

# Personal assistance services as a workplace accommodation

Susan Stoddard\*

*Rehabilitation Research and Training Center on Personal Assistance Services (PASCenter), University of California San Francisco, CA, USA*

**Abstract.** This paper describes current US trends and practices regarding workplace personal assistance services (PAS) as part of available work accommodation options. Workplace PAS include task-related assistance at work, such as readers, interpreters, help with lifting or reaching, re-assignment of non-essential duties to co-workers, and other help related to performing work tasks; and personal care-related assistance such as helping someone with using the rest room, eating, or drinking while at work. The results reported here are based on forty-one telephone interviews conducted in 2004, which included 20 workplace PAS users and 21 US employers familiar with workplace accommodations. Employers and consumers described a range of workplace personal assistance currently used. Barriers to expansion of workplace PAS include negative co-worker or supervisor attitude, cost to employers and workers, waiting time for accommodations, employee attitude and knowledge, and confusing terminology. Development of organizational culture that encourages employment of people with disabilities and developing employer-employee partnerships in arranging for accommodations can contribute to workplace PAS solutions. The survey findings contribute to better understanding of current practices related to workplace PAS.

Keywords: Personal assistance services, disability employment, accommodation, disability

## 1. Introduction

Personal Assistance Services (PAS), also called personal attendant services or personal care, refer to help provided to people with disabilities to assist them with personal care tasks essential for daily living. These tasks include bathing, dressing, getting around, using the rest room, eating, shopping, remembering things, and other activities. PAS, along with assistive technology such as wheelchairs, text readers, and hearing aids, help people with disabilities participate in activities at home, at work, and in the community [4].

When we expand the concept of PAS to the work environment as a workplace accommodation, we need to consider help with work tasks as well as personal care. Work settings are complex, and accommodations, like

the activities they support, vary greatly from job to job. Some individuals with more severe disabilities may require personal assistance services in addition to assistive technology to successfully carry out job responsibilities and other activities at work. Workplace Personal Assistance Services (workplace PAS) can include task-related assistance at work, such as readers, interpreters; help with lifting or reaching; re-assignment of non-essential duties to co-workers; as well as personal care assistance, such as helping someone with using the rest room, eating, or drinking while at work.

However, little is known about the use of workplace PAS as an accommodation, nor about the cost, payment for, and attitudes of employers and employees toward them. This paper describes findings from a survey of employers and employees regarding current practices of using PAS as a workplace accommodation. The specific aims of the survey were to identify current PAS accommodations and the processes for arranging PAS at work.

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\*Address for correspondence: Susan Stoddard, InfoUse, 2560 9th Street, Suite 320, Berkeley, CA 94710, USA. Tel.: +1 510 549 6520; Fax: +1 510 549 6512; E-mail: sustoddard@aol.com.

## 2. Background

### 2.1. PAS in public policy

There is currently a growing awareness of the needs for PAS at work [7]. With a recent US policy focus in the New Freedom Initiative [9] to improve employment opportunities for people with disabilities, employers and employees alike are more aware that appropriate accommodation, including workplace PAS as well as assistive technology, improve an employee's ability to succeed on the job [3]. For each worker with a disability, there will be a different combination of employer services, public services and personal resources for use at home and at work.

However, within public policy, there is some discrepancy about how PAS fits into the workplace as an accommodation. The Americans with Disabilities Act (ADA), in calling for reasonable accommodation, focuses on job-related adjustments or modifications. In his policy brief on "The Applicability of the ADA to Personal Assistance in the Workplace," Silverstein points out that the employer obligation does not include personal tasks, and refers to Department of Justice regulations stating: "This part does not require a public accommodation to provide its customers, clients or participants with personal devices, such as wheelchairs; individually prescribed devices, such as prescription eyeglasses or hearing aids; services of a personal nature including assistance in eating, using the rest room, or dressing [5]."

While the ADA specifically excludes the tasks related to personal care at work from required accommodations, the language in the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIA) is not as restrictive [8]. TWWIA was intended to increase employment of people with disabilities by improving access to benefits and reducing disincentives to employment. When TWWIA mentions PAS, it is as "a range of services provided by one or more persons designed to assist an individual with a disability to perform daily living activities on or off the job that the individual would typically perform if the individual did not have a disability. Such services shall be designed to increase the individual's control in life and ability to perform everyday activities on or off the job [8]." Based on TWWIA, the Center for Medicare & Medicaid Services (CMS), US Department of Health and Human Services has authorized states to use Medicaid supports for providing greater availability of personal assistance services [2,6]. If these state initiatives are

successful, there will be more opportunity to use PAS at work. However, many employers will need information and examples of successful solutions, because this concept as a formal employment accommodation is relatively new.

### 2.2. Need for workplace PAS

Despite the growing policy initiatives, there is still a need for workplace PAS. The US National Health Interview Survey Disability Supplement (NHIS-D), 1994–1995, included questions on need for accommodation and whether accommodations are received. Seventeen categories of accommodation were examined, including three related to PAS. In their analysis of the NHIS-D, Zwering and colleagues [10] found that 15.6% of all workers with disabilities reported need for work accommodations, and 12.2% reported receiving them. Of these workers with disabilities who needed accommodation, 7.1% reported a need for a personal assistant to help with job-related tasks. Specific types of need included need for a reader, oral or sign language interpreter (1.3% of people needing an accommodation), and need for a job coach to help train and supervise (3.8%). With the exception of job coaches, where the need appears to be met, there were gaps in meeting the need expressed by the workers responding to the NHIS-D questions. For those reporting any need for PAS accommodation, almost two-thirds reported that they received them. For those requiring readers or interpreters, one-half reported that they received them.

The 2003 American Community Survey (ACS) conducted by the US Census included one disability measure related to personal assistance as related to self-care [1]. There were approximately 20.6 million people of working age between 18 and 64 years old who reported some disability. Approximately one-sixth of these individuals (3.4 million) reported difficulty performing self-care activities.

The need for assistance with self-care can limit participation in the labor force and employment opportunity. Of the 7.8 million people with disabilities who were employed, 596,000 (7.7%) reported a self-care difficulty [4]. The percentages are higher for individuals who are in the labor force but unemployed (8.6%) and for those who are not in the labor force (not working and not looking for work) (23.5%).

While recent policy initiatives encourage workplace PAS as an accommodation, there is little information on the extent to which this accommodation is currently provided or whether more individuals who need help

with personal care and/or work tasks would be able to retain employment, enter the labor force or find employment if such accommodations were more available. Our interviews with employers and current workplace PAS users were designed to help in understanding this accommodation need and some of the approaches that are currently in place. This formative research can contribute to better understanding of workplace PAS as a factor in supporting expanded opportunity for employment.

### 3. Methods

The results reported here are based on forty-one telephone interviews conducted in 2004, which included 20 workplace PAS users and 21 US employers familiar with workplace PAS.

#### 3.1. Sample

Workplace PAS users were recruited through outreach to national advocacy and independent living organizations including the American Association of Persons with Disabilities and the National Council for Independent Living, as well as through the employer contacts of the Job Accommodation Network, our own employer interviews, news stories and other published information, and other project sources. These 20 individuals were currently using PAS at work. Nine were female and eleven were male. Over half (12) were ages 45 to 64, seven were between 18 and 45, and one was over 65. Seventeen of the interviewees were white, two were African American and one was Filipino. Eight of the people interviewed (40%) described their disability as spinal cord injury or quadriplegia, six (30%) reported vision impairments including blindness, and three (15%) reported a head or brain injury. Cerebral palsy, diabetes, learning disability, paralysis, speech impairment and fourteen other disability descriptions were also self-reported by one or more of the respondents as primary or secondary disabilities. The 21 employers were selected from published lists of businesses that have received recognition for actively hiring people with disabilities, have participated in Department of Labor's Office of Disability Employment Policy's Business Leadership Network, have attended employer based conferences on employment of people with disabilities or were recommended by other interviewees and project advisors. Nine of the 21 were for-profit businesses, 6 were non-profit employers, and the re-

maining 6 were government employers (local, state, and federal). The employers represented all sizes of businesses: from 5 employees to over 1,000 employees. These organizations were geographically diverse, located in the western, Midwestern and eastern US.

#### 3.2. Interviews

Telephone interviews were conducted with the respondents. The telephone interviews were based on information protocols designed for each of the three respondent groups. The first part of the interviews focused on a series of respondent descriptors – for instance, for employers we asked about the size of the workforce, number of workplace locations, type of organization, industry type, number of employees with disabilities, and whether employees use PAS at work for either tasks or personal care. Descriptors were followed by a series of open-ended questions regarding the use of PAS at work, processes and procedures used, and successes or barriers to implementing workplace PAS. Telephone interviews were 30 minutes to one hour in length. All respondents were asked about information sources and resources, and whether they would suggest any model programs that provide workplace PAS.

### 4. Results

#### 4.1. What PAS were used

The twenty consumers in our interviews used PAS services, both at home and at work. While most individuals combined paid hours with additional unpaid hours provided by family members, friends or co-workers, some people relied entirely on paid or unpaid hours. The consumers reported an average of 49.1 paid hours of PAS per week (range 0 to 168 hours), including 17.3 hours of paid PAS at work (range 0 to 40 hours). They used an additional 15.6 hours of unpaid or "informal" PAS (range 0 to 100 hours), including 5.9 hours at work (range 0 to 40 hours).

Employers described a range of task-related workplace personal assistance currently used (see Table 1), to help the worker perform tasks and participate at the workplace. Of the 21 employers interviewed, 14 provided workplace PAS in some way. The most frequent workplace PAS was provision of sign language interpreters (93% of the employers who provided workplace PAS). Re-assignment of nonessential tasks to other workers was also a frequent approach, used by nine

Table 1  
Use of Workplace PAS by Employers reporting some Workplace PAS ( $n = 14$ )

Type of PAS Used	Number of Responses	Frequency of Use
Task-related workplace PAS	14	100%
Sign language Interpreters	13	93%
Re-assign nonessential task to others	9	64%
Job coaches	7	50%
Lifting, moving	6	43%
Personal care-related workplace PAS	5	36%
Service animals	3	21%

of the employers (64%). Seven employers (50%) provided job coaches, six (43%) provided assistance in lifting or moving, and three (21%) mentioned use of service animals. Other PAS accommodations mentioned by at least one employer included assistance with using Powerpoint and writing out instructions.

While employers were very familiar with task-related accommodations including PAS, they were less informed about personal care services used at work. Eight of the 21 employers interviewed (38%) were not aware of any employees who used personal care assistance at work. Five employers (24%) described some levels of personal care provided at work, either informally by other workers or by providers and informal helpers, such as help with eating, shaving, putting on a jacket and tying a tie, help with showering, adjusting headsets or seating, help getting in or out of the building, help with taking medications, independent living training, and cutting up food.

#### 4.2. *Organizational commitment and co-worker attitudes*

Employers stressed the importance of organizational commitment to make workplace PAS succeed. Six employers (43% of those providing PAS) described the value of an overall organizational culture of acceptance and diversity. Other factors included top management commitment to employment of people with disabilities (36%), supportive co-workers (36%), and success in establishing sign language interpreting services in the workplace (21%).

Six employers spoke of the barriers to PAS in the workplace that occur through co-worker attitude: generally this involved the person with a disability needing to establish being a “team player” who can “pull his own weight.” One employer noted that getting “light duty” (an accommodation) is considered favoritism among the union members in that organization, and that the union perspective is that if people cannot do the job, they should not be there.

More than one employee with a disability described experiencing the resentment of others who are required to help with tasks. As one interviewee said, “the fact that you are relying on the kindness of strangers, that it is not part of your job. It sets up a difficult situation. Even though she’s comfortable with it, it sets up a potential for difficult situations. Especially for supervisory role – someone is not required to do it, and there are no repercussions to not doing it. As a person with a disability climbing a managerial ladder, it becomes an issue.”

While a positive organizational culture may foster diversity and workplace accommodation, one problem most frequently mentioned was a lack of disability awareness, resulting in negative co-worker attitude. PAS users discussed the need for disability awareness training at their companies; with an understanding of what the person with a disability was going through, barriers from co-worker attitudes could be mitigated. One PAS user said, “First, management has to be attuned to disabled people, and comply with assisting people with their work tasks. They have to know this is not a complaint, but a life issue.”

At work, PAS users depended, in part, upon an informal network of assistance from co-workers. In the interviews, co-worker resentment was mentioned as a problem by both employers and PAS users – either resentment of being required to help, or simply resentment that someone else is getting preferential treatment.

#### 4.3. *PAS funding*

In arranging for workplace PAS, most of the users who responded cited receiving payment from more than one source. Eleven (55%) reported that employers paid for workplace PAS. Fifteen (75%) used some public benefits, including eight who reported Medicaid (7, 35%) or a state grant (1, 5%). Ten (50%) reported personal payment, and of these, eight also used other sources of funding. One respondent’s PAS was paid by private insurance (see Table 2). For these consumers,

Table 2  
Sources of payment reported by Users ( $n = 20$ )

Payment Source	Number of Responses	Frequency of Use
Public benefit	15	75%
Employer paid	11	55%
Personal payment	10	50%
Medicaid	7	35%
Private insurance	1	5%
State Grant	1	5%

the average personal cost was \$148 per week for services in the home (range \$0 to \$500), and \$34.50 average per week for services in the workplace (range \$0 to \$250). These estimates do not include services paid for by employers or other parties.

Among those services paid for by employers, one approach to reducing accommodation costs was to share the costs among several employees. Employers reported a strategy of shared resources to meet both the needs of PAS and the high cost of AT (such as an accessible elevator used by all employees). Examples of shared PAS from five employers interviewed included on-staff interpreters or interpreter services, shared attendant services, and staff who help with task-related assistance such as filing or copying.

A separate but related concern was whether the costs for an accommodation should be born by the unit where the employee works, or shared company-wide as part of the overhead. In one large organization, the company-wide approach was followed, because some workers were reluctant to request accommodations if they were perceived to be a drag on the efficiency or profitability of their group. One respondent explained: "The cost of accommodations are funded through a central budget so as not to cost the supervisor any money." Accommodations were often part of a larger human resources budget, tracked separately or not.

In addition, local expenditures proved in some cases to be easier to track if they were centralized. One employer, for instance, reported use of central purchasing for most assistive technology and assistance, and use of local acquisition for hardware purchases.

Insurance risk was an additional concern. One employer raised a concern about company liability if employees were to bring their own assistant. All of their employees were insured, but the outside assistant was not. In his organization, any decision for employees to purchase accommodations ended up as department-wide discussions, weighing benefits and risks.

#### 4.4. *Waiting time for accommodations*

Delays in arranging for a needed service were identified as a barrier to continued employment. The

PAS users described varied experience in arranging for PAS services at work. Seven respondents (35%) said that they received accommodations "at once" (6) or within a few days (1) when requested. For four more (20%), the time period was between two weeks and two months. Three respondents (15%) reported a seven to nine month period of waiting for PAS to be available; in one case it took two years and another person reported that the request was fulfilled after nine years.

## 5. Discussion

Workplace PAS is provided in a context of confusing terminology and expectations. Workplace PAS terminology is confusing, because "workplace personal assistance services" can mean mutually exclusive task-related or personal care-related services. For example, when approached from an ADA focus, it deals exclusively with task-related services because that is the only type of assistance that employers are required to provide. When funding is provided by Medicaid, however, the focus moves to personal care-related services. While the specific definitions may be effective within a well-understood situation, such as a human resources department responding to a request for a reader or an interpreter, our survey process showed that it is not easily understood by employers or potential workplace PAS users. As it is unlikely that someone would need PAS at work and not need it at home, the challenge is to manage services in more than one environment and likely with more than one payer.

Employers attempting to respond to policy requirements regarding workplace PAS can find the current information and conflicting provisions confusing and difficult. Without clear guidance about these services and how to provide them, and without good examples of successful workplace PAS provision, employers and employees need to invent the approaches on a case by case basis. Because this is an emerging area, much remains to be learned about current prevalence and patterns of practice.

### 5.1. *Employee attitude and organizational commitment*

While the employer has responsibility for complying with the ADA, it is the person with a disability who needs to initiate the request for an accommodation. Unfortunately, this is often not the case. As one employer stated during our interviews, "People take work and never communicate about their needs. Then the employer is unprepared."

In her keynote talk for the State of the Science Conference on Workplace Accommodations, Atlanta, Georgia, September 15, 2005, Sharon Rennert of the US EEOC emphasized the importance of employees and employers working in partnership to find workplace accommodation solutions. This means that rather than an adversarial situation where an employee might demand an accommodation, the best solutions can come in situations where both employer and employee contribute to the solution. Ms. Rennert's vision of partnership is particularly important in those areas which are "beyond the ADA" in terms of employer responsibility – the solutions won't be limited to minimum requirements, excluding such needs as personal care, if there are ways to work out creative solutions to needs in all areas of PAS.

This is consistent with the comments of the employers in our survey who stressed the importance of an organizational culture that promotes diversity, to the importance of top management goals for hiring and retaining employees with disabilities, and the importance of education and preparation for employees and co-workers alike.

### 5.2. *PAS funding*

In our interviews with PAS users, we identified many different solutions combining both paid and unpaid PAS hours and usually combining payment from more than one public, private and/or personal source. While initiatives such as the Medicaid Infrastructure Grant have the potential for expanding the resources for workplace PAS and for reducing economic disincentives to work, our interviews did not indicate that at that time these resources were available to many consumers, or used by employers.

While task-related services were arranged and usually paid for by employers, employer respondents had little knowledge of whether individual employees used personal care services, since such services would be arranged privately.

## 6. **Conclusions**

The concept of PAS at work is new to some employers. Both task-related and personal care workplace PAS belong in the spectrum of work accommodations. The respondents to the survey have assisted in clarifying current practice in providing personal assistance at work, and have identified areas where more research is needed.

Many people who rely on PAS at home to perform activities of daily living will need some level of PAS at the workplace. In addition, PAS can be used as an accommodation for performing work-related tasks, and it should be included in the accommodation assessment processes as part of the menu of work accommodation options that are available. This service can make the difference between being able to work and being unemployed or out of the labor force entirely. Current policy efforts may expand the demand for workplace PAS accommodations; if such expansion does occur, employers vary in terms of knowledge and attitudes about hiring people with disabilities and will need information on the best ways to respond. The commitment of top management and the development of supportive organizational culture will facilitate the development of good workplace PAS solutions.

The workplace PAS experience of current employers and consumers is valuable in identifying what works and what more is needed. By identifying good examples of current practice through interviews, the research can assist other organizations in establishing PAS services at work. In addition, further research is needed to identify the unmet need for PAS in the workplace among current and new employees, whether an expanded PAS supply will increase employment, and how better models of workplace PAS can be developed and implemented by employers.

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