistant as a reasonable accommodation on the job, the employee may have many barriers to overcome before the support is in place. The employee with a significant disability may still have to come up with funding to cover such tasks as feeding and assistance in the restroom. An employee's salary might be too low to offset that expense. There are ways to overcome this expense by using Social Security Work Incentives. The cost of the PAS can either be claimed as an Impairment-Related Work Expense (IRWE) or can be covered under a Plan to Achieve Self Sufficiency (PASS). By utilizing either of these SSA work incentives, the employee could keep some level of Social Security benefits to pay for that assistance. (See Chapter 7 for funding issues).

When the employee is able to pay for PAS of a more personal nature, he/she still must find a person who is willing to come to the job for possibly a limited number of hours. Driving for an half hour to an hour just to work a limited number of hours is not very cost effective for the personal assistant. Therefore, the employee must try to come up with creative ways of finding this type of support. One of the best ways to solve the problem of getting some one to assist with lunch and restroom needs is to convince the person who is assisting with work-related PAS to also assist with personal needs as well. Also, some employees have used other co-workers who may need extra cash to perform these intimate services. This approach may work if the employee is frank and honest about the level of support needed and if it is agreeable to the other co-worker. One tip the employee might want to consider is asking a co-worker who is not directly connected to his/her department for assistance, this avoids the possible embarrassment some people feel in asking more immediate co-workers for assistance with personal needs. Again, be frank and honest. Also, the use of casual conversation and humor can increase the comfort level of the co-worker who has agreed to assist. These relationships take time to develop and will either work or not depending on the personalities and attitudes of the parties involved.

Because PAS as a workplace support is relatively new, some employees lack the skills to train and manage personal assistants for workplace duties. In these cases, the employee with a disability should seek out a Personal Assistant Management Training Program that is usually provided by a local Center for Independent Living (CIL). Even though the dynamics may be a little different for managing personal assistants in the workplace compared to the home, many of the same management techniques can be utilized when training personal assistants for workplace and home-based duties. The basic rule for managing personal assistants in any environment is clearly articulating the support needed and specifying how those needs can best be met. A thorough discussion of how to train and manage a personal assistant in the workplace can be found in Chapter 3.

◆ SUMMARY

PAS as a workplace support will potentially unlock the door to employment for tens of thousands of people with significant disabilities. It can have the same impact for people with severe physical disabilities as supported employment has had with over two hundred thousand

individuals with all types of disabilities. However, to achieve this level of impact, PAS as a workplace support must be fully understood by employees with significant disabilities, potential workplace personal assistants, and employers. PAS can no longer just be considered a tool to facilitate community integration for people with all types of disabilities. PAS must be fully utilized as an employment tool in assisting people with the most significant disabilities find and maintain careers in all segments of the economy. When PAS is more widely used in the workplace, it can help reduce the 70% unemployment rate among people with significant disabilities. When it becomes the norm to utilize PAS as a career support, all Americans with and without disabilities will be in a win-win situation.

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